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## Just a walk in the Park

*But Oh, what a difference a day makes!!*

*It was smiles and sunshine all 'round at the third annual Parkinson's Unity Walk, hosted by Parkinson's Victoria at Federation Square on Sunday 28 August.*



*Rhonda Kennedy from our Bendigo Support Group surrounded by family and friends at the 2011 Parkinson's Unity Walk.*

Some interesting facts about this year's event:

- Just under 2000 people participated – once again making it **THE largest gathering in Australian history in support of those living with Parkinson's**
- Just over \$80,000 (nett) was raised.
- 123 Unity Walkers actively fundraised. Many others made generous donations.
- The first 100 fundraisers to raise \$200 received a fantastic Gecko Stylus + Pen from Gecko Gear ([www.geckogear.com](http://www.geckogear.com)).
- 63 dogs were registered to walk.
- More than 700 sausages were sold at the Unity Walk/Glenferrie Rotary BBQ
- There was a total of 105 teams walking
- The largest team – Karyn's Crowd-boasted almost 100 members
- Approximately 20% of Unity Walk participants had Parkinson's – and 80% were friends, family and supporters
- 5% of participants used a mobility aid to complete the Yarra Walk
- 44.5% were past participants
- Number of Tribute Cards worn – unknown
- Our event photographer Mosaic Photography generously donated 100% of all photos sales.

- The event garnered more than \$300,000 in free publicity and media, across national, state and local radio, local and major newspapers, and print publications (including: RACV magazine, The AGE weekend lift-outs and Take 5 magazine), television (6.30 with George Negus, Channel 7 and 10 News, and The Circle)

**Check out your photos!** All the fun and faces of this year's **Parkinson's Unity Walk** can be viewed on our Facebook page: <http://www.facebook.com/parkinsonsvic>

**Thank you to everyone who Walked and all those who contributed towards this year's Unity Walk fundraising goal.**

**While we didn't reach our target of \$150,000 to help fund our programs and respond to the increasing need for information and support, we will continue to work hard. With your support we can lighten the load for Victoria families.**

**Thank you to the following, without whose support Unity Walk would not have been possible:**

### Major sponsors

- Outlook Financial Solutions
- BankMECU
- Martin and Pleasance
- St Jude Medical

### Sponsors

- Australian Unity Retirement Living
- Bunzl Australasia
- Boehringer Ingelheim
- City of Melbourne

### Supporters

- Federation Square
- Cargo Apparel
- Ernie Kemplay Trio
- The Jazz Cats
- Rotary Club of Glenferrie and Members
- Timeout Café
- Gecko Gear
- City West Water
- Lincoln Flynn Graphic Design
- Perfect Events
- La Manna Direct
- Delica Meats
- Jolimont Espresso
- Il Pomodoro
- Café Chinotto
- Monet Press

*And, special thanks to those Unity Walkers who graciously shared their story with the media to help increase awareness and publicity!*

# News & Highlights

## 30 years of service & growth

In 2011, we marked 30 years of service to the community and never has our mission been more important to the organisation and the people we serve.

We want to ensure that **all people living with Parkinson's have access to comprehensive and relevant services, encouraging independence and improved quality of life.** We started the year with our Strategic Plan in mind and as I review the year, I am proud of the achievements we have made.

Our Strategic Plan has six key result areas.

- The provision of innovative, relevant, quality services; available to all people living with Parkinson's (PLWP) throughout Victoria
- An increase in public awareness
- Advocacy which results in better services, improved treatments and quality of life
- The advancement of Parkinson's research
- Financial sustainability
- Excellence in corporate governance.

This year we have delivered in each of these key areas.

The State government funds us to assist 2500 people per year. Our Health Team has assisted over **4000** people, almost **twice** the number of people for which we are funded. Our team of 3 full time and 1 part time health professionals delivered more than 200 community and professional education seminars.

We have also been proactive in increasing public awareness of Parkinson's and Parkinson's Victoria. These efforts culminated on Sunday, 28 August at Melbourne's Federation Square, when we hosted the third Victorian **Parkinson's Unity Walk** - the largest event of its kind in Australia with almost 2000 people in attendance.

Our advocacy has been successful: We saw the implementation of a **Movement Disorder Clinic** at Western Health, which means people with Parkinson's living in the western metropolitan area now have access to a specialist movement disorder clinician. We continue to work with regional health care network providers in the implementation of movement disorder clinicians.

We helped advance research: We partnered with the **National Health and Medical Research Council** to set up a **Transition from Research into Practice** scholarship. We continued to fund the **Parkinson's Victoria Research Registry** and support the **Victorian Brain Bank Network**. This year we also funded a non-clinical research program through the Southern Academic Primary Care Research Unit at Monash University.

It is always pleasing to see the efforts and initiatives of our organisation and staff formally acknowledged and this was our year for Awards. In partnership with Outlook Financial Services, we were winners in the **Aged Care and Community Support, Community Service Awards**, a Rotary Southbank initiative. In the SACS Leadership Victoria awards, Judith Mooney won an award for her leadership in fundraising.

While government funding makes up just 14.4 percent of our total budget, our organisation remains in good shape financially, thanks to the loyal and generous support of donors and members which enables us to continue providing high quality services and support.

**Thank you for your continued support. We will continue to work on our mission to assist people, families and communities affected by Parkinson's.**

**From myself, the Board and staff, best wishes for the coming holiday season. We wish you happiness and good health, and look forward to working with you in 2012.**



*Ann Burgess*

**Ann Burgess, Chief Executive Officer**

## Compelling story a media winner

In August, Karyn Spielberg shared her very personal journey of undergoing Deep Brain Stimulation surgery for Parkinson's with hundreds of viewers across the country when she was interviewed – and her surgery filmed - for the television program **6.30 with George Negus**.

Karyn went on to complete the 2011 **Parkinson's Unity Walk** – her goal before and after surgery, and we are grateful for her courage in sharing this journey to help increase understanding of Parkinson's in the wider community.

You can view Karyn's story on our Youtube page: [www.youtube.com/parkinsonsvic](http://www.youtube.com/parkinsonsvic)

**We are also very pleased to announce that Karyn's story and reporter, Emily Rice, were acknowledged with a recent Yooralla Media Award.**

**The Yooralla Media Awards recognise reporting across all media that has helped to challenge stereotypes that unfairly define people with a disability. It is awarded for coverage that**

**accurately, positively and sensitively portrays the achievements of people with a disability and the myriad issues they face.**

**Congratulations Emily – and Karyn!**

## *Medication alteration prompts caution*

Our Health Team has recently been advised that Merck Sharp & Dohme (Australia) Pty Ltd, manufacturers of the Parkinson's medication **Sinamet**, have made alterations to the appearance of Sinamet tablets (100mg/200mg) but this information has been slow to be passed onto consumers.

**Note: These alterations apply to the presentation of the pill only. The dosage and drug formulation have NOT been altered and the active ingredients remain the same.**

Key changes to Sinamet medication are:

- The Sinamet tablet is now round (no longer oval)
- Each tablet is no longer scored so is unable to be broken/cut in half.

We have received some calls to our Helpline regarding adverse affects as a result of the new presentation. This is most likely caused by under-or overdosing on the medication: Due to the inability to halve a tablet, where a half dose has been prescribed, many people are not able to administer their specific dosage accurately and this has led to wearing off or dyskinesia.

**If you have questions in relation to Sinamet or have any concerns about your Parkinson's medications contact our Health Team.**

**People experiencing any unusual or adverse reactions to the new presentation of Sinamet are encouraged to report their experience.**

**For reporting or advice on adverse drug reactions or errors associated with medicine use contact The Adverse Medicine Events (AME) Line: 1300 134 237. You can also request that your GP or neurologist complete the Adverse Drug Reaction "blue form".**

## *Parkinson's nurses take action*

**The Royal College of Nursing Australia** is the peak professional body for nurses in Australia, and the **Movement Disorder and Parkinson's Nurses Faculty** has been formed as part of this dynamic organisation.

The role of the faculty is important as it enables Movement Disorder Nursing to be identified as a speciality area, and provides a national forum for nurses working in the area of - or with an interest in - movement disorders.

The Faculty provides a platform to raise the profile of movement disorders, in particular Parkinson's, amongst nurses, health care professionals and at government levels. Through its affiliation with the Royal College of Nursing, the faculty is able to contribute directly to policy affecting those living with Parkinson's, and to highlight the value of community access to a Parkinson's Nurse.

Former Parkinson's Victoria Board member and Parkinson's Nurse, Mary Jones and Victor McConvey, Parkinson's Nurse Consultant with our Health Team, were recently appointed as Chair and Vice Chair respectively of the **Movement Disorders and Parkinson's Nurses Faculty Advisory Committee.**

**Congratulations to both Mary and Victor on their appointments. We look forward to providing updates on the activities of the Committee and Faculty in future editions of Signpost.**

## Lost property – Unity Walk 2011

We collected a small number of personal effects following this year's Unity Walk at Federation Square.

**If you have lost a pair of sunglasses, a brooch and/or a small cloth bag please contact our office.**

## Holiday Office Hours

Over the holiday season, the office of Parkinson's Victoria will be closed from 2.00pm on 23 December 2011 and will re-open on Tuesday 3 January, 2012.

