

Inside this ISSUE

Unity Walk1

News & Highlights..... 4

Question Time 6

Ambassadors of Hope 7

Medication & Symptom
Management..... 8

Tulip Girls.....9

Postcards from Paris
Part 2 10

Young Parkinson's..... 12

Support Groups 13

Access, Advocacy
& Assistance 14

Fundraising & Events ...16

Medication & Symptom
Management.....18

Our Supporters.....19

Tulip Tributes20

Full steam ahead for Parkinson's Unity Walk 2010

Parkinson's Awareness Week this year began on Sunday 30 August with our major event, Parkinson's Unity Walk.

1,026 people, young and old, babies in prams through to seniors in their 90's, gathered at Federation Square for the 4 km walk along the banks of the Yarra River. People came to participate from across Victoria, from as far away as Wodonga, Tooleybuc, Deniliquin, Donald and Cohuna.

The event had a wonderful atmosphere: people with Parkinson's, families and friends, as well as supporters from the health profession, all united to raise funds for research and services, as well as raising community awareness.

Walkers were greeted by our friendly volunteers at the registration marquee, where they received their Unity Walk T shirt, and then moved on to visit our event sponsor's tents or - for the children (and some adults) to have their faces painted.

Our President, Royce Pepin, officially launched the event from the main stage of Federation Square, and celebrities Wilbur Wilde and Shane Jacobsen kept the crowd entertained leading up to the walk start time at 12.00pm.

Jill Goss, Shane's mum and Co-leader of the Essendon Support Group, helped to limber walkers up prior to the event with some gentle exercises, and then it was off to the start line, where Shane and Jill cut the ribbon.

It was a great spectacle to see so many people walking along the Yarra in their Unity Walk T shirts, and participants commented they felt proud to come together in support of Parkinson's.

Following the walk, participants collected their show bags and complimentary fruit provided by La Manna Direct, and were entertained by the Charlie Lim Band, with 3AW's David Mann volunteering his services



Essendon Support Group leader Jill Goss and son, actor Shane Jacobsen, cut the ribbon to mark the official start of the Parkinson's Unity Walk (Victoria) at Melbourne's Federation Square.

as master of ceremonies. A highlight after the walk was a wonderful and unexpected donation of \$9,000 presented by Nerissa Mapes to Parkinson's Victoria from her own foundation, POP (Perspectives on Parkinson's).

Together, Walkers and their supporters fundraised \$63,000 for research and services, a tremendous result.

The success of the day was very much due to the wonderful support of the Parkinson's community, and we are hopeful that the support will continue to grow in future years to the extent that Parkinson's Unity Walk becomes an annual fixture on the Australian events calendar.

The Walk was also successful in raising Parkinson's awareness; generating radio, newspaper, television and magazine articles to help inform the community about Parkinson's disease.



Walkers celebrate completing the 4km course.

Highlights from Unity Walk

Publication details

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Print Post Approved PP33962/00002

Designed and printed by:

Doran Printing: (03) 9587 4333

www.doranprinting.com.au

Frequency:

Signpost is published quarterly and distributed to members of Parkinson's Victoria. If you would like to become a member call (03) 9551 1122 or email info@parkinsons-vic.org.au.

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

Many supporters and members of the public were keen to promote the event to their networks and generously displayed and distributed posters at their work, gym, local library and community centres.

A special thank you to all of our volunteers, event sponsors, and support groups and to you for making Parkinson's Unity Walk for such a resounding success. We look forward to building on that success in coming years, starting with next year's walk – Unity Walk 2010.

We are pleased to announce the winners of our various Unity Walk competitions.

Early Bird registration prize:

2 nights luxury accommodation at the Langham Hotel (Southbank), including breakfast for two and valet parking, courtesy of the Langham Hotel.

Winner: **Mrs Laura Murray of Kew**

"I am so excited to win this prize. It really couldn't have come at a better time. My husband and I are very much looking forward to it. One of my dear friends, Nerissa Mapes, was diagnosed with Parkinson's when she was 28, and my family and I participated in the walk for her. I like feeling I helped in some small way to make the future better for Nerissa and everyone else who is suffering from Parkinson's".

Highest individual fundraiser prize:

A fantastic 5day/4night accommodation package for 2 people to Hawaii, including return economy airfares, courtesy of Hawaiian Airlines, Hawaii Tourism and Outrigger Enterprises Group:

Winner: **Mr Peter Raymond of Glen Waverley raised a total of \$6858**

Mr Raymond is also the winner of the Puma Prize pack, presented to



Event emcee, David Mann from radio's 3AW, conducts an impromptu interview with "Batman" during the event's stage entertainment.



Families and friends came together to show their support for loved ones.



These people certainly didn't turn their backs on the cause - they wore their support with pride, telling the world they were walking in honour of Nat Bianchin.



Jill Goss and family pose with celebrity emcee, entertainer Wilbur Wilde.

the highest fundraiser who had also nominated their football team. Go the Saints!

Highest Corporate Team fundraiser prize:

Corporate box for 10 people on Day 2 of the Boxing Day Cricket Test including welcome drinks and buffet lunch, courtesy of The Melbourne Cricket Club.

Winner: **Team Telstra raised a total of \$5262**

We hope all our winners enjoy their prizes and congratulate them on their amazing fundraising efforts!

We also acknowledge and thank all those who fundraised for Unity Walk and Parkinson's Victoria, and especially our top fundraisers who did such an amazing job:

Henry von Bibra \$2645

Anne Atkin \$2509

Bethwyn Todd \$2000

Margi Gould-Cameron \$1735

Daniel Madhavan \$1731

Julie Hetherington \$1552

Hayley Bell \$1470

Martin Davies \$1460

Angela Page \$1425

Carol Wood \$1410

And Special Mention goes to 10 year old Brendan Judge \$883

We also thank the following Teams:

- Team Aunming
- Team Beattie
- Dicko's for Parkies
- Team Hasret
- Team Lina
- Marthese's Mates
- One for All
- OxheyandBushey
- Pappa Maglieri
- PD Fighters
- POP
- Team Riddell's
- Team Horat
- Team Lewis
- Team Olive
- The Hills
- The Simmies
- Wonboyn Walkers

Thanks especially to our

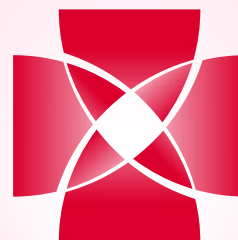
Parkinson's Unity Walk Sponsors:

Presenting: Telstra

Supporting: Novartis

And, Hawaiian Airlines and Hawaii Tourism, Outrigger Enterprises, The Langham Hotel (Southbank), Melbourne Cricket Club, In Touch Direct, Artisse Organic Muesli Bars, The Pharmacy Guild of Australia, Boehringer Ingelheim, Secure Parking, 3AW and Magic 1278, Puma.

For more images from the day, turn to page 17



TheAlfred

Movement Disorders Program

Do you have
Parkinson's disease
and experience
dyskinesias?

Clinical trial volunteers required

Medical specialists are currently looking for volunteers for a clinical trial who:

- Are aged 30-80
- Have moderate to severe medication-induced dyskinesias/ involuntary movements with Parkinson's disease

If you wish to find out more about this study please contact:

[Movement Disorders Program at the Alfred Hospital, Melbourne](#)

Research Coordinator, Sue Varley:
phone (03) 9076 5187 or (03) 9076 5231.

This study has been approved by the Alfred Health Human Research Ethics Committee.

