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Fellowship findings

Over the last few editions of Signpost, we've updated you on the progress of team member AMANDA SPILLARE's Churchill Fellowship. Amanda was awarded the fellowship in order to travel overseas to conduct research into the USA and Europe's young onset Parkinson's support programs. Now, Amanda shares with you the highlights from her research, as well as her findings.

Thanks to the kind support of the Churchill Fellowship, I was able to research an issue that I feel extremely passionately about; supporting people diagnosed with young onset Parkinson's.

The aim of my fellowship was to create a model for developing the first national young onset support network in Australia.



Members of the Staten Island Young Onset Support Group (affiliated with the APDA)

The fellowship enabled me to travel to the UK and US to meet some of the most inspirational people in the Parkinson's arena, including authors, people at the core of service development for young onset Parkinson's and people living with Parkinson's.

Fellowship highlights

- ☛ Meeting Tom Isaacs, author of **Shake Well Before Use** and Co-founder of the **Cure Parkinson's Trust**, at his home in Rickmansworth.
- ☛ Attending the **Movement Disorder Society Conference** in Chicago to hear the latest insights into Parkinson's.
- ☛ Discussing young onset issues over a delicious dinner with the coordinator of the Young Onset Centre and fellow social worker, Julie Sacks and her colleague.
- ☛ Experiencing the kindness extended to me from each and every person I came in contact with throughout my fellowship. People not only gave

their time, but personally ensured I had all the information I needed. The warmth and connectedness of the Parkinson's community is truly inspiring. Their enthusiasm and passion was contagious!

My fellowship involved meeting and interviewing:

- ☛ Ruth Hagestuen, **Director of Field Services and National Programs**, NPF (National Parkinson's Foundation)
- ☛ Julie Sacks, **Director**, National Young Onset Centre, APDA (American Parkinson's Disease Association)
- ☛ Karen Leis, **Vice President of Development**, Michael J Fox Foundation
- ☛ Kate Gendreau, **Executive Assistant** to the CEO, Michael J Fox Foundation
- ☛ Robin Anthony Elliott, **Executive Director**, PDF (Parkinson's Disease Foundation)
- ☛ Elizabeth Pollard (Eli), **Special Events**, PDF
- ☛ Christiana Evers, **Director of Communication**, PDF
- ☛ Ronnie Todaro, **Director of National Programs**, PDF
- ☛ Dr Maestroni, **Director of Scientific and Medical Affairs**, APDA
- ☛ Staten Island **Young Onset Support Group**, APDA
- ☛ Adolfo Diaz, **Field Services Manager**, NPF
- ☛ Lizzie Graham, **Secretary General**, EPDA (European Parkinson's Disease Association)
- ☛ Tom Isaacs, Author of **Shake Well Before Use** and Co-founder of the **Movers and Shakers: Cure Parkinson's Trust**
- ☛ Linda Fernando and Phillip Lee, Young Onset couple and Harrow Support Group leaders
- ☛ Rachel Raymond, **Director of Community Services**, PDS (Parkinson's Disease Society)
- ☛ Tina Walker, **Committee Member**, **Young Parkinson's Network**, PDS
- ☛ Emily Choy, **Moderator for PDS internet forum**, PDS

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News & Highlights

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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.

Bridging the Gaps project launch

After months of consultation, planning and research, we are pleased to announce that our Bridging the Gaps resources are now available.

The booklets and Help Sheets feature information about Parkinson's in 10 languages (plus English) and aim to inform and support those from culturally and linguistically diverse communities to better understand and manage Parkinson's.

The new resources have been funded by a major grant from the Lord Mayor's Charitable Foundation.

The official launch will take place on **12 November at the Melbourne Town Hall**, with Foundation President and Melbourne Lord Mayor Mr John So formally presenting the resources to the community. Media and community members from the target language groups will also be in attendance, as well as various VIPs. The materials will be rolled out to other states in the coming months.

Contact us for your free copy of the booklet Understanding Parkinson's disease and/or Help Sheets on the following topics:

- **What is Parkinson's disease?**
- **Medical Treatments for Parkinson's disease**
- **Living with Parkinson's disease**
- **Where to go for help (Victoria)**

Language options:

- **English only**
- **Bi-lingual versions in English and (either) Arabic, Chinese (Traditional), Croatian, Greek, Italian, Macedonian, Russian, Spanish, Turkish & Vietnamese.**

Specialist information available

There are some Parkinson's symptoms and other physical and emotional changes that occur that are simply not that easy to talk about. However, learning more about these issues and talking about them is often the best way to manage them.

In recent months, we have developed a number of resources that can assist individuals to understand and manage some of the more unusual or private concerns linked to Parkinson's. These include fact sheets on depression, constipation and sexuality. There is also a DVD on sexuality, based on our 2007 seminar, **The Triple "S": Senses, Sensuality and Sexuality in Parkinson's**. And we are pleased to announce that, in partnership with Beyond Blue: The National Depression Initiative, we have produced a free DVD and Help Sheet on **Depression and Parkinson's** which is now available.

The resources are an ideal introduction to these issues and are designed to help people begin talking about their experiences and concerns. They also offer suggestions on where to go for further help.

If you would like a copy of any of these resources, or would like to know about other resources, please contact one of our health professionals.

Support for those with MSA

In June, Parkinson's Victoria held the first information and support meeting for those living with Multiple Systems Atrophy (MSA), a Parkinson's 'look-a-like' condition, for which there is currently no Australian peak body organisation and very little condition-specific community support.

While people living with MSA often attend Parkinson's Support Groups, the recent meeting held at the Parkinson's Victoria office provided people living with MSA, their partners and family members, with a unique opportunity

to meet others, share experiences and learn more about life with MSA.

Parkinson's Victoria recognises the great need for people living with 'Parkinson's Plus' conditions, such as MSA and PSP (Progressive Supranuclear Palsy) to access information and support that is targeted to the symptoms and issues specific to their condition.

With this in mind, Parkinson's Victoria is keen to continue developing and providing better support for those living with MSA. If you are living with MSA and would like to be involved in upcoming MSA meetings, or if you know someone who might, please contact Catherine at Parkinson's Victoria. If you are interested in contacting the PSP Support Group, contact Parkinson's Victoria or Support Group Leader Anne Mooney: (03) 9568 7748.

Holiday office hours

The office of Parkinson's Victoria will be closed for the festive season from Thursday 25 December and will re-open on Monday 5 January, 2009.

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

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



Have you volunteered for Parkinson's Victoria during 2008?

We'd love you to join our team and other volunteers for our annual Volunteers Christmas/ Thank You Lunch in November. Invitations are currently being mailed out.

To RSVP or if you haven't yet received your invitation, contact Volunteer Coordinator Donna Willis: (03) 9551 1122.

National Conference update

The Parkinson's Australia National Conference was held in Sydney on 16 and 17 October, with more than 200 delegates in attendance, representing people with Parkinson's, friends, family, health and allied health professionals.

Keynote presentations included the inspiring John Bell of Team Parkinson's (America), who was diagnosed in 1983. John is about to complete his 14th marathon raising funds and awareness for Parkinson's research.

Dr Abraham Lieberman, who heads the **Muhammad Ali Parkinson's Clinic**, spoke on the benefits of good posture and exercise in managing Parkinson's symptoms. Dr Lieberman was an outstanding speaker, with an ability to convey complex medical concepts in everyday language which all attendees could understand. Of particular interest was Kate Ward's moving presentation of her experience of being diagnosed at the age of 42. Kate, from South Australia, spoke of the lack of information and support she received from her neurologist at the time and that she had to find these on her own. Kate identified three things that people who are newly diagnosed with Parkinson's need: help, hope and direction. She went on to highlight the important role that Parkinson's organizations around Australia have in providing these to the community and individuals.

The organising committee from Parkinson's New South Wales recorded keynote and core sessions during the conference and the DVD's will be available soon. Details on how to order these will be included in the first edition of Signpost for 2009 (out February).

The team at Parkinson's New South Wales is to be commended for coordinating an impressive and informative program of speakers, not to mention a professional and successful event.

From the desk of the CEO

Parkinson's Awareness Week (the first week of September each year) is one of our busiest weeks.

