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New CEO highlights a steep learning curve



This is my first contribution for **Signpost** and I hope it will be the beginning of a creative **conversation** between all Victorians affected by, or living with, Parkinson's.

I bring to my new role as CEO of Parkinson's Victoria 12 years experience in managing not-for-profit agencies. I understand the health care system, its challenges and weaknesses, and the frustrations felt by families when trying to negotiate the system and find the health care they need. Aside from my professional experience, I have "been there" personally: In 2009 and 2010, I underwent two years of treatment for cancer.

Over the past six weeks, I have tried to get the "beat" of this wonderful Victorian Parkinson's community. I've been listening to and learning about the wisdom held by medical people, and by individuals and families, and paying attention to the value of what's already here.

I have met people living with Parkinson's like retiree Heather Jobling. Heather is turning 70 later this year and recently fulfilled a dream of skydiving from a plane! Along the way, she wanted to raise awareness and funds to support our work. Having Parkinson's has not slowed her down. You can read more about Heather on page 7.

Art teacher Anne Atkin coordinates and runs our **Painting with Parkinson's** classes. Anne has recently published a book of cartoons on the challenges (and lighter side) of living with Parkinson's, and she is now working on a second.

I have met volunteers who have given up their time to be Ambassadors or who have "tin rattled" at local train stations.

Six weeks in, I know that we have insufficient services to adequately support people right now. Our Health Team boasts two experienced professionals, including one nurse, who take calls for assistance from across the whole of Victoria; around 20,000 people in need *directly*, and many more *indirectly*. In contrast, in the UK, for every 300 people living with Parkinson's there is a dedicated nurse specialist. We are pleased to advise that a third team member joined us earlier this month (we introduce her on page 2).

Our health team answers more than

40 calls for assistance every day. Our website receives more than 12,000 hits per month. Our staff deliver more than 100 education sessions per year to the community and health professionals. And, we have 47 affiliated Support Groups across the state who provide peer support to their local community and who assist members in their Parkinson's journey.

People need and want education and support. We need your help to continue our work providing these services. There are a number of ways you can show your support and help us to make a difference, **every day**. You can read about upcoming events and activities on page 12.

Six weeks in, and I've also learnt that the incidence of Parkinson's will increase by approximately 15 percent over the next five years. Parkinson's Victoria wants to ensure that it delivers high quality services **today** – and **every day**; to pay attention to what is important, to build resilience and sustainability, and to educate and provide support wherever and whenever it is needed – **now, and in the future**.

You can also help us grow by writing to your local Member of Parliament. Tell them the problems you have finding services, about the costs of medications and lack of respite for carers in your region. Tell them about the difficulties you have with the local hospital, getting medication on time and the lack of movement disorder clinics. The official time horizon for politicians doesn't extend beyond what will happen after the next election. As a community, we can expand their time horizons and reinforce the need for action, and expose their assumptions about people with Parkinson's to some fresh air and a new way of thinking.

I started this piece by saying that I hope **Signpost** will be a place of creative conversation. **Let us know what you want**. If we know the stories and the issues, we can assist you to advocate for and access improved services, deliver the information you want and need, support your local community with awareness and education for health professionals, and ultimately improve the lives of everyone living with and affected by Parkinson's.

If you would like to join the "conversation", please call: 1800 644 189 or email info@parkinsons-vic.org.au with your thoughts, comments, concerns, feedback and support.

Ann Burgess, CEO

News & Highlights

One Step at a time

In April we launched our first ever donor newsletter **Steps**, providing donors and supporters with a snapshot of what Parkinson's Victoria has been up to and how we have been putting your financial support to work improving lives.

Steps will be a bi-annual publication and will be an important communication tool used throughout the year to inform supporters, prospective and current sponsors, corporate supporters, grant makers, partners, government and all interested members of the wider community. The publication has been extremely well received, with a number of readers prompted to make a donation. In addition, we have had a number of calls and letters of support from the community and a number of enquiries in response to information about our activities and events. If you would like a copy of **Steps** please contact our office.

You may be interested to know why we have called this publication Steps? We realise that our vision of 'A world without Parkinson's' is not going to happen overnight; it is a journey and we are in it for the long haul.

In the meantime, our every day work takes us one step closer by supporting research for a cure, improving quality of life and empowering individuals and families by providing support and information. And, just as we encourage you to add your voice and make some noise in the fight against Parkinson's, you can also add your footprint when we march to make a difference by joining us for Parkinson's Unity Walk on Sunday, 28 August!

New Health Team Member

We are pleased to welcome a new member to our Health Team, **Breanna Wotherspoon**.

In 2009, Breanna completed a double degree in Science and Law at the University of Melbourne, where she developed a strong interest in Health Education and Promotion. She pursued this interest last year when she spent 3 months working as a volunteer on HIV education in Kenya. As much as Breanna enjoyed living in a mud hut and being the only white person in the village, she is very excited to be back home and starting work with Parkinson's Victoria! Aside from her African adventures, Breanna has also worked and travelled around Europe and is now looking forward to spending more time seeing the sights here at home. When she's not gallivanting around, Breanna enjoys reading, cooking and cuddles with her cat Leopold.

As our dedicated Health Promotion Officer, Breanna will work closely with our Support Groups as Coordinator, working to assist and strengthen these important local peer support networks. She will also be involved in developing resources to improve general wellbeing in relation to Parkinson's. You may also get to know her as the voice on the "other end of the phone", as she will be assisting with day-to-day enquiries through our help line.

Breanna looks forward to creating greater awareness of Parkinson's in the community, and to helping people to live well with Parkinson's.

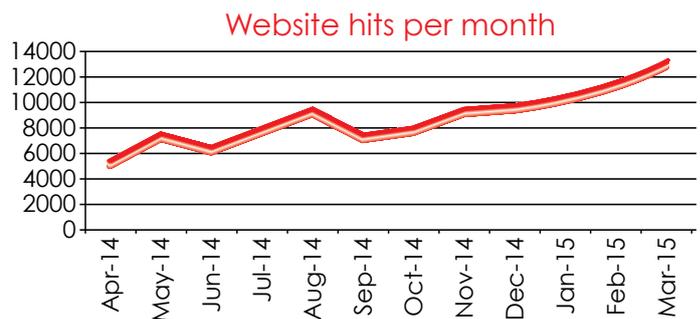
Another year over

The 2009/10 Annual Report of Parkinson's Victoria was published late last year. Members will have received a copy with the summer 2010 edition of **Signpost**. If you did not receive a copy or would like to, please contact our office.

At your fingertips

If you haven't checked it out yet, our website can be found at: www.parkinsonsvic.org.au

With two mouse clicks, you can access a world of useful information about "living well" with Parkinson's, from information for people recently diagnosed or from CALD communities, to news and resources about support options, advocacy initiatives and financial and legal advice, not to mention personal stories and information about fundraising and special events. Our **Help Finder** provides help on issues such as local support groups, counselling and support, aids and equipment and treatment options.



We utilise social media and new technologies to deliver the Parkinson's message and information to a wide audience, and we are always exploring new ways to communicate. You can see from the graph which tracks 'hits' (or visits) to our website that there has been a significant increase in visits to the site in recent months. This is likely a result of increased need by the community for relevant and credible information, but also to our efforts to ensure material is constantly updated, especially with topical and useful information and support news.

For example, thanks to our partner **Outlook Financial Solutions**, we've recently uploaded a series of financial information videos to the website. These have been developed specifically for people with Parkinson's and provide advice on issues such as accessing agencies like Centrelink and insurance companies.

We are also currently experimenting with "webinars", a way of delivering a seminar via the web. Read more on page 4.

Website: <http://www.youtube.com/parkinsonsvic>

Facebook: <http://www.facebook.com/parkinsonsvic?v=wall>

You Tube: <http://www.youtube.com/parkinsonsvic>

Medication side-effects class action

The potential for negative side effects occurring as a result of a certain class of Parkinson's medications has gained significant public attention in recent years.

Many of those who developed **Impulse Control Disorders (ICD)**, a desire to engage in pleasure-seeking behaviours and which typically manifest as excessive gambling, shopping, eating and hobbyism, as well as hypersexuality, have been unaware of the association between their ICD and Parkinson's medications. As a result, these people have been significantly affected by the consequences of their ICD.

In 2008, an Australian class action was initiated by lawyers on behalf of a group of people who had been placed on **dopamine agonist medication** and who developed an Impulse Control Disorder as a side effect. Now, lawyers are encouraging others to come forward. Specifically, anyone who was prescribed Cabaser or Permax in the late 1990's-2005, and who developed an ICD, and who believes they were not adequately informed of the potential side effects by their administering doctor are encouraged to join the class action.