News & Highlights

New Website to help people living with PSP

PSP Australia's new website, www.psp-australia.org.au, provides a wealth of information for anyone affected by Progressive Supranuclear Palsy (PSP), including people diagnosed, their family members, friends and carers, as well as health professionals.

Visitors to the site can download Help Sheets covering topics such as managing symptoms, living with PSP and where to go for help. The site also has personal stories from people affected by PSP and useful links to other relevant websites in Australia and overseas.

PSP and Movement Disorder Seminar

PSP Australia, in partnership with Parkinson's Victoria, is proud to present, an education seminar for health professionals, titled, **The Challenge of Movement Disorders; Exploring diagnosis, management and best practice interventions in relation to Progressive Supranuclear Palsy (PSP), Multiple Systems Atrophy (MSA) & Cortical Basal Degeneration (CBD).**

This one-day professional development seminar is for allied health professionals that work with clients and carers who are living with PSP, MSA or CBD, and for other interested members of the health profession.

Attendees will gain an insight into these conditions, and learn practical advice and strategies for assisting patients and their carers.

During this seminar, PSP Australia and Parkinson's Victoria will launch a dedicated PSP manual of information and Help Sheets. This publication will be the first of its kind in Australia.

TIME: Registration: 8.45am; Forum: 9.15am—3.30pm (lunch included)

VENUE: Florey Neuroscience Institutes, Executive Lounge, Level 1, Alan Gilbert Building, The University of Melbourne (cnr Grattan and Barry Streets, Carlton South).

COST: \$110 (includes GST, morning tea and lunch)

BOOKINGS: To book your place, contact Parkinson's Victoria: (03) 9551 1122; free call: 1800 644 189; email: info@parkinsons-vic.org.au

Editor's note: Victor McConvey, our Parkinson's Specialist Nurse Consultant, recently published his report *Unlocking Parkinson's Plus Syndromes- Developing information and Support resources for Patients, Families, Carers and Health Care Professionals.*

The study was made possible through a June Allen Fellowship grant, which Victor was awarded earlier this year.

You can access a copy of the 12-page report online at: <http://www.nbv.org.au/web/guest/final-research-reports>

Special Events

What lies beneath

- An information session on DBS Surgery

All members of the community and interested health professionals are invited to a special presentation on Deep Brain Stimulation Surgery (DBS), a surgical intervention to manage the symptoms of Parkinson's.

The seminar will feature keynote presentations by Neurosurgeon Dr Richard Bittar and Neurologist Dr Richard Peppard.

Attendees are encouraged to stay for lunch and the Parkinson's Victoria AGM.

See details below.

Notice of Annual General Meeting - Parkinson's Victoria Inc

Parkinson's Victoria Members and non-members are invited to attend the Parkinson's Victoria **AGM**

Event Details

The DBS seminar and AGM will both take place on Friday 27 November, 2009 at the Kingston City Hall, 985 Nepean Highway, Moorabbin.

10:30-11.00am Registration

11:00-12:30pm Deep Brain Stimulation Seminar

12:30-1:15pm Lunch

1:15 - 2.00pm Parkinson's Victoria Annual General Meeting

Includes presentation of Sir Zelman Cowen Award for outstanding voluntary service to the Parkinson's community and lifetime achievement awards.

Please note: There is no charge to attend the seminar, lunch or AGM, however you will need to RSVP by Friday 20 November.

To book your seat contact our office: (03) 9551 1122 or free call: 1800 644189.

Alternatively, complete and return the enclosed RSVP form included in this edition of Signpost.

The Kingston City Hall is a 3-minute walk from the Moorabbin train station (Frankston line). Off street parking is available at the rear of the hall, enter via South Road or Nepean Highway (service road). Melway reference 77 D5. There are also bus lines to Moorabbin Station.

Project still reaching out to diverse communities

A \$10,000 Department of Human Services grant is helping Parkinson's Victoria continue its work with Culturally and Linguistically Diverse (CALD) communities. Last year our **Bridging the Gaps Project** saw the production of Parkinson's Help Sheets and other information in 10 languages. The next stage of the project will see further distribution of these materials and new resources developed.

A multi-lingual brochure is currently being developed to further raise awareness of Parkinson's and to encourage contact with Parkinson's Australia via the telephone interpreter.

The new funds will also be used to develop audio materials in key languages for people with limited reading abilities and for play on ethnic community radio.

In addition, a Turkish information session is being planned, with the assistance of the Essendon Parkinson's Support Group, which has secured funding from Hume City Council and Department of Human Services, North West Region. This will be presented by Turkish speaking Parkinson's practitioner, Senior Clinical Neuropsychologist Dr Evrim March, from St Vincent's Mental Health.

If you know of any opportunities to help raise awareness with culturally and linguistically diverse communities in Victoria, please contact Project Worker, Jackie Jenkins at Parkinson's Victoria.

Christmas Appeal

Included with this edition of Signpost is our Christmas letter appeal. Please take a moment to read this letter and consider making a donation to Parkinson's Victoria this Christmas.

Parkinson's Victoria receives only \$190,000 in government funding each year. We rely on your financial support to offset the shortfall in funding in order to provide services and support.

We ask that you consider making a tax deductible donation at Christmas time and to help us to help others.

If circumstances do not allow you to make a donation, why not consider remembering Parkinson's Victoria in your will? For more information, please contact Parkinson's Victoria CEO, Glenn Mahoney: (03) 9551 1122, or by email gmahoney@parkinsons-vic.org.au.

Season's Greetings and holiday office hours

The office of Parkinson's Victoria will be closed for the festive season from 2.00pm Thursday 24 December (Christmas Eve) to Friday 1 January 2010 inclusively. We will re-open the office on Monday 4 January.

If you require assistance during this time of office closure, please contact your treating GP or neurologist or in the case of an emergency, dial 000.

The Board and Staff of Parkinson's Victoria wish all our members, supporters and readers a safe and happy festive season and a wonderful New Year!

A gift that keeps on giving

The late Harry Secomb, a member and supporter of Parkinson's Victoria, established a charitable trust fund through Perpetual Trustees in his final years to support neurological research.

We were delighted when Michael Carroll from Perpetual Trustees rang to inform us that the trustees had agreed to support Parkinson's Victoria with a cheque for \$50,000 from the late Mr Secombe's trust fund.



Pictured: Parkinson's Victoria CEO Glenn Mahoney (second from right) receives a cheque for \$50,000 from Bruce Harding, the late Mr Secomb's brother-in-law, and Julie Frans, both trustees of the charitable trust. Michael Carroll from Perpetual Trustees is pictured far left.

It is through the generosity of gifts such as this that Parkinson's Victoria is able to provide and develop services and support to people living with Parkinson's across Victoria.

Question Time

Q. Will hot weather affect my Parkinson's?

A. While Parkinson's is not a condition directly worsened by hot temperatures, exposure to heat can have an affect on the illness and individual.

One of the body's mechanisms to stay cool in hotter climates is to perspire. Typically, the hotter the temperature, the more you perspire; meaning maintaining adequate fluid intake becomes very important.

Becoming dehydrated can be serious and is a leading cause of hospitalisation, particularly in older people during the summer months. In addition, if you experience dyskinesias or tremor with your Parkinson's, these involuntary movements can increase your body's temperature, so staying cool and keeping your fluids up are especially important.

Having Parkinson can also affect your levels of perspiration, with some people experiencing excessive sweating and others, though less common, experiencing reduced perspiration.