Our preparation was challenged this year when we had a break in at our offices just ten days before Awareness Week, with laptop computers, equipment and money stolen. One of the items stolen was Amanda Spillare's laptop, which contained all of her Churchill Fellowship research and photos. Channel Nine News and the Derryn Hinch program ran a story on the robbery, with a plea for the return of the laptop. Following the media coverage, Moorabbin CIB made an arrest and was able to reclaim Amanda's laptop and some of our equipment. We have since reviewed security and will be installing a back-to-base security alarm, among other measures.

Despite the break in, Awareness Week was a great success. We launched our new **Guess Which One** poster which was displayed at Connex railway stations throughout the network. (The poster appears on the back cover of our Annual Report). Parkinson's Victoria banners stating "**It can Affect Any Body, Any Age**" adorned Flinders Street train station, and our tin rattle, collecting donations from city commuters, was our best ever, raising \$4356 in just two hours.

Media coverage included Nerissa Mapes on Channel Ten's national morning program, Channel 9 News, Vision Australia Radio, Joy FM Radio and the Australian Jewish News. It was particularly pleasing to see the number of Regional Support Groups who were proactive in gaining media coverage. Major stories appeared in the Shepparton News, Bairnsdale Advertiser, Caulfield Leader and the Portland News. The Mildura Weekly had a two page colour spread featuring members of the local Support Group.

We had a record attendance of 160 at our Recently Diagnosed Seminar, with attendees from across Victoria. Our Geelong seminar had more than 120 attendees, with 25 General Practitioners from Geelong and surrounding districts attending our GP seminar.

90 people attended a research update presented by specialist neurologist Dr David Williams, followed by our Annual General Meeting at the Camberwell Centre.

We were delighted that Sir Zelman and Lady Cowen were able to join us once again. Harold Waldron was a worthy recipient of the annual **Sir Zelman Cowen Award** for outstanding voluntary service to the Parkinson's community. Harold has led the Geelong Support Group for the past 27 and is still going strong.

Royce Pepin, our President, was re elected to the Board, and at the Board Meeting following the Annual General Meeting, was re elected as President. Members of the 2008-09 Board of Parkinson's Victoria are: President: Royce Pepin, Vice President: Kate Brown, Chairperson Finance Committee: Peter Walker, Sandra Eisner, Mary Jones, Peter Raymond and Fred Van Ross.

At the AGM, Royce presented a \$5500 cheque to Fairlie Hinton, Coordinator of the Victorian Brain Bank, to support their work in Parkinson's research. An article on the Brain Bank is included in this edition of Signpost.

Special Announcement: Parkinson's Victoria re-launches our own Unity Walk

You may recall that in 2004 and 2005, the Parkinson's Unity Walk was established in Victoria to raise funds and increase Parkinson's awareness. The original Organising Committee included Margaret Bagnato, Karyn Spielberg and Amanda Tehan.

The Unity Walk originated in New York City in the mid 90's and is now a major fundraising event, with many thousands of participants raising funds to support Parkinson's research by walking around Central Park.

Parkinson's Victoria will be re-launching the Unity Walk here in Melbourne in 2009, with a tentative date being Sunday 30 August. The event will coincide with the NSW Unity Walk.

We will be seeking volunteers to assist with the event, with a view to establishing an organising committee. In addition we will be seeking sponsorship to help offset associated expenses and, of course, people to participate! Our aim is 500 walkers and raising \$50,000.

Please contact Judith Mooney on (03) 9551 1122 if you would like to be involved or can assist.

On the subject of fundraising, please support our 2008 Christmas Letter Appeal. We receive only \$185000 in government funding each year, and rely on community support to provide and develop services. Your tax deductible donation makes a difference.

As this is the last **Signpost** for 2008, may you have a joyous festive season and a happy, safe New Year.



Glenn Mahoney
Chief Executive Officer

Fellowship Findings

Continued from page 1

From the many interviews and meetings conducted, I was able to draw key insights and lessons from those who had been there before. A full copy of my report is available on the Parkinson's Victoria website and the Churchill Fellowship's website: www.churchilltrust.com.au.

Findings

One of the key challenges in mobilising a network for young onset Parkinson's in Australia is that there is no set formula. Parkinson's support associations however, must play a key role in facilitating young people to drive the process of developing the network, capturing their ideas and enthusiasm.

From my research I would conceptualise a consumer driven Young Onset Network in Australia as having several functions:

➤ Galvanising the support and cooperation of the Parkinson's Australia network

will help to ensure the network's success. This can be achieved by using the EPDA's **Road Show** concept, where different state representatives get together and throw their ideas into the proverbial melting pot.

➤ Securing recurrent funding of \$150000 (within 12 months)

to develop and evaluate a national demonstration project. The funding would ensure the establishment of the first **National Young Onset Project Centre**, auspiced by Parkinson's Australia.

➤ Appointment of a Young Onset Project Worker to coordinate the development of the network and have a key role in implementing the initiatives outlined below.

At the end of the 2 year demonstration, the project would be evaluated against the original key aims and objectives.

- With the full support of Parkinson's Australia and having secured funding for the national demonstration, the network would need to engage and be driven by influential people with young onset Parkinson's. These people would form the **Consumer Advisory Group** (of 6 – 8 people) and would be the driving force of the network and decide on activities. The network should be *driven by young people, for young people*, with the project worker providing expertise around facilitating this process.

Conducting an analysis of the needs of young people in Australia could be one of the first activities the group undertakes.

Advocacy and lobbying government for increased funding for support and research could also be one of the key functions of the consumer advisory group. The network also needs clear processes for evaluation, and have representation from all states.

- I would also recommend hosting an **Inaugural National Conference/Event**, in consultation with the Consumer Advisory Group. The agenda would be set by people living with young onset Parkinson's. This could be hosted over a weekend and must have a sufficient balance of unscheduled time, fun activities and opportunities for people to make meaningful connections with others.

Training a small group of **five people with Young Onset Parkinson's** to act as mentors would also be an important recommendation.

The **Peer Support Program** should be developed by a professional and would act as another form of connecting with and supporting young people who are living with Parkinson's. Appropriate evaluation is also an essential element that will need to be built into this model.

Due to the complexities of moderating live chat rooms (internet discussions) and recent findings from the Movement Disorder Society, I would not recommend that Parkinson's Australia become involved in developing an internet chat group at this stage. An alternative would be developing an **Internet chat group's referral list** that has links to valuable online moderated web chat.

Developing a **national young onset publication or e-newsletter** that is coordinated by the young onset project worker is another important recommendation.

Young people need a forum to learn more about their condition and receive reliable, relevant information.

Where to from here?

There are many recommendations and issues that have arisen from my research into existing support models for those diagnosed with young onset Parkinson's. The report has been tabled for a forthcoming Parkinson's Australia meeting, and we are confident that other state organisations will support the findings

and recommendations.

As a united voice, we will be looking to approach government with the recommendations for funding and support. **We are hopeful that with adequate funding support we can implement the recommendations of this report in the near future.**



Amanda with Adolfo Diaz, Field Services Manager, NPF



Amanda with Rachel Raymond, Director of Community Services, PDS (centre) and Tina Walker, Committee Member, Young Parkinson's Network, PDS.



Author Tom Isaacs and Amanda.

Research

Have you ever wondered what goes on behind the scenes of Parkinson's research? For instance, while researchers are working hard exploring possible cures, diagnostic tools and improved treatments, have you ever thought about how these theories and ideas are tested and how the "testing" ground itself is created to ensure realistic outcomes and credible, useful data?

Using the mouse to model Parkinson's disease

In the same way that the recently formed Parkinson's Victoria Research Registry aims to create a "living database" of people with Parkinson's from which to gain vital, accurate information about the condition (as well as providing suitable research participants), so too do living, breathing mouse models create an opportunity to study the condition, its progress and treatments. But, as PhD graduate SONIA GEORGE explains, not just any mouse will do!

In 2007, Sonia presented her research and findings on the value of current mouse models in studying Parkinson's and current and potential treatments to an international audience. Parkinson's Victoria has been fortunate to have Sonia join our team as a volunteer in recent months, while she takes a well-earned break from studies, but she was more than happy to share some of her findings.

Many mouse models of Parkinson's have been reported in scientific literature, but there is no current mouse model that mimics **all** of the pathological hallmarks, or movement and behavioural disorders, associated with the condition.

There are three main classes of mouse models used to research Parkinson's:

- 1) Genetically modified 'transgenic' models
- 2) Rodents which lack a specific gene, termed 'knockout' models and
- 3) Mice administered toxins or 'toxin-induced' models.

