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## Parkinson's Victoria pays tribute



### Sir Zelman Cowen 1919 - 2011

Last year, on 13 December, Parkinson's Victoria was honoured and privileged to be represented by its President Peter Raymond and CEO Ann Burgess at the State Funeral of Sir Zelman Cowen (1919-2011).

The two hour service covered a truly grand life of dedicated and outstanding service to family, country, the body politic and commerce.

A brilliant Rhodes scholar and lawyer, University Vice-Chancellor, respected Governor-General and passionate St Kilda supporter, Sir Zelman, diagnosed with Parkinson's aged 76, was also a friend and supporter of Parkinson's Victoria.

Sir Zelman, accompanied by his wife Lady Anna, was a warmly welcomed attendee at our Annual General Meetings since 2005, and he had proudly presented an annual award in his name to a volunteer whose service stood out as both exemplary and long-standing. Sadly, Sir Zelman was too ill to attend our 2011 AGM in November - just weeks before his passing.

It is our intention, after consulting with his family, to continue the presentation of the **Sir Zelman Cowen Award for Outstanding Voluntary Service to the Community**.

Parkinson's Victoria is all the better for having had Sir Zelman and Lady Cowen as friends and supporters. His dignified, warm, courageous and good-humoured manner were an inspiration to us all.

**The Board, staff and members of Parkinson's Victoria extend to Sir Zelman's wife, children and extended family our sincere condolences.**

# News & Highlights

## Tell us what you think

**Signpost**, the quarterly newsletter of Parkinson's Victoria, has been published in its current format for the past 5 years.

While we receive great feedback about the newsletter and its contents, we are always looking to improve.

Your feedback will help us identify what you like about **Signpost**, what you don't and how we can make it even better!

Enclosed with this edition of **Signpost** is a brief, 2-page survey which we ask you to complete and return to:

- By mail: Attention: **Signpost**, Parkinson's Victoria PO Box 2606 Cheltenham, VIC 3192
- By Fax/email: (03) 9583 9952 or [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au).

You can also complete this survey online. Visit [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) and click the link.

**Feedback will assist us in reviewing and revamping the current newsletter, while keeping you informed of the news and information you need and want to know - so keep an eye out for a brand new-look Signpost later in the year!**

## From the desk of Parkinson's Australia

A Happy New Year to all involved in working to improve the quality of life of people living with Parkinson's, their families and carers.

Parkinson's Australia held its Annual General Meeting late last year and elected a new National Board, made up of representatives from the State organisations, including a new President, John Bird from Queensland. New Board members are Peter Raymond from Victoria and Paul Davies from South Australia. The PA Annual Report for 2010/2011 is available from: [www.parkinsons.org.au](http://www.parkinsons.org.au).

During December, a lot of work was put into developing and submitting a number of applications for federal funding from the new flexible funding arrangements. These are currently being considered and we will know by March if they have been successful.

The new year sees Parkinson's Australia preparing advice for the Medicare Locals about the benefits of employing Parkinson's Nurse Specialists as an integral part of their primary health care services.

Medicare Locals are to be the Federal Government's primary health care providers across Australia, and there is clear evidence in Australia and around the world that specialist nursing provides significant benefits to people with Parkinson's and to the health care system through more focussed services and reduced costs. I will report on the progress of this in future updates.

**Darryl Smeaton, CEO Parkinson's Australia**

## DBS surgery under the spotlight

Deep Brain Stimulation (DBS) surgery continues to enthral the media and the wider public.

The idea of brain surgery while the patient is conscious, combined with the surgery's capacity to help reduce the effects of a range of "mysterious" conditions including Parkinson's, depression, severe obsessive compulsive disorder, epilepsy and even Tourette's syndrome make it sound like the stuff of science fiction, so the appeal to both media and the general public is obvious.

Approximately 400 Australians undergo the procedure each year, with about half of those being people with Parkinson's.

Most recently, the current affairs program **Today Tonight** and the ABC's **Radio National** featured stories that discuss the procedure, highlight the conditions it may be helpful for and the potential benefits, all through the eyes and experience of those who have undergone the surgery.

**View the Today Tonight story at: <http://au.news.yahoo.com/today-tonight/> (view stories from Tuesday 31 January, "New Hope for Depression"); Hear and read the transcript of the ABC interview (from Monday 16 January on Radio National) here: <http://www.abc.net.au/radionational/programs/healthreport/deep-brain-stimulation-surgery/3665282>. If you'd like to know more about DBS contact our Health Team.**

## National Parkinson's Conference

The bi-annual **Parkinson's Australia National Conference**, hosted this year by Parkinson's Queensland, will take place on 13 and 14 July at the Brisbane Convention & Exhibition Centre, Queensland.

**The conference theme is: "Better knowledge, better outcomes"** and is designed as the 'must attend' event for everyone in the Parkinson's community: people with Parkinson's, carers and family members, neurologists, general practitioners, allied health professionals, researchers, pharmaceutical manufacturers and anyone with an interest in this challenging disease.

The conference, which will feature several keynote presentations and breakout sessions, will address issues such as:

- Causes and Impacts
- Advances in Surgical Treatments
- Advances in Drug Treatments
- Young Onset – Special Issues
- Exercise Treatments for Parkinson's
- Depression and Anxiety in Parkinson's Disease
- People with Parkinson's in Aged Care
- Balance and Falls
- Nutrition and Parkinson's Disease
- Caring for the Carer's
- My Life with Parkinson's
- Parkinson's Nurse Specialist Service
- Speech Therapy

**Registration is now open.**

[www.parkinsonsconference.com.au](http://www.parkinsonsconference.com.au)

**Early bird registrations close 11 May, 2012. Full registration (\$500 early bird) includes all conference sessions and social functions.**

## President steps down

During our 2011 AGM, President Royce Pepin announced his decision not to stand for re-election. Then Vice President Kate Brown gave the following speech in his honour, acknowledging the contribution Royce has made to Parkinson's Victoria and the Parkinson's community:

"Friends and Colleagues in Parkinson's, I am very pleased to have this opportunity to share with you a few thoughts about the difference that Royce Pepin has made to Parkinson's Victoria.

In 2004, the then President of Parkinson's Victoria moved to NSW, and I was given the task of finding a new President. I had been advised of a new member who some thought may be a suitable candidate due to his extensive not for profit board experience. I arranged to meet Royce at his office in Footscray.

It wasn't the football paraphernalia proudly displayed on the walls that won my admiration, it was the energy and intellect that was demonstrated during that discussion.

For, despite the constant interruptions to which Royce responded regarding his diverse range of interests and responsibilities, he remained focused on the issues I had raised and how he could help. Fortunately for Parkinson's Victoria, Royce agreed to consider my invitation to join the Board as Chairperson. And, when he attended the next Board meeting and met the rest of the Board, we must have passed muster as he agreed to become Chairman.

As a result of Royce's leadership during the following years, much has improved, as can be seen from a review of our annual reports. However, I will highlight those changes which to me, have been the most significant for the future of the organisation.

- October 2005 APPDA Conference with a visit from Rasheda Ali, daughter of **Muhammad Ali**
- Parkinson's Victoria's 25th birthday celebrations (in 2006)

- Appointment of our first Parkinson's Nurse
- The instigation of the *Sir Zelman Cowen* award to recognise outstanding volunteer services
- The establishment of the *Parkinson's Victoria Research Registry* at Florey Neurosciences Institute
- *Lord Mayor's Charitable Foundation Grant* for our *Bridging the Gaps* project, (translating Parkinson's information into other languages)
- Updating of the organisation's Constitution
- Commencing Parkinson's Victoria's Unity Walk, now a major event
- Moved us to a financially robust organisation
- Total equity in 2007: \$1,191,485 - now over \$2m
- Established an Endowment Fund from bequests which now holds over \$1m, and the interest on which makes a valuable contribution to our service delivery.



Royce, you have focused the Board on governing well, which has resulted in an organisation that is respected by its members, the public and the corporate sector. On behalf of our members, I thank you for a job well done.

We also express our thanks to your wife, Joyce, who has graciously attended many a Parkinson's Victoria function and who is recognised by many members for her friendly support.

I am very pleased that I made that phone call so long ago. We all wish you both the very best for the future."

**Kate Brown (former) Parkinson's Victoria Vice President**

## Parkinson's Victoria World Parkinson's Day Seminar

To mark World Parkinson's Day, Wednesday, 11 April, we will be hosting an information seminar for the general public. Guests will have the opportunity to hear a special update on some of the latest developments in Parkinson's research and future directions, followed by afternoon tea. In addition, you'll be able to meet our Health Team, learn about our comprehensive range of support services and programs, meet Ambassadors and Support Group Leaders and

members and find out about upcoming events and education seminars.

**Parkinson's Victoria Seminar, Wednesday 11 April, 2012 from 1-3pm at Pioneer Presbyterian Church Hall, 8 Park Road Cheltenham (next to Parkinson's Victoria). Free street parking available.**

**This is a free event, however bookings are essential: (03) 9581 8700 or email [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au).**

## Improving information resources

*We are pleased to welcome back Jackie Jenkins to our Health Team.*

*In 2009, after Parkinson's Victoria received a major grant from the Lord Mayor's Charitable Foundation, Jackie project managed the translation of Parkinson's information into 10 community languages.*

*In 2012, Jackie will be working on a number of publications to enhance our current range of community resources. The new projects are:*

Thanks to an additional grant from the Lord Mayor's Charitable Foundation, Jackie will be developing information resources in Hindi, adding an eleventh language to our suite of Parkinson's information sheets in community languages. The new Hindi resources will be launched to members of the Indian community in May.