In both instances, you will need to take extra special precautions in hotter temperatures. If you have increased perspiration you will need to ensure that you are drinking enough to avoid becoming dehydrated. If you have a reduction in the amount of perspiration your body produces, it will be harder to stay cool and you may need to take some additional precautions, such as staying indoors and using an air conditioner or fan to stay cool.

It's important to remember that by the time you feel thirsty, your body has already begun to dehydrate. Sip water throughout the day to ensure good levels of hydration.

Note: People living with Parkinson's who have a concession card or receive a pension are eligible for the Summer Energy Concession which is a 17.5 percent discount on your summer power bills. Contact our Health Team for more information.

Q: Is Parkinson's affecting my ability to have erections.

A: It's not surprising that this question is typically one that men are reluctant to discuss with their Doctor, due to feeling embarrassed or that it is unrelated to their Parkinson's. However, Parkinson's can definitely impact upon a male's ability to obtain and maintain an erection.

In most instances, erectile dysfunction associated with Parkinson's can be easily overcome. Often simply adjusting the Parkinson's medication is enough, and your neurologist is the ideal person to help.

If problems persist, other medications are available that can be safely taken in conjunction with Parkinson's medication, and your GP is the best person to discuss these options.

It is important to remember that other illnesses, depression and medications for other conditions can also impact upon the ability to obtain and maintain an erection, and it's important that you feel comfortable discussing your situation and concerns with either your GP or neurologist. You should also mention any changes that you experience in sexual desire, as some medications commonly used in Parkinson's can increase libido or cause hyper-sexuality, which is an issue that your neurologist needs to address.

Q: I often experience constipation. Is this related to Parkinson's?

A: Constipation is a very common difficulty experienced by people living with Parkinson's, and is caused by the decreased or slowing movement of the gut and also by decreased mobility (both symptoms of Parkinson's).

Most medications used for Parkinson's do not improve this symptom and may even worsen constipation.

One exception to this is the early stages of taking Dopamine replacement medication (Sinamet, Kinson or Madopar), which may cause some diarrhoea but typically resolves itself, or if you are taking medication that contains Entacopone (Comtan and Stalevo), which can cause a more persistent diarrhoea.

Some simple measures can help manage or reduce the incidence of constipation in relation to Parkinson's:

1) Make sure that you are drinking enough fluid; at least two litres per day and more in warmer weather, unless you have a medical condition where you need to restrict fluids.

2) Engage in plenty of exercise.

3) It is often useful to add some additional fibre to your diet (psyllium husks, available from health food stores and supermarkets, are an excellent source of added fibre, and fibre supplements, such as Metamucil™ or Benefibre™ can also assist).

Many people may need to take regular medication for constipation. To discuss your individual circumstances and optimal solutions, please contact the Parkinson's Victoria Health Team: (03) 9551 1122 or free call: 1800 644 189 or phone the National Continence Helpline: 1800 33 00 66.

Do you have a question about Living with Parkinson's?

Our qualified Health Team is able to answer a wide range of questions about Parkinson's-related issues and we encourage all members of the community to ring our Help Line.

Ambassadors of Hope

Are you going to be much longer?

The audience hushed as the Parkinson's Ambassador stood to speak. It was another presentation on behalf of Parkinson's Victoria, this time to an Elderly Citizens' Day Centre.

The 'elderlies' had just enjoyed a hot roast lunch, followed by apple-pie and custard. Warm rays of sunlight streamed through the window, picking up particles of dust.

The introductory slide was up on the screen. Information booklets were stacked up, ready to be distributed at the end of the presentation.

The Ambassador cleared his throat and looked expectantly at the group of senior citizens, men and women, some frail and some fit.

"Good afternoon. My name is Peter Raymond and I am delighted to share with you today my personal experience of living with Parkinson's."

It was then that a quizzical eighty-year old voice from the front row piped up.

"Excuse me. Are you going to be much longer?"

Everyone laughed and the Coordinator said, "Don't worry about Amy. She's always hard to please."

Hard to please indeed! What an understatement...!

Since assuming the role of Coordinator of the Parkinson's Victoria Ambassador Program in 2006, Peter Raymond has organised Ambassadors to speak to groups and organisations all over Victoria. Sometimes the group is small enough to meet in a private lounge room. Sometimes, the Ambassador presents to auditoriums and function rooms containing hundreds of people. Maybe it is a school assembly, a dinner-dance or a fundraising ball.

The process is simple. Typically, Parkinson's Victoria takes a phone-call from an organisation such as Rotary or Probus seeking a guest speaker. The request is forwarded to Peter who allocates a speaker from the group of trained and registered Ambassadors - all 'People living with Parkinson's'.

More often than not, one speaking engagement leads to another. Some Ambassadors actively seek out their own opportunities to speak.

Some requests pose quite a challenge. Ambassadors have been asked to relate their personal story, explain all about Parkinson's and take questions. Time allocated: ten minutes!

However, Peter is yet to receive a response that is anything but positive and grateful, and regularly reads comments such as: "It was an absolute inspiration to us all and certainly met all



Peter Raymond, Ambassador Coordinator, shares his story with students from Korowa Anglican Girls School.

expectations" and "One of the best speakers we have ever had."

Mind you, satisfaction is not all one way.

Ambassador Fred Van Ross "gets a buzz out of talking about Parkinson's...I find it rewarding and it also helps me cope with the constant changes that is Parkinson's."

Anne Atkin has found being an Ambassador the best thing she has ever done. "I just love it. Meeting people, educating them about Parkinson's, and having an audience - what more could an ex-teacher want?"

The Ambassador Program is supplied free-of-charge to community, social and sporting groups, schools and corporates, and there is no expectation that donations will be forthcoming.

However, from time to time, it is obvious that the message has been powerfully conveyed, and over the years spontaneous donations have been received, some in excess of \$2,000.

The Ambassador Program is not confined to metropolitan Melbourne. Ambassadors are active in Geelong, Warrnambool and Shepparton.

In the last 12 months, the Program has also spread to the Greek, Arabic, Russian, Turkish, Italian and Chinese communities as a result of Parkinson's Victoria's very successful multi-lingual information project.

"It is most important that opportunities to speak and engage with all levels of the community continue to come our way. I have a dedicated group of Ambassadors, some of whom are very active, and some of whom would appreciate more appointments," said Peter Raymond.

For further information about the Parkinson's Victoria Ambassadors of Hope program, or to book a speaker for your next function, please contact Parkinson's Victoria or Peter Raymond, Coordinator: 0438 400 259 or email pdr@netspace.net.au

Medication & Symptom Management

Allowing yourself to “go off*”

Taking regular medication for Parkinson's becomes second nature for most people living with the condition, but it is often a frustrating interruption to one's activity and is simply exasperating when it doesn't work as effectively as desired or causes side effects.

Often, to assess the effectiveness of Parkinson's medications or to “re-organise” a drug regime, your neurologist may stop all of your medications and then slowly re-introduce them, monitoring the effect as you go. When you have a “Drug Holiday” (or Levodopa challenge) your neurologist will arrange a stay in hospital as the Parkinson's symptoms will worsen once you are “off” and will remain that way until medication is re-introduced.

Recently ANNE ATKIN, Parkinson's Victoria Ambassador and coordinator of the [Painting with Parkinson's](#) program, underwent a medication review. Anne has been generous enough to share her experience and thoughts.

“I was diagnosed exactly four years ago next month. Four years! I can't believe how quickly it has gone.

I remember being told by a neurologist back then that I could expect three to five “pretty good years” from the medication before problems would start. At the time, 3 to 5 years seemed like forever.