To find out more please contact Catherine on (03) 9551 1122 or catherine@parkinsons-vic.org.au

New "on call" support service

The **Apomine™ Nurse Support Service (ANSSER)** is a national program composed of mobile, registered and Parkinson's-trained nurses.

The **ANSSER** Program provides vital nursing support services to clinicians, nurses and patients, both in-unit and out in the community, who are using or administering this medication*.

Nurses, patients, carers and related specialist care team members can call the free number: 1800 276 6463 to receive information and advice, and to further enhance patient care and outcomes using this drug. It also gives peace of mind to patients and carers.

The ANSSER nurse provides access to nursing support for patients and specialists in metro, as well as non metro and private centres who may not have previously been able to consider Apomine™ as a treatment choice due to the lack of nursing support.

The Apomine™ support service (phone line) is available during normal business hours only. The service can only be engaged by patients who are currently on active Apomine™ therapy.

***Apomine™, a Dopamine Agonist medication for people living with Parkinson's, is usually delivered via an infusion into the skin and is an alternative to some oral medications. It is usually prescribed for those who have had Parkinson's for some time (advanced Parkinson's). Dopamine Agonist-based medications minimise motor fluctuations and reduce "on-off" symptoms (read more on page 9).**

STOP PRESS: Parkinson's Victoria moving to a new home

After almost 15 years in our current office on the Kingston Centre site in Cheltenham, we are excited to share the news that we will soon be moving to new office space at 8B Park Road, Cheltenham.

These offices provide greater accessibility for visitors and the general public as the building has street frontage. Cheltenham train station (on the Frankston line) is also just a short walk away, and there is a bus stop literally outside our new front door (Westfield Southland is a short bus ride away)

While we aim to be in the new premises as of 1 July, please bear with us as we settle into our new surroundings. Our priority and commitment is to ensuring that delivery of our services and responding to your requests and enquiries is not compromised during this period.

We will be hosting an Open Day on Monday 1 August at the new office. We look forward to seeing you then and in the future.

Our current phone numbers will remain the same in the new building.

**Our postal address will be: PO Box 2606, Cheltenham, Victoria, 3192
Street address: 8B Park Road, Cheltenham, Victoria, 3192**

Share your story

Are you living with Parkinson's or caring for someone who is? Are you keen to share your experiences and help people better understand what it is like to live with Parkinson's? We want to build up a 'bank' of people living with Parkinson's who are happy to share their story and who represent our diverse community.

- As part of our daily operations we liaise with media to increase awareness about Parkinson's.
- We also respond to media requests for specific news stories about living with Parkinson's.

By publishing personal experiences in **Signpost**, in the media, on our website and through our Ambassador program, we aim to highlight Parkinson's as a condition that impacts on individuals, families and the wider community. In this way, people can more closely relate to the diverse challenges faced by someone living with Parkinson's.

These activities form part of our mission to educate the public, advocate and support those living with Parkinson's, and to improve the lives of everyone affected by this condition.

Everyone has a story and every personal story is empowering. Yours could also be enlightening and beneficial to others. Please consider sharing your experience.

**You can send your story to:
judith@parkinsons-vic.org.au**

Access, Advocacy & Assistance

Planning for the future

Financial planning is important for everyone, it helps you to face the future with peace of mind and make informed decisions. But when you have a health or medical concern to think about as well, it's even more pertinent to understand and consider your financial options. This need is heightened in the case of reduced independence and need for care. The team at Outlook Financial Solutions has put together some basic information to assist those providing long term care for a loved one plan for the future.

Providing for a future without you

A family member with a permanent disability presents a day-to-day challenge for their carers. And, depending on their medical condition, if they outlive their carer this presents a whole new set of challenges. Will they be provided for adequately when their carer isn't around? Where will the money come from and how can you be sure they'll receive it? In this article we look at a couple of ways you can set things up now so that in the event of your death your family member can continue to receive financial support long after you've gone.

Binding death nominations

These are nominations you can set up that legally bind the trustee of your super fund to pay your benefit to a specific person or persons in the event of your death.

If you don't have a Binding Death Nomination (BDN) in place, your super will be paid into your estate and there is a risk that it may not be distributed as you'd intended. To give you greater certainty about who receives your payout, a BDN gives you the opportunity to nominate who will receive your super. It can also provide a more tax-effective way of distributing your estate. Setting up a Binding Death Nomination is straightforward. Talk to your super fund to get things started. If you have more than one super fund, this may be a good reason to consolidate your super into one fund, along with the fees you'll save.

Reversionary pensions

You can also choose to have one of your dependants as your reversionary pensioner in the event of your death. This means that when you die, your super fund will continue to pay the remaining balance of your pension account, as a pension, to the person you have nominated. You must nominate your reversionary pensioner before your pension commences and nominations can generally not be changed once your pension begins. You can only nominate a child as a reversionary pensioner if they are either:

- between age 18 and 25 and financially dependent on you immediately prior to your death;

or

- permanently disabled

Once your child reaches 25, any remaining balance would then be paid as a lump sum amount, unless

they are permanently disabled. If this is the case, it will continue as a pension until it runs out.

We don't like to think about life after us, but when someone in the family needs lifelong care it's important to put some things in place for them when we're no longer there for them.

This information was provided by Outlook Financial Solutions who specialise in finding solutions to help people achieve their goals - regardless of their current financial circumstances, or stage they're at in life. This covers anything from advice on one small issue, through to a complete investment strategy, or a full financial plan.

For more information, call 1300 657 872 or visit www.outlookfs.com.au.

Disclaimer: This publication has been prepared for general information and has not considered any particular person's investment objectives, financial situation or needs. Accordingly, no recommendation (express or implied) or other information should be acted on without obtaining specific advice from an Authorised Representative of Outlook Financial Solutions Pty Ltd. (ABN 40 083 233 925, AFSL 240959).

Financial information seminars

Parkinson's Victoria and Outlook Financial Solutions (Outlook) invite you to attend a free Seminar or WebCast to learn about important financial considerations for people living with Parkinson's or caring for a close relative with Parkinson's.

(A WebCast is an online, interactive session where you can participate in a live seminar with an Outlook adviser, all done from the comfort of your own home, or office computer - wherever you log in).

We are hosting WebCast and Seminar sessions on one important topic, Managing Your Financial Future. It's easy to be involved.

To register your interest or find out more about these sessions contact Parkinsons Victoria.

Proposed dates, times and locations:

WebCast: (Approximately 25-30 minutes)

- **Tuesday 14 June 2011, 12.30pm or 7.00pm**

Seminar: (Approximately 1 hour, plus light refreshments after)

- **Tuesday 21 June 2011, 6.00pm start – Hawthorn**
- **Tuesday 5 July 2011, 6.00pm start – Maribyrnong**

Outlook Financial Solutions

We are pleased to announce that we have partnered with **Outlook Financial Solutions** to provide you with access to high quality, professional financial advice.

Visit youtube.com/parkinsonsvic for an insight into important financial issues such as managing **cashflow, superannuation, insurance cover and government benefits** for people living with Parkinson's.

Access, Advocacy & Assistance

The power of one

The Parkinson's community is dynamic and robust. And, we are only getting louder, stronger and more visible. The "noise" we are making comes from individuals who have been diagnosed and their families; children, parents, siblings, friends, workmates, support groups, community groups, business owners and employees who have been touched by the impact of Parkinson's.

Every individual member of 'our community' can play a valuable role in making a difference, not just in their own lives, but for the greater community and future generations. Whether we are simply trying to get through our own daily challenges or we are thinking "big picture", every action has the potential to create significant and positive change. Here, SHARON BENSTED shares why joining the fight against Parkinson's is important to her, and how you too can get involved.

"My name is Sharon Bensted and I am 40 years old. When I was 31, I was diagnosed with Young Onset Parkinson's.

People tell me at 40, my life has just begun. I reply by telling them that my life began at 39, and it just keeps getting better.

Last year (when I was still 39), I decided to tell my story via video and I entered it in the **2010 World Parkinson's Congress** (WPC) video competition. Soon after, still at age 39, I found myself at the Congress in Glasgow, meeting many of the 3,000 attendees who are living with, caring for or working with people with Parkinson's.

A lot of the people I spoke with had seen my film and been inspired by it. I had reached out to people without realizing how much impact a little bit of positivity could have. To me, telling my story was a small act, but it had affected so many. I realized that everyone is capable of making one small act that can positively affect many, and I want to tell you how.