Contact us if you would like copies. They will also be available to download from our website.

Parkinson's information sheets in community languages provide a simple overview of the main aspects of living with the condition for people with Parkinson's, their families, friends and community members. They are bi-lingual so that English readers can share the information. They are also a great community education tool, helping to raise awareness of Parkinson's among people from culturally and linguistically diverse (CALD) backgrounds. Combined with presentations from our Parkinson's Ambassador Program, CALD groups throughout Victoria are receiving the message that with support, information and specialist treatment, people with Parkinson's can continue to enjoy a long and productive life.

### **Information Kits for people living with Multiple System Atrophy (MSA) and Cortico Basal Syndrome (CBS)**

These rare neurological conditions, along with Progressive Supranuclear Palsy (PSP), belong to a group known as **atypical parkinsonisms**.

PSP Australia has funded this project and Jackie has been engaged to produce and compile information in the vein of the **PSP Information Kit** (which she collaborated on in 2010).

Each Kit will offer a plain language outline of the condition, as well as information about managing symptoms and where to go for help.

The Kits will be available in late March. Contact Parkinson's Victoria for further information.

**Suggestions and feedback on these projects are always welcome. For further information or to provide feedback, please contact Jackie:**

**jackie@parkinsons-vic.org.au**

**or call our office: (03) 9581 8700.**

## *Standing ovations for outstanding service*

At our AGM last year, we were very pleased to announce Val Lester (below), leader of our Bendigo Support Group, as the recipient of our 2011 **Sir Zelman Cowen award for Outstanding Voluntary Service to the Parkinson's Community**.



The Bendigo Support Group has been running for 25 years (since 1986) and Val has been there from the beginning, initially supporting others in the role of Leader, and more recently taking on the role herself (since 2009).

While she was diagnosed with Parkinson's more

than two decades ago, she originally joined the group because her sister had severe symptoms.

The recent recognition of her contribution and service is a long way from the Val of those early days; "I knew nothing [then] and I thought I was going to be dead in seven years," Valerie said. "I was devastated and it took me a week to process it. But you don't dwell on it because if you dwell on it you get worse."

While Val ensures meetings are fun and informative for everyone, she admits the support group has been a big help to her, "I enjoy [the group get together], you meet up and you're like a big family," she said. "There are down days when you don't feel like going but you do because they depend on you." "It's good helping everyone and seeing the smiles on their faces."

**Valerie was featured in the Bendigo Advertiser in November 2011 and was also interviewed on ABC radio. Congratulations Val and thank you for all you do to support the local community and Parkinson's Victoria.**

We also acknowledge the contribution of Nola Matuschka (below), leader of our Portland Group, who received special recognition at the AGM with a 10-year achievement award.

Nola's long term commitment to helping the Parkinson's community goes back to 1999, when husband John was diagnosed.

The group started in February 2000, thanks to Nola's initiative, and she has been coordinating it ever since.

**Congratulations Nola!**



## Carers Corner

*Carers Australia has identified that in Australia there are 300,000 carers under the age of 24; 150,000 carers under the age of 18; more than 1.5 million carers of prime working age (18 - 64) and 520,000 carers over 65 years of age. Carers Australia also identified that on average, carers spend approximately 40 hours per week providing care. And yet, many carers do not rate "taking care of themselves" as important.*

*DIANNE RAYNER, Client Services Officer and PSP Support Worker, highlights the importance of caring for our carers.*

It is not unusual to see close relatives and friends providing most of the care for a person with Parkinson's and the day-to-day reality of caring is a demanding and difficult one.

Carers provide essential care and support to the individual, often throughout the various stages of the condition's progression. Typically, people living with Parkinson's will, over time, have built up a "care team" and family carers are a vital part of that team.

Not only do the effects of Parkinson's impact the health and well-being of the person diagnosed with Parkinson's, but also the health and well-being of their carer/s.

An increase in emotional, physical and financial stress for the carer occurs as the disease becomes more severe and the carer assumes more responsibility in their role as carer.

It is therefore very important that carers receive support as well. Support can come in many different shapes and sizes and include respite care, emotional support, counselling, flexible working arrangements, job protection, and financial assistance.

Carers also need easy access to information regarding the management of the condition and palliative care options, as well as services that will enable them to maintain their own health and wellbeing.

While their own health and wellbeing is usually not at the top, or even near the top of the list for carers, they can compromise their health (and capacity to provide care), if they fail to look after themselves.

While the stress that impacts on the carer is immense and has an impact on everyone around them, they are likely to feel they don't have the time to look after themselves or to take 'time out'. Because they may identify as 'the healthy one', they may feel they can simply keep going or even feel guilty about the idea of taking some 'time off' from their caring role.

Stress is the body's way of responding to any kind of pressure from an individual's environment. It can be caused by both positive and negative experiences. It can also be physical/environmental (a fear of something) or emotional/internal (worrying about something). And, it can also be triggered by tiredness, doing too much and over working. Take a moment to reflect on your own situation caring for a family member or friend living with Parkinson's and consider if stress is having an impact on you and your environment.

Look out for physical signs that the body gives out when stress is increased. This includes increased heartbeat, faster breathing, excessive sweating, cold hands, feet and skin, nausea, a feeling of 'butterflies' in your stomach, muscle tenseness, dry mouth, the need to go to the toilet more often, increased muscle spasm, headaches, fatigue, change in appetite, change in your sleeping patterns and nervous behaviours. Physically, the symptoms of stress can lower your immune system and make you tired and restless, cause worry and feelings of anxiousness and being overwhelmed.

These physical symptoms can obviously have an adverse affect for the carer, and even impair judgment and affect decision making. Concentration can become difficult and you can be left feeling anxious, frustrated or angry. How you feel can have an impact on others too.

The good news is that emotional support for carers is available. Professional counselling provides a confidential, "safe space" to talk to someone about things that are troubling you. For carers who may be experiencing stressful and difficult times as a result of their caring role, talking to someone can help to find solutions to resolve an issue, or develop coping skills to enable you to manage these times better. Counselling may be short-term, either one or two sessions, or longer if required.

Either way, taking timeout to talk to a trained professional about the impact your caring role is having on you, your family and your relationships should be placed close to the top of your priority list. You need someone to talk to about your feelings as much as you might need practical advice. Caring appropriately for someone doesn't always come naturally and carers may need to learn new skills in order to perform their role effectively and to reduce any additional stress or hardship that may occur as a result of that role.

**Parkinson's Victoria can help with all this by providing information about the condition, referrals to counselling and access to support groups. For more information please contact our Health Team.**

# Special Events

## Shedding light on Parkinson's disease at the Florey

Neurologist Professor Mal Horne will offer an introduction to Parkinson's at this special event.

**What:** What is Parkinson's disease?  
A free public lecture

**When:** March 15, 2012

**Time:** 6.30-7.30pm

**Where:** Melbourne Brain Centre auditorium, cnr Royal Parade and Genetics Lane, Parkville (opposite the Royal Melbourne Hospital) [Melways ref: 43 F4](#).

**Parking:** Ample, reasonably priced parking (including disabled) is under the Melbourne Brain Centre.

**Bookings:** [www.florey.edu.au](http://www.florey.edu.au)

**The lecture is proudly supported by Parkinson's Victoria:** [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au)

## Getting to know you

Over the upcoming months Parkinson's Victoria will be undertaking a series of research projects to understand how we can enhance and develop our support programs for the Parkinson's community.

Disegno Group have been retained to deliver this project and over the next few months will be engaging with individuals diagnosed with Parkinson's, family members, and the medical profession.

The research to be undertaken will be face-to-face/phone interviews and an online survey and your participation would be enormously valuable as we search for ways to improve our service and outcomes for those diagnosed with Parkinson's.

**If you would like to participate in this important research please contact our office on: (03) 9581 8700 and speak with Judith Mooney or Ann Burgess or email [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au).**

### Meet the Experts

Hosted by Parkinson's Victoria, this unique workshop style seminar will take place on Sunday 20 May from 10am-3pm (registration from 9am) at the Hemisphere Conference Centre, 488 South Road Moorabbin.

This is a free event but places are limited. To register please contact our office on (03) 9581 8700 or email [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au)

**The Colin and Sheila Marshall Trust has also funded a dedicated education session for health professionals and researchers, to be held as a pre-event to the 7th World Congress for NeuroRehabilitation, being held here in Melbourne from 16-19 May, 2012.**

## News Flash – UNITY WALK 2012 is COMING

Plans are already underway for this year's **Parkinson's Unity Walk** and we hope to see you and all your family and friends at Federation Square on Sunday, 26 August!

**Parkinson's Unity Walk** is all about raising vital funds, raising awareness, coming together as a community and remembering and celebrating loved ones. **It's about taking over this Melbourne landmark for one day and putting the fight against Parkinson's firmly in the spotlight.**

Your support will make this year's Unity Walk the biggest in Melbourne's history and we hope – the biggest in Australia!