Well, it isn't and, almost “just as the doctor ordered”, as my 4th anniversary approached, I could feel that my 4-hourly medication was not lasting 4 hours. It was lasting 3, and this one hour had become a time of frustration and apprehension as I tried to live a life not knowing if - and when - I would be 'off'. You know; walk into the shopping centre, but you can't walk out? Drive to a friend's house, but you have to stay extra time because the 'off' time won't let you drive or even get out of the chair?

I hated it.

So that is why I was booked in on 20 July for a Levodopa Challenge, understanding that I would be completely off my medication.

Totally off.

None in me.

“I would get to see how far the Parkinson's had progressed” I enthused to myself. “Won't it be interesting to see what I'm like?” I babbled to friends and family. “I wonder how rigid I'll be?” I pondered.

I found out.

I use to say to people that I was just like the tinman when I was 'off'.

But being totally 'off' left the tinman for dead: I was



Anne Atkin (centre) in Federation Square during Australia's Unity Walk for Parkinson's in August.

the Iron Man, I mean a very rusty iron man. I felt like a block of concrete and I think my face had all the animation of one too.

All jokes aside, I was stunned and shocked by how I looked and felt. “Oh my heavens”, I sluggishly thought. “Why on earth had I thought this would be interesting?”

The novelty wore off very quickly. “Lift your foot”, I was asked. It wouldn't. “Try to get out of the chair”. I couldn't. “Move your fingers. Wriggle this. Turn that.” My body and brain were disconnected. I moved in slow motion. A 2-toed sloth would have outraced me. I felt sick.

I was eventually given a largish dose of Levodopa. I couldn't wait to get it into my system.

After 20 minutes I could feel something, like I was defrosting. I was responding very well to the medication, I was told.

Oh thank heavens!

After 40 minutes, I felt so different I couldn't believe it. The concrete block had gone. My face could reflect how I was feeling.

That was on the Monday and Tuesday, and now, here I am writing this on the Wednesday.

My fingers are able to move over the keyboard and write this. I can get up and make a cup of tea, turn my head and think more clearly.

All I can think is what hell it must have been for people diagnosed with Parkinson's before the discovery of Levodopa. How on earth did they get through each day?

I think to myself, thank heavens I am in this century with Parkinson's. Things aren't always wonderful with the medication, but at least I am having a life and there are many, many moments of laughter and joy.

Yes, the Levodopa Challenge was interesting and I am glad that I experienced what it was like. It will help my neurologist to refine my medication regime, which is a positive outcome. And I've learned not to take my medication for granted or the 'on' times.

No, I will not waste 'on' time sitting and watching TV. If the weather is not too bad, I'm going to ring a friend and go for coffee, potter in the garden, draw, because I won't take this time for granted again.

Now, I've finished this, it's stopped raining, and I think I'll go and get those veggie seedlings planted."

Anne Atkin

*Off/On times refer to fluctuations that occur in response to Levodopa therapy in which the person's mobility changes suddenly and unpredictably from a good response (on) to a poor response (off).

Editor's note:

Not long after Anne sent us this reflection, she sent an additional piece:

"It's interesting looking back over the last couple of weeks since I went off the meds because I had become quite depressed and I couldn't work out why as my depression had been under control for a couple of years.

Then it hit me, when I was talking to a very close friend last Thursday - I started crying and couldn't stop. I had had a taste of my future.

It has been a bit of a battle since then, but I am now looking at each morning when I wake up with more appreciation. That Levodopa challenge actually gave me a bit of a wake-up call. I had started to take things for granted but now I am not trying to make time fly. If I have spare time, I don't feel guilty about doing nothing because just sitting and looking is not doing 'nothing,' I look at the world around me or I think. I think about my sons and how much I love them, even though the little sods made me wait for 9 years; I think of all the people who have sponsored me for the Unity Walk; all the people I have met because of Parkinson's.

Parkinson's has given me so many new skills- I am a better artist; I can get up and speak to an audience; I am not nervous in front of a camera. Parkinson's has taken away much from my life but it has given back more.

I have no regrets."

**Interested to learn more about "on/off times"?
Medication reviews? Parkinson's medications?
Hospital stays? Do you have a question about any
Parkinson's related issue? Please contact our Health
Team.**

**If you have a "hospital experience" or medication/
hospital experience", good or bad, that you would
like to share, please contact our Health Team or send
your story in writing with your contact details to the
editor, Judith Mooney: judith@parkinsons-vic.org.au
or via post: 20 Kingston Road, Cheltenham, 3192.**

A beautiful partnership

In 2008, mother and daughter, Julie Sewell and Jo Hill hosted the inaugural Tulip Ball. The event was a resounding success, raising just over \$35000, and importantly also raising awareness of Parkinson's. All proceeds from the event were donated to Parkinson's Victoria.

This year, Julie and Jo hosted Tulip Cocktails at the Melbourne Savage Club. 80 invitation-only guests attended this exclusive event, which offered a rare opportunity to see behind the famous 'red doors' in Bank Place. This event raised just over \$4300.



From left: John Sewell, Judith Mooney (Fundraising Coordinator, Parkinson's Victoria), Jo Hill, Glenn Mahoney (CEO, Parkinson's Victoria), Julie Sewell and Peter Raymond (Parkinson's Victoria Ambassador).

Julie and Jo plan to host the Tulip Ball every second year, with a smaller fundraiser every other year. While the ladies confess they "love to host special events", the decision to dedicate their efforts to raising funds and awareness for Parkinson's was inspired by Julie's husband John, Jo's father, who was diagnosed with Parkinson's 9 years ago.

Keen to 'do something' to show their support for John and on a larger scale to make a difference for the wider Parkinson's community, they came up with the idea of hosting fun and stylish fundraising events at various locations throughout Melbourne. They also decided to link the Parkinson's tulip to their fundraising projects in order to raise the profile of the condition even more.

Did you know...? In 1981 a Dutch horticulturalist who had Parkinson's created a prize tulip cultivar which he named in honour of Dr James Parkinson's. Since then, the tulip has become the international symbol for Parkinson's organizations and awareness.

Well, one of Julie and Jo's goals is to make the tulip/Parkinson's connection as well known as "cancer and the daffodil" and the 'red nose' for SIDS and Kids.

With two major events under their belt, Julie and Jo are quick to point out that they still face various challenges, including receiving "no's" in response to their request for support - in spite of the worthy cause.

The ultimate goal for the Tulip ladies is seeing their event grow large enough to be hosted at the Crown Palladium.

If you are interested in supporting Julie and Jo with their next event by providing corporate support and donating items or services to be used a fundraising prizes, particularly for the 2010 Ball, please contact Parkinson's Victoria and your details will be forwarded.

Highlights from the Movement D

Postcards from Paris Part 2

In this second and final update from the World Congress held in June this year, our Parkinson's Specialist Nurse Consultant, VICTOR MCCONVEY, explores the management symptoms encountered in advanced Parkinson's, non motor symptoms and the challenges that living with Parkinson's presents in developing communities.

Symptom Management in Advanced Parkinson's

While people with Parkinson's typically live a long and full life, the illness continues to progress and treatment regimes become more complex over time. During the Congress, research presented and discussed explored possible options for refining Parkinson's treatments and improving symptom control. This discussion had three key themes: **PILLS** (oral medication), **PUMPS** (Apomine and Duo-dopa) and **PULSES** (Deep brain stimulation).

