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## Staying positive after diagnosis

The Parkinson's Victoria **Recently Diagnosed Community Seminar** has become one of the most well-attended events on our calendar, and a highlight of National Parkinson's Awareness Week (1-7 September).

Credible, timely and relevant information and support can make a significant and positive difference in the lives of those living with Parkinson's. This can be especially pertinent in the early stages following diagnosis, as individuals navigate their way through the health system, medication and symptom management strategies, as well as a range of emotional and lifestyle changes.

Diagnosis at a younger age (those still of working age) typically creates additional challenges, which may have an impact on employment/ career decisions, family, financial security and relationships.

**Parkinson's is not a life-threatening condition – but it is certainly a life changing one.** With the right support, information and symptom management strategies, people with Parkinson's can continue to enjoy life and daily activities, as well as making a valuable contribution to their community.

A positive experience of the information, support and health system in the early stages of diagnosis typically leads the way for continued quality symptom management, maintained and/or improved quality of life and prolonged independence throughout the journey.

**The annual Recently Diagnosed Seminar delivers relevant and credible information from a range of professionals with expertise in the area of managing and living with Parkinson's.**

The unique program of information - designed to specifically address the

concerns, interests and needs of those recently diagnosed (defined as a diagnosis in the past 5 years) - makes this event a one-of-a-kind community seminar.

The event draws attendees from around the State and provides a sensitive, professional and community-like environment for those recently diagnosed (as well as carers, partners and family members) to not only become better informed about their condition and the future, but to feel supported and "not alone" in their journey. It's a great opportunity to hear from experts, learn about the various supports available, and meet and share your stories with others experiencing similar challenges.

*"Keep up the good work. The program was excellent and completely relevant. I thought all speakers and programs were brilliant. I am so much better informed having attended this seminar."* (2007 attendee)

*"Thank you so much for this seminar. So much good information, told in an interesting way. Such a great feeling that we are supported and not alone."* (2007 attendee)

This event is proudly supported by UCB.

**Date: Saturday 6 September, 2008**

**Venue: The Camberwell Centre,  
340 Camberwell Road, Camberwell  
(next to the Town Hall)**

**Time: Registration 9.00am  
Event begins: 10.00am  
Event concludes: 3.00pm.**

**Costs: Members - \$33  
Non-members - \$50**

**RSVPs are essential. Please complete the enclosed form  
or call: (03) 9551 1122  
or email: [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au).**

# News & Highlights

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## Disclaimer:

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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.

## Parkinson's Victoria Services update

**Community Development Worker, CATHERINE WATSON, delivers an update on what's been happening at Parkinson's Victoria over the past few months and offers an insight into what we have planned for the rest of the year.**

It seems only yesterday we welcomed you to the first edition of **Signpost** for 2008, and told you about the exciting initiatives we had planned for the coming months. The year so far has been filled with information sessions, road trips and support groups visits, client service calls and community events. Now we're heading into the busiest time of our calendar year, with National Awareness Week coming up in September, our two Regional Community Forums in September and October, and the launch of projects that have been in the pipeline over the past few months.

In order to deliver reliable and current information and support services, it's vital that our client services team stays on top of the latest Parkinson's news and research from around the world. It's also imperative that we continue to develop our services, pioneering new initiatives and materials that will assist those living with Parkinson's to better manage their condition and empower them to make the best decisions about their care, life-choices and the future. In pursuit of this, two members of our client services team recently jet-setted off to warmer climates – much to the jealousy of those left behind - all in the name of Parkinson's.

Client Services Co-ordinator, Amanda Spillare, has visited the USA and is currently in Europe undertaking research for a Churchill Fellowship. This prestigious award is enabling Amanda to investigate the way younger people with Parkinson's are supported by international Parkinson's organisations.

Amanda has emailed some updates from her trip so far, which has included

visits to a number of European and American Parkinson's organisations and interviews with staff and local residents. Amanda will be home in August to write up her report on the issue.



Amanda Spillare with Tom, Mary-Ellen, and Susie from the APDA Young Onset Support Group, Staten Island.

Parkinson's Nurse Consultant, Victor McConvey, returned in June from a visit to the Parkinson's Disease Society (UK). He also linked in with the Progressive Supranuclear Palsy (PSP) and Multiple Systems Atrophy (MSA) peak bodies to learn more about their services, in the hope that such insights might lead to improved support for Australians living with these conditions, typically referred to as **Parkinson's Plus**.