We need as many people as possible to show their support on **Sunday, 26 August**: Our participation goal this year is 2500 people!

Show your support by registering and getting together a team (great prizes on offer); asking friends and family to donate or hosting a Unity Walk Fundraising event (contact Judith for tips and ideas); and helping to spread the word (ask us for posters to display at work or in your local shopping centre).

*Imagine if everyone reading Signpost participated?*

*Imagine if all those people brought just one friend?*

*Imagine if everyone who attended last year's Walk was able to increase their 'team' by just one person?*

**And, if all that happened, imagine what the power of our 'voice' would be on Sunday, 26 August!**

Parkinson's Unity Walk is also about sharing loads of personal stories with newspaper articles and TV and radio interviews.

If you'd like to share your story about participating in this year's walk, who you're walking for and what it means to you - **or at any time of the year** - we want to hear from you. Please contact Judith on (03) 9581 8700 or [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au)



### Special thanks to the following VIP fundraisers from Unity Walk 2011:

**Fundraising SUPERstars:** Grant Riddell was our highest Unity Walk fundraiser in 2011, raising a whopping \$6475, followed by Peter Raymond who raised \$5975.

**Fundraising stars:** The following people raised over \$2000: Judy Phelan, Chris Eleftheriadis, Victoria Jones and Linda Vella.

**Fundraising heroes:** The following people raised over \$1000: Matthew Crute, Lauren Tassell, Paul Zajac, Cheryl Jones, Brenden Judge, Lisa Owens, Keoni Kidner, Lilianna Sanelli, Ann Robinson, Karyn Spilberg, Anne Mooney, Indra Jury and Barbara Lisa Marino.

# Tulip tributes



## Behind the scenes

The support and generosity of the wider community is absolutely invaluable to our everyday work and our ability to continue to respond to the increasing need for support. While financial support is always welcome, donations 'in kind' of goods and services help us to keep running costs to a minimum so we can direct as many funds as possible towards delivery of services.

Additional support from the corporate and small business sector comes by way of donating 'proceeds from the sale of items' – funds that would normally go straight into their pockets as profit are donated to Parkinson's Victoria. Throughout the year we receive several donations in this manner – sometimes small and sometimes quite significant amounts, but always so gratefully appreciated.

In 2010, while representing Parkinson's Victoria at the annual **Run Melbourne** event at Federation Square, I had the pleasure to meet competitor Suzanne Rangan, who was 'running to make a difference for those living with Parkinson's'.

Suzanne's sister Tanya from **Mosaic Photography** was there snapping shots and kindly gave permission for us to use one for marketing – what a dynamic duo! Tanya and Suzanne understand personally the impact of Parkinson's – their beautiful dad has Parkinson's.

Tanya and Mosaic Photography have since become generous supporters of our work – having captured our **2011 Parkinson's Unity Walk** and our **Back to the Future** movie extravaganza at the Astor last November.

In addition to helping us reduce associated costs for these two major events, Mosaic Photography also generously donated 100% of all proceeds from the sale of photos from both events (and spent several hours setting up the online photo gallery and processing orders).

Tanya and Mosaic Photography have provided a passionate and professional service, with unlimited enthusiasm, driven by the desire to make a difference in the lives of those living with Parkinson's.

**Thank you to Tanya and Mosaic Photography for such amazing support and such generous contribution to our work.**

[www.mosaicphotography.com.au](http://www.mosaicphotography.com.au)

**Editor's note: We'd love you to support those who support us – please visit our "Supporters Page" and find out who in our local community is getting behind the fight against Parkinson's!**

Support, Information, Education and Advocacy

# CEO Update

Happy New Year to all our readers.

For many people, this is the year of the Dragon. He is thought to represent power, wealth and change.

This year, we will see considerable change in the world of health services. The Federal Government will be introducing Medicare Locals. These are groups of local health services and hospital networks who will decide how many and what type of services are needed in particular regions.

In the past, governments have dictated what health services are to be offered. Under this new system, decision making about regional services will be done at a regional level. It's important that we make strong connections with this new system so that we can advocate strongly across Victoria for people with Parkinson's.

This year, the Federal Government is also introducing the National Disability Insurance Scheme or NDIS (you can read more about this on page 6). This scheme will provide insurance cover for people who have a significant and ongoing disability. The scheme would pay for long-term high quality care, support and equipment.

We will continue monitoring the NDIS scheme closely and providing information as it is released by the government.

Last year, we were fortunate to receive a significant bequest from the estate of Colin and Sheila Marshall. This year, we are thrilled to be able to allocate some of these funds as Colin and Sheila intended; to provide education and support to those living with Parkinson's and to help fund important research. We are currently finalising details to host an interactive workshop on 20 May, titled **Meet the Experts: Practical Advice from National and International Rehabilitation Experts on Physical Activity, Exercise and Lifestyle For Living Well with Parkinson's**.

The workshop will give a limited number of attendees that chance to hear from two internationally renowned health professionals in this field, along with a number of Australian experts. This event would not have been possible without the foresight and generosity of Colin and Sheila and we gratefully acknowledge their decision to remember Parkinson's Victoria - and others who are living with Parkinson's - in their will.

In late March, we will be seeking participants for a research project exploring mindfulness therapy, which Parkinson's Victoria has agreed to fund from our dedicated Research Account.

Dr Craig Hassed and his team at Monash University will be offering Mindfulness Therapy training to establish whether it has benefits for people with Parkinson's. Speaking of research funding, we have also committed to fund two National Health and Medical Research Council projects.

Keep checking our website, as we will be putting up more information about these projects as they come to hand. You can also call Catherine, Dianne, Victor and Breanna in our Health Team for more information and of course, I would welcome your call or email at any time.

**Ann Burgess**  
CEO

[aburgess@parkinsons-vic.org.au](mailto:aburgess@parkinsons-vic.org.au)



[www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au)

Parkinson's Victoria [ 7 ]

# Symptom Management

## Looking after you

There are several ways to increase your involvement in managing your Parkinson's and improving your health outcomes. VICTOR MCCONVEY, our Parkinson's Specialist Nurse Consultant, highlights some of the most effective actions you can take today.

*Parkinson's is often referred to as a 'designer disease', meaning no two people will experience Parkinson's in the same way.*

*Different symptoms and effective treatment options, including medication regimens, mean Parkinson's affects everyone differently. This can make Parkinson's a complex illness for health care professionals involved in helping people to manage their condition, even more so when appointment times with Neurologists and movement disorder clinics are limited, reducing the ability to comprehensively assess an individual's situation and concerns.*

*Patient empowerment is all about individuals playing an active (even pro-active) role in managing their health, illness and treatment options. You can and should be a key player in managing your Parkinson's. Not only will this maximise the effectiveness of treatments, but it will improve your general health and provide you with a sense of contributing to your own wellbeing. It will also give those providing care and treatment a useful insight into your specific needs – after all, no-one knows you and your body like you do!*

### Set some goals

Think about how Parkinson's affects you and what symptoms you would like to focus on addressing. There may be some symptoms which have greater impact on your life than others or are simply of greater concern.

An example might be to improve your ability to walk. On raising this with your neurologist, they may review your medications and refer you to a physiotherapist to provide appropriate strategies or a gait aid, such as a walking stick.

The goals you set are yours alone. They could include any aspect of your life, movement, sexual function, or mood. Having some treatment goals is a good way of starting a conversation with your neurologist and to let them know what is important to you.

### Waiting room amnesia

Have you ever walked into your neurologist's office and gone blank? Or left and realised you forgot to ask a particular question, or to tell them about a symptom you experienced?

Many people develop 'amnesia' the minute they enter a doctor's office and it can be frustrating for everyone.

Medical appointments are often stressful; before you

even arrive you may have had to deal with peak hour traffic and parking. In the waiting room or once in front of your doctor, you may be worrying about what news you are going to receive about your health and prognosis. All this can make it difficult to remember things you want or need to say. Getting things off your chest is one thing, but your questions and comments will also assist those providing care and treatments, so it's important to both you and your doctor that you raise any questions or concerns during your appointment.

To help avoid waiting room amnesia develop a plan; a list of questions can be invaluable.

A good place to start is keeping a *symptom diary* in the weeks leading up to your appointment and writing down any questions as they occur to you. Try to keep this information concise so that you are just providing the most essential information to your doctor and your thoughts stay focussed.

It may be useful to ask the doctor how they would like to receive this information. For example, some doctors will ask patients to complete a specific type of diary or request you send information by email a few days before your appointment.

(It will be interesting to see how methods for delivering this information develop in future: Kinetic watches and iPhone apps that measure tremor and dyskinesia are being trialled at the moment.)

Don't just focus on physical (or motor) symptoms - it's equally important to include information about how Parkinson's has affected you in other ways. These hidden symptoms may be poor or excessive sleep, constipation, depression, anxiety, hallucinations or changes to sexual function, and also include medication side effects such as nausea or Impulse Control Disorder (increased sex drive or desire to gamble, compulsive eating and shopping).

### Good medication habits

Practising good 'medication habits' and taking your medications on time, every time is essential, as is being aware of how your medications affect you.

To assist you in taking your medications on time consider using something that will remind you; it may be a simple alarm on your watch or a medication timer device.