Each model produces varying results in research tests and lacks the full scope of the human disease.

Genetically modified mouse models of Parkinson's have been developed to shed light on the progression of the condition and to allow the development and testing of therapies. These mice have been based on important genes linked to rare inherited cases of Parkinson's.

The most common mouse model utilises the important protein **alpha-synuclein**. Alpha-synuclein

abnormally aggregates (clumps) in the brain of people with Parkinson's.

As none of the current mouse models which have been genetically engineered to over-express alpha-synuclein display typical signs of the dopaminergic neuron degeneration (loss of the brain messenger chemical called dopamine) consistently, as seen in Parkinson's, there is obviously the potential for further research and refinement of these models.

Parkinson's is characterised by the triad of symptoms of resting tremor, bradykinesia and rigidity. However, Parkinson's is much more than just a movement disorder and non-motor symptoms often precede motor symptoms.

In my thesis, I tested for anxiety-like behaviour and cognition in the genetically modified mice which were over-expressing the important protein alpha-synuclein with the disease causing mutation. I analysed the mouse brains biochemically, focusing on a younger age which is often neglected in research studies and has not previously been the focus of research on this particular mouse model.

Prior to any motor impairment, these young adult 'transgenic' mice exhibited reduced anxiety-like behaviour, with the pathology and signs of increased cell stress.

Spatial memory was also investigated in young adult mice and indicated subtle cognitive changes.

This research showed, with limited success, that alpha-synuclein transgenic mice facilitate the study of the condition's progression and related symptoms to Parkinson's.

Future work that continues to analyse non-motor symptoms, especially in young adult mice, as performed in my thesis, will help map the progression of Parkinson's.

Determining potential parallels with the human experience of Parkinson's in mouse models will be beneficial in the pursuit of discovering efficacious therapies.

Sonia George completed a Bachelor of Behavioural Neuroscience at Monash University in 2004, with an Honours year at the Florey Neuroscience Institutes (formerly Howard Florey Institute) with Professor Malcolm Horne. Sonia then undertook PhD study in Parkinson's research in the Department of Pathology at the University of Melbourne with Dr Janetta Culvenor. Sonia presented her research findings at the Society for Neuroscience, USA in 2007 and at the Australian Neuroscience meetings.

Participate for Parkinson's

Can you lend a "hand"?

Difficulty performing tasks which require fine hand movements has been reported by people with Parkinson's, and a study entitled **Hand dexterity in Parkinson's disease** is currently being undertaken at The University of Melbourne to explore the symptom further. The study will measure performance on a skilled hand activity and participants are now being called for.

Participants will be timed as they place small rods into a board with holes. The study will also examine the effects of undertaking an additional task at the same time.

A comparison group of healthy adults without Parkinson's will also be tested.

If you have Parkinson's, have never had a stroke or any other neurological disease, and do not have severe arthritis or any other major problem affecting your arms or hands, you may be eligible to participate. Healthy people who do not have Parkinson's can also take part if they are the same sex and similar age to a participant with Parkinson's.

The testing will be held at the School of Physiotherapy and takes approximately one hour for a single session. Participants would need to be able to make their own way to the testing but free parking is available.

If you would like more information about participating in the study contact the School of Physiotherapy: (03) 8344 4171 and leave a message for Libby Proud or email lproud@unimelb.edu.au.

Join the "living database"

The Parkinson's Victoria Research Registry is still calling for participants in order to create a "living database" of 150 people with Parkinson's and 150 carers (people NOT diagnosed with Parkinson's).

This joint project with the Florey Neuroscience Institutes will provide valuable information to improve understanding of the condition and means for improving treatment and symptom control.

For more information or to register your interest, email gmahoney@parkinsons-vic.org.au or send a letter expressing your interest to: Parkinson's Victoria Research Registry, 20 Kingston Road Cheltenham 3192. Please ensure you include your contact details (name, phone number/s and address), and the year you began taking Parkinson's medications (if you are newly diagnosed and haven't started medications please state that).

Parkinson's, employment & quality of life

If you have been diagnosed with Parkinson's and are still working, researcher Louise Parker is keen to hear from you!

Louise's research project, **Parkinson's, Employment and Quality of Life**, which is being conducted through Swinburne University is an opportunity for working people with Parkinson's to tell how it really is. Given the increasing prevalence of Parkinson's in people of working age, and the myriad of challenges and concerns that this raises, it's vital that health professionals, rehabilitation specialists and employers have access to information that will optimise working conditions for people with Parkinson's. In addition, greater understanding of the workplace and Parkinson's situation will lead to improved information and support for those living with the condition, enabling them to make better decisions about the future. The main aim of the project is to identify where support and education is needed.

The Swinburne team is currently seeking participants to complete a short online survey about their experience as a person with Parkinson's in the workplace.

The online survey can be accessed at <http://opinio.online.swin.edu.au/s?s=4356>.

The outcome of the study will be made available through Parkinson's Victoria in late 2009.

Tissue donations needed

Many brain diseases, including Parkinson's, Alzheimer's and Lewy Body dementia, only affect humans. This makes studying the brains of people affected by these conditions essential if researchers are to conduct credible and relevant study into potential treatments and cures.

The Victoria Brain Bank Network, which is part of a National Network of Brain Banks across Australia, collects, stores and distributes post mortem brain tissue and related samples for research into Parkinson's and other brain diseases.

A post mortem brain donation will aid medical research and the development of diagnostic tests and treatments.

Progress can be made towards understanding Parkinson's if researchers are able to compare brains from those affected with those who were not affected. This is known as 'control' tissue. Unaffected family and friends may also consider registering as donors.

For more information about donating tissue to research, contact Ms Fairlie Hinton, VBBN Coordinator: (03) 8344 1900 or email f.hinton@mhri.edu.au.

Medication News

Medication diaries

One of our members recently shared with us how keeping a Parkinson's diary helped her to better manage her condition.

Keeping a diary is often recommended to people diagnosed with Parkinson's, and the following highlights my recent experience of putting this suggestion to work.

After several years on Parkinson's medication, where sometimes the medication failed to reduce or manage my symptoms, I was feeling anxious – not to mention immobile.

I read the fact sheets **Keeping a Diary** and **Motor Fluctuations** on www.parkinsons.org.uk (located under the section titled **Publications, Information Sheets**).

At first, I simply recorded the amount of medication taken and the time of day I took it. I also recorded any difficulties I was having and when they occurred. Difficulties included fatigue, anxiety, stiffness, freezing, extra movements and confusion. After a few days I refined the sheet with headings: Medication (Amount), Movement (On/Off), Activity (Description), Mood (Up/Level/Down), and Thinking (Able to Plan/Muddled).

I kept the sheet handy to note what occurred hourly during the day. On the fourth day I could see a pattern. 'Off' times, muddled thinking and being passive all coincided with the hour just prior to each new dose of medication. With this information after consulting with my neurologist I was able to adjust the timing of my medication, taking less each dose, but increasing the frequency. Within two days of this change the anxiety disappeared, so too did the 'Off' periods; ditto the muddled thinking and the extra movements.

As a result of keeping my Parkinson's diary, I gained some insight into the connection between levodopa, mood, and movement, clear thinking, exercise and enjoyment of life. This enables me to balance aspects of life better. I feel very happy that, without increasing my daily total amount of medication, my symptoms are better controlled.

Client services advice:

Parkinson's Victoria encourages people with Parkinson's to keep a diary, especially in the few days leading up to a doctor's appointment. Simply writing down your medications and mood (what you take, when you take it and how you feel throughout the day), can be very helpful to your treating doctor, (who typically will only see you for a brief window of time in your day to detect patterns in your cycle).

Don't forget to take note of how things are at night,

as people often forget to talk to their neurologists about sleep and night time difficulties. Keeping a diary also helps you to understand more about your own health situation and will make talking to your doctor easier.

If you find your medications are not working as well as they were, or as you would like, Parkinson's Victoria advises that you talk to your treating doctor before making changes to your medication plan.

Safety updates for Parkinson's drug

Cabaser (cabergoline) 4mg tablets will be deleted from the available dosage range following links to fibrosis and valvulopathy in cumulative doses of the medicine.

Pfizer Australia announced in September that following ongoing review of clinical studies it would release new safety updates to the drug's product information which will come into effect on 1 November this year.

The manufacturer has also decided to reduce the maximum daily dose of Cabaser from 6mg per day to 3mg per day.