Pills, and patches

Dyskinesias (abnormal movement of voluntary muscles) and "wearing off" are two of the most significant issues encountered in advanced Parkinson's. The role of selective and careful use of Dopamine Agonists was discussed as a possible option for managing dyskinesias, which occur at peak dose of Dopamine replacement therapy. Dopamine Agonists, drugs such as Sifrol, Cabaser or Neu-pro, work on the D2 receptor cells (the cells that take-up Dopamine and normalise movement) and increase efficiency of the uptake of Dopamine.

If the dopamine uptake is enhanced then the level of dopamine-replacement therapy can subsequently be reduced. There also follows a reduction in dyskinesias.

While it was acknowledged that dopamine agonist medications are often related to the individual developing some non-motor symptoms, such as impulse control disorders, it was suggested that these medications are often essential for achieving optimal symptom management and that side effects - when they occur - can be effectively managed by reducing doses or changing drugs. In addition, it was stressed that health care professionals must continually screen for such side effects.

There was also exciting news about the development of drugs such as Neu-pro and a once-a-day controlled release medication

called **Requip ER** that will further refine the use of dopamine agonists in managing advanced Parkinson's.

Minimising the *Pulsatile* - or fluctuating levels of Dopamine Replacement Therapy - which is a contributor to wearing off, was also discussed as a possible method for refining Parkinson's treatments and improving symptom management.

The **STRIDE-PD Study** looked at the role of adding a COMT inhibitor (either separately or in the form of Stalevo™) to the medication regime and its affect on minimising the pulsatile nature of Dopamine Replacement Therapy.

(A COMT inhibitor blocks the production of a brain chemical that breaks dopamine down and has the effect of making dopamine last longer, leading to a reduction in the fluctuating levels of dopamine).

There was also reference to the ADAGIO and TEMPO studies that investigated the use of MAO-B inhibitors in early diagnosis. This research not only suggested that these drugs were potentially neuro-protective, but also appeared to reduce motor fluctuations experienced in later illness.

Pumps - Apomine and Duo-Dopa

Delegates at the congress acknowledged that infusion therapies *Apomine and Duo-dopa* have a significant role in controlling symptoms in people who have had Parkinson's for some time.

Apomine, which is an infused form of Dopamine agonist, was identified as being a valuable medication.

Apomine is a powerful dopamine agonist and especially beneficial in those who are experiencing motor fluctuations, particularly dyskinesias. By strongly stimulating the dopamine receptor cells, this medication allows for a reduction in Dopamine Replacement Therapy, subsequently reducing dyskinesias and, as it is an infusion method, it provides a constant level of stimulation, minimising motor fluctuations.

The introduction of the new Apo-go pump has supported a more refined use of Apomine, making it an important drug in advanced Parkinson's.

The emergence of Duo-dopa as a way of managing advanced Parkinson's was also discussed. Duo-Dopa, which is a form of Dopamine Replacement Therapy, comes in the form of a liquid gel and is infused directly into the duodenum (upper aspect of the small intestine). This drug is currently on trial in Australia.

Pulses – Deep Brain Stimulation surgery

The congress acknowledged the value of Deep Brain Stimulation in managing many of the symptoms of Parkinson's, recognising that over recent years DBS surgery has become increasingly sophisticated and a treatment we no longer consider a "last resort".

Variable stimulation and introducing stimulation to other parts of the brain were discussed as recent developments in DBS surgery. The congress also noted that surgery is not universally available, with less than 16 percent of the delegates having a funded surgical program available to Parkinson's patients and some areas of the world not able to offer surgery at all. However despite limited access to surgery in Australia, we were considered a centre of excellence within our region, with better than average surgical outcomes.

(Read more about our upcoming DBS information session on 27 November, 2009, on page 4 of this newsletter).

Non Motor Symptoms

Depression

During the Congress it was acknowledged that depression was a common, but often under-recognised Parkinson's symptom. As such, it was highlighted that screening for depression and sadness must be integral to managing Parkinson's, and that a combination of counselling and consideration of involving anti-depressant medications in the drug regime were also important.

Depression in Parkinson's is thought to be related to two factors; a reactive depression (becoming sad in response to a life event such as being diagnosed with Parkinson's) and directly to the low levels of dopamine seen in people with Parkinson's.

A lower mood, which is linked to dopamine levels, explains why sadness, and sometimes anxiety, are symptoms of "wearing off".

Hallucinations

Hallucinations, which are commonly seen in advanced Parkinson's, were acknowledged as an issue in up to 60 percent of people living with Parkinson's. Hallucinations, thought to be related to Dopamine Replacement Therapy, are often worsened if depression or sleep difficulties are experienced.

Presenters proposed that someone who presents with hallucinations should undergo all the routine tests for delirium, infection and underlying dementia and they should be treated appropriately.

Further, that a Neuroleptic medication should be administered, if required, with Seroquel typically the preferred version.

Memory changes and Dementia

During this session, presenters emphasised the various changes to memory that can take place as a result of Parkinson's. Difficulties in executive function, such as putting complex tasks together (or *multi-tasking*) were acknowledged as commonly occurring in Parkinson's.

Dementia is less common in Parkinson's, although in later stages of the condition it was more likely that some dementia-like memory changes could occur. Age-related memory changes will become more common in all communities, not just for those diagnosed with Parkinson's.

Presenters argued that common memory tests, such as the MMSE, lacked sensitivity and to more accurately assess memory changes in the individual, a thorough Neuro-psychology assessment was recommended.

Other interventions, such as reducing medications that may contribute to developing confusion, as well as cueing and exercise should also be considered in managing memory changes.

The Challenges of Movement Disorders in the developing world

Given that the Congress is an international meeting point for representatives from around the world, including those from developing nation, it was appropriate that the final session focused on the many challenges faced by those living with Parkinson's in the developing world, and the health care providers who aim to assist them.

It is estimated that there are currently as many as 1.3 million people living with a diagnosis of Parkinson's in the developing world, with most lacking access to specialist health care providers. A sobering comparison is the neurologist-per-head of population ratio in Australia (1:70,000), while in the developing world this ratio is 1:1.3 million.

Compounding the limited access to health care professionals is limited access to medication. Only Levodopa and Bromocriptine are considered "essential" by the World Health Organisation (WHO), and pharmaceutical companies consider most of these nations are not economically viable enough in which to market treatments. Other significant public health challenges, such as Tuberculosis (TB), HIV and Malaria, also dominate health care agendas. Added to this are traditional beliefs and cultural influences that impact on how people respond to

illness, and the limited means of people accessing treatment also plays a significant part in how those in developing communities are able to manage their symptoms.

In response to all these issues, medication therapies are being reviewed by the UNHCR and a number of initiatives and small scale Parkinson's-specific aid programs have been undertaken.

These initiatives have included embedding Parkinson's Nurses into communities who are then able to identify those living with Parkinson's and to initiate medical and other treatments, such as rehabilitative cueing. Health care exchange programs, such the **Movement Disorders Visiting Professor Program** further address this need.

All in all, the Congress was an exciting and comprehensive event to be a part of, and the Australian presenters and delegates were valuable contributors. It was encouraging to hear that the methods and the opinions of our movement disorder professionals are highly sought after and respected. It was also reassuring that the Movement Disorder Congress is actively engaged in exploring all aspects of Parkinson's, from diagnosis through to improving care and treatments along the continuum of the illness.

Christmas cards now on sale

Show your support for people living with Parkinson's by purchasing Parkinson's Victoria Christmas cards this year.

View and order cards securely online www.parkinsonsvic.org.au [click on the dove image] or contact our office.