When you meet or communicate with your neurologist (such as through your **Symptom Diary**, see above), ensure you advise them of **all** the medications you are taking, not just the ones they have prescribed or those just for Parkinson's. This will give them the opportunity to identify any drug interactions that may be a concern.

Medication reviews are also useful and should be done from time to time under the direction of your treating doctor. Speak with your GP, who may review your current medications or refer you for

# Support Groups

a **community pharmacist review**. Again, they will identify any potential drug interactions and check whether or not you need to continue with all the medications you are currently prescribed.

## *A holistic approach*

Parkinson's is a complex condition and those living with Parkinson's benefit from the expertise of a range of healthcare professionals.

For example, consulting an Occupational Therapist in the early stages of diagnosis can be helpful in addressing fatigue by developing *energy conservation* strategies. Other allied health professionals, such as physiotherapists, dieticians and social workers can assist in managing different aspects of Parkinson's that will contribute to improved wellbeing and symptom management.

Access to these professionals is possible through **Movement Disorder Clinics**, the **Community Based Rehabilitation** services in your local area or under an **Enhanced Primary Care Plan** available from your GP.

Complementary therapies such as massage, acupuncture, meditation, yoga and some naturopathic supplements can be pursued alongside the medications and treatments your neurologist has prescribed. Complementary therapies often address the 'whole person' and in doing so may address some Parkinson's symptoms.

You should always discuss incorporating or trialling a complementary therapy with your neurologist beforehand.

## *Caring for your carer*

Parkinson's doesn't just affect those diagnosed with the condition – it also impacts on carers and partners (and family too), but because of their caring role, they may not feel able to express how Parkinson's is impacting on them. This can make a difficult situation worse. It's important to be understanding and patient, to acknowledge their needs, and encourage them to look after themselves, as well as letting them know how you feel.

There are opportunities for carer support through Parkinson's Victoria and Carers Victoria. (Read more on page 5.)

Taking control, setting some treatment and lifestyle goals, and effectively communicating with your treating doctors will all help to ensure you are maximising the best treatment options available. Utilising the expertise of allied health specialists and exploring various complementary therapies will also help to reduce the impact of Parkinson's, and help you to feel more 'in control'.

**The Health Team at Parkinson's Victoria is able to provide support and information on ways to look after you and how you can be proactive in managing your Parkinson's. Contact our Health Team to learn more.**

In November last year, the **Geelong Parkinson's Support Group** and the **Ringwood Parkinson's Support Group** both celebrated their 30th birthday. These two groups are the longest running Parkinson's Support Groups in Victoria, and were established in the same year as Parkinson's Victoria (though our organisation was then known as the Parkinson's Disease Association of Victoria).

Both groups marked the occasion with a party attended by past and present members, as well as Parkinson's Victoria staff, and there was plenty of opportunity for informative discussion, friendly conversation and cake all 'round!

Congratulations to all those involved with these two groups; 30 years and still going strong is a wonderful achievement and an invaluable support for people living with Parkinson's.



Members of the Ringwood Parkinson's Support Group celebrate the occasion of the group's 30th Anniversary.



Geelong Parkinson's Support Group Leader Harold Waldron does the honours cutting the group's 30th Anniversary cake.

**If you are interested in attending or learning more about a Parkinson's Support Group in your area, please contact Breanna in our Health Team: (03) 9581 8700 or email [breanna@parkinsons-vic.org.au](mailto:breanna@parkinsons-vic.org.au)**

Living with or caring for someone with Parkinson's can be challenging, but you don't have to feel alone. Parkinson's Support Groups offer members a chance to meet and talk with others who share similar experiences, situations and problems. They can be a great source of information and support. Monthly meetings are informal and friendly, and new members are always welcome.

## Frequently Asked Questions about Tissue Salts

An article about Tissue Salts that was featured in a recent edition of **Signpost** prompted a number of calls to our Information-Helpline, with people interested to find out more. We also received some feedback querying our decision to include information about complementary therapies.

Parkinson's Victoria promotes the right of every individual to play an active role in their health care, and we believe this demands providing and facilitating the dissemination of information on a broad range of information and therapies. This includes the benefits of "therapies" such as exercise, diet, community connectedness and peer support, and mindfulness therapies which can support wellbeing and enhance quality of life.

We also advocate for informed decision making and encourage and remind people to be vigilant when researching or reading any information and in considering any treatment or therapy. "Complementary" and other therapies should never replace Parkinson's medication and we encourage individuals to consult their GP or specialist to discuss their interest in a particular therapy, and to speak with their doctor prior to making any changes to their medication.

*SUSAN GIANEVSKY, Brand Ambassador - Women's Health and Homeopath for Martin and Pleasance, answers some Frequently Asked Questions about Tissue Salts.*

### What are Tissue Salts?

Tissue Salts are homeopathically prepared minerals which support healing processes in the body by regulating mineral levels in the cells. Tissue Salts are the 12 vital minerals that the body needs daily to support cell metabolism and ensure that the minerals which the body ingests from food are evenly distributed.

Tissue Salts were developed, promoted and successfully put into practice as a therapeutic system by the German physician, Dr. Schuessler at the end of the 19th Century.

### The 12 Tissue Salts are:

1. Calcium Fluoride (Calc Fluor)
2. Calcium Phosphate (Calc Phos)
3. Calcium Sulphate (Calc Sulph)
4. Ferrum Phosphate (Ferr Phos)
5. Potassium Phosphate (Kali Mur)
6. Potassium Chloride (kali Phos)
7. Potassium Sulphate (Kali Sulph)
8. Magnesium Phosphate (Mag Phos)

9. Sodium Chloride (Nat Mur)
10. Sodium Phosphate (Nat Phos)
11. Sodium Sulphate (Nat Sulph)
12. Silicon Dioxide (Silica)

There are also a selection of **Combination Tissue Salts** which are said to target specific conditions such as hayfever, poor circulation, Indigestion and Fibrositis.

### What's the difference between minerals and tissue salts?

Tissue Salts are homeopathically prepared minerals that stimulate cell metabolism. Common mineral tablets, such as magnesium or calcium, have similar properties, but they simply "fill up" the body's mineral reserves. Tissue Salts do not need to be broken down in the digestive tract before being assimilated, which allows them to be extremely effective.

### Why are Tissue Salts important to our health?

A proper mineral balance is necessary for normal cell function. When our blood is lacking the necessary nutrients, our bodies become prone to illness. Tissue Salts provide the cells with essential nutrients that might be lacking. They help improve the overall absorption of nutrients coming into our body and encourage overall good health and wellbeing.

### What causes Tissue Salt deficiency in the cells?

Stress, poor diet, electrosmog\*, bacteria, viruses, pollution, injury and so on, can all result in a lack of salt in the cells, resulting in a blockage in the regulation of cells. Salt deficiency can be corrected by introducing Tissue Salts into the system, thus bringing the healing process into motion.

(\*Electrosmog is linked to mobile phones and computer "addictions" (excessive use) and the microwave frequency signals that such electrical equipment generate, however scientific evidence supporting the effects of electrosmog is, as yet, inconclusive).

### How do I take Tissue Salts and for how long do I need to stay on them?

It is recommended that you take 1 *tablet* 4 x per day, or 4 *sprays* 4 x per day. In regard to using the cream, it is best to apply the cream topically at least 2 – 3 x per day.

It is best to stay on the Tissue Salts for at least 1 – 3 months and to visit your health professional who will provide further information and advice in relation to your specific needs.

### How are Tissue Salts absorbed in the body?

Tissue Salts are absorbed into the body via the blood vessels in the mouth, ensuring they are quickly and directly absorbed.

It is recommended that the tablets are chewed and not swallowed whole. In addition, holding the

chewed tablets in your mouth for a few seconds before swallowing is useful. The same applies to the oral sprays; hold the liquid (from 4 consecutive sprays) in the mouth before swallowing.

## Can I take Tissue Salts alongside prescriptive medicine?

Tissue Salts are non-toxic and non-addictive. They are considered safe for everyone, including children, with no known side effects. There are no known interactions with medications.

## Can I use the Tissue Salt cream alongside cortisone cream or other creams?

Both creams are very different – one is natural and one is synthetic. The Tissue Salt cream will not interfere with the cortisone cream, but it is recommended that the Tissue Salt cream be applied first as it works differently to cortisone cream and also needs to penetrate the layers of skin.

## Wouldn't it make sense to take all twelve tissue salts at the same time?

Dr. Schuessler developed and prescribed the Tissue Salts for use against specific disorders in the body. While a combination of all twelve will not harm the body – it is recommended that you select specific Tissue Salts or Tissue Salt combination formulas based on your current symptoms.

## Can I give the Tissue Salts to my children?

Yes, the regular Tissue Salts range are suitable for children, however a range has been specially formulated for all children to benefit. The **Kidz mineral range** is a range of 6 formulas that support children's health and they are ideal for children aged between 0 – 12. Children older than 12 can take the regular range of Tissue Salts.

## I am lactose intolerant, can I still take the Tissue Salts?

Tissue Salts in chewable form are delivered in a lactose base (minimal) however, Martin and Pleasance have formulated Tissue Salts in an oral form, using an ethanol and glycerin base without lactose. Tissue Salt creams are delivered in an aqueous base.