"It is anticipated that the reduction in the recommended maximum daily dose of Cabaser along with the current recommendations for assessment of patients prior to commencing therapy and during maintenance therapy included in the Cabaser product information, should help reduce the risk of fibrotic reactions," said product physician Dr Louise Canny.

The changes do not affect the availability of Cabaser 1mg and 2mg tablets which will continue to be available through the Pharmaceutical Benefits Scheme (PBS).

Existing stock of the 4mg version was no longer PBS reimbursed as of 1 November, 2008.

www.pharmacynews.com.au

New medication on PBS

Sifrol (pramipexole) is the latest Dopamine Agonist medication to hit the Australian market. It was listed on the PBS in June this year, but has been available overseas for a number of years.

Sifrol differs from other Dopamine Agonists available in Australia because it is **non-ergot derived**. Ergot has been linked with the build up of tissue on the lungs in some people. Sifrol removes the risk of this side-effect.

As with all Dopamine Agonists, there are potential side-effects associated with this medication, so it is important to consult with your treating doctor who can discuss whether this is an appropriate option.

Respite without the tears

Over the past two years, Carers Victoria and Parkinson's Victoria have been collaborating on finding ways to support carers when using respite 'without the tears'. Carers Victoria's Carer Education Unit has now developed a workshop which needs to be trialed.

Are you available to participate?

The workshop being trialed is based on information gathered from carers during the **Respite without the Tears** workshops which took place in 2007. The workshop is focused on helping carers find solutions to some of the challenging aspects of using respite.

When: Wednesday 24 November 2008

Where: Wurundjeri Room, Carers Victoria, 1/37 Albert Street, Footscray (1-3.00pm)

For more information or to RSVP contact: Amanda Spillare: (03) 9551 1122 or amanda@parkinsons-vic.org.au or Joyce Rebeiro: (03) 9396 9509 or joycer@carersvic.org.au.

Managing late stage Parkinson's

The team at Southern Health will be addressing the issue of managing late stage Parkinson's during a seminar in March 2009.

This will be addressed by various health professionals from neurological, psychiatric, nursing and allied health perspectives. The seminar is aimed at health professionals who are working with patients with late stage Parkinson's in residential facilities and in the home, however members of the community are welcome to attend. People with advanced Parkinson's and their carers would find the seminar of most relevance, and we stress that the content may be distressing to some.

Date: 16 March, 2009

Time: 1-4.15pm

Venue: Seminar rooms 1, 2 and 3, Central Bayside Community Health Centre, 335 Nepean Highway, Parkdale

Cost: \$30 (professional staff, no charge to Southern Health staff) and \$15 for caregivers

For more information and to RSVP (closing date 12 March 2009) call: (03) 9265 1411 or (03) 9265 1481.

"Does becoming emotional very easily have anything to do with Parkinson's?"

Some people with Parkinson's find they tend to be more emotional in situations which they wouldn't normally. In other words, they have a higher level of emotional lability.

This can manifest in different ways, such as becoming angry or irritable, or becoming teary quite easily.

Although heightened emotional reactions can be attributed to being a symptom of Parkinson's for some people, it is important to consider some of the secondary factors that often contribute to changes in a person's emotional state.

If you find yourself or someone you know overly emotional, be aware of the impact that stress and fatigue (both common in Parkinson's) can have, making a person more vulnerable to reacting in an emotional way.

It is also important to acknowledge the grief and loss that comes with dealing with a diagnosis of Parkinson's, not to mention the ongoing changes and adjustments associated with it.

If a person is experiencing frequent emotional lows, it may be worthwhile looking into other potential reasons for the change, such as depression. While not all feelings of sadness, anger, apathy or low mood, equate to clinical depression, if these feelings are present for most of the time over a period of two weeks or more, it is important to see your GP or treating doctor to discuss getting further help.

Parkinson's Victoria has a DVD and Help Sheet providing information about Parkinson's and Depression.

If you, or someone you know, is experiencing heightened emotional lability it is important not to ignore it. For more information, contact our health professional team who will be able to discuss your experiences and offer advice.

Volunteers needed for research exercise trial

Did you know that movement rehabilitation strategies and strengthening are thought to affect mobility and assist with falls prevention in people with Parkinson's disease?

Healthy men and women who have Parkinson's are invited to participate in a large Michael J Fox Foundation funded research project being undertaken at Kingston Centre, Cheltenham and Essendon commencing early in 2009.

For more information contact Professor Meg Morris or her assistant Illy at the University of Melbourne: 1800 428 688 or (03) 9344 7715

National Parkinson's Awareness

National Parkinson's Awareness Week provides Parkinson's Victoria and our supporters with the opportunity to connect with the community and raise much needed funds that will go on to help support those living with Parkinson's.

The week aims to enhance our efforts to:

- Increase awareness and understanding of Parkinson's disease
- Reduce the stigma associated with the condition, and
- Educate those living with Parkinson's and the wider community about the support and services available that can enhance quality of life and independence.

During Awareness Week 2008, and in the weeks following, Parkinson's Victoria hosted educational, fundraising, media, community and awareness activities.

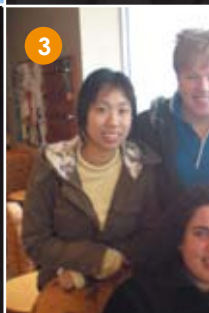
In addition, many of our affiliated Support Groups also conducted activities in their local community, workplace and within their social network.

1.2.3. Thanks to the corporate support of Connex, we again conducted our Awareness Week tin rattle at city loop train stations on Thursday 4 September.

The tin rattle is not only a fantastic opportunity to fundraise, but gives Parkinson's a "face" while increasing public awareness and understanding.

4. Thanks to the support of the Classic Cinema, Elsternwick, we hosted a successful movie night to raise awareness and funds. Guests enjoyed pre-movie nibbles while sampling wines from our long-time supporter alias wines (a flyer promoting our Summer Wine Drive is enclosed with this Signpost). Before enjoying the film, **The Mummy: Tomb of the Dragon Emperor**, the 50+ guests listened to a moving speech by Nerissa Mapes, diagnosed with young onset Parkinson's at the age of 28.

5.6.7.8. The AGM provided a backdrop to some special presentations. On behalf of the Ballarat Support Group, Leader Elaine Maberly (#7), presented Parkinson's Victoria with a cheque for \$1000. Elaine acknowledged the positive changes that had taken place at Parkinson's Victoria in recent years and the organisation's growth, as well as our friendly, caring and professional team. President Royce Pepin, on behalf of Parkinson's Victoria, presented Fairlie Hinton of the Victorian Brain Bank with a cheque for \$5500 to support the organisation's work in Parkinson's research (#5). And we were pleased to present Harold Waldron, Geelong Parkinson's Support Group Leader with the 2008 Sir Zelman Cowen Award for Outstanding Voluntary Service to the Parkinson's community (#8). Image shows from left: Geelong Support Group member Jan Thompson with Harold Waldron, Sir Zelman Cowen and Royce Pepin, President Parkinson's Victoria. The **Sir Zelman Cowen Award** is the highest honour awarded by Parkinson's Victoria to an individual. It is named in honour



ess Week – Highlights 2008



of former Governor General Sir Zelman Cowen (who held office from 1977-1982), who was diagnosed with Parkinson's in the early 1990s. The Governor General is the Patron of Parkinson's Victoria.

We were fortunate to have Neurologist Dr David Williams present a research update on Parkinson's on the morning of the AGM (#6). Image shows Dr David Williams, third from right, with our client services team (from left): Jackie Jenkins, Catherine Watson, Victor McConvey, Lauren Cowling and Amanda Spillare).

Dr Williams is passionate about Parkinson's and an enthusiastic supporter of the work of Parkinson's Victoria. In the past 12 months alone Dr Williams has generously given of his time and professional knowledge, assisting us by responding to media requests and being interviewed for news stories, writing articles for our publications and presenting keynote speeches to audiences around Victoria. We thank him for his valuable support and contribution to our work.



9. A positive and colourful addition to our annual Flinders Street banners was our **"Guess which one has Parkinson's?"** poster, which was launched during Awareness Week. The posters were on display at a number of Melbourne metro train stations and, thanks to support groups and other supporters, they were also visible around the community. (You can read more about the posters on page 20).