The **Global Parkinson's Pledge**

www.parkinsonspledge.org was launched in 2010 at the 2nd World Parkinson Congress in Glasgow, Scotland. Its aim is to build a global Parkinson's movement, make Parkinson's a priority health, social and economic issue around the world, and to help advance the search for a cure. The goal is one million signatures by the next World Parkinson's Congress in 2013.

Your small act is to sign the pledge and encourage everyone you know to do the same. You may think that the simple 30-second act of signing an online pledge won't have much effect, but never underestimate the impact of using your **voice**. Without your support, the pledge will not grow. At the time of writing this, 8823 people have



Sharon Bensted with daughters Leah, Claire and Sarah.

signed the pledge (yet there are around 6.3 million people living with Parkinson's worldwide!). These are people like you and me; people who are positive in their belief that people with Parkinson's deserve adequate health care, that they should all have access to support, and that research should continue the search for a cure.

Last year, my positive outlook left its mark on many people in Glasgow and soon after I arrived home, I made a short video on why I signed the pledge. Shortly after I had entered this second video in the **World Parkinson's Congress** pledge competition, I was asked to become an Australian ambassador for the **2013 World Parkinson's Congress**. Once more, I saw the impact of staying positive. As an Ambassador, I will be speaking to as many people as I can about the benefits of attending the 2013 WPC Congress. Attending the congress changed my life. I know that if you go, it will change yours. It was informative and inspiring and I became empowered to advocate for others who are still finding their voice. Please take this opportunity to sign the pledge, have your voice counted and make a difference. If you want to make a positive impact, please sign the pledge, and encourage others to do the same. You have a voice, Australia has a voice and the world is listening."

- **If you would like to see my story, go to <http://www.youtube.com/watch?v=nHOMSSYPoec>**
- **To watch my pledge video, go to <http://www.youtube.com/watch?v=oAeanwuc5nc>**
- **To use your voice, please sign the pledge at www.parkinsonspledge.org.**
- **To find out more about the World Parkinson's Congress 2013, go to www.worldpdcongress.org or feel free to contact me at Parkinson's Victoria: info@parkinsons-vic.org.au**

Personal Reflections



Living with Parkinson's changes things. For better, and worse. It opens eyes and hearts. It motivates and challenges. It prompts decision making – often tough decisions, well ahead of time. MARC BILLING (left) recently wrote to us about the myriad changes that he has gone through – and continues to, since being diagnosed. He was keen for us to share his story with you.

In 2001, aged 41, I noticed my little finger began to bounce. It would stop when I flexed my hand or was asleep. I went to a doctor, who sent me to a neurologist. "It could be a familiar tremor. Come back in 6 months." "Let's do an MRI on your brain to be safe." (My mum has Multiple Sclerosis and my father died of a brain tumour. As a family, I consider us a neurological disaster!).

Six months later, I had self-diagnosed Parkinson's (PD or *Parky* as I call it). The doctor, after some physical tests to assess my walking and reflexes, agreed.

One of my first reactions was to try and get fit, so I took up swimming. Unfortunately, as *Parky* got worse, I found swimming in circles or into others was not very helpful. Now, walking the dog is a little easier.

Early days in my diagnosis, *Parky* was little more than a discomfort that seemed easily overcome. The medication seemed to work well and it was a minor inconvenience. I could not understand what all the fuss was about. However, it became clear that I was not the same as I used to be.

I used to pride myself on my quick mind, but suddenly it seemed like my head was in a cloud. One person who had not seen me for some time thought I had suffered a stroke.

My Deep Brain Stimulation (DBS) operation helped me emerge from that cloud. But, I can see now that the constant movement disorder put enormous strain on my general wellbeing.

Because I have learnt so much about the disease (through Parkinson's Victoria and the Internet), I am really surprised how little is known about it in the community and hence – regrettable but not surprising – is the lack of government funding and support.

I began to get involved in the **Young @ Parkinson's (Y@P)** support group around 2006. My first motivation was simply to find out whether or not I could still ride my motorbike. One of the members had a Harley – so I sought him out and asked if he still rode. He looked at me as if it was an absurd question, and said "No".

I saw people whose symptoms were much more advanced than mine and I swore I would not be like them. I was different. How wrong I was.

Since then, the group has become incredibly important to me. I can sit with people my age and know they understand something of what I feel and struggle with every day.

A disease like *Parky* puts enormous strain on relationships, and financial, social and intimacy concerns are still very real issues for me.

The danger of *Parky* is that it can be like a jealous lover; it never quite lets you go, it is very dependent on you, and can cause you to be very self-absorbed.

My wife has had to put up with this for a long time and to her credit she helps me to focus on the needs of others (not just my own).

I have found it extremely important for my self-worth not to give up being with and helping others. These days I am involved in my bike club (**God's Squad Christian Motorcycle Club**), even though I ride very little these days. And, last year, my church asked me to manage the Christmas gift giving. I believe it was this short, simple period of volunteer work that was the beginning for me of "getting my mojo back", my enthusiasm for life.

Soon after this, I applied for a position leading a team who help people with disabilities get jobs. (A year before I was Managing Director of a welfare organisation. It was my dream job. Then, just before my DBS operation and with much regret, I accepted their offer of redundancy (after a stressful period when they tried to terminate my employment). I do miss the cut and thrust of working for that organisation and while I have moved on, it took me a year to do so.)

Since my diagnosis I have

- Successfully managed an overseas trip (with my wife's help) including being patted down in every airport as the magnetic fields can cause my DBS stimulator to turn off.
- Battled - and now have under control - several addictions including gambling, as a result of taking certain Parkinson's medications.
- Fought off a golden staph infection
- Ridden a motorbike again after giving riding up and selling my motorbike
- Continued to raise 3 boys (as best I can)
- Continued my religious journey
- Stayed with my partner, despite the struggles of *Parky*
- Learned to cope with the "flapping about" of dyskinesia

Ten years, three neurologists and one DBS operation later, I have now made *Parky* my friend, rather than my enemy. We're not on talking terms all the time, but I know that, unless a miracle occurs (which we all hope for), I must learn to share my life with *Parky*. *Parky* is a bit like religion, sex, and politics: extremely personal. But, I do not apologise for talking about any or all of these in this article, as this is who I am.

Editor's note: Mark would like to thank the following for their support: wife Paula, Young@Park founder and Coordinator Karyn, Neurologist Richard and his practise nurse Mary.

Reaching for the skies!

Jumping for Parkinson's

Former nurse and grandmother, Heather Jobling believes that being diagnosed with Parkinson's doesn't mean giving up on life and living. Neither does turning 70, which she will do later this year. To prove the point, Heather took to the skies... with the aim of planting her feet firmly back on the ground!

To get from "A" to "B", Heather and best friend Rosemary Murphy literally plunged to earth in April, in a 220km freefall during a tandem skydive at Melbourne Skydive Centre.

They were joined by Denise Perkins (from Parkinson's Victoria) and Shane Murphy, from our **Young at Parkinson's** group and who also has Parkinson's. Along the way, the fearless foursome helped raise awareness of Parkinson's with the wider community and raised \$10,500 (and counting) to contribute to research in the field of Parkinson's and assist us in our everyday work supporting people living with the condition. This far exceeds their original goal of \$5000 and equates to around \$3 for every metre they fell!

Heather, who was the 'brains behind the idea', felt the jump was the perfect way to celebrate her forthcoming birthday milestone, while highlighting that life with Parkinson's can still be full of adventure.

Heather and Rosemary were interviewed twice for their local newspaper, Hobson Bay Leader (including a fantastic front cover story and photo!), and the story even prompted complete strangers to make a donation in support.

While each Jumper contributed to the fundraising effort, it was Heather who really drove things. The personal approach was extremely important to Heather when asking for support and she visited local businesses in person, put up flyers about the activity in her local community, and arranged for collection tins to be placed in various retail outlets.

While the dive was originally planned for 9 April (to mark World Parkinson's Day, 11 April), bad weather on the day meant the fearless foursome had to dive on different days, but we're pleased to report they all landed safely on the ground!

(From the Hobsons Bay Leader, 8 March, 2011)
"I was in denial about [being diagnosed] for about two years and I couldn't talk about it...Then I realised I still had a life to live, with children and grandchildren and I was going to enjoy it for them," Said Heather. With the help of Parkinson's Victoria, husband Michael, her family and friends like [Rosemary] Murphy, [Heather] is now living life to the full. "I really see life as a gift and when something happens that isn't part of the plan, like what's happened to us, you have to make the most of it," she said.

And, after the jump...

(From the Hobsons Bay Leader, 26 April, 2011)
"[Rosemary and I] had an absolute ball...It was the most fun experience...I didn't feel nervous at all, even though I was sitting right by the open door of the plane... As we were leaving the plane, the suddenness of it took my breath away for a moment."