## Can pregnant women take Tissue Salts?

Yes, Tissue Salts are considered safe to be taken prior, during and after pregnancy and while breastfeeding as they do not build in the system but rather support the cells to complete the necessary processes for health to be activated.

## Can I give Tissue Salts to my pets?

Yes! Even pets can benefit from Tissue Salts which can help improve the health of their cells and efficiency of their metabolism. All the Schuessler Tissue Salts can be given to your pets. The Tissue Salts can be crushed and added to your pet's food, or simply add 2 sprays to the pet's water a few times a day, making sure to change the water each time.

**For more information on Schuessler Tissue Salts visit [www.martinandpleasance.com](http://www.martinandpleasance.com) or email your details to: [info@mandp.com.au](mailto:info@mandp.com.au) to be included on their database.**

**You will find naturopaths, kinesiologists, homeopaths, iridologists and a number of other therapists will prescribe Tissue Salts for various conditions.**

Parkinson's Victoria believes in informing people about a range of complementary therapies that may help improve wellbeing and quality of life. It is our role is to provide and facilitate access to credible and reliable information on a broad range of topics, and to empower individuals, through education and resources, to become advocates for their own health and well being in the pursuit of optimal quality of life.

We encourage feedback from readers about the information and articles contained in **Signpost**, and also suggestions for future topics. Please send your email to the editor: [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au)

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# Education

## Surfing the 'net

CATHERINE WATSON, *Community Development Worker with our Health Team, offers some suggestions for useful online resources.*

In recent years, there has been an explosion in what the Internet has to offer in terms of worldwide information sharing and networking. The Australian Bureau of Statistics (ABS) reports that over 79 percent of Australians have home Internet access<sup>1</sup>, so why not have a look at some of the resources relevant to those living with Parkinson's?

You don't need to be very tech savvy to use these resources, and in many cases they are free (excluding download data charges with the Internet provider).

It is important to remember that, as with all online resources, any member of the public can create an online resource (this includes articles, information, websites, blogs etc) so care must be taken when exploring what is available and in assessing credibility and reliability.

Let's start with an introductory **A-Z of online resources**, what they offer and how to access them.

### Phone Apps

The name is an abbreviation for **Applications** which are programs that can be downloaded to mobile phone or tablet computer devices.

Apps are a relatively recent technology and their full potential is still to be seen. Some Apps that are relevant to people with Parkinson's include programs which include medication alarms and a system for recording symptom fluctuations. Others can suggest exercise programs and provide voice training exercises (**please only use in conjunction with the advice of your allied health professional**).

Apps for Apple computers are available at the Apple iTunes online store. Search for 'Parkinson's'. (iTunes is a free computer program which allows users to manage files as well as download music, games, apps and podcasts).

### Blogs

A **blog** is an online diary which is available for others to read and comment on in writing. In this sense it is 'public' and can be viewed by just about anyone.

Aside from the process of 'thought-sharing' being therapeutic for the author, blogs can be helpful to those who read them as they provide insight into another's experiences from a very personal perspective.

To find a 'blog', simply type into a search engine (such as Google) the topic you wish to know more about, along with the word 'blog' - you'll find no shortage of blogs to take your pick from.

Founder of the Young @ Park (Melbourne) group, Karyn Spilberg created a blog following her recent Deep Brain Stimulation Surgery. You can check it out here: <http://karynsjourneywithdbs.blogspot.com>

### Chat

An **online chat** is a typed, real time conversation with others who are also online. One of the great benefits of online chats is that it brings people together from different locations to talk about topics of interest.

As yet, there are no official, moderated Australian Parkinson's chat rooms, however for those interested in seeing what it's all about, the Victorian Young @ Park group have a good relationship with an American Parkinson's chat room: <http://www.yap.org.au/connect>

### E-Newsletters

E-Newsletters are regular information updates that are sent directly to your email account "inbox".

There are numerous e-newsletters produced by organisations, information and community groups that you can subscribe to. Once you provide your details (often as little as your name and email address), the e-newsletter will be sent to you on a regular basis, and you can unsubscribe at any time.

- The **Michael J Fox Foundation for Parkinson's Research** publishes an online monthly newsletter called 'Fox Flash': <http://www.michaeljfox.org> (click 'get email alerts' at the top of the page)
- The **American National Parkinson's Foundation** (NPF) has a monthly e-news which highlights various activities and online webcasts which they organise. To register, visit their website: <http://www.parkinson.org>

Parkinson's Victoria is currently looking at developing its own e-newsletter to provide brief updates and short articles to supporters, members and interested members of the general public. This will be an ideal way for us to stay in touch on a more regular basis, while providing useful and timely information about our organisation's activities and other news of interest to the Parkinson's community.

If you prefer to receive **Signpost** electronically to your email inbox, send us an email: [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au)

### Facebook

**Facebook** is a social media program where people can set up personal profiles, "post" messages and photos and keep in touch with others who also have a Facebook account. Organisations and companies can also set up pages and when people choose to 'like' a page, they will receive news updates from that organisation or company direct to their own profile wall (a bit like a public noticeboard).

Parkinson's Victoria's Facebook page can be viewed here: [www.facebook.com/parkinsonsvic](http://www.facebook.com/parkinsonsvic) (don't forget to 'like' us!)

## Message Boards

**Message Boards** allow people to pose questions and others viewing the message board can write answers and comments. Anyone on the Message Board can read what others have posted. Peak-body organisations have moderated Message Boards to ensure that discussion and content is appropriate.

- Victorian Young @ Park:  
<http://www.yap.org.au/connect/message-board>
- Parkinson's UK:  
<http://www.parkinsons.org.uk/pdsforum>
- National Parkinson's Foundation:  
<http://forum.parkinson.org>

## Podcasts

This technology allows you to download audio and video files which are typically recordings of a lecture, interview, radio or television program.

**Podcasts** can then be listened to via your computer or downloaded onto a portable device such as an iPod (so you can listen "on the move" while on the train, in a doctor's waiting rooms, etc).

- The Michael J Fox Foundation provides numerous podcasts on a range of research projects their team has been involved in. They can be downloaded from the site below or from iTunes: [http://www.michaeljfox.org/newsEvents\\_podcasts.cfm](http://www.michaeljfox.org/newsEvents_podcasts.cfm)

## Twitter

Twitter is not just for chasing celebrity news! Some describe Twitter as the "SMS of the Internet": It's a combination of social networking and microblogging.

Twitter and "twittering" or sending "tweets" is an effective tool for brief, instant updates from organisations or individuals to inform people about news, events or other topics of interest (each message can only be a maximum of 140 characters). You can have followers (people who follow (read) your updates) and you can follow someone else. British actor, author and media personality Stephen Fry has **3,795,400** tweet followers!

If you set up an account, all the updates of the people you choose to 'follow' appear on your page. It can be an effective way to get a 'conversation' going and build interest and momentum in a particular topic or issue.

- Parkinson's UK - <http://twitter.com/ParkinsonsUK>

## YouTube

YouTube is a free, online video sharing site. If you prefer watching videos to reading an information sheet then you can watch a number of short videos about absolutely everything on YouTube. Lost the manual for your mobile phone? Need to learn how to tie knots? Want to listen to a presentation from our Health Team (but be able to take a break if you

need to?) YouTube can help because you truly can find a video presentation on just about any topic.

- Parkinson's Victoria Television:  
<http://www.youtube.com/parkinsonsvictoria>

From the Parkinson's YouTube channel there are links to other reliable YouTube channels.

## Websites

Websites are like a modern day Yellow Pages, only online.

Most businesses and organisations have an online 'presence'. Perhaps it is only their contact details featured, but in many cases, the website provides a comprehensive insight into all aspects of that organisation or company, such as its product lines, history, testimonials, useful web links, and further information and contact details (including handy location maps).

Organisations such as Parkinson's Victoria use websites as a way of providing the public with information on the latest news and events. Our website also features downloads of most of our print and video resources so that anyone, anywhere can access them.

- Parkinson's Victoria: <http://www.parkinsonsvic.org.au> (On the homepage, click 'useful links' to view other valuable national and international websites).
- Parkinson's Movement: <http://www.parkinsonsmovement.com>. This is a new site run by people with Parkinson's for people with Parkinson's.

## Webcasts & webinars

An exciting development in online education is **webinars** and **webcasts**. This is when a presentation is filmed 'live' and streamed via the website allowing people elsewhere to view the presentation in real time.

The technology also means that those viewing the presentation from their own computer have the opportunity to engage with the speaker by asking questions (via an audio 'hook up' or using their computer keyboard). This enhances the experience of feeling they are physically 'present' and participating in the event.

In addition, presentations can also be recorded and downloaded by the viewer at a later time.

- The National Parkinson's Foundation has an extensive video library of reputable speakers and interesting topics:  
[www.parkinson.org/Parkinson-s-Disease/PD-Library/Videos---Webcasts.aspx](http://www.parkinson.org/Parkinson-s-Disease/PD-Library/Videos---Webcasts.aspx)

**Whenever you are 'surfing the 'net' it's important to remember that many resources originate from international sources. As such, the information and advice may differ to that provided by Australian sources or in an Australian context. For more tips or information about online resources contact our Health Team.**

<sup>1</sup>Australian Bureau of Statistics, '8146.0 - Household Use of Information Technology, Australia, 2010-11', [www.abs.gov.au](http://www.abs.gov.au)

# Fundraising & Events

## Fundraising is absolutely vital to the work of Parkinson's Victoria.

We undertake a number of fundraising initiatives each year and we are pleased to provide a calendar of upcoming events so you can book them into your diary early!