10.11.12. Our annual recently diagnosed seminar drew a crowd of 160 people from all around the state, including those diagnosed in the last five years, family and friends.

During the day, attendees heard presentations from health professionals on topics including research, symptom management and lifestyle, as well as personal stories from people diagnosed with Parkinson's and carer/partners.

The panel discussion (#12) gave attendees the opportunity to ask specific questions of our speakers and was a valuable addition to the formal presentations.

We would like to thank our speakers who generously gave their time: Nerissa Mapes, POP Founder and Dr Kate Kofschet (pictured left #10), Associate Professor Mal Hopwood, John Berrick, Maurice Blackburn Lawyers, Brendan Lourey, Norma Foster, Gwenda Husson. We are also grateful to Anne Atkin who runs the Art for Parkinson's group who displayed artwork from her collection and spoke with attendees about the program (#11).

We would also like to formally acknowledge and thank our major sponsor, pharmaceutical company UCB, and corporate supporters Pulse Pharmacy, Mor Cosmetics and Hunter Leisure for providing some wonderful goodies for attendees to take home and enjoy.

Guess which one has PARKINSON'S DISEASE?



... They all do!

In Australia today, there are 80,000 people living with Parkinson's disease. 25 more people are diagnosed every day. Parkinson's disease affects adults of all ages. To date there is no cure. Parkinson's Victoria needs your support to provide help for today, and to give hope for tomorrow.

Help make a difference. Donate today. www.parkinsonsvic.org.au.
For more information and support call: 1800 644 189



Access, Advocacy & Assistance

Recharge your batteries

The **RECHARGE Scheme** website has been developed to support people who use an electronic scooter or wheelchair to find one of the many RECHARGE point locations across Victoria and to plan their trip accordingly.

All of these points can be located on the website's "RECHARGE finder", where you simply click on your municipality and find all the RECHARGE points in your area.

Along with the RECHARGE finder, the website contains information and an online video about how the RECHARGE scheme works, frequently asked questions relating to recharging electronic scooters and wheelchairs, and a list of useful accessibility resources.

To find out more visit: www.rechargescheme.org.au.

Get your teeth into this

In spite of attempts to abolish the Medicare rebate for the Enhanced Primary Care (EPC) Dental Scheme, we are pleased to advise that at this stage, the rebate will continue.

The rebate (up to \$4250 for an individual), is applicable to anyone, either working or on a pension, who has a chronic illness and complex care needs where dental treatment will alleviate their illness or where oral health is impacting on their general health.

GPs assess eligibility and, in most cases, will be able to prepare a 'GP Management Plan' and 'Team Care Arrangements'.

How do I access the EPC Dental Care Scheme?

Make an appointment to see your GP as soon as possible (You may need a longer appointment than usual to enable the GP to prepare a 'GP Management Plan' and 'Team Care Arrangements' - check with your doctor or clinic).

Ask your doctor if you are eligible. Your doctor will provide a referral to a private dentist. (Ask if they know one that bulk bills - or you can suggest a dentist if you know one).

Your doctor will then send paperwork to Medicare. You cannot start dental work until the 'Care Plan' is completed and Medicare has processed your information.

Make an appointment with the dentist you have been referred to, and take your Care Plan and GP referral letter to your first appointment.

If your dentist does not bulk bill, ask them for a quote that includes; X-rays, history taking, examination, treatment and/or cleaning. If you have to pay up-front take the receipts to Medicare to claim the rebate.

For more information speak to your GP or contact Medicare: 132 011
www.medicareaustralia.gov.au

Know your rights at work

The Chronic Illness Alliance will soon be launching new materials on workplace discrimination to empower individuals to make informed decisions about their future and enhance knowledge of their rights. The material, which can be found at <http://www.chronicillness.org.au/workwelfarewills>, will feature comprehensive information about what constitutes discrimination, what remedies are available and where to go to have your case assessed.

One of the agencies that will be able to offer free legal advice and also take on cases is the **Association for Employees with a Disability (AED) Legal Centre.**

AED represents people with a disability who have issues relating to their disability in the areas of employment, education and training. AED operates as a free state-wide service and staff are able to visit clients in rural areas or if they are unable to attend the Melbourne offices.

AED Legal Centre: Suite 4, Level 5, 2-26 Elizabeth Street, Melbourne

Phone: (03) 9639 4333, Email: noni.lord@aed.org.au

Lobby for new PBS drug

Duodopa is a new treatment for Parkinson's that is currently under consideration for subsidy on the PBS.

The treatment may be suitable for people who have been living with Parkinson's for some time and may be experiencing difficulties with unpredictable motor fluctuations, such as freezing and dyskinesia, or who may be troubled by variable response to existing treatments.

Under the new PBAC listing rules, consumers are able to comment on medicines being considered for listing on the PBS. Duodopa will be submitted in time for the March 2009 PBAC meeting.

From now until 11 February 2009, interested individuals or groups can access the next PBAC

meeting agenda and make comments. Your comments can be made via the form at the Department of Health and Ageing website at http://www.health.gov.au/internet/main/publishing.nsf/Content/PBAC_online_submission_form

Make sure your voice is heard before the government makes its decision. We encourage all our members and Parkinson's supporters to access this site and support the listing of Duodopa on the PBS.

Further information on Duodopa can be found at www.parkinsonsdecisionaid.eu.com/medInfo/duodopa/

Staying independent at home

Wesley Homeshare uses an innovative community development approach to support frail older people and people with disabilities to remain in their homes and communities rather than be admitted to residential care.

It involves the careful matching of older or disabled people wanting to stay in their homes (householders) with younger people of integrity seeking affordable accommodation (homesharers). In exchange for their accommodation, the homesharer provides companionship, an agreed amount of help around the house to support the householder, and also security at night when many older/disabled people are vulnerable.

The model has been well tested and found to be very effective, both in terms of the health and well being outcomes it achieves for older or disabled people and in terms of economic outcomes.

Since commencing in 2000, more than 200 matches have been achieved, including being successfully utilized by a young person living with Parkinson's.

For further information visit:

<http://www.wesley.org.au/programs/homeshare.html> or ring Wesley Homeshare: (03) 9666 1231.

Free sundays

Public transport on Sundays is now free for carers and people receiving disability pensions in Victoria. (Victorian senior card holders are also eligible). A Sunday Pass Metcard must be obtained in order to utilise the free service, which is valid on trains, trams and buses travelling in metropolitan Melbourne and also on town bus services in Ballarat, Bendigo and Geelong.

Two off-peak free travel vouchers will also be provided to eligible users to use on the metropolitan and V/Line transport network.

Am I different to what I used to be?

Am I different to what I used to be?

Am I the person I like to be?

I ask these questions just to see

If I am really the same old me.

I fall a lot when I have to walk

I also find it hard to talk

My limbs all hurt from when I wake

'Till Sleep takes over the wretched ache

With knees both bruised and very red

I attempt to raise my body from bed

Try as I might, I await the green light

That will trigger my brain into flight.

The dog is eager to get to the park

She doesn't care that it's still very dark

I dress then pour my first cup of tea

Then it's off to the park, my dog and me.

With ball held firmly in jaws of steel

The dog heads home keeping well at heel

On arrival there I must not forget

To connect to James on the internet.

I speak to James most every day

The internet lets me speedily say

That a party is planned for the end for the month

It will take the form of a celebratory lunch.

James arrived home with the love of his life

A charming young lady who could end up his wife

They could only stay for just four days

But helped arrange things in many ways.

The Gold Wedding luncheon was quite a delight

The food, the wine, the company all very bright

Lyndells catering was very professional

With remarks being made that it was just sensational.

The mail kept coming all of that week

With cards and cables all worthwhile to keep

The Victorian Premier and Prime Minister too

Sent us their greetings, they were some of the few

James rang us from Rome, he keeps us amazed

TO give us the news that he has just got engaged

to Danielle, the love of his life...

Who is soon to become his adoring wife.

Phillip Bebarfald, Glen Waverley, 2006

Author's note: The James referred to in the poem is one of our four children and lives in the Caribbean on Grand Caymen Island. The party I refer to is mine and my wife's Golden Wedding celebration. I have had Parkinson's for around 15 years.

Editor's note: This poem is republished from Spring Signpost, 2008. We apologise for the omission of the author's name in the original publication.

Fundraising & Events

The weather's warming up, the days are getting longer and the holidays are almost here. It's the perfect time to get together with friends and family to relax and enjoy life, to reflect on the past year and celebrate the new one!