Congratulations to Heather, Rosemary, Shane and Denise on meeting this adventure head on! And thank you for such a fantastic job raising awareness and donations to support our work.



Heather Jobling before and after her 3000m fall: being suited up; a grateful hug with her skydiving co-pilot; happy landings and back on land!

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Living well

Stress, Anxiety and Parkinson's

Everybody gets stressed or anxious at times, it's part of modern living. But sometimes the experience of anxiety can be extremely distressing. Psychologist LOUISE COOPER is the Program Co-ordinator at the Anxiety Recovery Centre Victoria (ARCVic) and has researched the psychosocial aspects of Parkinson's for her doctoral thesis at Swinburne University.

Anxiety can affect relationships, can interfere with doing the things that you want to do and it can make life thoroughly unpleasant.

Anxiety Disorders are the most common mental disorders affecting Australians. Around one in four Australians will at some stage in their life suffer from an anxiety disorder. Most Anxiety Disorders have a chronic course, waxing and waning throughout the life span, with onset usually around early to late adolescence.

Living with Parkinson's involves a lot of unknown and unpredictability, so it's not surprising that many people with Parkinson's also have difficulties with anxiety, whether they had a pre-existing condition or not. Excessive concern about what might happen or what people might be thinking about you are common features of anxiety. Sleep disturbance and an inability to concentrate are also par for the course with anxiety.

As a society we have tended to define people with anxiety as 'stress heads' or 'worry warts'. This implies that anxiety is part of their personality and can't be changed. However, there is growing recognition that anxiety disorders are conditions that can be treated and, over time, people can learn how to manage their anxiety and stop it from interfering with their lives.

Unmanaged anxiety is unlikely to help Parkinson's symptoms. In fact, some of the symptoms of anxiety may be confused with Parkinson's symptoms. Learning about anxiety and how to manage it may therefore be part of learning to live with Parkinson's.

GP's, books, counsellors, psychologists and psychiatrists can all be part of the learning process. To find out more contact the Anxiety Recovery Centre of Victoria's Information and Helpline on 1300 269 438 or contact the health team at Parkinson's Victoria.

Anxiety Workshop

Psychologist Louise Cooper is facilitating a special workshop series for people with Parkinson's and family members on **Managing stress and anxiety** on behalf of Anxiety Recovery Centre Victoria.

The program, which will include 6 consecutive, two and a half hour sessions (1.00-3.30pm) from Wednesday, 27 July – 31 August, 2011, will take place at the **Centre for Emotion Focused Practice** (Level 1, 102 Toorak Road, South Yarra). The cost for the 6-week program is \$180.00 and Medicare rebates are available.

To register your interest in attending this group, please contact Catherine Watson from our Health Team: (03) 9551 1122 or 1800 644 189 or email catherine@parkinsons-vic.org.au

On the road again

On Wednesday 4 May, our health team presented its first Regional Parkinson's Allied Health & Nursing Seminar in Bendigo!

A similar seminar run in Melbourne late last year was a great success, and we were pleased to take this multidisciplinary learning opportunity out to one of our Regional support areas.

Keynote speaker, Dr Kelly Bertram, a neurologist with a special interest in dystonia, Parkinson's and other movement disorders, gave an insightful look into the pathology, diagnosis, prognosis and treatments of Parkinson's. Presentations from Mary Danoudis, a researcher at the Kingston Centre Movement Disorders Clinic and Coordinator of the Michael J. Fox Clinical Trials at the University of Melbourne, and Margarita Makoutonina, Senior Occupational Therapist at Cabrini Health addressed strategies to promote safety, improve mobility and maintain independence.

Victor McConvey and Catherine Watson from our Health Support Team completed the day with sessions on nursing care and social and emotional considerations.

The day was a valuable learning experience for all involved and we hope to be conducting more Parkinson's Allied Health and Nursing Seminars around Victoria in the future.

Special thanks to our keynote speaker Dr Kelly Bertram, and guest presenters Mary Danoudis and Margarita Makoutonina.

Medication & Symptom Management

Wearing off

In questionnaires about quality of life, respondents typically highlight the issue of “wearing off” as the symptom of Parkinson’s that most impacts their lives. Aside from the obvious physical impact, “wearing off” is also a symptom that is hard to detect and often under recognised by treating health professionals. Our Parkinson’s Specialist Nurse Consultant VICTOR MCCONVEY explains the condition, why it occurs and offers some useful tips for managing this symptom.

So, what is “wearing off”? Wearing off is a complication that occurs in some people who take Parkinson’s medications known as dopamine agonists. **Dopamine agonist** drugs are one of the main ways to treat Parkinson’s symptoms.

Parkinson’s symptoms are caused by a decrease in the levels of the chemical messenger **dopamine**, due to the death of the nerve cells in the brain that make it. This can make movement difficult. Dopamine agonist drugs act like dopamine to stimulate your nerve cells (dopamine receptors) and thereby reduce motor fluctuations (which negatively affect mobility and ease of movement)

Medication is taken at various intervals throughout the day, according to the individual’s drug regimen.

“I first notice that it is harder to write, and usually at the same time get the feeling that I need to stretch as I feel stiff, I also find it harder to concentrate.”

Wearing-off is a complication that can occur after a few years of using levodopa to treat Parkinson’s. During wearing-off, symptoms of Parkinson’s start to return or worsen before the next dose of levodopa is due, and improve when the next dose is taken. Many people refer to themselves as ‘on’ while their medication is working, and ‘off’ when the medication has worn off. The medication effectively tops up the dopamine levels in your brain for several hours providing a degree of effective symptom control. Because Parkinson’s is a slowly progressive condition, the symptoms experienced will change and develop over time. As dopamine levels in the brain gradually decline, dopamine – related medications have to work twice as hard to be effective, often being effective for shorter periods of time. When this happens, people may start to experience fluctuations in symptom control. Sometimes, wearing off is called the **fading effect** or **end of dose effect** and in Australia, the relevant drug-brand names for dopamine agonists are Sinemet, Madopar, Kinson and Stalevo.

“It a bit like the fog coming in, it becomes harder to think and doing more than one thing at a time is impossible”

In an “off” state, the person may experience an increase in their Parkinson’s symptoms and become

very stiff and slow. They may experience difficulty walking and may even be unable to move for a few minutes. Wearing off will also include some non-motor symptoms, such as feelings of anxiety and sadness, and in some cases, hallucinations.

In some cases, the “on-off” fluctuations are somewhat predictable. People know that the effects of levodopa when they can expect their medication to wear off and can plan accordingly. For other people, the “on-off” fluctuations are unpredictable, and this of course is the more dangerous state.

Wearing off is also an evolving symptom and the impact and effect of the phenomenon can be very subtle and may go unrecognised for some time.

Some of the symptoms include; tremor, difficulty with speech, anxiety, pain, stiffness, worsening balance, cloudy mind, panic attacks, lowered mood and fatigue.

If you are experiencing symptoms regularly it is important to speak with your treating GP or specialist, they may recommend changing your medications or drug regimen.

Why/When might “on/off” happen? Vigorous exercise can increase the body’s metabolism of dopamine medication, meaning it gets used up more quickly and can lead to “on/off” symptoms. In addition, certain foods (such as those with a high fat content) may alter the uptake of these drugs.

Some recent studies indicate that experiencing wearing off is related more to duration of illness, rather than the medications no longer working or having diminished effect.

Like many symptoms of Parkinson’s, people tend to experience wearing off in an individual manner. Increasingly, Neurologists are acknowledging that wearing off symptoms are more than simply a re-emergence of motor fluctuations such as tremor or stiffness, and further that non motor symptoms can be a significant symptom of wearing off.

To help identify wearing off, it’s important to have good awareness of your symptoms and the effects of your medication and there are a number of tools and resources that help, as well as making it easier for you to update your neurologist.

It’s important to remember that help is available if you are experiencing wearing off and the best person to help is your neurologist.

Wearing off can be easily managed and experiencing wearing off does not mean that your medications have stopped working; it is simply the body indicating that it needs a little more dopamine. Developing good medication habits and communicating these changes to your neurologist or treating doctor will ensure that wearing off is identified early and managed effectively.

Contact our health team on our free help line or email: info@parkinsons-vic.org.au if you have any questions or concerns about wearing off, medication or would like information about any aspect of living with Parkinson’s.