On the topic of providing local support to people living with Parkinson's Plus conditions, Parkinson's Victoria recently hosted a morning tea for those living with MSA. Guests had the opportunity to ask questions of Victor and of each other, and to generally learn more about living with MSA while sharing personal experiences.

*It is important to note that there is currently no peak body organisation to support those living with MSA in Australia, while the only Australian PSP Support Group is Victorian-based, and meets at the Parkinson's Victoria office.*

Meanwhile, the Parkinson's Victoria office is full to the brim of staff and volunteers working hard to provide and improve on services. Just two of the many initiatives we have on the go at the moment are our online and multi-lingual projects.

# News & Highlights

After several months of research, interviews, surveys and ground work, Jackie Jenkins, **Bridging the Gaps** project worker, and Lauren Cowling, our **Get Connected** project worker, are sinking their respective teeth into the final stages of these exciting initiatives.

Jackie is busy meeting and consulting with advisory groups to ensure our Parkinson's material is linguistically and culturally appropriate prior to being translated. Lauren has her hands full mapping out the maze of support services available state-wide to assist individuals to link into local community services, and converting this information into an online database.

These projects were made possible by grants from the Lord Mayor's Charitable Fund (Bridging the Gaps) and the AUDA Foundation (Get Connected).

Our 47 affiliated **Support Groups** have been incredibly busy in their own right, conducting regular meetings and outings for their members, as well as organising guest speakers. In addition, several groups have been very pro-active in pursuit of increased awareness and fundraising within their local community and media. We'd especially like to acknowledge those Support Groups and Support Group members who have given their time and energy to support our **Team Parkinson's Challenge** participants by hosting and helping with various fundraising activities. (You can read more about the Challenge on page 8).



Team Parkinson's Challengers Kim Harris and Sue Dutton (centre) with Noelle Bright, President South Gippsland Support Group, Glenn Mahoney, Parkinson's Victoria CEO and Tevor White, Secretary, Treasurer and Coordinator of the Support Group, as featured in **The Star** newspaper in May.

While improved community awareness is a priority of Parkinson's Victoria and a constant theme in our events and planning, the message is never more in the spotlight than during **National Parkinson's Awareness Week**. The event takes place from the first Monday of each September and in 2008 will be 1 – 7 September.



Keep an eye out for our Flinders Street banners during Awareness Week.

Improving community awareness is an integral part of improving support for those living with Parkinson's. The more that is understood about Parkinson's, the less stigma and discrimination those living with the condition will experience, and the more government, business and service providers will respond accordingly with improved services, resources and subsidies.

As usual, Awareness Week will involve a series of events and activities that further promote awareness of Parkinson's to the wider community. It will also offer those living with Parkinson's the chance to enhance their understanding of the condition and symptom management options, and connect with peers while hearing from leading health professionals.

You'll find more information about local events taking place during the 2008 National Parkinson's Awareness Week, including our Recently Diagnosed Seminar and Annual General Meeting, on page 8 and 9.

If you're interested in raising awareness in your local community or are interested in conducting a fundraising activity – perhaps at your work or social club, contact Marketing Coordinator Judith Mooney on (03) 9551 1122 or email [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au).

While we have achieved much in the first 7 months of 2008, there is still much more to be done. We hope this brief snapshot provides an insight into our activities and plans for the coming months. We look forward to continuing to respond to community needs for information, support and education, and hope we can count on your continued support.

## Parkinson's, employment and quality of life

**“Work and Parkinson's?” A bemused look accompanies this common reaction when Swinburne University researcher LOUISE COOPER, tells people what she is currently investigating. Clearly the public's perception is that people with Parkinson's do not work. How wrong can they be?**

Contrary to popular belief, the majority of people with Parkinson's are of working age at the onset of their symptoms, if not at the time of diagnosis. Many are working full time and those with early onset may be at the peak of their working life. Mortgages, dependent children and family activities are very much on the agenda. Planning for later years may be underway, making the most of an income to fulfil retirement dreams.

Work is not only necessary to fill up the car with petrol and pick up the weekly groceries, it is also an important part of who we are and the role we play in our community, whether we have Parkinson's or not. Swinburne University's 4-year research project, **Parkinson's, Employment and Quality of Life**, is an opportunity for working people with Parkinson's to tell how it really is. Researchers, Louise Cooper, Dr Simon Knowles and Professor Susan Moore believe people with Parkinson's will be only too willing to relate their experience.