## Tulip tributes

### *Feet do the talking*

Special thanks to Shepparton resident Darnley Montgomery for his efforts in raising both awareness and funds to support our work.

Darnley has been interviewed on his local radio station about his personal journey with Parkinson's and has also been active fundraising locally.

**Congratulations and thank you Darnley for "taking to the streets" and not only sharing your story but actively fundraising to make a difference in the lives of others living with Parkinson's.**

# Health & wellbeing

## The benefits of social connectedness

*If you are looking for a way to improve your health without taking extra tablets or worrying about increased side-effects, look no further than the people around you; your family and friends, members of your book club, church community, rotary group, golf club...*

*More and more studies now show that social engagement leads to better overall health outcomes. CATHERINE WATSON, Community Development Worker with our Health Team, explains.*

The notion that there are a number of ways to improve health and wellbeing is not new. Avenues include a balanced diet, exercise (our Health Team is particularly vigilant about promoting this), "good" sleep and reducing stress levels. But did you know that visiting friends and family, or participating in your local community group, such as the local **U3A**, can actually be good for your health as well? *Often, the simplest things in life are the best!*

It is not surprising to think that people who are engaged in regular social interaction feel better. Catching up with friends is good for improving mood and relaxation, while participating in community activities or learning new skills provide a sense of achievement and can boost self-esteem.

When you are out and about, you are typically being more active than you would be staying at home and therefore this type of activity also contributes to your daily exercise needs.

Whether you are playing a round of golf, discussing the latest political situation with friends, engaging in paid employment or volunteering, you are also giving your brain cells a workout. This all contributes to good health outcomes.

**So how can Parkinson's impact on your interaction with others?** Depending on your individual situation, Parkinson's may mean you have to re-think some of the ways you engage in activities, but - where possible - Parkinson's should not stop you from undertaking or enjoying those activities.

Here are some tips for troubleshooting common concerns:

**Fatigue:** Many people with Parkinson's find that they do not have the same energy levels they used to, and therefore find activities they once enjoyed tiring and burdensome.

Try changing your routines: If you get tired in the afternoon, catch-up with friends for weekend brunch instead of dinner. If 18 holes of golf is too much, don't give up playing golf altogether, but try

9 holes instead. If your community group meeting takes place in the morning, don't offer to babysit the grandkids that afternoon. Certainly don't give up minding the grandkids though - another valuable social interaction - but do so when that becomes your one main priority for the day and you can better devote your energy to it.

**Communication:** Some people with Parkinson's get frustrated in social situations when they feel they are unable to keep up with the conversation, are stuck for words, or find they are being spoken over.

Try meeting up with friends and family in quieter venues rather than larger, noisier ones which are full of distractions. When you speak, focus on projecting your voice by pretending the people you are speaking to are further away than they really are (you may even feel as though you are shouting but odds are, you won't be and your friends will be able to hear you clearly).

**Explain to those around you how Parkinson's affects not what you want to say, but the time it takes you to say it.** Ask them to keep this in mind, ensuring that you are given regular opportunity to participate fully in the discussions taking place around you.

**Self esteem:** If you feel self-conscious of your Parkinson's symptoms when at work or out in social situations, this may make you feel less inclined or reluctant to participate, or to withdraw from these circumstances all together.

The catch is that as human beings we need to continue engaging in work, social and community activities to find meaning in day-to-day living and this is vital for maintaining self esteem.

Do not be too hard on yourself if you are no longer able to achieve a goal that you used to. Re-evaluate your goals so that you still have something to strive for and you find a sense of achievement in working towards them. Perhaps you might not be able to run a marathon like you once planned, but instead undertake a shorter run or even the walk component of the event (many Fun Runs offer a range of events to choose from). You may even set a fundraising goal to take the focus off the physical challenge!

Maintain a sense of humour when you can. Sometimes we have bad days and sometimes we have good ones. Nothing is going to change that, so try and find humour in life's unexpected circumstances.

**Stress:** If you find that participating in a particular activity is stressful, consider ways you can alter the task to ensure it remains enjoyable.

For example, if you are the secretary of your local community group and handwriting or typing is becoming difficult, consider job sharing the position with another group member or look for ways you can still participate in the group through another role.

Consider aids or items to help manage Parkinson's more discreetly. There are all sorts of clever products on the market to help people engage in various activities.

If you are still working, your employer is legally required to make a reasonable effort to ensure you have what you need to perform your duties. Seek advice from an Occupational Therapist who can help identify aids and strategies to make tasks easier and reduce feelings of self-consciousness about symptoms.

Contact Parkinson's Victoria for referrals and further information on this subject, including your rights at work and how to discuss Parkinson's, symptoms or needs with your employer or workmates.

**Independence:** Not driving anymore? Don't be too proud to ask someone for a lift.

Depending on the activity, find out if alternate transport is available. Some government-funded programs, such as half-price taxi cards, can help make your situation easier. Initiatives such as Companion Cards are aimed at keeping people living with a disability engaged in community activities by providing a carer or companion with free entry to events and venues.

**Awareness:** Improved community awareness of Parkinson's starts with each individual. Explaining Parkinson's to the people you work for or with is the easiest and best way to help them understand how to support you. Consider asking a Parkinson's Ambassador to speak to your Rotary group, church group, U3A group or social club to help friends understand Parkinson's while taking the pressure off you to explain.

**Connect:** Staying involved and actively engaged with your community is vital. Now is the time to ring that friend you haven't seen in ages or invite family over for dinner (perhaps ask your guests to bring a plate instead of bearing the burden of cooking yourself).

Explore ways to become more involved with your community and to strengthen your social circles. Contact your local neighbourhood community centre and see what activities they have on offer for you to try; you'll learn new skills and meet new people too.

If you're not working, consider volunteering. Volunteering comes in many shapes and sizes and there are usually opportunities to suit a range of interests and skills, and the time commitment will vary to suit a number of lifestyles.

What about joining a Parkinson's Support Group? They are not meetings of 'tea and tears' but rather informal get-togethers where group members share an understanding of life with Parkinson's and a positive message of "getting on with life". There is laughter and many groups also share fun excursions and afternoon tea.

**Maintaining social networks is a very manageable way of improving your health – without the need for a prescription from the doctor. So go out, socialise, eat, drink, be merry... and know that you are healthier for it too!**

**Health Team note: Although this article is written with people diagnosed with Parkinson's in mind, those in a caring role also need to ensure they are maintaining their social connectedness as well.**

## New Support Groups

Living with or caring for someone with Parkinson's can be challenging, but you don't have to feel alone.

Parkinson's Victoria 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.

A new Parkinson's Support Group has just begun in **Williamstown!**

Meetings take place at The Village, Williamstown, 1-49 Paas Place, at 1.30pm on the last Wednesday of every month (excluding December).

In 2012, new Support Groups will be starting up in the areas of Frankston, Pakenham and Epping.

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

# Volunteers

*Volunteer Coordinator, JOSEPHINE BETHELEMY reports.*

## Many hands

First and foremost, I would like to express our gratitude to the 116 people who volunteered for **Parkinson's Unity Walk**, held on Sunday, 28 August at Melbourne's Federation Square.

Every single volunteer, whether course marshal, event ambassador, or registration, merchandise or information assistant – helped make this year's event the huge success it was.

Unity Walk is the biggest event hosted by Parkinson's Victoria and the largest event of its kind for the Parkinson's community in Australia.

With almost 2000 people taking over Federation Square for a day, pulling this event together is no mean feat.

Unity Walk requires months of planning and coordinating, and on the day – it's all hands on deck. Given Parkinson's Victoria is a team of just 10, our volunteers play an integral role in making sure everything happens when and how it is supposed to, so the community can come along and enjoy a fantastic day.

Behind the scenes, volunteers assisted with setting up the event and packing down, and distributing T-shirts and showbags. Volunteers were also instrumental in helping to create a wonderful, friendly and engaging atmosphere on the day.

Every single volunteer lent a hand – with a smile – and contributed towards a sensational event. Without this generous assistance, the Walk simply could not have taken place.

**So hats off to everyone who kindly gave up their Sunday to be a part of the third Parkinson's Unity Walk. We look forward to planning an even bigger and better event in 2012!**

### *Thanks-a-Bunch*

On Sunday, 4 December, we will once again host **Thanks-a-Bunch**, a special event to show our appreciation to all the volunteers, ambassadors, support group leaders and others who have made such a wonderful contribution to our organisation and the Parkinson's community by volunteering their time to help.

**Best wishes to all for the upcoming Festive Season. I wish you happiness and health in the New Year.**

### *Calling new volunteers*

We rely on enthusiastic members of the community to volunteer their valuable time or skills to help us.

**If you would like to help, please contact Josephine: [jo@parkinsons-vic.org.au](mailto:jo@parkinsons-vic.org.au)**

# Ambassadors

## The power of sharing

*Every year, our Ambassadors play a unique and vital role supporting our efforts to raise awareness and understanding of Parkinson's in the wider community. In sharing their personal journey with audiences, young and old, they shed light on this still mysterious condition, de-bunking myths and misconceptions. At the same time, their story – in words, actions and attitude – affirms that life can and does go on. Ambassador PETER YATES (below) shares his experience.*



An Ambassador for Parkinson's Victoria? I thought that sounded interesting. Newly retired from an Executive Director role at Monash University on the grounds of ill health because of my Parkinson's, I'd come to the Parkinson's Victoria website out of boredom; a break from the maximum 20 simultaneous

games of on-line Scrabble I'd been playing. I contacted Peter Raymond, Co-ordinator of **Parkinson's Victoria's Ambassador Program**, with a commitment to make a contribution. Very impressed by observing one of Peter's presentations at **Doncaster Probus Club**, I was keen to give it a go.