Here are some great fundraising ideas to help you celebrate the season and support our work in the community.

Christmas Cards

Share our vision of a world without Parkinson's by choosing Parkinson's Victoria CHRISTMAS CARDS. All cards feature our logo and a message about how we support the community. **All proceeds from the sale of cards goes right back into our information and support programs.**

An order form is enclosed with this edition of **Signpost**. You can also purchase cards securely online www.parkinsonsvic.org.au or contact our office.

Make it personal

In partnership with Charity Greeting Cards, we also offer CORPORATE SUPPORTERS the chance to add their own personal message and/or logo to their choice of Christmas cards. Log onto: christmascards4charity.com.au/parkins (5 percent discount on online orders). 40 cents from every card sold will be donated to Parkinson's Victoria.

Message in a bottle

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: (03) 9769 6065. Don't forget to mention you want to support the PARKINSON'S LABEL FUNDRAISER.

Top up your wine store

Order your holiday wine now and support our SUMMER WINE DRIVE. Grab a great selection for

just \$12.50 a bottle or \$158 per dozen (plus delivery) and a percentage from every sale will go directly to helping the fight against Parkinson's. All bottles carry the Parkinson's Victoria label. www.parkinsonsvic.org.au to download an order form

Inaugural Tulip Ball

Earlier this year, two inspirational women approached Parkinson's Victoria with an idea to host a fundraising ball with all proceeds going to support the work of Parkinson's Victoria.

Julie Sewell and her daughter Jo Hill know personally the effects of living with Parkinson's; Julie's husband John – Jo's father - was diagnosed in 2000.

The inaugural **Tulip Ball** is the result of their creativity, passion and commitment to making a difference for those affected by the condition. The evening of entertainment and fundraising will include raffles and auctions, and a special presentation will be given by Peter Raymond (Ambassador Coordinator and Parkinson's Victoria Board member). Tickets are now on sale and we encourage you to support this event.

Event details

Date: Saturday 22 November, 2008

Time: 7.00pm – midnight

Venue: Royal South Yarra Lawn Tennis Club, Williams Road North, Toorak

Tickets: \$120 each (includes dinner, beverages and entertainment)

To book: Contact Julie Sewell: 0417 384 954 (sewelljj@bigpond.net.au) or Jo Hill: 0417 503 803 (johill@interchem.com.au).

Remembering Parkinson's in your will

Making a will is an important part of planning for the future. After you have provided for loved ones, please consider including Parkinson's Victoria as a beneficiary in your will. **For those who cannot give today, this is a way they can "give in the future"**. Suggested wording for specific bequests is available on our website under the "How you can help" section.

If you do intend making Parkinson's Victoria a beneficiaries, or have already done so, please let us know. As well as being of assistance for our future planning, it gives us an opportunity to acknowledge and recognise your generosity and to discuss your wishes. Any information you provide will be in the strictest confidence.

The role of Vitamin D in Parkinson's

Could the "sunshine vitamin" lower your risk of developing Parkinson's?

People with lower levels of vitamin D are more likely to have Parkinson's disease, claim researchers.

A study in the U.S. shows a link between the disease, which leads to movement disorders, and insufficient blood levels of the "sunshine" vitamin.

The part of the brain most affected by Parkinson's is highly sensitive to vitamin D, suggesting it may be important in maintaining the health of this region.

But it is not clear whether lack of the vitamin in the blood is a cause of the disease or arises as a result.

There is mounting evidence vitamin D may help prevent disease, although most experts say sun exposure tops up natural levels more effectively than through diet.

U.S. researchers last year claimed vitamin D 'deficiency' may be to blame for 600,000 cancer cases worldwide a year, particularly in northern Europe where sun exposure levels are relatively low.

Researchers in the U.S. investigated whether Parkinson's and Alzheimer's may be linked to vitamin D deficiency, says a report in the journal Archives of Neurology.

Three groups of 100 people with an average age of around 65 took part in the study. Two consisted of Parkinson's and Alzheimer's patients while the third was made up of healthy individuals

Blood tests showed that 55 per cent of the Parkinson's patients had insufficient levels of vitamin D compared with 41 per cent of patients with Alzheimer's disease and 36 per cent of the healthy group.

The proportion of patients with the lowest levels of vitamin D - assessed as deficient - was also 'significantly' higher among people with Parkinson's. Study leader Dr Marian Evatt, from Emory University

in Atlanta, Georgia, said: "We found vitamin D insufficiency may have a unique association with Parkinson's which warrants further investigation."

Vitamin D is found in salmon, tuna and other oily fish and is routinely added to milk.

Source: Northwest Parkinson's Foundation, <http://www.nwpf.org/News.aspx?Item=2543> written by Jenny Hope.

Client services note: It is recommended that people taking Parkinson's medications take extra care when exposing themselves to sunlight as medications can increase the risk of developing skin cancers.

Calisthenics Extravaganza for Parkinson's

The **Calisthenics Coaches Association of Victoria** is celebrating its 50th anniversary this year and will be hosting a **Calisthenics Extravaganza** to mark the occasion.

The program will showcase standout items originally performed during the 2008 competition season, in which the state's 200 registered clubs participated.

All proceeds from the event will go to Parkinson's Victoria to help fund our support and information services and programs.

Event details

Date: Sunday 14 December

Time: 7.00pm

Venue: Hamer Hall, Melbourne Arts Centre, 100 St Kilda Road, Melbourne

Tickets: \$42 (adults), concession/children under 16 \$32

To book: Contact Calisthenics Victoria: (03) 9543 3757

Parkinson's Victoria Ambassador Program

Help spread the word! Increased awareness and understanding of Parkinson's and its impact on individuals and families is a high priority of Parkinson's Victoria on behalf of the Parkinson's community.

If your social, service, or sporting club or school is interested in hearing one of our Ambassadors speak about their experience living with, or caring for someone with Parkinson's, contact Peter Raymond, Coordinator Ambassador Program: 0438-400-259 or email pdr@netspace.net.au, or Donna at Parkinson's Victoria: (03) 9551 1122 or email donna@parkinsons-vic.org.au.

Symptom Management

Parkinson's: It's not just about 'the shakes'

In this article, Parkinson's Nurse Specialist VICTOR MCCONVEY investigates symptoms of Parkinson's which affect the Autonomic Nervous System, as well as suggestions on how they can be managed.

Parkinson's disease can affect individuals in many different ways. The common perception is that symptoms mean stiffness, developing a tremor and the tendency to move more slowly – all symptoms which affect mobility and movement.

Many people however also experience more unusual symptoms, which may not initially appear related to Parkinson's. Many of these symptoms are the result of the condition's impact on the *Autonomic Nervous System* (ANS). The ANS is responsible for involuntary movement and affects heart rate, digestion, respiration rate, salivation, and perspiration, diameter of the pupils, micturition (urination), and sexual arousal. Whereas most of its actions are involuntary, some, such as breathing, work in tandem with the conscious mind.

Examples of some of the autonomic-based symptoms that may be experienced by people with Parkinson's are constipation, changes in blood pressure and increased perspiration.

Constipation and reflux

Constipation is a very common, and often early, symptom of the Autonomic Nervous System's involvement in Parkinson's.

Constipation in Parkinson's is related to a slowing of the nerve impulses that enable bowel muscles to function and the result is a slowing down of the gut action. This is often worsened by certain Parkinson's medications and sometimes by chewing and swallowing problems (also related to Parkinson's), which reduce the amount of food and fluid consumed.

Constipation typically responds well to simple measures such as increasing your exercise and the amount of fibre in your diet and fluid intake, both of which will help keep stools soft and easy to pass. Sometimes, if the problem is persistent, using a mild aperient (laxative) can be helpful. *(For advice on the most appropriate aperients to use contact Parkinson's Victoria or the National Continence Help line: 1800 330 066.)*

The slowing of gut motility (its ability to move spontaneously and actively) may also mean that food stays in the stomach for longer which can cause gastric reflux. Again, this can be managed with simple measures such as ensuring you sit up for meals and not lying down too soon after eating.

Many people who experience this symptom also find a gentle walk after meals helps.

If this problem is persistent, discuss it with your Neurologist or GP, who may consider prescribing medication to assist in managing the level of acid in your stomach.

Bladder and urinary difficulties

People with Parkinson's may experience difficulty emptying their bladder and this can occur for a variety of reasons.