“Preliminary interviews indicate that people with Parkinson's are supporting each other by sharing their experiences in order to deal with the challenges presented at work,” says Louise Cooper. “When it comes to Parkinson's, there seems to be a gap in information and policy relating to employment for people with chronic disease. Awareness of the condition is increasing amongst health professionals and this means that diagnosis is likely to occur earlier and at a younger age. There will be more and more people with Parkinson's in the workplace in the future. It's important that health professionals, rehabilitation specialists and employers have access to information that will optimise working conditions for people with Parkinson's.”

[In addition, Parkinson's Victoria believes that government must also respond accordingly to support people with Parkinson's in the workplace, through appropriate legislation, policy and funding.]

Ms Cooper's father lived with Parkinson's for over twenty years. “I'm sure he'd forgive me for describing him as “bloody-minded”! she says. “He never let his symptoms stop him from trying

to continue doing the things that he wanted to do, including continuing to work for as long as possible. What I have learnt through my research so far is that it probably wasn't as easy for him as it appeared at the time and for some people it would seem impossible”.

Although information is scarce, some things have been established: Not everyone feels able to tell their employer or work colleagues that they have Parkinson's for fear that it might affect their job prospects and their relationships with others. It is not uncommon for people with Parkinson's to be overlooked for promotion or considered unable to perform a job properly. Some people with Parkinson's start themselves to feel inadequate in their usual role. For others, a Parkinson's diagnosis presents an opportunity to reassess a work situation and make changes that give more emphasis to family life. For most people, the support and understanding of employers, work colleagues and friends or family appears to be crucial. For everybody, there is a difficult period of adjustment following diagnosis and a desire for reliable information on which to base decisions.

“The main aim of this project is to identify where support and education is needed,” says Ms Cooper. “We are expecting to find a variety of experiences but hoping that common threads will emerge in relation to an ability to make work-related decisions.”

**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.**

The Access Economics' report, **Living with Parkinson's Disease: Challenges and Positive Steps for the Future**, commissioned by Parkinson's Australia and published in 2007, was viewed as pivotal in the move to address issues related to Parkinson's in the work place. This current study, which emphasises the psycho-social aspects of employment for people with Parkinson's, is further indication that the time has come to see Parkinson's as a question of quality of life rather than a set of medical symptoms, and to urge governments and policy makers to fund appropriate action.

# Parkinson's around the world

## The other side

**Parkinson's Specialist Nurse VICTOR MCCONVEY provides a brief snapshot of some international experiences of Parkinson's.**

**Africa:** 25 years ago, an interesting statistical trend was identified, there was a relatively low incidence of Parkinson's in Africa however the incidence was seen to become the same as other countries in those Africa nationals who had emigrated. This trend was not linked to environment, but to the shortened life span, caused by war, the AIDS epidemic, other illnesses and lack of access to basic health care. Scientific leaps forward in how we treat illness and massive aid has seen the average life span increase in Africa. And while a huge, positive step forward, this has unfortunately led to illnesses common to the older adult, such as Parkinson's, subsequently becoming more common.

Peak bodies such as the World Health Organization, UNHCR and the International Congress of Nurses have commenced planning for this emerging health care issue, aiming to ensure that culturally appropriate health solutions can be provided.

Such solutions must recognise that families and communities play a vital role in supporting someone with Parkinson's in this country, and that care is typically carried out by family members in a home setting (as compared with Australia).

Much of the early work being done on this issue focuses on identifying how the illness is perceived in different communities, and dispelling associated beliefs. For example, some communities believe the illness is sent from their god or spirits as punishment.

Access to medication and health professionals, such as physiotherapists who can assist people in living better, longer, are also priorities in meeting this emerging need. Currently there are few formal supports for people living with Parkinson's in Africa. Parkinson's South Africa is the only support agency in Africa and is funded by donations.

**The United Kingdom:** The UK has long been considered the world leader in delivering innovative care for people living with Parkinson's.

In 1989, the Parkinson's Disease Society UK, in partnership with the National Health Service, developed the unique health post of the **Parkinson's Nurse Specialist**, enabling increased access to a Parkinson's Nurse. The nurse's primary role is to work with other health care professionals, essentially facilitating access to the multi-disciplined team from both the hospital and community.

The organisation is also considered a world leader in developing materials for both people living with Parkinson's and health professionals to increase awareness of symptoms, and is a major research funder.

In recent times, the society has embarked on a major restructure and decentralization, which has resulted in extra support services in local communities, and the development of another new post, the **Community Support and Development Manager**, whose role is to identify services that will be of use to individuals who have Parkinson's.

The Parkinson's Disease Society UK does not receive any public funding and relies on bequests and donations to fund its support services.