My first assignment was a presentation for North Yarra Community Health – 60 people, many language groups, seven interpreters in 45 minutes. I shuddered at the thought of them all paraphrasing me in sequence! "Ditch the Powerpoint" I concluded.

"If you get through this," said Peter "you'll be fine."

I did and I was. In fact, the interaction was so stimulating that I am now also volunteering with that organisation in a number of areas.

The next gig was at the **Probus Club in Creswick** in Central Victoria, a few miles from my home town. It was fun – a bit of a homecoming. Ninety people, lots of questions, a chance to illustrate by example and weave in a few stories. I was amazed by how little people actually know about Parkinson's, but also how interested they were to learn!

Finally, last week, I presented at **Woodend Probus**. Again, there were a lot of questions and they laughed and were serious in the right places.

I was a bit daunted at the start when a lady approached me and said: "I used to work at Parkinson's Victoria." When I was fumbling, as you do, to find the evaluation sheets at the end of the session, she interjected and said: "Don't worry, I'll ring the office and tell them you were good." That was good enough for me.

I enjoy this role. The work is important. I thank Peter Raymond for his support and look forward to future opportunities to contribute.

**For more information about booking an Ambassador, please contact Josephine: (03) 9581 8700 or [jo@parkinsons-vic.org.au](mailto:jo@parkinsons-vic.org.au) or Peter Raymond : 0438 400 259 or [pdr@netspace.net.au](mailto:pdr@netspace.net.au) Visit [youtube.com/parkinsonsvic](http://youtube.com/parkinsonsvic) to view a short video by Peter Raymond about the Ambassador Program.**

## Brain matters

*Parkinson's Victoria has been supporting the important work of the Victorian Brain Bank Network (VBBN) for a number of years. We are pleased to provide an update on some recent research findings from CATRIONA MCLEAN at the VBBN.*

Firstly, I would like to acknowledge the financial contribution received last year from Parkinson's Victoria to support the **Victorian Brain Bank Network (VBBN)**.

As well as facilitating scientific research into brain and mind disorders, the VBBN also provides a vital diagnostic service to confirm neuropathology diagnosis, and supports continuing education of the next generation of medical and allied health professionals.

Many brain diseases, such as Parkinson's disease (PD) only affect humans. This means that researchers depend on post-mortem brain tissue to investigate the physical attributes underlying behavioural symptoms. Such research may lead to improvements in diagnosis, development of early diagnostic tests, therapeutic interventions and/or the development of preventative strategies.

Post-mortem human brain tissue, such as that held by the VBBN, allows researchers to study changes in the human brain, providing valuable information about the underlying causes of diseases.

Scientists are able to investigate the human brain and ascertain the physical differences between "normal" or control brains, and those of people diagnosed with various diseases, such as Parkinson's, which may in turn lead to targets for new treatments.

### *Annual progress report 2010 - 2011*

The VBBN has had another productive 12 months in relation to the number of brain donations received, and the number of tissue requests

for Parkinson's (and related diseases) research projects in Victoria.

### **Central Nervous System (CNS) samples:**

Over the past 12 months the VBBN has collected, processed and stored 74 (34 more cases than this time last year) new brain donations of which 20 (5 more cases than this time last year) cases were confirmed neuropathologically as either, Parkinson's disease (PD), multiple system atrophy (MSA), corticobasal degeneration (CDB), Lewy body disease or progressive supranuclear palsy (PSP). Furthermore, in 10 of the 20 cases, cerebrospinal fluid (CSF) was able to be collected.

The VBBN now has a total of 144 Parkinson's disease and related cases available for research.

### **Registered potential donors to date:**

We currently have 52 registered donors that have Parkinson's disease or related diseases.

### **Research projects:**

Over the past 12 months tissues have been provided to 5 new or continuing research projects. Projects are currently being conducted at: **The University of Melbourne, Bio21 Institute, Monash University** and **The Mental Health Research Institute**. This equates to 836 diseased and 'control' samples being provided to researchers.

**Catriona McLean, MBBS, BSc, FRCPA, MD, is Head of the Victorian Brain Bank Network at The Mental Health Research Institute. She is also Unit Head and Professor of Pathology at the Alfred Hospital.**

Parkinson's Victoria recently received a submission from the VBBN for additional funding so that it may continue vital research. We believe in the value of a broad range of research aimed at diagnosis, treatment and a cure, as well as quality of life research. We will continue to show our support by channelling funds from our research account into viable and promising research projects, such as those undertaken by the VBBN.

Advertisement

## We offer specialist massage & acupuncture for Parkinson's disease

As part of our commitment to offer people living with Parkinson's disease (PD) the highest level of care at Neurology Network Melbourne we have developed a program that takes advantage of the proven health benefits of massage and acupuncture: non-drug treatments for PD. Massage has been shown to reduce muscle pain and stiffness. Specifically in PD, massage appears to mildly reduce symptoms for at least one week following treatment.<sup>1</sup> Acupuncture is established as a non-drug treatment for many of the muscle and orthopedic injuries that are common in PD (e.g. frozen shoulder, joint and muscle pain). It appears to improve the 'quality of life' in people living with PD.<sup>2</sup>

**Our Parkinson specialist massage therapist and acupuncture doctors welcome all enquiries, as no GP referral is needed**

Medicare and Health Fund rebates apply to most treatments

Massage	Jennifer Drummond
Acupuncture	Dr Michael Ben-Meir MBBS FACEM Dr Allen Yuen MBBS FACEM
Neurologists	A/Prof David Williams PhD FRACP Dr Kelly Bertram MBBS FRACP Dr Saman Punchichewa MBBS FRACP

References: 1 Movement Disorders (2006), 2 Journal of Complimentary and Alternative Medicine (2006)

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# Fundraising & events

## Christmas wishes

Parkinson's Victoria's 2011 range of Christmas cards features two exclusive designs by artists Anne Atkin and Jean Smith, who are both living with Parkinson's.

All cards can be purchased securely online at: [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) or contact our office for an order form.

You can also purchase our cards from the following outlets:

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

Corporate cards, e-cards and hampers can also be purchased, with a percentage of the sale price donated to Parkinson's Victoria.

- CORPORATE CARDS: <http://www.christmascards4charity.com.au/parkins>
- HAMPERS: <http://www.charityhampers.com.au/parkins>
- E-CARDS: <http://www.charityecards.com.au/parkins>

## The perfect drop

If you're looking for an innovative way to say **Merry Christmas, Thank You** or **Congratulations** to clients, what about a bottle of wine with your company logo and a personal message?

Parkinson's Victoria has again partnered with alias wines to create a unique and effortless way to support our work in the community, while promoting your business or celebrating in style!

Personalised labels for birthday celebrations, weddings and other special occasions are also available.

**Place an order for customised corporate or personalized wine labels and alias wines will donate a percentage of the order's value back to Parkinson's Victoria.**

Contact Kevin at alias wines to discuss your needs: 0400 696 065. Don't forget to mention the Parkinson's Victoria Wine Drive.

## Top up your wine store

The holiday season is almost upon us – so it's the perfect time to top up your wine store!

Order your holiday wine now and support our SUMMER WINE DRIVE. Grab a dozen and a percentage from every sale will go directly to helping the fight against Parkinson's. All bottles carry the Parkinson's Victoria label.

**Visit [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) to download an order form [go to the Fundraising & Merchandise tab and scroll down].**

## Moving to make a difference

Every year, we receive wonderful support from people who are keen to put their passion into action by actively fundraising through an initiative of their own – we call this **"Moving to Make a Difference"**!

Throughout 2010/11 members of the community raised funds and donations by:

- Requesting donations in lieu of gifts at birthdays, anniversaries and weddings
- Jointly running or cycling thousands of kilometres
- Holding garage sales
- Hosting special events including **Party for Parkinson's**, movie nights, live music concerts, cake stalls, art exhibitions, fitness events, and a gala ball
- Jumping from a plane
- Opening their homes and gardens and
- Getting creative and selling cards, woollen garments, artwork and music CDs.

Fundraising online is a simple and straightforward way to invite friends to support you – and Parkinson's Victoria. Contact Judith in our Marketing Team to find out more or sign up today at [http://www.everydayhero.com.au/event/parkinsonsvic\\_community](http://www.everydayhero.com.au/event/parkinsonsvic_community)

Several major fun runs (City to Sea, Melbourne Marathon, and Run Melbourne are just some examples) are also linked into online fundraising, so if you or a family member is the active type – this is the perfect option!

If online fundraising is not your thing, you can still organise your own fundraising event.

Perhaps there is an event you already host regularly that you could enhance by making it a **'fundraiser' for Parkinson's Victoria?** It doesn't have to be a gala ball; many clubs and hobby or social groups have fundraised with cup-cake days or requested a gold coin donation as part of their regular meeting. You may like to suggest to your club or company that they purchase Parkinson's Victoria Christmas cards or get a group together to join us for our next movie night or Unity Walk!