Massage magic provides relief

There is increasing evidence that massage contributes to the well-being of patients with Parkinson's over and above the obvious relaxation and stress release that is expected. JENNIFER DRUMMOND has been involved with the treatment of patients with Parkinson's for the past seven years, and has built her techniques around a thorough knowledge of medication, motor fluctuations and dyskinesias.

What are the benefits of Therapeutic Massage?

In general, therapeutic massage can have the following benefits:

- Exercise, stretch and loosen weak, tight, fatigued and atrophied muscle tissue to relieve muscular pain and tension, reduce spasms/cramping.
- Stimulate blood supply allowing lymphatic removal of toxins, pump oxygen and improve circulation.
- Ease pain and discomfort by calming the peripheral nervous system.
- Improve muscle and joint mobility through the lengthening of muscles which increases flexibility.
- Improve posture.
- Help release endorphins, the body's natural painkiller.
- Improve stress related symptoms, improving energy and concentration, enhancing sleep quality, reducing anxiety and fatigue.

Research

Research has shown massage to have significant, positive gains for those living with Parkinson's. In Atlanta, Georgia (USA), a controlled pilot study took place investigating the effects of Neuromuscular Therapy or NMT (massage which incorporates trigger point therapy) in patients with Parkinson's. 'Thirty-six people with moderately advanced, clinically stable Parkinson's were recruited over a 6 month period. All treatments were administered by the same therapist. Neuromuscular Therapy was chosen over other forms of body-work because it is a widely accepted form of massage. There is also a significant body of evidence to support the use of NMT in muscle relaxation, leading to relief of pain and spasm. The treatment relied on direct compression of trigger points to alleviate muscle pain and spasm. Gliding and lengthening strokes with moderate compressions were applied to muscle bundles in the neck, back and extremities.'

Results

All people completing the study reported a benefit from their treatment. Neuromuscular therapy significantly improved parkinsonian motor function by an average of up to 5 points on the Parkinson's rating scale, which was retained for 8 days after the last treatment. Tremor and slowness of movement (bradykinesia) were most responsive to the massage therapy. Other measures of movement function

significantly improved after the therapy, for example finger tapping (improved by an average 11 percent), fine motor skills (improved by 8 percent) and symptoms of anxiety also improved. No adverse affects were associated with the treatment'.

The results of this four-week study suggest that **massage therapy applied twice a week can significantly reduce parkinsonian disability. The effect of massage was not limited to a relaxation response, but provided additional health benefits in the form of improved sleep and circulation.**¹

In another study conducted by Touch Research Institute of Miami, along with staff from the University's Neurology Department, Parkinson's symptoms were reduced by massage therapy. In this study, sixteen adults with Parkinson's received two half hour massages twice a week for five weeks. They experienced improved daily functioning, increased quality of sleep and decreased stress hormone levels. These findings suggest that massage therapy enhances functioning in progressive or degenerative central nervous system disorders or conditions.²

This research suggests that massage, and specifically Neuromuscular Therapy can:

- Improve motor function, tremor and bradykinesia
- Improve fine motor skills
- Reduce anxiety symptoms
- Improve sleep
- Decrease stress levels
- Improve daily functioning

With the varying and changeable symptoms that Parkinson's presents, I am consistently encouraged given how well Parkinson's symptoms respond with therapeutic massage, especially when used to complement existing medical treatment.

Taking part in this form of regularly scheduled self-care will play a huge part in managing Parkinson's symptoms. Budgeting time and money for bodywork at consistent intervals is truly an investment in health and is likely to reduce problems that can be associated with this progressive condition. Consider massage appointments as a necessary element of your health and wellbeing plan. Consider therapists who have knowledge and understanding of Parkinson's and who will work closely with your Neurologist and medical specialists to establish a treatment plan that best meets your needs.

Jennifer Drummond is a qualified Massage Therapist with 17 years massage experience in the health and fitness industry. She has recently joined the team at Neurology Network Melbourne specializing in massage for Parkinson's.

To book an appointment with Jennifer phone Neurology Network Melbourne: (03)9500 8366 or contact our Health Team.

1. Lauren H. Craig, Anna Svircev, Michael Haber, and Jorge L. Juncos. Controlled pilot study of the effects of neuromuscular therapy in patients with Parkinson's disease Mov Disorder. 2006 Dec;21(12):2127-33.

2. Hernandez-Reif M, Field T, Largie S, et al. Parkinson's disease symptoms are differently affected by massage therapy vs. progressive muscle relaxation: a pilot study. J Bodywork and Movement Therapies 2002;6:177-182

Stepping out for Parkinson's

As the saying goes, the greatest journey begins with a single step. And on 8 August, 64-year old father of four, grandfather, and business man PETER CURTIN will set out to prove the point as he begins what will undoubtedly be the most challenging, but rewarding journey of his life – with just one small step.

Not only will it be the first step of thousands, as he begins the 840km Pilgrimage along the renowned **Camino de Santiago de Compostela in Spain** (otherwise known as The Way of St James), but along the way, Peter hopes to raise awareness of the challenges faced by those living with Parkinson's and, most importantly, he hopes to raise \$20,000 to support our work.

With apologies to Neil Armstrong, Peter says he hopes "one small step for a man, is one giant leap for those living with Parkinson's disease".

The irony of Peter's decision to use the simple activity of walking as the means to achieve his goals is not lost on those familiar with Parkinson's: Parkinson's is a progressive, neurological condition for which there is currently no cure and which affects an individual's ability to move freely and with control.

Inspired by a long-time friend who was diagnosed with Parkinson's in 2009, Peter has committed to undertaking the formidable walking track that has inspired and challenged thousands before him.

"For me, this is a way to assist Parkinson's Victoria in providing important support services and help to people living with this disease.

The Camino de Santiago de Compostela is actually a collection of old pilgrimage routes that take one the breadth of Northern Spain.

Peter will extend his route, as others have, to conclude in Finisterre, considered in medieval times as the end of the world - making a total of 840kms, and which Peter hopes to complete in approximately four weeks and four days.

In the lead up to his departure, and along the route, Peter will be keeping supporters updated with regular emails and photographs.

"A small donation of just 10 cents per kilometre that I walk means \$84 donated to Parkinson's Victoria" says Peter. "I'm more than happy to do the hard yards [walking], if everyone else is prepared to put their money where my feet are!"

As Peter explains, "knowing people have literally supported me every step of the way, and knowing that each step I take means another dollar to support the work of Parkinson's Victoria will be a constant reminder that this is not just about me."

Make a donation to

http://www.everydayhero.com.au/peter_curtin

Interested in joining Peter on his *Walk for Parkinson's?*

Contact: (03) 9551 1122 or judith@parkinsons-vic.org.au

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Fundraising & Events

Grandparents Wanted

"Generations – Their Story" is the first in a series of beautiful hard cover, limited edition coffee table books showcasing Grandparents and their extended families. It is a wonderful opportunity to capture your special loved ones, alongside a story of their life, loves, treasured memories and words of wisdom that will be recorded forever to be passed down in your family and along the way, to make a real difference to others.



Grandparents Wanted

We are looking for grandparents and extended families to be included in a unique coffee table book

'Generations'



Your \$75 participation

fee (which guarantees your inclusion in the finished publication) **will be exclusively donated directly to Parkinson's Victoria!** We have partnered with **Ella+Friends Photography** to produce this professional publication that will become a beautiful family keepsake and a stunning presentation book. Ella+Friends Photography has already published six gorgeous books: **Kids of Bayside and WOOF!** The popularity of these books raised over \$70,000 for other charitable causes. We believe **"Generations – Their Story"** will be even more popular and we hope to raise in excess of \$10,000 from the sale of this **first limited edition publication.**

So, gather the eldest of your Generation, involve the extended family and be part of this once in a lifetime opportunity. Registrations will fill quickly and close on 30th June 2011. Contact the friendly team at **Ella+Friends Photography in South Melbourne today: (03) 9095 8200.**

One for the kids – big and small!

Kick off the winter school holidays with a bang! Join us for a charity movie screening of **Cars 2** (Disney Pixar's follow up to the original smash hit). We've kept ticket prices low so everyone can attend this event and support Parkinson's Victoria: \$18 per person includes refreshments. There will be some great raffle prizes to win too!

Cars 2: Sunday, 3 July, at Palace Dendy Cinemas, Brighton at 10.00am. Purchase tickets online: <http://www.trybooking.com/MMX> or call us at the office.

A vine romance

Gisborne Peak Winery is stunning vineyard located just out of Melbourne (20 minutes from Tullamarine Airport) and throughout the month of August they are offering a special on their **Adopt-a-Vine™** program.

Fifty dollars from every vine "adopted" during this month (RRP\$75) will be donated back to Parkinson's Victoria when you mention our name! What a great gift idea – perfect for Father's Day (Sunday, 4 September).