**Canada:** In Canada, the socialised health care system is very similar to the Australian Medicare system.

In the 1990's, national health care reform saw many services cut, including specialist services for people living with Parkinson's. In response to this, Parkinson's Canada worked with healthcare agencies to develop regional movement disorder services, often funding the hours of the health care professionals, to enable people with Parkinson's to access services in their area.

Parkinson's Canada is funded through donations and is able to access some government funding and sponsorship for special initiatives.

**USA:** On the other side of the border the situation couldn't be more different. The majority of the American health care sector is private, and services are limited for progressive illnesses that are often expensive to treat.

There are some specific services, but these tend to be developed in areas where a group of health care professionals have a particular interest (often in a state that funds the very limited public health programs more generously or where small programs have developed within the private sector).

There tends to be an absence of specific Parkinson's related health care professionals, however the greater specialisation within the health care sector results in staff that are knowledgeable in regards to the needs of people living with Parkinson's within medicine and neurology.

The Parkinson's disease foundation in the US is funded through donations and subscriptions.

## Help for Today, Hope for Tomorrow

Parkinson's Victoria recently incorporated the theme *Help for Today, Hope for Tomorrow* into its logo and service philosophy. It really sums up what Parkinson's Victoria is all about: providing practical help and support to the 20,000 Victorians currently living with the condition, and hope for the future - not only for those already diagnosed, but for the 2,000 and more people who will be diagnosed every year until a cure is discovered.

Today, I ask you to consider helping Parkinson's Victoria in a very practical and personal way: by remembering Parkinson's Victoria in your will in the form of a bequest.

Our work is only possible because of donations and bequests. One of our most significant sources of funding is through the bequests we receive when people remember Parkinson's Victoria in their will. Every gift - large or small - makes a difference to our work and the people we help. Often people are able to leave a gift in their will that they are unable to give during their lifetime.

A will is a legal document that determines how your assets will be distributed. Sadly, the Law Institute of Victoria estimates that up to 50 percent of Australians pass away without having a current will. In these cases, the government may decide on the distribution of an individual's assets, which can lead to further distress among families.

A will is the only way to be confident your affairs will be settled as you wish. A will can be a way of expressing your love and concern for family, friends and close associates, and organisations with whom you have a strong affinity or commitment to.

We recommend you seek professional advice to ensure that your wishes are expressed correctly in your will.

If you have, or are thinking of leaving a bequest to Parkinson's Victoria in your will, it would really assist us to know your intentions, as it will help us plan for the future. It will also enable us to say *thank you*.

If you would like further information about remembering Parkinson's Victoria in your will, or would like to discuss this with me personally, please contact me on (03) 9551 1122 or toll free on 1800 644 189.

Making a bequest is a way to give beyond our life time, a way to make a lasting contribution towards the fight against Parkinson's. **A way to provide help for today and give hope for tomorrow.**



Glenn Mahoney, CEO

**"I'm worried about my mum who is starting to slow down. It's impacting on her mobility and independence. Should we start looking for a nursing home? What should we do?"**

For many, a nursing home might seem the most practical solution. However, there are numerous factors to take into consideration.

Firstly, and most importantly, you need to ensure your mother's Parkinson's is being managed optimally through regular consultations with her treating specialist (preferably a neurologist). Allied health therapists, such as a physiotherapist, occupational therapist and/or speech therapist may also provide advice and strategies to help her maximise her mobility and safety.

That said, sometimes an individual (or couple) will find they need extra support at home in order to remain independent.

You may find your mum is eligible to access a Community based support service which can offer a suitable long (or short) term solution.

Home support services, such as home cleaning, meal provision, personal care assistance, in-home respite and transport assistance, can often be provided through your local Home and Community Care (HACC) provider. As her care needs increase, your mother may require extra support and may benefit from a visit from the Aged Care Assessment Service (ACAS).

### How does it work?

ACAS is a free 'one-stop-shop' for aged care services. A member from the ACAS team will visit your mother in her home and discuss the activities she is still able to perform independently, and those in which she requires assistance. The team member will then explain the different options available, from accessing Community Care Packages to enable her to continue living at home, to accessing Respite Care services, or - when the time comes - making the move into permanent residential care.

This assessment is the key to accessing care support in the community.

The team member will also explain how to organise the help and services accessed and generally make navigating the service system less daunting and stressful for your mum.

The main thing to remember is that there are services in the community to assist those who are frail-aged or who live with a disability to remain independent.

To find out more about these services and be put in contact with your local provider, call the Commonwealth Carelink centre: 1800 052 222. This is a free national service that specialises in providing information about support services in your local area.