It would be wonderful if we did not have to focus so intensely on raising money and could put all our energy into providing services, but because recurrent government funding only covers about 14% of the income we need, we have to find the rest through other means.

As well as running actual fundraising activities, Parkinson's Victoria will continue to apply for one off government grants to aid us in the development of new and improved resources.

Some of our events are designed to be affordable for everyone and to foster a greater sense of community for our members, such as **Parkinson's Unity Walk**. Others are aimed at engaging the wider community, such as movie nights and Bunnings Sausage Sizzles. These events may be a little more expensive, like our great **Back to the Future** movie spectacular last year. Our events **always** have a dual purpose; combining **fundraising** with **awareness** raising.

We understand that not all events will appeal to all members, but you can get involved in other ways.

A great way for members to assist is to pass on information about our events to other family members, friends and colleagues. You may be surprised to learn how keen your family and friends are to show their support by attending an event, and how much they see this as a way of 'making a difference'. Also, some people prefer to show their support by attending an event, rather than making a donation.

Another way you can get involved is to pass on details for any contacts you may have for individuals, companies or organisations which may be able to assist by donating prizes or as sponsors for our events. Please contact Judith our Fundraising Coordinator who would be happy to discuss your ideas and follow up with any contacts:

[judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au)

We are always very grateful for the generous support of our **Team Parkinson's Fundraisers**; people who take it upon themselves to organise an activity, with Parkinson's Victoria as the beneficiary of funds. These activities include fashion parades, gala balls, open gardens, music events, sporting events, and so on. If you'd like to organise an event, Judith, our Fundraising Coordinator would love to hear from you.

Supporting the efforts of our **Team Parkinson's** fundraisers, perhaps attending one of their events, is also a great way to get involved – and to experience the community of people who care that is growing every day.

Our hope is that by fundraising, we will be able to continue to provide at little or no cost, our services, information, education, resources and support programs to all those who need them – not only today, but tomorrow.

## Parkinson's Victoria upcoming fundraising and special events for 2012\*

|               |  |
|---------------|--|
| 24 February   | BUNNINGS BBQ (MENTONE)   |
| 24 February   | BACK TO THE FUTURE 3 MOVIE EVENT                                     |
| 15 March      | TRAIN STATION TIN RATTLE   |
| 24 & 25 March | OPEN GARDEN – YARRA GLEN, TEAM PARKINSON'S EVENT                     |
| 1 April       | ENTERTAINMENT BOOKS NOW ON SALE AT THE OFFICE                        |
| 11 April      | WORLD PARKINSON'S DAY – INFORMATION SEMINAR and AAMI PARK LIGHT SHOW |
| 15 April      | BUNNINGS BBQ (MOORABBIN)   |
| 26 April      | PERIDOT THEATRE NIGHT  |
| MID April     | STEPS DONOR UPDATE   |
| May           | MID YEAR ANNUAL APPEAL   |
| Late May      | SPRING VALLEY CHARITY GOLF DAY                                       |
| Late May      | WINTER SIGNPOST  |
| 7 June        | TRAIN STATION TIN RATTLE   |
| 15 July       | RUN MELBOURNE, TEAM PARKINSON'S EVENT                                |
| August        | SPRING SIGNPOST  |
| 3 August      | BUNNINGS BBQ (MORNINGTON), TEAM PARKINSON'S EVENT                    |
| 11 August     | BUNNINGS BBQ (MOORABBIN)   |
| 18 August     | BUNNINGS BBQ (MORNINGTON), TEAM PARKINSON'S EVENT                    |
| 26 August     | PARKINSON'S UNITY WALK   |
| September     | CHRISTMAS CARDS AND HAMPERS NOW ON SALE                              |
| 7 October     | MELBOURNE MARATHON, TEAM PARKINSON'S EVENT                           |
| November      | END OF YEAR ANNUAL APPEAL  |
| Mid November  | SUMMER SIGNPOST  |
| 9 November    | PERIDOT THEATRE NIGHT  |
| 11 November   | CITY TO SEA, TEAM PARKINSON'S EVENT                                  |
| 15 November   | ANNUAL GENERAL MEETING   |
| 24 November   | TULIP BALL, TEAM PARKINSON'S EVENT                                   |
| 2 December    | THANKS A BUNCH VOLUNTEERS EVENT                                      |

**Keep an eye on Signpost, our website and Facebook page for information about other events and activities including movie nights, wine drives, Parkinson's Passion rose sales, and other Team Parkinson's Events. If you would like further information about any of the events listed above, please contact Judith on (03) 9581 8700 or send an email to: [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au)**

\*For information about **Health Team events** (Parkinson's community education, workshops, support group visits, special events) please contact our office or send an email to: [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au)

# Volunteers

If you didn't already know, Parkinson's Victoria has an active volunteer program with fun and diverse roles needing to be filled.

Volunteering is a great way to get involved in the work of Parkinson's Victoria and to make a valuable contribution; meet friends; stay in touch with us; and experience our work 'behind the scenes'.

Volunteers are integral to many of our fundraising events: Charity sausage sizzles, tin rattles, Parkinson's Unity Walk – to name a few, simply wouldn't happen without their dedication, and selfless support.

## Thanks a Bunch

Last year, 275 people generously volunteered their time to assist with organising and running a range of events and they were all invited to our Thanks a Bunch special event.

On Sunday, 4 December, we welcomed over 80 guests, including volunteers, special supporters, Ambassadors and Support Group leaders to Sandy by the Bay in Sandringham to say **Thanks** and celebrate the conclusion of a successful year.

Guests enjoyed finger food, a glass of bubbly and the opportunity to meet others who have helped the organisation in one form or another throughout 2011.



Our Volunteer Coordinator and Events Assistant Josephine (Jo) with her kids, Louis and Alessia during our Thanks a Bunch party.

We forgot to mention that Jo is also an amazing baker and our Thanks a Bunch guests were treated to some delicious cupcakes with Jo's signature attention to detail!

## Ready to volunteer?

Volunteers play a vital role in enhancing and expanding the services and activities provided by Parkinson's Victoria.

### How do you volunteer?

- Contact our office.
- Complete a 'volunteer registration form' to be added to our confidential volunteer database.
- We'll let you know about upcoming events and you can nominate whether you wish to participate. You are never under any obligation - your volunteering time is totally up to you!

**For more information, contact Josephine Berthelemy, Volunteer Coordinator:**  
**(03) 9581 8700 or [jo@parkinsons-vic.org.au](mailto:jo@parkinsons-vic.org.au)**

# Participate 4 Parkinson's

Research is taking place around the world – and getting involved is easy and a tangible way to help make a difference. (Research projects promoted and/or funded by Parkinson's Victoria have appropriate ethics approval.)

## Exploring the impact of Parkinson's

Common conditions associated with ageing, including stroke and Parkinson's, affect an individual's health, functioning and social participation. Social, cultural, economic and geographic factors influence how people adjust to life after a stroke or a diagnosis of Parkinson's.

Researchers from the School of Psychology and Psychiatry at Monash University are undertaking a study to explore the understandings and experiences of people who have experienced one of these conditions. The project will also examine what factors might impact upon individual and family adjustment and how and whether this changes over time.

People who have had a stroke (in the last 3 years) or who have been diagnosed with Parkinson's are invited to participate in this Monash University study.

Participants should be Australian-born of European descent or from an Indian cultural background, and should reside in Victoria.

Each participant will be invited to participate in four interviews over a two year period, and each interview will last less than one hour.

If you consent to participate, you will also be requested to undertake a small photographic exercise. Participants will be given a small gift in appreciation of their time.

**If you are interested in participating or finding out more about this important research, please contact Darshini Ayton, School of Psychology and Psychiatry, Monash University: (03) 9903 1660 or via email [Darshini.Ayton@monash.edu](mailto:Darshini.Ayton@monash.edu)**

## Trail blazing Trial Finder

The Michael J Fox Foundation's **Fox Trial Finder** is now available to those living in Australia (although participation may require travel!).

This new Web tool makes it easy to find trials that are urgently seeking eligible participants. It's also a great place to see what sort of research projects are currently underway or on the horizon.

**Questions, concerns, feedback or suggestions for Fox Trial Finder can be emailed to: [support@foxtrialfinder.org](mailto:support@foxtrialfinder.org).**

**Health Team note: The Parkinson's Victoria Research Registry is the best place to link into research taking place here in Victoria (soon to be Australia-wide) however, the Fox Trial Finder (FTF) is likely to attract a wider range of **general** Parkinson's researchers who are conducting social, emotional and wellbeing type studies.**

# Health & Wellbeing

## Helping Hand

*Occupational Therapists (OTs) assist clients to achieve maximum function and independence despite illness, injury or disability. Occupational Therapist PAMELA FARRINGTON, an OT with more than 10 years experience working with Parkinson's clients, explains how an OT can provide specialist expert advice and information to assist people living with Parkinson's.*

OTs can specialise in many different health fields. There are OT's in hospitals, rehabilitation centres, community health centres, schools, mental health centres and private practice, to name a few.