Adopt-a-Vine™ is fun, yet educational too. Adopt a red or white grape variety (adoption rights are for three years) and receive an Adoption Kit with information and pictures. You'll also receive:

- Personalised Hang-tag (on the vine) and *Adoption Certificate*
- Adopt-a-Vine® Newsletters
- Order personalised wine labels
- **Hands-On Days** in the Vineyard (including the chance to prune your vine in winter, with a lesson from the vineyard manager, of course, and pick the grapes from your vine at vintage)
- A 25 percent discount on wines purchased (for the three year period)
- First notification of wine specials and events
- Option to receive a bottle of wine from the grapes where your Adopt-a-Vine® is located.



www.adoptavine.com.au;
www.gisbornepeakwines.com.au

Pizza & Wine Fundraiser

Join us at **Gisborne Peak Winery** on Sunday, 6 August for a wonderful family day amongst the vines and a special fundraising event.

Enjoy wood fired pizza (made fresh in the on-site oven) and a glass (or two) of the local drop, with a percentage of proceeds to Parkinson's Victoria. There'll be some great surprises and prizes up for grabs, and a stunning artwork by Helen Cottle will be raffled on the day.

Fundraising & Events

Party for Parkinson's

We know you're already familiar with **Tupperware's** innovative product range, but did you know Tupperware can be a fantastic fundraising activity!?

We've recently been approached by two lovely Tupperware Consultants – Trina and Letetia (who each have a close family member living with Parkinson's, so the cause is one close to their hearts), who are keen to help out by conducting **"Tupperware Parties for Parkinson's"**.

How about **"Taste of Tupperware"** to learn about Tupperware's baking range? Or an **"Outdoor Party"** with the fantastic range of picnic essentials and BBQ products to make outdoor dining, trips to the beach/races/park or camping hassle free!?

10 percent of all sales from your Tupperware Party for Parkinson's and \$10 for every party booked on the day is donated to Parkinson's Victoria. Orders can also be taken over the phone (you don't have to attend a party)! Contact Parkinson's Victoria and we'll put you in touch with Trina or Letetia.

Sharing the love

Whether you're celebrating a birthday, hosting a special event or taking on a personal challenge (like sky diving, shaving your hair or going a month without chocolate!) you can help us to provide **Help for Today and Hope for Tomorrow** by asking your friends, family and workmates to support your fundraising efforts.

Create and personalise your own online fundraising page, choose a fundraising target and send the webpage link to your network.

In fundraising for Parkinson's Victoria, you're also becoming an Ambassador for the Cause. We encourage you to share your story and why supporting the fight against Parkinson's is important to you.

You can also commemorate and celebrate the life of a loved one by creating an online **"In Memory of..."** Tribute Page in their name, and request donations to Parkinson's Victoria. You may like to create an **"In Memory of..."** Tribute Page to commemorate the anniversary of their passing or special occasion in this person's life, such as their birthday.

We thank you for thinking of others at this time.

Community and In Memory Fundraising for Parkinson's Victoria is easy and can be as personal as you want it to be. Create your own fundraising page at www.everydayhero.com.au (search under Charity for PARKINSON'S VICTORIA).

Turn up the heat

Come along and support Parkinson's Victoria at Bunnings Moorabbin on Sunday, 7 August. Tick off some DIY tasks and grab a snag, while meeting some of our team of volunteers and of course, supporting a great cause!

Corner Fairchild and Warrigal Roads, Moorabbin.

Christmas in... June?!

To make way for new stock and for a limited time only, we're pleased to offer a special price on last year's Christmas cards. Purchase packs of 10 (mixed designs only, with envelopes) at the discount rate of \$7.00, including postage. These cards are in perfect condition (they are NOT damaged stock).

Our new range of Christmas cards will be on sale from August (online orders welcome!).

A great read

The **2011/12 Greater Melbourne Entertainment Book** is now available from Parkinson's Victoria. Still just \$65 (\$13 of each book sale is donated to Parkinson's Victoria), and still great value with discounts and special offers across food, retail outlets, accommodation, and sports and leisure activities.

Contact our office for your copy today and start saving!

Back To the Movies

Great Scott! You're invited to a special 25th anniversary exclusive screening of one of the most popular movies of all time!

Following similar celebrations around the world, it's Melbourne's turn to **hit 88 miles per hour and come 'Back to the Future' at this exclusive charity screening of the original classic, hosted by Parkinson's Victoria.**

Be part of the red carpet glamour and meet some of the 'stars' of the film: the DeLorean, Doc and Einstein. Plus a huge collection of film props and memorabilia. (Unfortunately we haven't been able to confirm Marty McFly, a.k.a Calvin Klein, a.k.a Michael J Fox!). Great prizes up for grabs too, including best costume!

We can't confirm the date just yet... but it's likely to be in September to coincide with National Parkinson's Awareness Week. Register your interest by emailing judith@parkinsons-vic.org.au and be first in line to secure your tickets to this exclusive event! Tickets available **online soon.**

Bloomin' Terrific

Last chance to see our stunning Parkinson's Victoria logo adding a bit of colour to the lives of city pedestrians! Check out the floral bed located on St Kilda Road, at the base of the path leading to the Shrine. The bed will be changed in the coming months to feature another charity.

Thanks to Parks Victoria for such a great job!

And don't forget our annual National Parkinson's

Awareness Week tin rattle at a train station

near you on Thursday, 25 August.

Ambassadors

Our Ambassadors play an important role sharing their story with the wider community, with the aim of increasing awareness, reducing stigma, and debunking the myths and about what people think Parkinson's is, and isn't! New Ambassador, JUDY PHELAN (below) shares some of her story with us for Signpost.

Life with Parkinson's is not all doom and gloom. Sure, there is some of that. Okay, maybe I lied. There is a lot of that, but there is plenty on the bright side of things too. One of these has been becoming an Ambassador for Parkinson's Victoria after I attended a workshop in 2010 for people interested in taking on this role.

I've gained the confidence to speak to groups, not only about my story but to educate listeners about the various aspects of Parkinson's such as symptoms.

Another 'bright side' has been unexpected donations to Parkinson's Victoria following my presentations. Learning to use a laptop and digital projector has also been a bonus and I gratefully acknowledge the Rotary Club of Oakleigh, which allows me to borrow this equipment when I do a presentation.



My first "gig" (in August 2010) was actually for the Rotary Club of Oakleigh where my husband, Ian, is President. Some might think that would make it easy, but knowing the audience can actually make me a little more nervous. I guess I could say that I was both nervous and anxiously excited at the same time. Once I had set up, with Ian's help, a Club Member advised that he wanted to videotape the presentation. That made me even more nervous and during the presentation, as I happened to become fairly "jiggly", he had trouble keeping me in view! In hindsight, having a DVD of my talk was quite beneficial to review later to see what needed improvement.

I have since done another four presentations (to large and small groups) and as much as the Parkinson's facts and figures remain the same on the PowerPoint display, the way I portray them and "my story" depends on the way I am feeling at the time and the way the audience responds. Also the time

allocated can vary from 20 to 60 minutes, and as I feel quite comfortable telling "my story" now, I can reduce or expand this as required. I find question time quite interesting and rewarding as well.

They say that after a diagnosis of Parkinson's, the first 10 years are the best. I was 53 when diagnosed and I am now 63 (My husband Ian and I have been married for 42 years). Ian is a wonderful carer, although, as he is currently recovering from prostate cancer, we had a carer-role-reversal for a few weeks after his operation.

Ian is usually my trusty assistant when I do a presentation. He likes to control the remote for the PowerPoint display, and this not only keeps me on time with my talk, but if I am suffering dyskinesias at the time, I usually drop it anyway!

My life (or I should say **our** life) changed on 16 December, 2000; it was the day I was diagnosed with Parkinson's.

Prior to being diagnosed, I had run a catering business for 25 years, specialising in functions on trains. We often worked 7-day weeks and very late hours and I would sometimes wonder how I would get off this merry-go-round.

A few months before I was diagnosed, I had told my doctor that I had a "dicky elbow". I thought I had injured my right elbow because I was favouring it and it didn't swing when I walked. Whisking an egg, cleaning my teeth and even writing were awkward and I wondered why my runners were "clompy" when I went for a walk. I had never put these problems into one basket until I was diagnosed.

I will always remember the first things I said to the Neurologist: **"I am glad something has happened to make me stop"; "Is it hereditary?"; "Does it affect your sex life?"**

I knew *nothing* about Parkinson's. I had been involved with the Multiple Sclerosis (MS) Auxiliary for 25 years, so I knew all about MS and thought *that's* what I have!