Corporate Christmas cards

To purchase corporate cards for your staff or clients, log onto christmascards4charity.com.au/parkins (online orders receive a 5 percent discount) or phone our office to request an order form. Orders are dispatched professionally and quickly and 40 cents from every card sold is donated to Parkinson's Victoria.

Corporate Hampers

Log onto charityhampers.com.au/parkins to view and order from the selection of festive hampers on offer (from \$50-\$150).

Hampers feature a Parkinson's Victoria sticker to show your support and 10 percent of the retail price is donated back to Parkinson's Victoria.

Have you - or someone you know - been diagnosed with Young Onset Parkinson's?

What is Young Onset Parkinson's?

Because the average age of diagnosis is over 60, when someone of working age receives a diagnosis of Parkinson's, it is referred to as "Young Onset" Parkinson's.

While most symptoms are the same regardless of the age at which Parkinson's develops, managing the condition can be particularly challenging for a younger person and that person's family – medically, psychologically and socially.

Around the world, those diagnosed with Young Onset Parkinson's have been identified as a unique group requiring specialist support and information. Following the lead of International Parkinson's organizations, Parkinson's Victoria is now spearheading a national response for Australian's living with Young Onset Parkinson's.

Young Onset Project Up

The Young Onset Parkinson's Project is progressing in a very positive direction. The Project came about in response to our investigation into the unique needs of this demographic and existing overseas models of support.

Over the past few months, people diagnosed with Young Onset Parkinson's have been asked to complete a nationwide survey scoping the main issues and concerns of "younger people living with Parkinson's".

Researcher Dr Chris Fyffe, who has been commissioned by Parkinson's Victoria, is currently collating these surveys to identify key themes and issues. This data will then be used to direct discussion through a series of focus groups.

The experiences and personal stories shared in these focus groups will prove invaluable in helping us to understand the challenges faced by those diagnosed with Young Onset Parkinson's and their families, with a view to establishing appropriate support systems. In addition, the data will be invaluable in our advocacy to the government for funding.

In the coming months, representatives from each Australian state will also come together to discuss potential directions for a strategy on moving forward as we work to meet the needs of younger people living with Parkinson's on a national level.

Young at Park (Y.A.P) Support Group

If you are interested in attending a Young at Park (YAP) function, contact our health team.

Parkinson's Victoria is hosting an education session about Deep Brain Stimulation surgery on November 27. Read more on page 4.

A shoulder to lean on

Our 45 Support Groups located across the state, play a vital role, not only supporting their local communities but supporting our work in providing information and support, as well as raising awareness.

We are proud of the work of our Support Group leaders in particular, but also the efforts of all members, and their valuable contribution to the lives of people living with Parkinson's. Here are just some of the highlights from Support Groups' recent activities.

A colourful event

Members of the Geelong Young at Park support Group (YAP) organized a special event around the planning of Parkinson's Passion at the City Council, with Mayor John Mitchell and Geelong Support Group Leader Harold Waldron joining the Geelong YAP group leader, David Hayes for the formalities.

The event gained local media coverage and David has also been interviewed on local radio promoting the group and sharing his story.

Fundraising for Parkinson's

The fundraising efforts of Carolyn Alkemade (Gippsland Lakes Community Health worker and Parkinson's Support Group Leader) were featured in her local Lakes Entrance newspaper. Carolyn participated in Australia's Unity Walk for Parkinson's and her good friend Bec Ballam flew all the way from Perth to join her!

Taking it to the streets

The Warragul Support Group organized a raffle and sold tickets at a street stall which various members manned all day. They raised \$940 (donated to Parkinson's Victoria) and their efforts were featured in the local paper, which also carried some key messages about Parkinson's and the local support group.

Lending a Hand

The South Gippsland Support Group has always been an active one, hosting events, activities and various fundraisers. They found the perfect outlet for their creativity earlier this year when supporting two of our Vietnam Charity Challengers, Kim and Sue, helping the girls to exceed their combined fundraising goal of \$12,000!

A New Year's Eve dance, staged by the Southern Dance Group to celebrate the coming of 2009, was the final fundraiser. A member of the dance group, Russell Harrison is also a member of the South Gippsland Support Group and proceeds

from the event were donated to the support group which were then added to Kim and Sue's Charity Challenge tally; an amazing \$1413 from this one event!

Kim and Sue were also assisted in their fundraising efforts by members of the Moe and Warragul Support Groups.

Hosting Special Guests

Throughout 2009, many Support Groups invited local, state and Federal members of government to join a support group meeting.

These visits present fantastic opportunities to highlight the various issues faced by people living with Parkinson's and to advocate for improved services and funding (as well as to secure media stories!)

Key messages and facts and figures become even more powerful when combined with the personal stories of our members.

The more that people in positions of authority hear the message, the greater the chance of having these messages acted on by decision makers and creating change.

Painting a Picture for awareness

Anne Atkin and her Painting for Parkinson's Support Group continue to be a colourful news story for local newspapers. Wherever Anne and her art group go, the local media is keen to follow! Members of the Lakes Entrance Support Group recently painted up a storm and the subsequent news article helped raise awareness of the condition but also highlighted that people with Parkinson's are still keen – and able – to laugh and enjoy life!

Local Events

The Mildura, Warnambool and Yackandandah/Beechworth Support Groups all hosted special events for National Parkinson's Awareness Week which were open to the wider public.

A Slow Walk for Parkinson's was held by members of the Mildura Support Group; more than 30 people came together for the event which was featured twice in the local Sunraysia Daily newspaper.

The Warnambool Support Group also hosted a **Walk along the Bay** and were joined by Warnambool City Mayor, Michael Neoh and members of the public. The Walk was featured in the local paper.

And, the **Yackandandah/Beechworth** group hosted a luncheon. Almost 80 guests attended and the event raised almost \$2000 for Parkinson's Victoria.

Access, Advocacy & Assistance

This section aims to inform and empower individuals to play an active part in managing their Parkinson's – or to assist a loved one – by providing information about your rights, assistance schemes and subsidies, as well as aids and support.

Just one touch

EasyTouch Discovery is an easy to use mobile phone designed for older Australians and people with a disability.

Developed by the User Interface Design and Planning team at Telstra, the phone features large buttons on the handset to make it easier to use for the elderly as well as people with visual or dexterity impairment. It also features simple menu, large fonts, a bright, clear screen that doesn't bleach out in daylight, a loud speaker phone and simple access to advanced features.

In addition, the EasyTouch Discovery phone has a number of features for people with hearing impairment, including specially designed ringtones with different frequencies to aid different levels of hearing impairment.

The phone comes with a DVD explaining how to use all of the phone's features.

It's interesting to note that before the prototype was made widely available Telstra consulted with members of their Telstra Connected Seniors program (helping older Australians embrace technology) and the Telstra Disability Forum (representatives from peak national disability consumer groups convened twice a year by Telstra) to ensure the product met the needs of these groups.

The EasyTouch Discovery phone is available from Telstra Stores or T [Life] Stores.

Access all hours

The Emergency After-Hours Response Service, or EARS, provides free, short-term support, in-home and non-medical emergency after-hours assistance to eligible people with a disability, older people and their carers who find themselves in unexpected times of need.

What is an emergency or crisis? It can be generally defined as something that cannot "wait until the next morning".

Examples include:

- If an older person has fallen out of bed and cannot get back up
- If a support worker cannot attend work and a substitute support worker needs to be found

- If you are needing extra help with a person for whom you are caring

Support includes short-term personal care, telephone and in-home support.