Some OTs make home visits or workplace assessments. They may also be qualified with VicRoads to assess or reassess driving skills or can create splints for clients to assist in the repair of an upper limb after injury or deformity. You can find OTs working with clients from all age groups, some as a team member and some as sole practitioners.

OTs are trained to think objectively and creatively (while also being aware of the medical limitations of illness and/or injury) to address a client's difficulties and concerns and together with their input, work towards a solution. Not all issues can be resolved but often alternatives can be suggested and encouraged. The most important concern is to assist people to function as independently as possible with their own sense of wellbeing and purpose.

### *How can an OT assist a client living with Parkinson's?*

Below are just a few examples of how an OT may be able to assist a person living with Parkinson's.

**Writing remediation and strategies to help:** Often the first sign a person notices that something isn't quite right is that their signature is not the same as it used to be: letters become smaller towards the end of their name, a word or sentence, and the text may even work its way up to the top of the paper (rather than in a straight line). Fortunately, there are a few tricks to try to improve your handwriting and reduce the impact of this symptom of Parkinson's on your day to day life. Firstly, stop and think about what word you will write next. Then, try moving your writing wrist around in the air in a figure of 8 before you go back to your writing.

You may find that different types of pen grips and paper/positions are helpful. Also, try to do most of your writing (letters, cards etc) when you are not tired, your medication is working at its peak, and there are no other distractions in the room such as television or music.

**Home Visits:** These may be necessary to address issues of safety both in and around the home.

### *Outside the home:*

For example, what is the external access around your home like? Are there steps? Is a handrail needed? Maybe a ramp is required if a walking device or wheelchair is used.

A common potential 'hazard' are those pot plants we love to decorate our steps with. While they certainly look attractive, they can make walking up and down stairs challenging, even with the use of a handrail because your body's centre of gravity is altered when you lean over the pots to hold it!

Some people with Parkinson's tend to fall because of reduced mobility and stability and increased rigidity, so it's important to make your environment as safe as possible: no rugs, glass coffee tables, electrical cords from heaters or fans draped across the floor, no books, papers or clutter between where you sit and the doorway, TV or table.

### *Inside the home:*

An OT will assess the chair/s you sit in for correct height and back support (both lumbar support and arms on chairs are recommended for periods of extended seating). (Note that remote control armchairs are not necessarily helpful for someone trying to get up if they happen to experience freezing!)

An OT will also look at the height of your bed and whether or not an aid, such as a bed stick or specially made sheets with a satin middle, would assist you to turn over or move your body across the bed (this can be difficult for some people with Parkinson's).

The toilet and bathroom are also assessed for rail installation or other equipment that might be helpful to increase safety and mobility/ease of use such as toilet raisers, shower chairs or a handheld shower hose. There are also lots of handy tips an OT can offer, for example, putting a bar of soap into a pair of pantyhose and tying the hose to the rail so if you drop the bar you don't have to bend down to pick it up! Many clients have difficulty performing more than one task at a time, such as holding onto soap and washing themselves, so simple things like putting the soap into a washable glove can be very helpful.

An OT will also explain safe ways of entering and exiting the shower.

**Prescription of aids and equipment and application to SWEP (state wide equipment program):** This is another important role of an OT.

SWEP is a government funded scheme for clients who have a permanent disability not covered by any other scheme or organisation such as Veterans Affairs.

**Fatigue Management:** Many people with Parkinson's experience increased fatigue and it's important to conserve energy for 'important' things like showering or meal preparation. An OT can suggest some simple strategies to help combat fatigue, such as collecting all the items you need for getting dressed from your cupboard at one time rather than walking back and forth many times.

**Relaxation and stress management** are helpful strategies for everyone, regardless of age or health concerns, but can be particularly important for those experiencing the fatigue, anxiety and frustration of living with a chronic illness.

Relaxation, which may come from various sources such as progressive muscular relaxation or meditation, helps our mind and body to better manage stress and tension.

Many private OTs and community centres offer relaxation classes, but relaxation does not have to be formal and there are many inexpensive (and

free) options to consider. Simply walking the dog or listening to a favourite CD can allow your mind to switch off from everyday business.

Relaxation techniques should be practised regularly to enjoy the greatest benefits: it is important to factor "time out" every day to help your mind and body rest and recharge.

**Recreation and Leisure Pursuits:** OTs are also skilled in advising and modifying or adapting tools/equipment in leisure activities that will help promote physical and mental wellbeing. If you are unable to pursue an existing hobby, another stimulating one might be just around the corner – just ask.

**To find out more about how an OT can assist you or someone you know, contact Occupational Therapy Australia: (03) 9481 6866 or visit [www.oftaus.com.au](http://www.oftaus.com.au) to find a therapist in your area.**

**This article was written by Occupational Therapist Pamela Farrington. Pamela has extensive experience working as a community based OT and currently practices in the Peninsula/Eastern region. To contact her for an appointment call: 0408 135 488 or email [pamelafarrington@gmail.com](mailto:pamelafarrington@gmail.com)**

## Ambassadors - Help spread the word

Nearly every week of the year, somewhere in Victoria, a Parkinson's Ambassador stands up in front of an audience and delivers from the heart the story of their personal journey of living with Parkinson's. In so doing, they educate and inform the wider community, helping to raise awareness and correct misconceptions about what Parkinson's is – and isn't. They also promote the services and work of Parkinson's Victoria.

Parkinson's Victoria is truly indebted to this dedicated group of people who volunteer their time and often have to travel great distances, while overcoming the usual phobias associated with presenting to a group of strangers (sometimes with the aid of an interpreter just to make it a little more challenging)!

Audiences range from service clubs such as Rotary and Probus, to schools, community clubs, senior citizens and non-English speaking social clubs.

While public speaking is not for everyone, and

may be the furthest thing from your mind – you can still support our Ambassador Program and help 'spread the word'!

How? By promoting the Ambassador Program to your church, business or social club; in fact to any group you know or are involved with that might be looking for an informative and engaging speaker.

**Jo Berthelemy, our Volunteer Coordinator, would be delighted to hear from anybody with contact details for your organisation, work, club or association with a view to booking an Ambassador presentation (this is a voluntary program and there are no booking fees).**

**Word of mouth recommendations and referrals are the ideal way to promote the Program and secure engagements – so please let us know who we should contact and feel free to 'make an introduction'. You can reach Jo at Parkinson's Victoria on Tuesdays, Wednesdays and Thursdays on: (03) 9581 8700 or [jo@parkinsons-vic.org.au](mailto:jo@parkinsons-vic.org.au)**

# President's Report

We are pleased to announce our new Board President, Peter Raymond, elected at the Board Meeting on 14 November, 2011.

Peter was diagnosed with Parkinson's in 2001 and since then he has been closely involved with Parkinson's Victoria, as our Ambassador Program Coordinator (and an active speaker) and a Board Member.

Peter has also been an active advocate and supporter of the cause and our work on a more personal level; He has shared his story with the media on numerous occasions, volunteered to help and supported many fundraising events, and represented the organisation in an official capacity at various public events.

Peter's background in Marketing and Human Resources has been a great asset to the organisation already, and he has been integral to establishing some of our key corporate relationships.

Peter is always looking for opportunities to leverage in the fight against Parkinson's and to enhance our day-to-day work raising awareness and providing support. He is passionate about the role of Parkinson's Victoria to make a positive and long term difference in the lives of others living with Parkinson's and never hesitates to offer his time and experience.

At the November Board meeting, Peter was also nominated to represent Victoria on the Board of Parkinson's Australia.

Pete Walker, retired by rotation and being eligible, offered himself for re-election for a further 3 year term.

The number of candidates nominated did not exceed the number of vacancies. Therefore, Joanna Hill, Professor Meg Morris, Andrew Suggett and Peter Walker were all elected for 3 year terms.

At its Meeting on 14 November, the Parkinson's Victoria Board also elected existing Board Member Fred Van Ross as Vice President and Peter Walker as Chairman, Finance Committee.

On behalf of Parkinson's Victoria and Board, I congratulate all candidates on their appointments.

It is now our responsibility to work with the CEO and staff, volunteers, service users, members and other stakeholders to ensure that Parkinson's Victoria is effectively and properly run and meets the needs for which the organisation was established.

The Board is collectively responsible and accountable for ensuring and monitoring that Parkinson's Victoria is performing well, is solvent, and is complying with all its legal, financial, and ethical obligations.

**There are exciting times ahead for our organisation as we work towards our vision of a world without Parkinson's and we want to share this journey with you at the most grassroots level. Your support, contribution, feedback, participation, advocacy, honesty and active involvement is absolutely essential and so greatly valued as we move forward.**

**Parkinson's Victoria will benefit from the experience, wisdom and commitment of our Board members as we begin this next phase. So too will they benefit, personally and professionally, from being involved with an organisation that means so much to us all.**

*Parkinson's Victoria Board President PETER RAYMOND provides an update following our 2011 Annual General Meeting.*

Friday, 11 November last year was not only Remembrance Day but it was also Parkinson's Victoria's 2011 Annual General Meeting.

After an appropriate silence and traditional "Lest We Forget" at 11.00 am the President, Royce Pepin, took the chair for our 30th Anniversary meeting.