Ten years on and the words of my favourite singer Judith Durham are an inspiration to me... *"The very longest journey must begin with just one step but you have to have a little dream to start, and then maybe someday you will find it's gonna be your turn, if you hold on to your dream within your heart."*

I have been asked to share with readers "what it means to me to share my story". Well I think what it means is that by talking about "my dream" it helps to keep it alive in my heart. I am passionate about my dream and I suppose my story is special to me and I hope my Ambassador presentation and story will inspire others to HELP Parkinson's Victoria today, so we can all HOPE FOR TOMORROW.

My story and my dream (which I made happen 9 years ago) will have to wait for another time!

Judy Phelan, Parkinson's Victoria Ambassador

Actions speak louder than words

- Special thanks to Judy and Ian Phelan who generously donated a stay at their beautiful B & B accommodation **Between the Bays** (located near Cape Schanck) as a prize for the annual **Spring Valley Charity Golf Day** major raffle (Friday 27 May).

www.betweenthebays.com.au

- Big thanks to Dr Barry Vieira (from Joondalup WA) who kindly donated two "Gold Class" tickets to see the incomparable Bob Dylan in April. This is the second time Dr Vieira has supported us; late last year, he and partner Margaret Whiterod donated 2 tickets to see Leonard Cohen. These were raffled off during the National Young Onset Conference and raised \$350. This time we sold the tickets on eBay and raised \$250 – a bargain for young Kate and Rob who made the winning bid, and a great donation for us!
- We are currently in full swing organising a bigger and better Parkinson's Unity Walk on 28 August. Securing corporate sponsorship is critical and we've put together some fantastic sponsorship packages. To make the pitch, we've created a great sponsorship kit, and thanks to the team at **Action Replay**, it's complete with an evocative DVD capturing all the fun, faces, and emotion of **Unity Walk 2010**. Thanks to the Team at Action Replay for looking after us!

The support we receive from the community comes in many forms. In-kind donations such as these are greatly appreciated and make a wonderful contribution to our events and fundraising efforts.

Girls on film

Congratulations to Sharon Bensted for winning the **World Parkinson's Congress video competition**. The competition asked entrants to highlight the importance of the Parkinson's Pledge and encourage the world-wide community to add their signature to the growing list of supporters. Single mother of three Sharon is a worthy award winner, and an enthusiastic Ambassador in the fight against Parkinson's. She's also a terrific role model for living "well" and positively with Parkinson's.

Music to our ears

We received a wonderful donation recently, the proceeds of a musical afternoon organised by Jonathan Dods.

Jonathan is a musician and his father was recently

diagnosed with Parkinson's. After feeling a "little bit helpless", he realised he could channel his talent, his desire to make a difference **and** support his dad *all at the same time*. The result was a terrific afternoon of music at the Rifle Brigade Hotel in Jonathan's hometown of Bendigo.

Jonathan, thank you so much for sharing your talents to help the cause!



Jonathan Dods (under the blue and white umbrella) entertains the crowds during his recent musical fundraiser.

A special wedding gift

Juan and Emily Nolan (nee Nugent) invited people to make a donation to Parkinson's Victoria during their recent wedding celebrations.

Thanks, and congratulations to the happy couple!

A worthy drop

We are especially grateful to be the recipients of one of only 100 signed bottles of Penfolds Grange Hermitage wine which the Governor-General, Ms Quentin Bryce AC, was donating to charities for fundraising purposes. The as yet un-valued bottle will be no doubt be one of the most popular and exclusive items up for auction at this year's annual Tulip Ball event – an evening soiree in November, further details to be advised.

Special thanks to the Governor-General Ms Quentin Bryce AC.

A night with the stars!

Perspectives on Parkinson's (POP) founder and long term Parkinson's Victoria supporter Nerissa Mapes hosted a special screening of the film **Love and Other Drugs** at the St Kilda Open Air Cinema in February, which resulted in a donation of \$725 to Parkinson's Victoria. The film follows the life of Maggie (Anne Hathaway) who, like Nerissa was diagnosed with Young Onset Parkinson's.

Thanks Nerissa for your continued support and work as an Ambassador for the cause. And thank you to Alex of Media Development Partners and the team at St Kilda Open Air Cinema.

Education

New initiatives

The past few months have involved new partnerships and the development of some exciting initiatives in the area of exercise, education and wellness. SHELLEY POLLAK from our Health Team provides an update.

Parkinson's Victoria embraces a holistic approach to healthcare, one that explores the broader picture of wellbeing – physical, psychological and spiritual – and which empowers people to take an active role in caring for their health.

In this vein, we have been working on a number of initiatives that aim to educate and empower people living with Parkinson's, and health professionals, with the aim of improving quality of life.

The first initiatives are two DVDs aimed at people living with Parkinson's, as well as health care professionals who want to learn more about Parkinson's.

Movement Strategies and Parkinson's is an educational DVD that looks at the researched movement strategies developed by Professors Robert Iansek and Meg Morris of Melbourne's Kingston Centre. These strategies work by redirecting control of automatic, well-learned movements from the part of the brain called the Basal Ganglia (which are compromised in Parkinson's) to the conscious part of the brain called the *Frontal Cortex*.

These strategies are recognised as the gold standard for improving movement for people with Parkinson's and the DVD aims to explain the basis for these strategies and how to use them in activities of daily living.

The second DVD, called **Exercise and Parkinson's**, includes two different streams of exercise; one for beginners and the other for those with a higher level of fitness. By including two streams, we have tried to make the DVD accessible for **everyone** in the community.

This DVD has exercises that address strength and fitness, as well as flexibility and posture. There is also a special section that runs through some modified tai chi exercises for people who have good balance.

All exercises can be done safely at home, and provide people with a good starting point to introduce exercise into their daily routines.

The second exciting initiative we have undertaken is to start a **Tai Chi for Parkinson's** class. These classes are being run at Uniting Aged Care in Oakleigh, and are run by a Master Trainer in Tai Chi, in [conjunction](#)

with Parkinson's Victoria. The first "semester" filled up almost immediately and to date, all participants are enjoying it immensely. These classes not only provide a new form of exercise for people with Parkinson's, but are also challenging everyone in the class to think differently about how their bodies move, the energy within them and the benefit of exercising in a group.

Of course, it is not enough to start up just one class in Oakleigh! And, for this reason we have partnered with Dr Paul Lam, creator of the **Tai Chi for Arthritis Program**, to run a **Tai Chi for Arthritis and Parkinson's Leader Workshop** for allied health professionals.

This workshop is aimed at training health professionals in the community so that more Tai Chi classes can be run throughout the state, and subsequently more people can participate in this excellent form of exercise.

Our decision to partner with the Tai Chi for Arthritis Program was based on the fact that it is a modified version of Tai Chi and its benefits as a safe and effective way to improve strength, balance and flexibility in people with chronic health conditions have been well documented.

This workshop will be run at the end of May.

Finally, we have scheduled a follow up **Physiotherapy Seminar** for allied health professionals and are now taking registrations. The inaugural seminar held last year attracted 130 physiotherapists from around the country. Such a strong attendance clearly demonstrates that we were fulfilling a need in the educational calendar of Australian health professionals. We certainly hope that by improving the knowledge and skill base of physiotherapists, people with Parkinson's will receive better care and better outcomes from their treatment.

By continuing to support and provide professional education to physiotherapists around the country, Parkinson's Victoria is working to ensure that people with Parkinson's are receiving the best care possible.

We are very excited about these initiatives and hope that they lead to better treatment from health care professionals, as well as providing a wider range of options for people living with Parkinson's to take control of their wellbeing and make informed decisions and choices about how to "live well".

If you'd like more information about any of these initiatives or have an idea about a new initiative you think we should explore, please contact our health team: info@parkinsons-vic.org.au

“Service to others is the rent you pay for your room here on Earth.” Muhammad Ali. JOSPEHINE BERTHELEMY, our Volunteer Coordinator, highlights some great volunteering opportunities.

Bi-annual “Tin Rattles”

To coincide with World Parkinson's Day on 11 April, our biggest ever tin rattle (to date) took place on Thursday, 7 April, at several stations along Melbourne's metro train lines.

A record number of 69 volunteers helped out at city loop train stations, as well as Caulfield, Camberwell, Essendon, Newport and Glenroy. Thanks to Support Group Leaders Fred Van Ross and Judy Buckley (plus support group members and friends). Thanks also be given to volunteers from South East Water and MLC.

All-in-all, a total of **\$6527.65** was raised! A brilliant result and one which we hope to surpass in August when we do it all again!