Funded by the Department of Human Services, EARS operates between the hours of 5pm – 9am weekdays and 24 hours on weekends and public holidays, every day of the year. EARS is available in the Grampians Region, Northern, Western and Eastern Metropolitan Regions of Melbourne.

For more information during business hours please contact Rosi Pinter: (03) 9687 7066 or email rosi.pinter@annecto.org.au

Health Team note: If you live outside the catchment areas for the EARS program (as outlined above), call the National Commonwealth Carers Respite Service: free call 1800 052 222. You can call 24hrs a day and you will be put through to your local centre who can assist you.

It's Ok to complain

If you are dissatisfied with a disability service then it's "okay" to make a formal complaint.

How to make a complaint:

First, raise your concerns directly with the service provider via their complaints procedures (under the Disability Act 2006, all disability service providers are required to have a complaint management process in place). If you are unable to resolve your complaint with the service provider, you can take your complaint to the Disability Services Commissioner.

Anyone in the community can make a complaint. This includes people with a disability, family members, and staff working in disability services or any interested community member. Complaints may be made in relation to the direct service provision of an organisation, or the way in which a complaint was handled by the disability service organisation. Services provided by the Commissioner are free of charge.

Remember that the Commissioner will work with you and the service provider to ensure that you are not adversely affected or fear retribution from the organisation.

To find out more, call: 1300 728 187 or to make a complaint, free call: 1800 677 342

An informative and comprehensive website is also available - www.odsc.vic.gov.au

Editor's note: This article is based on the information sheet 'Making a Complaint to the Commissioner', published by the Disability Services Commissioner.

You're never too young

When does the desire to make a difference start? When do you first begin to feel that you actually have the power to "make things happen"?

For Brenden Judge, it happened earlier this year, not long after his 10th birthday, when his mum Janelle suggested they join with Pop and Nana – Janelle's parents Bob and Wendy - to participate in **Australia's Unity Walk for Parkinson's**.

Brenden and his Pop are best mates. They love to go for bike rides and excursions to check out local car shows, or indulge in some healthy competition over a computer game, and you'll often find them exploring the internet together, researching a school project.

Since Bob was diagnosed with Parkinson's in March this year, nothing much has changed in that mateship, except the occasional time when Brenden wants to kick the footy around the backyard, but his Pop is too tired, or perhaps Pop has to miss watching him during sports days at school because of an appointment with his Parkinson's specialist.

But, even though things haven't changed much, Brenden was keen to do something to show his Pop how much he loved him, and to share with others how great his Pop was. So, when the opportunity to fundraise for Parkinson's Victoria came along, through **Australia's Unity Walk for Parkinson's**, Brenden approached the project with all the optimism and energy of youth, but also the maturity and confidence of someone twice his age.

A student at Mowbray College, Melton, Brenden and his mum Janelle first heard about the walk during a Parkinson's seminar hosted by Parkinson's Victoria earlier this year, and it wasn't long before Brenden embraced the idea of not only *participating* in the Walk, but *fundraising*, completely.

In emails to family and friends, and during school

presentations, Brenden explained the symptoms of Parkinson's that sometimes made his Pop's life challenging. Together, Brenden and mum Janelle created Brenden's online fundraising page, and Brenden's nana – Wendy – helped him to count up cash donations and taught him about the process of banking them.

Janelle has seen her son blossom during the last few months as a result of his fundraising efforts and not only learning about Parkinson's, but sharing this information with others. She believes Brenden's decision to fundraise for Parkinson's, inspired by his Pop's diagnosis, has opened her son's eyes and given him greater confidence. Pop (Bob) meanwhile, is proud of his grandson, and admits that, in some ways, Brenden's support helped him make the decision to inform his work about his diagnosis (who have been supportive and understanding).

Reading Rasheeda Ali's book "I'll hold your hand so you won't fall" helped Brenden understand what his Pop was going through and explained some of the unusual changes he saw in his Pop, including the lack of swing in his arm and his "penguin-like shuffle".

Brenden's original fundraising goal was just \$200, but before long he had surpassed this. Increasing it over the next few weeks to \$400, and then again, to \$650, Brenden's final tally reached just under \$900! His supporters came from near and far, from his school yard and all the way to Queensland.

Brenden hopes his fundraising will help find a cure for Parkinson's and help people who are living with the condition. And, he is already planning his fundraising efforts for next year's walk, including a "guess how many lollies in the jar" competition, and even being sponsored to lock up his gameboy for a weekend!

In 2010, he hopes to be part of the Mowbray College formal school fundraising program.

Congratulations Brenden on your amazing fundraising efforts!



Fundraising & events

Taking it to the streets

In the lead up to Parkinson's Unity Walk, the famous clocks of Flinders Street train station were adorned with eye catching banners, asking the question "Would you walk around the block to support someone with Parkinson's?"

The banners were designed for free by RAPP, a creative agency based in Richmond (but part of an international agency).

RAPP's creative team, led by Glenn Dickson and Ruben Cirugeda, and assisted by Melissa Fullerton, also came up with a novel way to help the general public 'experience' what it can be like to live with Parkinson's.

The **Parkinson's Skill Tester** (below), inspired by the traditional arcade game, replaced traditional prizes of soft toys and lollies with 'everyday items', such as milk cartons, mobile phones and remote controls.

Passers-by were encouraged to 'try their luck' using the machine's claw to pick up an item, and thereby experience some of the symptoms of Parkinson's, which can include loss of control over spontaneous movements, slowness and rigidity. The slogan was "Parkinson's disease makes easy things hard."

We are extremely grateful to the RAPP team for giving their time and creative expertise to help raise awareness, especially during Awareness Week.



Art exhibition tells the story

Beyond the Mask, an art exhibition, was hosted in 2005 to showcase the creative spirit of people living with Parkinson's. The original convenors, the Eastern suburbs support group, **Parkies with a Purpose**, is pleased to announce that **Beyond the Mask II** will take place as part of National Parkinson's Awareness Week in 2010, from 27 August – 14 September at Kingston Art Centre Gallery (979 Nepean Highway, Moorabbin).

Victorian amateur and professional artists of all mediums are invited to submit works for consideration.

For further information, registration forms, and to submit an expression of interest, please contact Parkies with a Purpose: Vanessa (03) 9585 2402 or Ursula (03) 9557 5153. Registration forms must be received by 30 May 2010.



The Faces of Parkinson's Unity Walk



Medication & Symptom Management

What lies beneath – Understanding DBS Surgery

Deep Brain Stimulation or DBS surgery is a medical procedure that may be beneficial in reducing some of the symptoms associated with Parkinson's in some people.*

What are the benefits of DBS surgery?

There is no known cure as yet for Parkinson's. DBS surgery will not halt the progression of the condition or provide a cure, however it may help reduce the symptoms associated with the condition, improving the individual's mobility and symptom control. It can often also lead to a reduction in the amount of medication needed to treat Parkinson's symptoms. If the therapy is discontinued (if the device is turned off or removed) symptoms will return.

What does the procedure involve?

DBS involves the placement of a pacemaker-like medical device in the muscles of the chest. This is connected to leads implanted in targeted areas of the brain, namely those responsible for movement.

Both the stimulator device and leads sit under the skin and nothing is visible on the surface (although the outline of the device may be visible). The device then delivers electrical stimulation to those parts of the brain which control movement, overriding the signals that cause the disabling motor symptoms of Parkinson's. The outcome is that individuals may experience greater control over their physical movements.

Are there any side effects?