**If you would like to discuss your own idea, please contact Judith: [Judith@parkinsons-vic.org.au](mailto:Judith@parkinsons-vic.org.au) or (03) 9581 8700.**

# Fundraising & events

## Stop the clock – movie marathon

GREAT SCOTT! What a fantastic day was had by all on Saturday, 5 November 2011! The sun was shining and **Back to the Future** fans raced to The Astor Theatre in St Kilda at “88 miles per hour” to see this iconic movie trilogy on the big screen and support Parkinson’s Victoria.

Highlights had to be sitting in the DeLorean Time Machine and hearing from Christopher “Doc” Lloyd, who had a special message for the audience.

**The day was a great success on all counts and raised a whopping \$15442 (nett)!**

Thanks to everyone who attended, dressed up and participated in the day’s activities, including trivia competition, lucky dip envelopes and children’s colouring corner.

We express our heartfelt gratitude to the wonderful volunteers whose efforts contributed to the event’s success.

If you were one of the lucky ones to have an official event photo taken, they are now available to be viewed and purchased online: [www.mosaicphotography.com.au](http://www.mosaicphotography.com.au). Mosaic Photography is generously donating **100 percent of sale proceeds** to Parkinson’s Victoria.

A limited number of our event promotional posters, in mint condition, are available for a lucky few – for those who would like to make a tax deductible donation to support our work. Please contact Jo if you are interested in obtaining one: (03) 9581 8700 or [jo@parkinsons-vic.org.au](mailto:jo@parkinsons-vic.org.au)

In the meantime, we gratefully acknowledge the following organisations which kindly donated some of the most fabulous prizes ever!

- RedBalloon; a 10 lap Formula Ford race car experience
- BMS; a week’s accommodation at Port Douglas Retreats
- The Hotel Windsor; afternoon high-tea for two
- Woodlands Golf Club; a round of golf for four
- Melbourne Theatre Company; double passes to a world premiere production
- Aesop; skin care pamper pack
- Gazal Corporation Ltd; Calvin Klein underwear
- All Star Comics; framed print of ‘The Time Machine’ and comic pack
- The Enchanted Maze Garden; family pass
- Collingwood Children’s Farm; family pass
- Melbourne’s Luna Park; two family passes
- Ford Discovery Centre; two family passes
- Palace Cinemas; four double passes

And we also thank the following for their professional services and support and really going above and beyond to help us out!

- Mat Tyler Multimedia
- Universal Pictures
- Mosaic Photography
- Supanova Pop Culture Expo and actor Christopher “Doc” Lloyd

**Most importantly, we thank “Doc” (Braun) with his DeLorean and the team at The Astor Theatre, St Kilda. Without their collaboration, support and passion to accomplish *nothing but the best*, we could we never have delivered such a magnificent triumph!**



Marty McFly (a.k.a. Rob Alec) with the “Doc” Braun’s Time Machine DeLorean at our BTTF charity screening.

## Merchandise with a message

This year’s **Parkinson’s Unity Walk**/Walk in the Park bright yellow T-shirts were a great hit with participants. Many walkers snapped up extra T-shirts on the day for friends and family who couldn’t make it and if you missed out or would like an extra shirt, there are various sizes still available. Doggie Bandanas and Unity Walk canvas tote bags are also available.

**Contact our office to place your order. Every additional T-shirt (\$15), Bandana (\$5) or Bag (\$5) sold will contribute to our Unity Walk fundraising!**

**For the sporty types, Team Parkinson’s sports caps (\$15) and singlets (\$25, limited sizes) are also available.**

## Looking forward to 2012

...when we’ll be doing it all again...  
PLUS MORE!

We are currently planning an exciting program of events and fundraising activities for 2012 and the calendar will include all the usual suspects; sausage sizzles, tin rattles, movie events and of course, Unity Walk (Put it in your diary now: Sunday 26 August, 2012 at Federation Square).

Plus, we’ll be conducting Wine Drives and Entertainment Book Sales, and be involved with events like Run Melbourne and the Melbourne Marathon, for those who want to support us by competing in a fun run!

For something completely different, we’ll *trip the light fantastic*, thanks to the Peridot Theatre Group in Mt Waverley.

They’ve generously given us the opportunity to host two preview charity performances of their 2012 program and we’re excited to give you advance notice of these special events. Mark them in your diary now: Join us for the preview of “The Peppercorn Tree” on Thursday, 26 April and “Me and Jezebel” on Thursday 8 November.

More information will be available in the New Year or contact our office to register your interest today.

# Access, Advocacy & Assistance

## Have you got a Power of Attorney?

*In recent weeks there has been some media attention around families encountering difficulties as a result of a parent handing control of their finances to one or more of their adult children.*

*The sensationalist coverage inferred that entrusting decision-making to a family member was a risky practice. For most families however, the reality is quite the opposite where it is properly documented and planned.*

### What is a Power of Attorney?

A Power of Attorney (POA) is a legal document that authorises someone to act on your behalf. If you find yourself in a position where you have lost the capability to make decisions for yourself, either permanently or temporarily, it's really important that you have a POA in place.

In the State of Victoria there are four recognised POAs, covering different types of decisions. Other States can vary, but in Victoria these are:

- Enduring Power of Attorney (Financial) enables someone to make financial and legal decisions for you
- Enduring Power of Attorney (Medical Treatment) enables someone to make decisions about your medical treatment
- Enduring Power of Guardianship enables someone to make personal and lifestyle decisions for you, e.g. a decision about your ongoing ability to cope in your own home
- General Power of Attorney enables someone to make specified financial and legal decisions for you. This POA only applies while you still have the capacity to make your own decisions.

You can have any or all of these POAs and assign different ones to different people if that is the best option for you.

### Why have a POA?

While we don't like to think about our health failing, the reality for many people is that general aging leads to a reduced capacity, or more effort being required, to reason, understand, retain, evaluate or weigh up the relevant information involved.

With this sobering thought in mind, it's vital that you organise a POA as soon as possible and definitely before you lose any mental capacity. If you reach a point where you can't fully understand the documentation for your POA (as verified by an authorised witness) you can't actually have one!

In addition, if you don't have a POA in place it can be a time-consuming and costly exercise for family members who find they need to make application to the courts for one.

### Key decisions to make now

When it comes to organising Powers of Attorney, you have two key decisions:

1. Who you should appoint as your attorney and decision-maker
2. What type or types of POA you should choose

Clearly these decisions will vary from person to person and from family to family.

A trusted and capable family member is a common choice for many people. However you need to be confident in their ability to look after your affairs and you should have second thoughts about appointing someone who you know to be experiencing financial or other difficulties themselves, as this may lead to impaired judgments on your behalf.

You can appoint joint attorneys, but be sure that all parties are likely to be available when required and can be relied upon to generally agree on the issues that will affect you.

Having an offspring who's a lawyer or a doctor doesn't necessarily mean they are automatic choices for Enduring POAs for Financial or Medical Treatment either.

**More information: Appointing a Power of Attorney is important and should ideally be done as soon as someone becomes an adult. For more information on POAs, including fact sheets about each type of POA, you can visit [www.publicadvocate.vic.gov.au](http://www.publicadvocate.vic.gov.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 Outlook Financial Solutions Pty Ltd. (ABN 40 083 233 925, AFSL 240959) or suitably qualified professional.**

## Tulip tributes

### Fit for fundraising

*Procure Fitness, a Sorrento based personal fitness group, was instrumental in supporting Peter Curtin in his efforts to complete the challenging Pilgrim's Walk in Spain in August. Not only did they guide him through a tough fitness regime to prepare him for the adventure, but they also supported his fundraising efforts, raising a total of \$780.*

**Thanks a Bunch to the team at Procure Fitness, particularly Jacinta, and their members and friends (a total of 47) who participated in the [Walk this Way](#) fundraising events hosted by Procure Fitness!**

**On behalf of Procure Fitness, we also thank the following businesses for their support in providing prizes: Athlete's Foot (Rosebud), Toast Magazine, Belle a Paris, Endota Spa (Sorrento).**

# Personal perspectives

## A colourful story

*In September, Mick Dee Prose, a member of Painting with Parkinson's, was invited to meet with Prime Minister Julia Gillard. Here, he shares the experience:*

On 28 September, 2011, my wife and I, Anne Atkin [**Painting with Parkinson's** Founder], her husband Gordon, and Wilma Lazaridis [also a **Painting with Parkinson's** group member], arrived at 4 Treasury Place, Melbourne to meet with Prime Minister Gillard. Top of the agenda was my presentation to Ms Gillard of a portrait I had done of her.

The Prime Minister welcomed us at her office door smiling, with hand outstretched and we all chatted informally - with a pinch of humour - for the next 25 minutes.

Anne explained a little about Parkinson's, as well as the **Painting with Parkinson's** initiative and the benefits of painting for people with Parkinson's. Anne also presented Prime Minister Gillard with a copy of her book, **Living and Laughing with Parkinson's**.

I presented my portrait painting to the Prime Minister, which was received with a thank you and the comment "you've made me look younger". I also presented a painting for Ms Gillard to take to her parents, John and Moira Gillard, of their hometown in Wales.