In presenting his Report, Royce acknowledged the dedicated work of two Board members, Kate Brown and Mary Jones, who were retiring after serving three elected terms. Royce also announced his decision, after six years, to retire as President of the Board.

Kate, Mary and Royce were acknowledged for their outstanding service marked by dedication and a committed enthusiasm to advance the well-being of people living with Parkinson's. They have helped Parkinson's Victoria grow to become a well-managed, financially secure organisation delivering quality services.

We wish them well in their future endeavours; they will always be welcome at Parkinson's Victoria.

Three candidates were nominated to fill their vacancies: Joanna Hill, Professor Meg Morris and Andrew Suggett.

## *2011 Members of the Parkinson's Victoria Board*

Peter Raymond, President  
Fred Van Ross, Vice President  
Peter Walker, Chairman, Finance Committee  
Joanna Hill  
Brendan Lourey  
Professor Meg Morris  
Andrew Suggett

**Peter Raymond  
President**

## **TULIP BALL 2012**

On Saturday 10 November, get ready for a night of sophistication at the historic Plaza Ballroom of Melbourne's famed Regent Theatre (191 Collins Street). The Tulip Ball, the premier charity event for Parkinson's Victoria since 2008, is back and sure to be the biggest and brightest yet!

**\$190 per ticket incl. 3 course meal, beverages, entertainment. 100% of monies raised are donated to Parkinson's Victoria. [www.tulipball.org](http://www.tulipball.org)**



# Supporters

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## 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.

*THANK YOU to those who have given so generously to Parkinson's Victoria. Listed are those who kindly donated \$250 or more, those in whose name In Memoriam donations were received, and corporate/organisation supporters from 10 November 2011 to 31 January 2012.*

*We extend our sympathies to the families who have lost loved ones, and we thank those who have donated anonymously.*

## Donations of \$4000+

Julia Ho

## Donations \$2000+

Reginald & Audrey Campbell  
Barry Williams

## Donations of \$1000+

Robert Buckle  
Arthur Hall  
Keith Hayes  
Fiona Lourey

## Donations of \$500+

Paul & Elizabeth Atkinson  
L & M Eysers  
Peta Hannan  
Jeremy Kinross  
Margaret Livermore  
Michael Ramsay  
Diana Russell

## Donations of \$250+

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B Matchan  
Ian & Gail Pagon  
Yvonne Pratt  
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Barbara Tomaszewski  
Harlan Winata

## Bequests

The Estate of the late Mr William Horace Hillard  
The Colin and Shelia Marshall Bequest

## In Memory and Remembrance of

Diego Azzolina  
Annunziato Bagnato  
Lauraette Blackham  
Graham Burslem  
Val Cafford  
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Bettine Dowie  
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Glen Grey  
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Ron Johnson  
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Alan Wrangle  
Gerald (Gerry) Whyte  
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Charlie Xerri

## In honour of...

Ms Lisa Blake  
Paul & Marlene Lonergan  
Jeff & Wendy Lee

## In celebration

Ingrid Brouze, Birthday  
Rebecca Eden, 80th Birthday  
Olive Judge, 90th Birthday  
Cheryl Rubinstein, Birthday  
Karyn Spielberg, Birthday  
Hayley Bell and Michael Lacy Wedding

## Team Parkinson's Fundraisers

### - \$1000+

Dartmouth Alpine Anglers Club Inc  
Gisborne Peak Winery  
Ernie Kemplay  
Richard McLoughlin

## Team Parkinson's Fundraisers

### - under \$1000

The Salvation Army Warragul  
Blue Hills Garden Group  
Ian & Gail Pagon  
Ian & Judy Phelan  
Adam Poulton

## Corporate, Community & other donations & support

Australian Unity  
Beta Sigma Phi  
Breville Pty Ltd T/As HWI Electrical  
Charity Greeting Cards  
Country Womens Association  
Fergusons  
Ferntree Gully Town Club  
Hesel Pty Ltd  
Ipsos Australia Pty Ltd  
Isuzu Australia  
LDB Chartered Accountants  
Melbourne Welsh Church  
Mentone Grammar  
Midwood Roses Pty Ltd T/As  
Treloar Roses  
Mosaic Photography & Design  
NSAA North East Victoria Sub Branch  
Pahran Seafoods Pty Ltd  
Raylee House "Day Care"  
Rolo Design & Project Management Pty Ltd  
Shadforth Financial Group

Holdings Ltd - (Part of Outlook)  
St Andrew's Anglican Church  
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St.Jude Medical Australia Pty Ltd  
The Inner Wheel Club of Williamstown Inc  
Warren Howard & Associates Pty Ltd  
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Breville Pty Ltd T/As HWI Electrical  
Fergusons  
Hesel Pty Ltd  
Ipsos Australia Pty Ltd  
Isuzu Australia  
LDB Chartered Accountants  
NSAA North East Victoria Sub Branch  
Pahran Seafoods Pty Ltd  
Rolo Design & Project Management Pty Ltd  
Warren Howard & Associates Pty Ltd  
St Andrew's Anglican Church  
Brighton Op-Shop  
Raylee House 'Day Care'  
Melbourne Welsh Church  
The Inner Wheel Club of Williamstown Inc  
Ferntree Gully Town Club  
Country Womens Association  
Charity Greeting Cards  
Midwood Roses Pty Ltd T/As  
Treloar Roses  
Mosaic Photography & Design  
Mentone Grammar  
Shadforth Financial Group  
Holdings Ltd  
St Jude Medical Australia Pty Ltd  
Australian Unity

## Matched Payroll Giving

Phaik See Chong

## Payroll Giving

National Australia Bank

*We gratefully acknowledge the generous support of all those who supported our regular appeals in 2011.*

→ Support for our **Mid year appeal** raised a total of \$26671 (\$8645.00 members; \$18026 non-members)

→ **Steps Spring donor update:** \$15638 (\$2550 Members; \$7215 non-members) and **Steps Autumn:** \$15638 (145 members/non-members)

→ **End of Year appeal** has so far raised \$2018 (\$9198 members; \$11,820 non-members).

# Tulip tributes

## *Hair raising adventure*

Richard McLoughlin and colleague Adrian Dingey (below left and right) were inspired to grow their beards as a fundraising activity when the father of a close friend of Richard's recently passed away.

While there were many who - apparently - didn't think the hairy-look worked for the boys, we think they look terrific!



**Just over \$1000 was raised through their efforts. Well done and thanks guys!**

## *What a catch*

In November last year, the Dartmouth Alpine Anglers Club hosted its annual Women's Fishing competition, with proceeds donated to Parkinson's Victoria. The weekend was an incredible success and we are very pleased to say that a donation of \$5134 has since been received.

While a serious event for most – especially with \$20000 in prizes up for grabs - there was no shortage of laughs and entertainment during the competition and at the social events.

**Congratulations to the competition winners and thank you to all competitors, members of the Dartmouth Alpine Anglers Club, event sponsors and the local community who generously supported the event.**

## *The Christmas spirit*

A big Tulip Tribute to the Taylor Family (Cathy, Barry, Scott, Melissa, Kate, Austin, Kai and 'their little bundle of joy on its way') for opting to make a donation to Parkinson's Victoria in lieu of sending Christmas Cards last year.

With their donation, we received a brief note explaining: "Our Dad, Grandpa and husband is suffering from this disease and although we can't always give a donation, we thought this was one small way our family could help".

**A thoughtful and generous contribution to our work. Thank You!**

**P.S. We also received a number of donations in lieu of Christmas Gifts from other generous supporters. Thank You!**

## *Forever in our hearts*

Special thanks to Joanne Cassar who sold 50 Parkinson's Victoria tulip badges through her office at Medicare Australia (Airport West).

Aside from helping to raise funds, Joanne's efforts helped raise awareness and, even more heart warming, several customers opened up to her about their own journey of living or caring for someone – with Parkinson's.

Joanne's much loved mum Leslee (below) passed away just before Unity Walk last year, after 40 years living with Parkinson's.

The family – including the pet dog – came together at the Walk to remember and honour Leslee, and this is when Joanne was moved to do even more to help the cause.

The following is an edited excerpt from the letter we received from Joanne:

"My beautiful mum Leslee had a long battle with Parkinson's. She lived at home with my dad Joseph, who was her full time carer, and she never complained about Parkinson's, but always tried to continue on with general life. If she could help you, she would bend over backwards to do it.

Parkinson's was part of mum's life and ours, but she never let it beat her, right up until the end.

Mum passed away in late 2011, but she never wanted to be remembered the day she died, so we put her birthday on all her memorial cards. And whenever anyone asked how old she was, mum would say 21, so we added **FOREVER 21**.

My mother was and is an inspiration. A real lady is now finally at Peace. We miss her dearly."

## *Little one takes the cake!*

We can all be inspired by the fundraising efforts of Jamie, a Grade 5 student at Silvertown Primary. In term 3 (last year), following a school project where she chose to talk about Parkinson's, Jamie – with the help of "mum" - made 90 cupcakes which she then sold at recess and lunch time. Jamie raised \$136.80 – and we agree, "That's a lot of money!"

Jamie acknowledged, in love and memory, her grandfather George. (Jaime's parents matched her fundraising with a donation of \$136).

**Congratulations Jamie – what a terrific effort!**