One of the common underlying causes is changes in the **basal ganglia**, caused by Parkinson's. Among its other functions, the basal ganglia also controls the detrusor muscle (located in the bladder wall) which is involved in urinary function. In this instance, the effects of Parkinson's causes the brain to send frequent signals to the bladder with the urge to urinate, even though there is actually only a small amount of urine to pass. (This symptom may also be a part of the normal ageing process; women may develop a stiffened bladder neck and males may develop prostatic enlargement.)

As there may be other changes taking place in the body, this symptom needs to be thoroughly assessed for possible causes and a referral to a Urologist is recommended. Your Neurologist or Urologist may prescribe medication that can assist in managing these symptoms if they are thought to be related to Parkinson's.

Some people living with Parkinson's also report difficulties in emptying their bladder effectively and develop a symptom called **urinary retention**. This most commonly occurs during "wearing off" (when an individual experiences reduced effectiveness of medication between doses) and to combat this, it is recommended that you ensure medication is administered on time.

If you are experiencing the symptoms of "wearing off" consult with your neurologist who will review your medication regime.

Nocturia (needing to go to the toilet frequently once you have retired for the night) is a common symptom of Parkinson's.

This is typically caused by several medications used to control the symptoms of Parkinson's, which may also slightly lower blood pressure while we are up and about, reducing blood flow to the kidneys and their function. On lying down at night, blood pressure and flow of blood to the kidneys is normalized, and urine production increases.

Talk to your doctor about this symptom as there are medications available that increase bladder tone and will reduce the frequency of having to get up

Symptom Management

at night to visit the bathroom. Nocturia may also be related to other medical or urological conditions so a thorough assessment is common to ensure the correct cause is identified.

Low blood pressure

Many people with Parkinson's experience difficulty in regulating their blood pressure. This most commonly presents as feeling dizzy or even fainting when changing posture (such as moving from a seated to standing position) or after eating a meal.

Postural or Orthostatic Hypotension, as it is officially known, is caused by Parkinson's and also the medications used to treat the condition which slow the response rate of arteries and blood vessels. In a "normal" state (someone without Parkinson's), these arteries and blood vessels constrict to keep blood pressure at a constant level. When the mechanism is impaired you may experience episodes of dizziness or feeling faint as a result of your blood pressure dropping as you move about. You may even experience feeling faint or dizzy when eating as blood is diverted to the stomach and the arteries may not compensate adequately, causing the symptoms of lowered blood pressure.

It is important to note that experiencing dizziness related to low blood pressure can heighten your risk of falling and may also contribute to difficulties such as Nocturia. To manage low blood pressure, you should have your blood pressure checked regularly. Also, if you are taking anti-hypertensive medications (to combat high blood pressure) these many need to be reviewed, and possibly reduced. Sensible measures such as staying well hydrated and avoiding large meals will also help. There are some medications available to assist in increasing your blood pressure and your Neurologist or GP may consider these if the symptom is difficult to control.

Skin and perspiration difficulties

Many people with Parkinson's also have difficulty with oily facial skin, or a greasy scalp and dandruff. The overproduction of oils on the face and head is thought to be triggered by the same area of the brain that is affected by Parkinson's (the basal ganglia). Sensible measures, such as washing your face twice daily with mild soap and using an anti dandruff shampoo regularly will assist. If your problems are persistent your GP may be able to prescribe medicated soap or shampoo.

Parkinson's may also cause an overproduction or underproduction of perspiration (some medications can also affect perspiration).

Perspiration is the body's natural cooling system, so if your ability to perspire is reduced as a result of

Parkinson's, you may need to take some additional measures to ensure you don't overheat.

Simple measures such as wearing lightweight cotton clothing and avoiding exercise in the heat are effective.

Excessive perspiration appears to be exacerbated when Parkinson's medication levels are lower and therefore may be more evident during "wearing off" or at night. Ensuring you take medication on time is important and other measures, such as wearing cotton clothing and taking regular luke-warm showers are also effective.

If you are experiencing excessive perspiration it is important to increase your fluid intake to compensate for the loss of fluid.

Sexual relations and intimacy

Other autonomic symptoms that can occur include erectile difficulties in males and loss of libido in females, as the vascular response to becoming aroused is altered by the effects of Parkinson's.

The reason for this is not fully understood but it is thought to be related to the fact that dopamine affects libido, therefore reduced levels of dopamine may reduce libido. (Dopamine is a brain chemical "messenger" that affects brain processes which control movement, emotional response and the ability to experience pleasure and pain.)

These symptoms and other effects of Parkinson's on the body, such as slowness and stiffness can significantly impact on sexual relationships.

There has been some recent research to support the use of Viagra in treating erectile difficulties in males and ensuring medication is taken on time will also help.

The cause of changes in intimacy is typically more involved than simply Parkinson's-related autonomic symptoms, so seeking sexuality and relationship counseling is very important in addressing these issues. Parkinson's Victoria also stocks resources (DVD and Help Sheet) that can assist in managing changes in intimacy.

Parkinson's affects many aspects of life, and often the symptoms are unexpected or unusual. Understanding that these symptoms may be the result of Parkinson's and employing some simple measures to address them are good first steps in managing them.

Discussing all of the symptoms you are experiencing, even if you think they are unrelated to Parkinson's, with your Neurologist or GP is important in developing a treatment plan to address them. You can also speak with one of the health professionals at Parkinson's Victoria, who will also be able to assist with information about these symptoms.

Reflections



Nerissa during the POP Art Charity Auction, 2007

NERISSA MAPES, diagnosed with Parkinson's at 28, has embraced the role of Parkinson's ambassador wholeheartedly in her quest to "find (and fund) a cure in her lifetime".

Telling people I have an 'alter ego' always gets their attention.

Some are too polite to ask what my alter ego is, while others dive right in with questions blazing. I am happy to talk about it; it's kind of what I do.

My day job is as a senior internal communications adviser with Telstra and my alter ego is the founder of **POP** (Perspectives on Parkinson's) and an ambassador for Parkinson's disease.

Having been diagnosed with Parkinson's disease at 28 [Nerissa is now 31], I soon realised I had a story people were interested in listening to, about a disease that doesn't have a voice in this country.

Although I have my own 'gig' with POP, I work with other Parkinson's organisations in Australia to help promote their events and initiatives. I see my job as being an ambassador for **Parkinson's disease**, not for POP or any particular organisation.

The first time I spoke publicly about Parkinson's was at a private function, a BBQ at a friend's house. It was the pre-launch of POP, where I wanted to tell friends what I planned to do. I spoke for about three minutes, walked downstairs and cried for 15! And I hardly mentioned Parkinson's.

Later, I was so nervous about speaking at the launch of POP (March 2007) that I pre-recorded my presentation! In the end, I did stand up on the night to share some personal thoughts on being diagnosed and living with Parkinson's disease. I almost cried. But I didn't.

Since 2006, I have spoken at various events and been interviewed by the media. Some highlights include:

A fundraising dinner with 200 guests: The MC introduced me as "someone with Parkinson's who was going to share their story". I had asked him not to mention my age for impact, and that was certainly achieved! You could almost see jaws drop when I walked through the audience to the stage.

I have been featured in a **7.30 Report** (ABC) which aired in December 2007, and a couple of segments on mid-morning television have taught me to be more assertive – not to mention quicker – to get the messages I feel are important across regardless of

the question. (While the producers often agree to a certain amount of time and questions, they can change both when you're finally on air.)

I've also presented to a group of around 100 young people from the advertising industry at an event called **Seven minutes of inspiration**. I got a standing ovation just two minutes in.

In Canberra at Parliament House I've spoken to representatives from Parkinson's organisations, media and politicians. I wasn't nervous, until Norman Marshall, CEO of Parkinson's Australia asked, "So, how does it feel representing people with Parkinson's all over Australia?"

On top of sharing my story as a young person with Parkinson's, this time I was presenting an Access Economics Report on Parkinson's to Mr Tony Abbott, who was Health Minister at the time.

A couple of days ago I spoke to 40 young people at a Rotary Camp and I was probably the most nervous I have ever been. After I finished – and received three rounds of applause – the President of the Rotary group congratulated me: "You sure had their attention. You could have heard a pin drop in the room. And for a full half an hour too," she said.