Our humble group agreed that it had been an honour and a privilege to meet with and spend time chatting with such a warm and sincere lady, Australian Prime Minister Julia Gillard MP.

One hopes these moments will penetrate one's life, and you feel the need to pinch yourself to believe it is happening. A memory treasured because of my painting and the **Painting with Parkinson's Program**.



From left, Anne Atkin, Mick DeeProse, Prime Minister Gillard and Wilma Lazaridis.

Are you a person living with Parkinson's or caring for someone who is?

Would you like to share your experience of diagnosis and/or the challenges and achievements in your life?

If you would like to share your thoughts about living with Parkinson's with readers, please send your submission to the editor, Judith Mooney: **Judith@parkinsons-vic.org.au** or post to PO Box 2606 Cheltenham, Victoria 3192. Please ensure you include your name and contact details.

Authors can remain anonymous on request. Please keep word length to a maximum of 700 words (stories may be edited for clarity and space). Photos are welcome.

# Tulip tributes

## Gisborne Peak Winery

Earlier this year, the Judge family - who have had a close relationship with Parkinson's Victoria in recent year's (see "Birthday Wishes" story above) - approached us with a fantastic idea! They wanted to partner with Gisborne Peak Winery to create an Action Day for Parkinson's - a special fundraising day at the winery with all proceeds to Parkinson's Victoria.

The result was a fun day, filled with novel fundraising activities and of course yummy Gisborne Peak pizza and wine! A total of \$2374 being raised. The raffle of Helen Cottle's stunning watercolour "**Winter Morning, Gisborne South**" was drawn on 14 November at the office of Parkinson's Victoria. The lucky winner was:

The day was also successful in raising awareness of Parkinson's - especially when Bob Judge shared some of his personal journey with guests, and thanks to support from local media!

**We are always overwhelmed when members of the community make such an amazing effort to support our work. We offer a BIG Tulip Tribute to the Judge family; 11-year old Brenden, mum Janelle, and grandparents Wendy and Bob for initiating this event and working so hard to make it a success.**

**Extra special thanks go to Bob and Barbara Nixon of Gisborne Peak Winery and their team. The event could not have happened without their enthusiastic and committed support. Bob and Barb's creativity and attention to detail was instrumental in driving the Action Day, and their generosity was humbling. Not only did they host the event but they donated a case of wine from their private cellar for auction, and donated a percentage of pizza and wine sales on the day and their "Adopt a Vine" program towards the fundraising tally. Thank you Gisborne Peak Winery!**

**Gisborne Peak Winery is located in a lovely spot at 69 Short Road, Gisborne South. The property features a picturesque lake, brand new eco-friendly accommodation cottages, cellar door and delicious homemade wood fired pizzas.**  
[www.gisbornepeakwines.com.au](http://www.gisbornepeakwines.com.au)

**We also gratefully acknowledge the generous donation of local artist Helen Cottle (frame donated by Gisborne Peak Winery).**



Bob Judge and grandson Brenden at Gisborne Peak Winery, standing next to their very own 'adopted' vine.

# Symptom management

*Education and information sharing is taking place around the world to advance our understanding of Parkinson's and to facilitate improved symptom management and quality of life. This year, VICTOR MCCONVEY from our Health Team attended the Movement Disorders Congress (MDC) in Toronto, Canada, where non-motor symptoms took centre stage.*

Presentations at the MDC confirmed that non-motor symptoms are not only very much a part of a Parkinson's diagnosis, but in many cases they actually precede the presence of physical (motor) symptoms. For most people living with Parkinson's this will come as no surprise.

Research linking seemingly unrelated psychological symptoms with the physical changes related to Parkinson's is growing.

## *Pre-clinical Parkinson's findings*

- At least 10 percent of people diagnosed with Parkinson's experienced **hyposmia** (loss of sense of smell) prior to diagnosis
- People with Parkinson's were seven times more likely to develop constipation prior to becoming conscious of a motor symptom and prior to clinical diagnosis
- Experiencing REM sleep disorder can occur up to 30 years prior to the onset of motor symptoms; 50 percent of people with Parkinson's experienced some degree of REM sleep disorder prior to their diagnosis.
- Rates of depression were significantly higher than average in people who later developed motor symptoms and were subsequently clinically diagnosed.

These pre-clinical symptoms and their link to Parkinson's are reinforced by the **STRIKE PD** and **Honolulu PD** studies. Both of these were large, longitudinal studies into Parkinson's that identified these symptoms as commonly occurring before motor symptoms.

## *Investigating the phenomenon of Impulse Control Disorders*

Impulse Control Disorders (ICD) are frequently associated with dopamine agonist medications.

To explain why ICD can occur in people with Parkinson's, a brain bank and neuro chemistry study of pathological gamblers (who did not have Parkinson's) was undertaken.

The study revealed some minor variants of the D2 dopamine receptor cells, however, in the D4 dopamine receptor cells there were several

identifiable variants seen in people who had exhibited thrill seeking and addictive behaviours.

These findings support the hypothesis that the use of medications that stimulate the dopamine receptor system (such as dopamine agonists) may trigger ICD's when these variants are present. However, the researchers stressed that environmental influences and socialisation are also influencing factors.

While many people do not ever develop difficulties with ICD, it is essential that people with Parkinson's - and those health professionals who work with them - are aware of the phenomenon and understand that, for people with Parkinson's, ICD can be triggered by the use of dopamine agonist medications.

## *Hallucinations & psychosis*

Presentations at the 2011 MDC also addressed the occurrence of hallucinations.

Increasingly, research such as the **Sydney Multi Centre Study** and the **EL-DOPA study** indicate that hallucinations occur in over 60 percent of those who have been living with Parkinson's for 10 years or more. Further, the research shows that hallucinations are more related to the duration of illness, rather than medication, as hallucinations have been identified in people with minimal exposure to medication (although medications may reduce the threshold of hallucinations).

This research is important in highlighting what is proving to be a common symptom, and an area in which treatments need to be improved.

The MDC also covered discussion on proposed treatments for hallucinations, identifying the best ways to manage the symptom and additional areas where more research is required.

For the person living with Parkinson's, recognition of the occurrence of hallucinations highlights the importance of discussing such symptoms with your treating physician as soon as they occur.

## *Depression & Parkinson's*

Depression has been recognised as a symptom of Parkinson's, frequently occurring prior to motor symptoms, and it is often improved with Parkinson's medication.

One of the possible explanations for this phenomenon that was discussed at the congress is the inter-relationship between the *serontiergic* system (which produces serotonin, a brain chemical needed for mood stabilisation and sleep) and the dopaminergic system (which produces dopamine).

It is thought that when dopamine production

# Symptom management

decreases so does the production of serotonin, resulting in mood fluctuations and in many cases depression.

(The congress noted that the dopaminergic system is also implicated in depression in people who do not have Parkinson's.)

Depression in Parkinson's is complicated and may have multiple causes, such as the disruption to dopamine and serotonin production, and lowered mood or reactive depression in response to the diagnosis or symptoms of Parkinson's.

Recommendations that were made during the congress for effectively treating this symptom included careful and ongoing screening of Parkinson's patients for signs of depression so that it could be addressed as soon as possible. Best management includes optimising Parkinson's treatments, providing counselling or **Cognitive Behavioural Therapies** and considering an appropriate anti-depressant medication.

## **Conclusion**

The Congress noted that non-motor symptoms must be acknowledged as an important and complex aspect of Parkinson's, and that these symptoms may precede the occurrence of motor symptoms.

Importantly, research has shown that these symptoms have been identified by people living with Parkinson's (including carers/family) as having the most impact on quality of life.

It was further noted that non-motor symptoms may be difficult to treat; that medication treatments for Parkinson's may not be enough; and that non-motor symptoms may require separate and specific treatment, and a number of treatment options were discussed.

**If you would like to discuss the information in this article with our Health Team, or have another question about any aspect of Parkinson's, please phone our office: (03) 9581 8700 or email: [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au) Enquiries may be anonymous if you wish.**

## Approach with caution: New Parkinson's treatments

*There have been a few instances recently of individuals and companies in the community claiming to have found a radical new cure or treatment for Parkinson's.*

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

*There are a range of complementary therapies available, and some may be useful in the management of Parkinson's symptoms, however caution should always be exercised when beginning any new treatment or therapy.*

Here some questions to ask when considering a new treatment option:

- How does the product or treatment work?
- How will the treatment help my Parkinson's symptoms?
- Are there any risks or side effects?
- Will this treatment interfere with my current Parkinson's treatments/medications?

**Never alter the treatment plan your doctor has developed with you without consulting them.**

- Is there scientific evidence to support this treatment for the symptoms of Parkinson's?
- Is the treatment likely to work for everyone?
- Who is promoting the treatment?
- Are they from a reputable organisation?
- What qualifications do they have?
- What experience do they have working with Parkinson's?
- How much will it cost?
- Does it sound too good to be true?