A breakdown of stations is as follows: Flinders Street: \$1840.50; Parliament: \$1274.60; Flagstaff: \$1076.50; Melbourne Central: 322.25; Camberwell: \$982.50; Caulfield: \$559.05; Essendon: \$318.10; Newport: \$87.85; Glenroy: \$156.30

Bunnings Charity Sausage Sizzle

On **Sunday 7 August**, we'll be hosting another charity sausage sizzle, thanks to Bunnings Moorabbin.

These events provide us with an invaluable

opportunity to not only raise funds, but penetrate the local community and raise awareness about who we are and what we do, and we're looking for help volunteering on the day or sourcing product.

Parkinson's Unity Walk

This is the major fundraising and awareness raising vehicle for Parkinson's Victoria.

Since its inception in 2009, it has received overwhelming community support. In 2011, we anticipate a crowd of 2500 – 3000, which means we'll need even more registration staff and course marshals to help ensure things run smoothly on the day.

Behind the Scenes

From time to time we have various administrative jobs that need a helping hand, from filing, copying and collating, to envelope stuffing, Christmas card packing and general cleaning out or archiving of materials. This could be your volunteering cup of tea!

If you are the sort of person that likes to make a valuable contribution and would like to donate your time or skills, or would like any information about these volunteering activities, please contact me: (03) 9551 1122 or jo@parkinsons-vic.org.au

I would like to thank all our volunteers who help make my job coordinating fundraising activities, so easy and trouble-free. You are all an integral part of the success of each and every event.

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Research

Researchers around the world are slowly closing in on diagnosing, treating and, most importantly, finding a cure for Parkinson's. Here we highlight some of the latest research.

New hope on Parkinson's

Despite obvious physical symptoms at later stages, Parkinson's is extremely difficult to diagnose. But now doctors may be able to use ultrasound technology to identify changes in the brain, increasing the chances of early diagnosis.

Associate Professor Kay Double, a principal research fellow at **Neuroscience Research Australia** [whom Parkinson's Victoria has worked closely with in the past] believes Parkinson's can be diagnosed using a simple 10-minute ultrasound.

Ultrasound is inexpensive and safe, unlike most brain-scan technologies, said A/Prof Double. It is also non-invasive and could be applied before the appearance of motor symptoms.

Early tests of the method had been promising and Professor Double's research team was recruiting more people to be tested.

Until now, doctors had been forced to rely on ambiguous physical symptoms such as tremors, muscle stiffness and slowness of movement.

"The problem is these symptoms can all occur for many other reasons," said Professor Double, explaining that about 30 per cent of initial diagnoses were incorrect.

Delays in diagnosis meant long periods with stressful, unexplained and often untreated symptoms. In many cases, people may have undergone expensive and time-consuming tests for other possible conditions, and even been medicated for those conditions, obviously to no effect.

A/Prof Double explains that "right now, we rely on detecting subtle problems with movement that the patient themselves may not notice for some years. By the time these become obvious, an enormous amount of damage has already occurred in the brain which makes treatment difficult".

"Ultrasound [normally associated with pregnancy] is non-invasive and readily available in the community. If our technique works, we could use it to inexpensively screen people before the disease takes hold."

"This new technique could be the first stage of preventing Parkinson's disease."

The disease destroys brain cells that control the body's movement, causing trembling, stiffness,

slowness of movement and a loss of fine motor control.

The study uses ultrasound to look at the brains of healthy older adults – specifically the part that controls the body's movements (the basal ganglia) – to see how this changes in people with Parkinson's.

"We want to see how the brain looks different in Parkinson's so we can use this as a marker – or test – for the disease."

People with Parkinson's can go for many years without developing symptoms, despite the death of large numbers of brain cells. Up to 70 per cent of susceptible brain cells can die before symptoms become noticeable.

"The brain has an amazing ability to compensate for damage," says A/Prof Double. "In addition to diagnosis, ultrasound may help us understand this process."

"If we can mimic and prolong the brain's own extraordinary coping mechanism, we could help people with Parkinson's remain symptom-free for longer, even indefinitely."

Source: Neuroscience Research Australia, November 2010

Participate for Parkinson's research

Participants wanted for Parkinson's study

Purpose

The **Monash Alfred Psychiatry Research Centre** at the Alfred Hospital is currently conducting a study to investigate how a new technique [**Electrovestibulography (EVestG)**] can be used to investigate the effects of levodopa in patients who have Parkinson's. They are seeking eligible participants to assist in their research.

What is required of participants?

EVestG is a new non-invasive procedure, which involves the participant sitting in a specialised hydraulic chair, while having their vestibular (brain wave) activity recorded. We require participants who are currently using levodopa.

Participants will be reimbursed \$30 for each session to help with travel costs.

For further information or to arrange an appointment please contact Cassie McDonald:
cmmcd6@student.monash.edu.au

Our Supporters

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

Parkinson's Victoria Inc.:

Parkinson's Victoria is a not-for-profit organisation and is the peak state body which provides information, education, advocacy and support to the 20,000 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. Unfortunately, due to the large number of donations we receive, we are unable to list all of them. Listed below are the names of individuals who kindly donated \$200 or more between 17 January and 28 April 2011, and individuals in whose name in memoriam donations were received. 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 are also pleased to list those companies, organizations and others who have also shown their support, either financially or in-kind. We thank those who have donated but wish to remain anonymous, those who have supported our **Ambassadors of Hope** speakers program, and those who made donations as part of our annual **World Parkinson's Day** tin rattle at various train stations, and in response to our recent **STEPS** donor newsletter.*

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Young Onset Parkinson's

KARYN SPILBERG, founder of the Melbourne-based Young@Park Group has always been a great believer in the value of friendship. She's also a strong advocate for the notion that, while a shared experience (Parkinson's) might be the prompt for friendship, it doesn't have to be the only topic of conversation... and it certainly isn't limited by geography! Here, Karyn shares the origins of Young@Park and how the group is making the most of new technologies.

"I started Young@Park in 2006, after experiencing small, informal get togethers with other "Young Onset" people and getting a lot out of the gatherings.

Back then, I felt there was a real gap to be filled by, and for, those living with Young Onset Parkinson's, people who were likely to still be working and with children at home. Most importantly, it seemed that many Young Onset people were not ready to attend their local Parkinson's peer support group, which typically catered to older people who were at a completely different stage of life. I knew others were like me; we wanted to talk about "different things" that were relevant to our lives and experiences.

Young@Park meets bi-monthly, usually at a pub, and often with a guest speaker. The emphasis is on a casual get together and everyone really enjoys the social atmosphere. Partners get as much out of the meetings as the people with Parkinson's, just by talking to others.

Some come armed with questions, many have never met another person living with Parkinson's, and others come simply to mingle with people who "understand".

Over the years, our group has grown and changed.

It's important that we continue to respond to the unique needs of group members and all people living with Parkinson's so we remain inclusive and relevant. New technologies provide a fantastic opportunity to reach out to the wider community and provide support that is easily and readily accessible. With this in mind, we are excited to announce the launch of our very own website: www.yap.org.au

The Young@Park website is the place where people can find out upcoming events, read personal stories from Y@P members, find information and links for Parkinson's information, a Message Board and a Chat Room. The website will be an organic, dynamic place to post and share information across a broad range of topics and issues relevant to those living with Young Onset Parkinson's. Members and visitors are encouraged to participate and contribute to the site and the growth of the Y@P community, both here and internationally."

I would like to give special thanks to our new "sub" group Y@P Geelong for their assistance in financing the website. We hope to grow the online Young Onset community and develop "on the ground" regional groups in locations around the state.

Also, we are especially grateful to Ari Kuchar who designed Y@P's new logo and website with such intuition that we now have exactly what we wanted: a funky, fresh, easy to navigate site, packed with lots of features.

But I'm not going to spoil it for you. Why not check it out for yourself? Visit www.yap.org.au

Karyn Spilberg

PS We're on Facebook too!

Medications on Time awareness project

Over the next couple of months, Parkinson's Victoria will have two 2nd year medical students completing a health promotion project for the organisation.

This project involves researching the Parkinson's-specific issue of getting **medications on time** in hospitals and residential care facilities.

The students will investigate strategies and develop awareness resources with the aim of improving this long standing issue for many people with Parkinson's who go into hospital, respite or residential care.

We are keen to hear from anyone who has a "medication on time" experience to share (good or bad), related to their hospital stay or nursing staff in general. This is a great opportunity to have your voice heard and for your experience to help others. If you would like to share your story with our students as they work with us on this valuable project and development of appropriate resources and tools, please contact Catherine on our Health Team.