By the time this edition of **Signpost** goes to print, I will have joined Norman Marshall again in Canberra (22 October). This time we're talking to a select committee from the Department of Health and Ageing, and specifically, I will be speaking about what they can do to help people with Parkinson's stay at work longer.

Being diagnosed and living with a chronic illness is hard enough and I'm sure some people think I'm a little mad for putting myself out there and sharing what are often the very personal and raw details of my illness. It isn't easy and it isn't for everyone. But there are things you can do to advocate for people living with Parkinson's:

- ***Stay up to date with what's happening in the world of Parkinson's (especially here in Australia – the news that is likely to affect you personally). Listen to the news and visit the Parkinson's Victoria website regularly.***
- ***Exercise the power of the pen: write letters to your local Member of Parliament about your experience of living with Parkinson's and ask what they plan to do to increase support and funding for their constituents.***
- ***Speak to Parkinson's Victoria about our Ambassador Program and invite an ambassador speak at your school or social or sports club***
- ***Host a Party for Parkinson's for your friends, neighbourhood and the wider community and invite your local Government representative.***

Our Supporters

Thank you to all our supporters who generously made donations in recent months.

Listed below are the names of those who kindly donated \$200 or more between 18 July and 15 October (2008), and individuals in whose name in memoriam donations were made. We extend our sympathies to those 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 all those who have donated but wish to remain anonymous.

Donations (individual)

ME Arnott
Anna Beesley
Laurence Beesley
Faye Clarke
Paul & Mandy Cockerall
Vitino, Johny & Mary Costa
William Delaney
Norma Flood
David Fuller
Doris Grinlington
SF Higgs
Paul Horton
Nancy Hunt
Kathleen Lawson
Margaret McManus
L Momsen
Sandra Morton-Pederson
Kenneth Quixley
Martin Royce
Lara Turner
Patricia Waters
Donna Willis

In Memory of

Lina Amato
Maurice Anthony
Leslie Arnott
Martin Bogunovic
Elwyn Bond
John Burke
Armando Corbo
Douglas Crook
James Curran
William H Deneys
Rae Lynn Eames
Stella Evans
Vincenzo Failla

John Fardell
Franco Ferri
Bruce Gibson
Gordon Hendry
Eric Hubbert
Andrea Ielo
Mavis Juniper
Ken Maynard
Donald McLeod
Charles Mondy
Geoff Morris
Calvin Naylor
Carmen Rapa
Robert Rodsted
John Rowe
Irene Ryan
John Ryan
Bryan Smith
Robert Snape
Jack Stevens
Shirley Stewart
Elaine Sullivan
Doric Symes
Vlachadis, Mr
Phyl Wilkinson
Fred Williams
William Woods
Ian Youngs
Sebastian Zarjac

In Celebration of

Peter Raymond
(60th Birthday)

Team Parkinson's Challengers

Leanne Barnes
Edward Beesley

Maxwell Bradfield
Sue Dutton
Clare Eisenberg
David Gibson
Kim Harris
Nahid Jones
Brendan Lourey
Kim Nicholson
Karyn Spilberg
Nicholas Taylor
Fred Van Ross
Christine Van Ross
Catherine Watson
Jenny Young

Corporate, Community & Other Donations & Support

Balnarring Primary School
Beyond Blue
Doctors of Ivanhoe Pty Ltd
Doutta Galla Lodge
Glenroy RSL
Hall, Mr Peter (MP)
Hunter Leisure
Mediterranean
Wholesalers Pty Ltd
MOR Cosmetics
Pressfast Industries
Pulse Pharmacy
RMAX
Rotary Club of Kerang
Take 2 Op Shop
The Anglican Parish of
Westmeadows/Bulla
The Monash-Aires
UCB Pharma
Wattle Valley Golf Club Inc.

Team Parkinson's (Auxiliary Fundraisers)

Peter Middleton
Clare Donlon
Kylie Ramsdale

Grants, Trusts & Foundations

The Ruth Fagg Foundation
(Victorian Community
Foundation)

We also received 3
donations from supporters
who wish to remain
anonymous.

**We would like to
thank all those
who generously
supported our
National Awareness
Week tin rattle at
Melbourne Central,
Flinders Street,
Flagstaff, Parliament
and Richmond train
stations, conducted
on the morning of
4 September.**

Correction: In the spring edition of Signpost, Jean Bowles' name was spelt incorrectly on our Supporters page. We sincerely apologise for this mistake. Jean is a member of the Moe Movers and Shakers Support Group and a generous supporter of the work of Parkinson's Victoria.

Every dollar counts in the fight to reduce the impact of Parkinson's.

We conduct only two official fundraising appeals annually and this edition of Signpost includes our annual end of year appeal. Whatever amount you are able to put towards the fight will make a difference. If you have recently made a donation, thank you for your generosity and ongoing support.

If you are unable to donate at this time, but would like information on our bequest program, please contact our CEO, Glenn Mahoney: (03) 9551 1122, 1800 644 189 or glenn@parkinsons-vic.org.au.

We are motivated by your reasons for supporting us. Please feel free to share your story with your next donation.

Donate online: www.parkinsonsvic.org.au/donate/donate.

Tulip Tributes

Speaker's Corner

Thank you to all who responded to our requests for media spokespeople and advocates on specific issues and who made themselves available for interviews, especially during National Parkinson's Awareness Week.

Being able to respond promptly to media requests results in Parkinson's gaining more media "air time". Personal stories are the perfect complement to the equally powerful facts and figures about Parkinson's.

Above and beyond

Throughout 2008, Support Groups made a fantastic impact in their local community, not only supporting their members but also in raising awareness of Parkinson's, fundraising and supporting Parkinson's Victoria events.

Many contacted their local newspaper and there was barely a week that went by this year that we did not receive a newspaper clipping highlighting a personal story (and fast facts) about Parkinson's!

It's wonderful to see so many groups getting active in this way and supporting our work in those vital areas of increased community support and awareness.

Model support

During National Parkinson's Awareness Week, 2008, we launched an exciting new awareness campaign with our **Guess which one has Parkinson's?** poster.

The image featured 25 people with Parkinson's from the Victorian community, representing men and women of all ages, backgrounds, and various stages of the condition. Most importantly, they represent the "25 Australians diagnosed every day".

Feedback about the concept from those involved was incredibly positive: "It was a privilege to be asked [to participate]. It's a wonderful idea, bringing people of all age groups together, to help the general community realize that Parkinson's affects younger people as well as older."

The poster has also been used nationally.

Parkinson's Victoria would like to thank each of the participants (27 attended the photo shoot and appear in the image on the back of our annual report) for generously giving their time. We'd also like to thank Spring Valley Golf Club for their support in providing access to their members lounge for the day.

Community Connection

From our Get Connected Project Worker, Lauren Cowling:

Thanks to all the Support Group leaders and members who completed questionnaires for the Get Connected project, and helped strengthen the service directory with valuable local information.

Further thanks to Anne Mooney (PSP Support Group Leader) for providing access to the UK PSP directory. I would like to give a special thanks to Alan Holman and Sonia for their skilful editing and comments.

Unsung heroes

"Volunteers don't get paid, not because they're worthless, but because they're priceless." – Sherry Anderson

Our volunteers truly **are** priceless and we'd love to give every single one of them an **ENORMOUS** Tulip Tribute.

To the volunteers who were ushers and guides at various Parkinson's Awareness Week functions: your friendly faces provided a warm welcome for those making their first tentative steps into the mysterious world of Parkinson's.

To the wonderful volunteers who gave up their morning to rattle tins at the city loop stations on Thursday 4th September (from 7-9.00am): With record numbers of volunteers we managed to exceed our previous total by collecting \$4356.90.

And, to those special volunteers who help out with odds jobs around the office: You are a vital part of our team, enabling the small Parkinson's Victoria team of 6 to look after the 20000+ people affected by Parkinson's.

To each and every one of you we say THANK YOU!

Helping Hand

The team here would like to give a special mention to the support of Fred Van Ross during our recent regional seminar in Geelong. Fred generously gave his time to attend this event (travelling from Essendon) and assisted with registrations on the day, answering questions and manning our information and resources table.

We were privileged to have Fred's support, as his current commitments keep him very busy. Fred is a Board member, leader of the Essendon Support Group and is currently undertaking our Vietnam Challenge, where he and wife Chris have already raised more than \$15000 for Parkinson's Victoria!

If you would like to acknowledge the support of someone special, send details to judith@parkinsons-vic.org.au. Photos welcome.