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

**If you have seen or heard of a treatment advertised for Parkinson's in the media or within your social or other networks and you are unsure of its credibility or if you have any questions or concerns, please contact Parkinson's Victoria. We can answer questions and investigate further. In most cases there will not be a concern, however on occasion, Parkinson's Victoria has taken action to report inappropriate advertisements which make misleading claims.**

# Access, Advocacy & Assistance

*The "Triple A – Access, Advocacy and Assistance" assist individuals and families to live well with Parkinson's.*

*This includes knowing your rights, being able to access financial, peer and professional support, and making the most of available assistance.*

*It also means empowering individuals to play an active part in managing their condition, providing opportunities to have your voice heard, and influencing decision makers and the community at large to ensure greater understanding and support for the Parkinson's community.*

## *Keep your cool*

People living with Parkinson's who hold a **Pensioner Concession Card, Health Care Card or DVA Gold Card** are eligible for the **Summer Medical Cooling Concession**.

This entitles card holders to a 17.5 percent discount off electricity costs between 1 November and 30 April each year.

**For more information contact Parkinson's Victoria, the Victorian Concessions Information Line (1800 658 521) or your energy provider.**

## *Numbers add up*

In October, new **Access Economics** figures were released about the Australian incidence and costs of living with Parkinson's.

The company, now known as **Deloitte Access Economics**, produced the first ever Australian-context data in 2007, based on research it conducted in 2005. This data had been used nationally by Parkinson's organisations to support advocacy initiatives in relation to seeking Government funding, grant applications and to support media stories.

Sadly, since the original report was released, things have not improved much for people with Parkinson's, and the projections for increasing prevalence and costs have been realized in the 2011 research findings.

The updated report highlights that an increasing number of Australians are living with Parkinson's and that Parkinson's will continue to be associated with significant and increasing health system, lost productivity and other costs.

Diagnosis statistics have increased from 25 Australians a day to 30, equating to one in 350 Australians with a diagnosis of Parkinson's.

While 80 percent of people with Parkinson's are aged over 65 years, there are approximately 2000 people aged in their 30's and 40's that are currently living with Parkinson's. With approximately 10950 new diagnoses each year, this equates to 2100 new Young Onset diagnoses per annum.

The report advises (conservatively) that there are 283 people per 100,000 diagnosed with Parkinson's in the total Australian population, or 857 per 100,000 among the population aged over 50.

**The report also notes that Parkinson's is quite prevalent, with an incidence rate higher than most cancers.**

We know that it is expensive to manage Parkinson's and the report estimates that it costs individuals more than \$12,000 per annum, an increase of 48 percent since 2005. **For someone living with Parkinson's for 12 years, the average lifetime financial cost is around \$144,000, which is on par with the lifetime cost of cancer (\$165,000).**

The report goes on to estimate that the **total Australian economic cost of Parkinson's is now \$8.3 billion** (up from \$6.8 billion in 2005).

One thing that remains the same is the limited government funding for services. The funding that **is** received in no way reflects the actual need or numbers.

Since the 2007 Access Economics report was published, limited progress has been made in relation to the recommended Positive Steps outlined in the report. There has been no improvement in the provision of movement disorder clinicians, access to surgery, pharmaceuticals, physiotherapy, respite and palliative care.

Parkinson's is not recognised as a chronic disease under the National Chronic Disease Strategy and there is little awareness in the community about Parkinson's.

**A full copy of the Deloitte Access Economics report will be available to download from our website in coming months.**

**Parkinson's Victoria will continue to advocate to government and relevant industry in pursuit of our mission: To ensure all people living with Parkinson's have access to comprehensive and relevant services, encouraging independence and improved quality of life.**

## *A little help from a friend*

Volunteer companions are now available to accompany people from the Flinders Street Station and the Southern Cross Station train and bus terminals to health care appointments in central Melbourne

The new **Melbourne Medical Companion Project** is funded through the Victorian Government's **Transport Connections Program**, which is a cross government initiative that helps communities work together to improve access and local transport options.

**Travellers Aid** already provides a range of travel-related assistance and information at Melbourne CBD Flinders Street and Southern Cross Stations, and will now provide this additional volunteer service for people who are unfamiliar with Melbourne and its health and transport systems.

**What Will The Project Do?** As part of this new program, Travellers Aid volunteers will meet passengers at the Flinders Street Station and the Southern Cross Station train and bus platforms, and accompany them to their Melbourne health care

# Access, Advocacy & Assistance

appointments and back again. Passengers will have the choice of using taxis, trams or buses whilst in Melbourne and the volunteer companions will be experienced in using all three modes of transport.

It is believed that the new Melbourne Medical Companion Project will improve access for many people who live in rural Victoria, who are frail, disabled, ill, or anxious about their journey, and will encourage many people to consider using public transport to attend their health care appointments instead of using the car.

The new volunteer service is free and designed to take the worry out of travelling to Melbourne for health care.

**People interested in accessing the new volunteer-assisted service when travelling to Melbourne should telephone Travellers Aid on 1300 700 399 at least 24 hours prior to their expected travel date.**

## *Support for a nation of carers*

For the first time in our history, Australia has a **National Carer Strategy**.

In August, 2011, **Minister for Families, Housing, Community Services and Indigenous Affairs**, Jenny Macklin MP, **Minister for Health and Ageing**, Nicola Roxon MP, and **Parliamentary Secretary for Disabilities and Carers**, Senator Jan McLucas launched the National Carer Strategy, which includes \$60 million in new funding over the next four years.

The Strategy delivers on the Australian Government's commitment to better respond to the needs of carers, and helps ensure carers have the opportunity to take part in all aspects of society, including the chance to participate fully in work, community and family life.

**For more information, go to [www.fahcsia.gov.au](http://www.fahcsia.gov.au)**

## *MP delivers message loud and clear*

In September, local Federal MP Josh Frydenberg joined the Elgin Street Men's Group for its monthly meeting. Following this meeting, his office contacted Parkinson's Victoria for further information about prevalence, symptoms, challenges and funding needs. Mr Frydenberg then went on to speak in Parliament about the challenge of living with Parkinson's in Australia.

**You can view Mr Frydenberg's speech on the Parkinson's Victoria Youtube site [go to our home page, click on the Youtube link on the left hand side of the screen and then click on the video link "Support for those with Parkinson's Disease" under Recent Activity].**

## Help at your fingertips

### *Better Health Channel, review by PETER RAYMOND*

The Better Health Channel ([www.betterhealth.vic.gov.au/](http://www.betterhealth.vic.gov.au/)) was established in 1999 by the Victorian State Government. It provides general health and medical information to assist individuals and their communities to improve their health and wellbeing. It is not designed to replace information or advice provided by medical practitioners and other qualified health professionals, nor does it provide health and medical advice over the phone or by email.

The **Better Health Channel** also provides links to other government, educational and not-for-profit health and health-related websites, such as <http://www.parkinsonsvic.org.au/>

### **HOW DO YOU GET STARTED?**

Firstly, you will need an **Apple iPhone or iPad**.

On your iPhone or iPad click "App Store", click "Search", type "[Better Health Channel](http://www.betterhealth.vic.gov.au/)", click "Search", click "FREE"

Or, if you prefer, you can end up at the same destination by going to the [Better Health Channel](http://www.betterhealth.vic.gov.au/) website [www.betterhealth.vic.gov.au/](http://www.betterhealth.vic.gov.au/), click "Free iPhone and iPad app", click "Available on the App Store", click "View in iTunes", click "FREE".

### **WHAT DO YOU GET?**

The opening screen is simple, bright and easy to read.

If you select **Health Conditions** you will be taken to another easy-to-read screen which covers everything from A to Z.

The articles on Parkinson's have been written and reviewed by the health team at Parkinson's Victoria, so information can be vouched for as being reliable and up to date.

In my opinion, one of the most useful capabilities is the GPS-driven service which enables you to find a Health Service (unfortunately only in Victoria). Now, no matter where we are or what day it is (weekend, public holiday, after-hours), there is no need to worry about finding a GP, pharmacy, dentist, emergency medical service or hospital.

With **Better Health Channel**, all you have to do is select **Find a Health Service** and you will be taken to Google Maps; the familiar red pins will show you exactly where the service is located. You can then refine the search by **language** and **After Hours!**

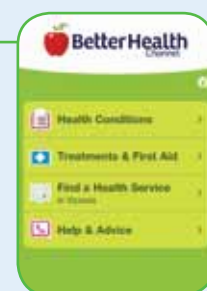
The **Help & Advice** tab will take you to a range of services including emergency services, **Nurse on Call** and **Worksafe Victoria's Emergency Response Line**, not to mention **Gamblers Help** and **Suicide Line**.

A similar service is available if you select **Treatments & First Aid** and **Allied Health Therapies** are listed as are **Complementary and Prescription Medicines**.

It's important to remember that websites and Apps should never replace personal, individualised care and advice from a GP or Neurologist.

The **Better Health Channel** is accessible, up-to-date, accurate and fun, unlike grandma's "Encyclopedia of Health and Home".

And, oh yes, unlike grandma's dusty tome, the **Better Health Channel** won't recommend electric shock, Indian hemp, sea bathing or a mixture of lard, starch and boiling water as remedies for Parkinson's!