Side effects of DBS surgery are rare but may include:

- Experiencing tingling sensations
- Worsening of symptoms
- Developing speech problems
- Experiencing dizziness or lightheadedness

Many side effects related to the effects of the stimulating device can be managed by adjusting the device's settings. Often several adjustments to the stimulation are required over the first six months as the specialist works to fine tune the settings in order to ensure optimal results from the procedure. These adjustments to both the settings and stimulation levels can be done non-invasively (in other words, additional surgery is not required to make adjustments).

The DBS procedure is completely reversible. And, as

with a cardiac pacemaker, the device (battery and neurostimulator) will need to be replaced at some stage.

Complications from the surgery are also rare, however DBS carries the same sorts of risks as other surgical procedure. Complications may include:

- Intracranial hemorrhaging
- Infection
- Pain at the surgery sites

How effective is DBS for treating Parkinson's disease?

According to Medtronic, manufacturers of the DBS device, clinical studies showed that 87 percent of patients demonstrated improved motor scores in the "off" medication state at the end of the 12-month evaluation. (**Therapy Clinical Summary, 2003; www.medtronic.com.au**).

*It is important to note that not everyone diagnosed with Parkinson's is a suitable candidate for surgery and that there are stringent measures in place to screen possible candidates, with the aim being to ensure the procedure is as successful as possible.

If you would like more information about DBS surgery, please contact Parkinson's Victoria or speak with your Neurologist. Or book into our DBS seminar in November. More details on page 4.

Support network for DBS patients

Expressions of interest sought...

Have you had Deep Brain Stimulation (DBS) surgery for Parkinson's symptoms? Would you like to meet and talk with others who have had this operation?

Parkinson's Victoria is seeking expressions of interest from people who would like to connect with others to share their post-operative experience of DBS.

We have already been contacted by several individuals and believe there is a genuine need and interest in establishing such a network.

The purpose of the get-togethers is to meet others who are keen to share their personal experience of DBS surgery, including the impact surgery has had on their lives, and to share information.

Health Team note: Please note, this group does not aim, nor is it equipped to be, a therapy group.

If you are interested in participating in this new Victorian-based initiative, please contact Catherine at Parkinson's Victoria: (03) 9551 1122 or email catherine@parkinsons-vic.org.au

Our Supporters

We gratefully acknowledge the generous donations that have been made by our supporters in recent months.

Unfortunately, due to the large number of donations, we are unable to list all our donors individually. Listed below are the names of those who kindly donated \$200 or more between 11 July and 15 October 2009, and individuals in whose name in memoriam donations were made. 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 also thank those who have donated but wish to remain anonymous, those who have supported our Ambassadors of Hope speakers program, and others who have generously supported our work in the community.

Donations \$200 and over (individual)

Steven Betts
K von Bibra
Simon Billings
Nellie Castan
Rob Clarke
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Ron Dunnington
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Donations \$1000 and over

Geoff Mitchell

In memory of...

May - October

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Robert Graham
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Radok Uwe
Anne Wyatt
September
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Giovanni DiVito
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Marie Ricketts
Joan Kay Ross-Jones
Rayford Timewell
Laurel Wheeler
Ronald Boswell
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Ella Goldberg

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The Pharmacy Guild of
Australia

The Sorrento Social Savvys
Turk Sports Bar
Wellington Latrobe Lions
Club
Westie Media
World Ship Society Victoria
Branch

Parkinson's Support Groups

Beechworth/Yockandanda
Bendigo
Essendon
Portland
Shepparton
Warragul
YAP (Young at Park)

Bequests

The Estate of Doreen Merle
Gardner
The Estate of
Audrey MacDonald
The Estate of Jaap Robyn
The Estate of Joe White

Trusts and Foundations

Handelsman Charitable
Trust
Harry Secomb Foundation

Team Parkinson's (auxiliary fundraisers)

Julie Sewell and Jo Hill
(Tulip Ball & Tulip Cocktails)

We would also like to thank all those who generously supported our National Awareness Week tin raffle at Melbourne Central, Flinders Street, Flagstaff and Parliament train stations, conducted on the morning of Wednesday 2 September. Together we raised just over \$5300 (beating our 2008 tally by more than \$1000) And of course, our amazing team of Unity Walk for Parkinson's fundraisers and their generous supporters who together raised in excess of \$60,000! Thank you for all your wonderful efforts raising funds and awareness to support the cause.

Tulip Tributes

We couldn't do it without you!

This is when we take time to acknowledge the special efforts of some amazing supporters.

There's no place like home

Special Thanks to Shepparton Support Group member Darnley Montgomery for his recent fundraising efforts amongst friends and the local community in Tallygaroopna, proving there's no place like home when it comes to support! Darnley raised a total of \$3048 for his support group! Well done – what an amazing effort!

Building Knowledge

A special thank you to Moira Lewis, a Parkinson's Ambassador and participant in the Victorian Government's Leadership Plus program.

Over the past 12 months Moira has been hard at work increasing awareness about Parkinson's and the importance of getting medication on time in health care facilities in Echuca and Rochester.

Moira's project both increased awareness and provided Nursing staff with valuable strategies to assist them in being able to deliver medication on time. Most recently, Moira arranged for Victor McConvey from Parkinson's Victoria to join her in presenting a lecture to the Post Graduate Nursing students at Bendigo Health, providing vital knowledge for future nursing leaders.

Planting the seeds of Change

One of the highlights for this year's National Parkinson's Awareness Week was the Parkinson's Passion Rose Planting that took place at the Morwell Centenary Rose Garden on Tuesday 1 September (below).

In attendance were members from support groups in Sale/Maffra, South Gippsland/Leongatha, Moe and Warrigal.

We were joined by the Friends of the Rose Garden (volunteers who take care of the grounds), as well Federal Member for Gippsland Darren Chester, and Latrobe City Mayor Lisa Price.



From left: Mayor Lisa Price, Federal Member for Gippsland Darren Chester and Edith Colley from Friends of the Morwell Centenary Garden get their hands dirty in honour of Parkinson's Passion.

Parkinson's Victoria gratefully acknowledges the generous support of Treloar Roses for kindly donating the 12 roses for the garden bed, to the Friends of the Garden for this wonderful opportunity to showcase Parkinson's Passion to their local community and visitors, and to the Latrobe City Council for donating the use of their offices for the afternoon tea. Next time you're in the area, make sure you visit the stunning rose garden and check out our beautiful rose bed and plaque dedication.

Celebrating a Birthday

Cynthia Hicks and members of the Wimmera Support Group recently celebrated the group's "20th Birthday" and our CEO Glenn Mahoney and Parkinson's Nurse, Victor McConvey attended the festivities.

The Mildura Parkinson's Support Group celebrated its 3rd year supporting members of the local community and were featured in the local **Sunraysia Daily**.

A wonderful comm-UNITY!

We would like to officially present colourful Tulip Tributes to our generous Unity Walk event sponsors and supporters. The following businesses gave financial or in-kind support to help make this event a success:

- Telstra
- Novartis Pharmaceuticals
- Hawaiian Airlines
- Hawaii Tourism
- Outrigger Enterprise Group
- Melbourne Cricket Club
- Secure Parking
- The Langham Hotel
- Magic 1278 and 3AW
- Intouch Direct
- The Pharmacy Guild of Australia
- Boehringer Ingelheim
- Federation Square
- City of Melbourne
- Artisse Organic
- La Manna Direct
- Ego Pharmaceuticals
- AB Food and Beverage



Following the planting in Morwell, guests enjoyed afternoon tea at the council chambers. Pictured are members from our Support Groups located in Warrigal, South Gippsland, Moe and Sale.