# Education

## Back to school

*One of the priorities at Parkinson's Victoria is education, whether for people living with Parkinson's, health professionals and GPs who are working with Parkinson's patients and clients, or the wider community.*

*Education events are not simply about providing information, they also play a vital role in increasing awareness and promoting valuable programs and initiatives and our support services. Education activities provide members of the public and health professionals with networking opportunities to increase their connectedness with the wider Parkinson's community, and ultimately result in improving the circumstances of those living with Parkinson's.*

### A "real life" patient

*Recently, FRED VAN ROSS, Parkinson's Victoria Board Member, Ambassador and leader of our Essendon Support Group, was asked to assist 4th year medical students during their final exams. Fred, who was diagnosed with Parkinson's in 2003, shares his experience.*

Following an unusual request to Parkinson's Victoria, I made myself available as a "real-life" Parkinson's patient for one of 10 practical scenarios for the final exams for student doctors from Melbourne, Ballarat and Sydney. (Students would graduate to become doctors officially in January 2012 - **if** they passed the final exams).

In previous exams, actors had portrayed patients with different conditions, and the examiners advised they were very happy that a real patient was available in this instance.

My scenario was for the students to make a correct diagnosis of Parkinson's from the symptoms they observed.

I was required for the whole day from 8.00am to 6.30pm on Saturday, 15 October 2011, and I agreed to forgo some of my medication to help mimic Parkinson's symptoms.

It was interesting to note that the examiners were conscious and sensitive to how I would manage the long day, and advised they had a backup actor to take my place if I felt I could not continue for the duration. However, I was determined not to allow that to happen.

The examiners explained the scene they wanted me to "play" (display tremor, stiffness and shuffling gait), and I was invited to comment on each of the students performances from a patient's perspective. The latter was an interesting and thoughtful request.

The students had just six minutes for the test: four minutes for diagnosis and two minutes to elaborate on the examiners' questions. There were two examiners covering my scenario, Professor Haydn Walters, **Associate Dean University Notre Dame & Head of Clinical School** and Associate Professor Michael Murray, **Discipline Leader of Medicine University of Notre Dame**.

All together, there were about 38 students undertaking all 10 different scenarios on a roster system.

The same scene was played over and over again, giving each student the same situation. The students all varied in their approach, many extremely nervous, some not remembering the facts or getting them wrong.

One of the examiner's questions was: **Tell the patient about the medication and the possible side effects**. Unfortunately, many students had difficulty and portrayed bad bedside manner (even when taking their nervousness into account) and didn't know how to deliver this message with care.

Many remained standing to deliver the message, though others made use of the spare chair to sit next to me and endeavoured to deliver the message with greater personal touch.

I made a strong point to the two examiners on the poor way this message was delivered and they both agreed that they would look at how to correct this for the future. Professor Murray took particular notice of my observations, as he indicated that this fell under his area of training, and both examiners expressed concern at the lack of empathy students had with their "patient", indicating that students had only recently spent time making rounds in hospital wards and talking to patients.

At the end of the day, I received favourable comments from both examiners and they were also grateful that I managed the full day without issue.

They also said that in future, they would contact Parkinson's Victoria when they required suitable Parkinson's patients.

I understand that I was the only real-life patient participating in these exams; the other participants were actors playing out other scenarios.

I did make the comment that it was very pleasing to find Parkinson's diagnosis being used as a test scenario for junior and future GP's. It certainly helps Parkinson's Victoria's agenda to have Parkinson's awareness up front on the medical and hospital platform and being used as part of the doctors'

training program. It is hoped that more instances of “real live Parkinson’s patients” are used in the training of our medical profession.

***I am pleased to report that I did not suffer too much after withholding my Parkinson’s medication during this project.***

### *Med Students deliver “on time”*

Second-year Medicine students, Ellie Finn and Marcus Kok from Monash University, recently undertook their Community-Based Placement (part of their degree program) with Parkinson’s Victoria.

Their task was to investigate ways to improve awareness of the importance of timely medication administration for patients with Parkinson’s in hospitals and residential facilities.

Ellie and Marcus achieved this by creating and conducting a tailored survey on the issue and followed up with a comprehensive report of their findings, which they converted into an Awareness Poster and a short video.

The awareness resources produced by the students were of a high quality and will be a valuable part of our Health Team’s teaching tools when educating health professionals. Specifically, the awareness poster and video will be used by our health team during professional development education sessions to hospital, community health, and residential care facility staff to help ‘get the message across’ about the importance of medication on time for people with Parkinson’s.

In addition, the video has been uploaded to our YouTube page where it can be viewed by the general public. You may like to encourage family members or friends to watch the video to help

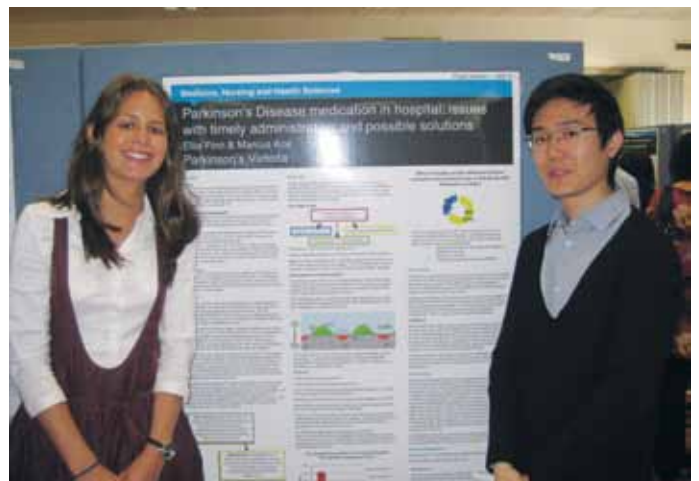
them understand the importance of Parkinson’s medication.

The project was a worthwhile and successful endeavour as it has increased awareness and understanding of Parkinson’s and related issues regarding medication management in health care settings amongst future medical professionals.

It is hoped that the report which the students produced will assist in developing other initiatives to address and deliver the **Get It on Time** message.

***We would like to thank those support groups and members who welcomed the students to their monthly meeting and who provided valuable input to those who completed the surveys, and in particular to those who shared their personal stories on camera for the awareness video.***

***We wish Ellie and Marcus all the best as they continue their studies.***



*Ellie Finn and Marcus Kok presented their project at the Monash University Community-Based Placement Poster Presentation morning.*

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# Participate for Parkinson's

## It's all in the mind

*There is increasing interest in the use of mindfulness and lifestyle interventions in the management of patients with chronic disease, such as Parkinson's. The **Essence of Health** is a holistic lifestyle and mind-body model developed by Dr Craig Hassed of Monash University. Parkinson's Victoria has recently committed to provide funding for this unique and promising research project.*

ESSENCE is an acronym, which stands for: **Education, Stress management, Spirituality, Exercise, Nutrition, Connectedness, Environment.**

The Essence program has been applied to a wide range of chronic conditions and, those involved in the research project believe no other research has been done with people with Parkinson's on such a comprehensive holistic program as the one based on the Essence model.

The research team will undertake a mixed methods evaluation of the impact on patients of a 6-week mindfulness and Essence-based lifestyle program with community living patients with stage 2 Parkinson's\*.

This mixed-methods study will look at the impact of the mindfulness and lifestyle program and explore the experiences of participating in the Essence program, and the impact of the program on participants' beliefs about Parkinson's and its management.

Participation will involve attendance at the 6-week Essence training program. Sessions will be delivered at the office of Parkinson's Victoria (located in Cheltenham) and will comprise 90 minute group education seminars.

The sessions will follow the Essence model and will be delivered by the program's author, Dr Craig Hassed of Monash University's Department of General Practice. Participants will also receive a book on the program and a 3-CD set on mindfulness.

The study is run by the **Southern Academic Primary Care Research Unit (SAPCRU)**, which was established in 2009 through a unique research partnership between the **Dandenong Casey General Practice Association, Monash University and Southern Health**, in order to further primary health care research and education in south east metropolitan Melbourne.

The three investigators are Grant Russell, Jenny Advocat and Craig Hassed.

Dr Grant Russell is the Head of the School of Primary Health Care at Monash University and inaugural Director of the SAPCRU. His research interests are directed towards understanding and measuring the impact of primary care reform on patients, clinicians and primary care practices. Dr Russell holds a Masters of Family Medicine from Monash University and a PhD from UWA.

Dr Jenny Advocat is the Deputy Director and Research Fellow at SAPCRU. Dr Advocat has a background in medical anthropology and received her PhD in health sociology from Monash University in 2007.

Dr Hassed is a general practitioner, Deputy Head and senior lecturer in the Monash University Department of General Practice where he has been teaching at both undergraduate and post-graduate levels since 1989.

Dr Hassed has been instrumental in introducing a variety of innovations into medical education and practice, with an emphasis on the application of holistic, integrative and mind-body medicine in medical practice, and reconnecting different knowledge systems (e.g. medical science and philosophy), in a way which is grounded, balanced, scientifically valid and clinically effective. He is a regular speaker in Australia and internationally on these topics and is regularly invited to contribute to a variety of community and professional groups.

Funded by Parkinson's Victoria, this project has the potential to benefit the Parkinson's community greatly by providing evidence about the impact of the Essence program for this population.

**The research team is currently seeking participants for this study who have been diagnosed as having symptoms consistent with Stage 2 Parkinson's\* and have no signs of significant depression. Eligible participants will be fluent in English, 60 years or younger and be willing to attend at least 4 of the 6 sessions of a mindfulness-based lifestyle program.**

**If you are interested in participating, please contact Dr Jenny Advocat: (03) 9902 4899 or email: [jenny.advocat@monash.edu](mailto:jenny.advocat@monash.edu)**

\*Parkinson's is a progressive condition and the clinical term of reference to indicate the condition's progress is 'stages'. These specifically refer to the Hoehn and Yahr Classification of Parkinson's disease: Stage 0 indicates no symptoms while Stage 5 features advanced symptoms with significant disability, such as the individual requiring full assistance to carry out all activities of daily living.

Most people with Parkinson's are diagnosed while in Stage 1, when symptoms are seen on one side of the body only (unilateral) and there is minimal impairment. Parkinson's is considered to be in Stage 2 once symptoms have become evident on both sides of the body, but without any impairment in balance.

Parkinson's is unique in both its progression and the symptoms experienced by each individual. As such, the length of each stage will vary from person to person. In addition, there is such a broad range of symptoms associated with Parkinson's, and while certain symptoms are associated with specific stages, many will experience symptoms from across stages. This can make assessment and symptom management extremely difficult and requires constant monitoring.

The diagnosis and progression of Parkinson's is rarely textbook and each person is assessed according to their individual experiences and symptoms.

# 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 donors who have made a financial contribution 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 8 July and 9 November, 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, organisations and others who have shown their support, either financially or in-kind. We thank those who have donated but wish to remain anonymous and those who have supported our **Ambassadors of Hope** speakers program.*

## Donations of \$1000+

Sir Ron Brierley  
Angie & Colin Carter  
Joanna Hill  
Mary Kentish  
Hugh Morris  
Donald & Jill Morrison  
Ian & Emma Scott

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A & N Murphy  
John & June Nixon-Smith  
Mandi Nugent  
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BR & GJ Reed  
Zoe Renshaw  
David Rhodes  
Ian Rohde  
Max & Jill Schultz  
Scott & Kylie Smith  
Rod Tartakover  
Lionel Wellcome

## Bequests

William Hillard

## In Memory of...

Filippo Abriola  
Evagg Arhondopoulos  
Ernest Baldrey  
William Burness  
Leslee Cassar  
Christine Cathie  
Antionette Cengia  
John Checkley  
pasquale Ciccio  
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John Strilokos  
Donald Stubbs  
Francesca Talia  
Sri Wenas  
Hans Wilker  
Maisie Williams  
Ted Wilson  
Alan Wrangle

## In celebration

Sue Blashki 70th Birthday  
Bob & Jan Collings  
50th Golden Wedding  
Anniversary  
Jim DeBona 76th Birthday  
Rebecca Eden 80th  
Birthday  
Olive Judge 90th Birthday  
Kevin Taylor  
Doris Whitlow 90th  
Birthday

## Team Parkinson's Fundraisers (third party)

Antonio Borazio  
Sarah Barnett  
Sarah Crosthwaite  
Ellen Cubit  
Chris Fogerty  
Tanya Grausam  
Michael Harkin  
Sneha Jacob  
Nina Jensen

Sarah Latimore  
Georgina McBride  
Kathleen Mckenzie  
Kay Millington  
Kevin Pruden  
Amanda Tehan

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Freemasons of Victoria  
Lions Club of Moorabbin  
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Group  
Poppthead Day Club  
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Rotary Club of Glenferrie  
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Society  
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## Parkinson's Support

### Groups

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Warragul  
Wimmera

## Mid year appeal update:

A total of 311 donations have been received, raising **\$26,271.00 (141 members and 170 non-members)**.

## Steps donor newsletter update:

A total of 64 donations were received in response to our Steps Spring (issue 2) donor update newsletter, raising a total of **\$9340 (20 members and 44 non-members)**.

Our **Steps** Autumn (issue 1) donor update raised **\$15,638**.

## End of Year appeal:

Our **annual End of Year** appeal letter has recently been sent out to members and supporters.

We make just two requests a year for your support and we **do not** purchase mailing lists. **We only send correspondence to – and ask for support from – those who have previously supported us in some way.** We hope you – and they will - continue to support us to support those living with Parkinson's in our community and to lighten the load for Victorian families.

**Special thanks to all those who gave generously, particularly our long-term supporters!**

# Tulip tributes

## *S'wonderful, s'marvellous Volunteers*

Over the years, many volunteers have braved the elements and early morning start – not to mention given their smile muscles a real workout - by joining us for one of our train station 'tin rattles'.

On the morning of 25 August, 39 wonderful volunteers collected an impressive \$6243 in donations from city and suburban commuters! We are also very grateful to those volunteers who assisted us back in the office counting the coins!

On Saturday 6 August, volunteers also collected \$2276 from footy fans heading to the MCG. This was the first time we had undertaken a 'footy tin rattle' and it was a great success – with our volunteers showing true grit battling what seemed like the wettest Melbourne day on record!

In addition, volunteers were integral in recent Bunnings Charity Sausage Sizzles, held at the Moorabbin and Mentone stores on Sunday, 7 August, Friday, 16 September and Friday, 14 October. Over the 3 events a total of 1199 sausages were served on 58 loaves of bread with 27 kilos of onions! And a total of \$3128 was raised - a fantastic effort!

## **Our heartfelt thanks and a big Tulip Tribute to the following volunteers:**

**BUNNINGS MOORABBIN (7 AUGUST):** Peter Raymond, Lynda Briffens, Ann Burgess, Bob Way, Shyan Muttukumar, Amy Peng, Moira Joseph, Shao Ping Yang, Hanya (Daisy) Liang, Helen Kaganov, Scott Morris, Angela Page

**BUNNINGS MENTONE (16 SEPTEMBER):** Jason Lee, Mike Sadik, Wenda Kwan, Joe Little, Anne Atkin, Gordon Atkin, Cathleen Kenneally, David Gibson and Steven Nguyen

**BUNNINGS MENTONE (14 OCTOBER):** Ted Beesley, Cathleen Kenneally, Peter Raymond, Angela Page, Debbie Cheng, Yannie Ngai and Kam Hou Yuen.

And of course, **BIG thanks to Bunnings Moorabbin and Mentone** for their continued support and to all their customers who purchased sausages!

**AWARENESS WEEK TIN RATTLE (25 AUGUST):** Julia Smith, Gillian Rawson, Marion Roberts, Andie Jane Webster, Scott Morris, Evan Lowden, Lyn Edwards,

**Pam Roberts, Anne Atkin, Gordon Atkin, Sherry Ma, Nihong Lou, Stephanie Leung Cheong, Cathy Do, Wayne Flavell, Bruce Dickie, Clare Hanson, Bill Howard, Judy Buckley, Bob Way, David Scanlon, Margaret Scanlon, Alan Ingram, Clare Gleeson-McGuire, Peter Raymond, Jill Raymond, Patricia Russell, Fred Van Ross, Chris Van Ross, Jill Goss, Bridget Purcell, Judy Laws, Angela Page, Max McPherson, Lynette Monks, Irene Milotic, Mohammed Razzak and Susan Wixted**

**MCG RATTLE (6 AUGUST):** Carol Wood, Bruce Wood, Kenny Wood, Belinda Searls, Sharon Daborn, Willis Mutasa, Jennifer Preston-Loh, Ling Tang, Sally Cutts, Alexandra McIver, Stephanie Bender Irianto, Averyl Hintz, Jacki Barnes, Vanessa Barnes, Lana Ross, Tatiana Brodaskaia, Michele Zorzi, Clare Hanson and Bill Howard.

## *Spinning a winner*

We love hearing about the different fundraising ideas people come up with to show their support and **The Handweavers and Spinners Guild of Victoria** is no exception.

Their "Footy Woolies" exhibition and "Bad Taste Fun Day" held in September were great fun for members and raised \$739! **Wow! What a great effort!**



*Guild members Marie Williams ("Miss Behaving") and Elaine Brooke (Winner of the Crimplene Ensemble section) during the Guild's Bad Taste fundraiser.*

## *Birthday wishes*

We received a lovely donation from Olive Judge following her 90th Birthday celebrations in October.

Olive had kindly asked friends and family to make a donation to Parkinson's Victoria in lieu of gifts – and the result was a total donation of \$565.

Olive is great grandmother to Brenden Judge (our youngest Unity Walk fundraiser and our top Unity Walk fundraiser in 2010). Brenden's grandad Bob (Olive's son) has Parkinson's – so supporting the cause really is a family affair.



*Four generations of the Judge Family (clockwise from top left): Brenden, his mum Janelle, Olive and Bob Judge.*

## *Raising more than a sweat*

Once again, we had several extra special supporters undertake a fitness challenge while raising funds for a cause that's important to them: the fight against Parkinson's. Many are on-going Parkinson's Victoria supporters, having competed in previous events while fundraising for Parkinson's.

- Kevin Pruden ran the **Melbourne Marathon** in October.
- Nina Jensen, Sarah Latimore, Michael Harkin, Ellen Cubit, Kay Millington, Sarah Crosthwaite, Sneha Jacob, Antonio Borazio, Sarah Barnett, Amanda Tehan, Georgina McBride, Kathleen McKenzie all competed in the **City to Sea** event on 13 November.
- And, long term supporter Gary Swanton is participating in the **XOSIZE Tri Series 2011/2012** triathlon competition!