Parkinson's Victoria can also help demystify accessing the community support system. Contact our team to discuss your particular situation.

## Complementary therapies

The following article is an excerpt from the booklet *Complementary Therapies and Parkinson's Disease*, published by the Parkinson's Disease Society (UK).

Unfortunately, there has not been a great deal of research into complementary therapies to date. When looking into complementary therapies you may find some therapies state there is research proving their benefits. This may well be the case. However, it is important to be aware that there are different views on what qualifies as 'good research evidence'. When claims such as 'research has shown a therapy to be beneficial' are made, you need to check the basis on which these claims are made. Even where plenty of references are given to back up claims, it does not always mean that the studies being referenced represent good, solid research.

The 'gold standard' for assessing new medicines and other treatments is the randomised, controlled trial. This involves a treatment being compared to alternatives (such as standard treatments already used) or a dummy drug/treatment placebo). It also involves complicated statistical procedures and the allocation of eligible patients is done using a random process, often computer-based to maximise security.

Some will be allocated to the new treatment and some to the alternative or placebo. Trials are also blind to safeguard against bias. In a single-blind trial, patients do not know whether they are taking the new medicine or the placebo. In a double-blind trial, no one (the patient, doctor or people conducting the trial) knows what treatment each person is taking. The aim of this type of trial is to make the research as objective as possible.

If it is clear that the complementary therapy research you are investigating has taken place as a randomised, controlled trial, you can be more confident of the benefits it claims to have.

### *Some other questions you should ask are:*

- Was the research carried out independently?
- Did it compare the treatment with other treatments, or no treatment, to monitor what improvements there might have been?
- What kind of study was it? Sometimes claims are made on the basis of laboratory studies that do not actually test treatments on humans.
- How many people were involved? Small studies

can produce interesting findings. However, sometimes claims are made for benefits that have only been helpful for a handful of people.

- What does the research measure?
- How recent is the research?

The Research Council for Complementary Medicine website provides a good guide to research in general including the different types of research that take place and the criteria essential to make a research study valid. [www.rccm.org.uk](http://www.rccm.org.uk).

### *Points to remember*

Tell your doctor you are considering trying a complementary therapy and discuss what you are hoping to gain from it. Some complementary therapies may be not advisable for people with Parkinson's or those with certain other conditions.

**You should not abandon your prescribed drugs: complementary therapies work alongside, not instead of, orthodox medicine.** Unfortunately, some complementary therapy practitioners may advise otherwise but such advice is untrustworthy. Use therapists who are appropriately qualified and belong to a credible professional association or society. Ask the therapist for details of their training, clinical experience and insurance cover and ask to see proof of their qualifications. Any reputable practitioner will be happy to answer any questions you have.

Some complementary therapists might raise your hopes and promise a cure. At present there is no known cure for Parkinson's disease.

Read up on what you think you might gain from the therapy and discuss this with your therapist. Insist on a proper treatment plan and cost estimates. Some complementary therapies can be very expensive.

Monitor your progress as you go. Try to decide whether the complementary therapy is doing you any good, but do not expect immediate benefits or miracles.

Decide whether any benefits are worth the effort and expense.

Remember, you may experience no benefits. However, a person's response to a therapy is as individual as Parkinson's itself, and what works for one person may not work for another.

**The complete booklet *Complementary Therapies and Parkinson's Disease* can be downloaded from [www.parkinsons.org.uk](http://www.parkinsons.org.uk) (available under the tab "Treating Parkinson's")**

# Fundraising & events

## *Notice of Annual General Meeting*

### *Parkinson's Victoria Inc*

You are invited to attend the AGM of Parkinson's Victoria

Date: Tuesday 2 September

Time: Registration from 10.15am. Official Welcome/ event begins 11.00am, concludes at 1.00pm. Please note: the event will begin with a research presentation and is followed by a light lunch.

Venue: The Camberwell Centre, 340 Camberwell Road, Camberwell (next to the Town Hall)

**Come early and hear a special presentation by eminent Parkinson's specialist neurologist Dr David Williams (Alfred Hospital), titled "Parkinson's disease - where are we headed?"**

Time: 11am-12.00pm. Attendees are encouraged to stay for the AGM which will follow the presentation and lunch.

**The research presentation and AGM are FREE events however RSVPs are essential for catering purposes. Members and non-members welcome. An RSVP form is included with this edition of Signpost. Please complete and return to our office or call us on: (03) 9551 1122.**

## *Meeting the Challenge*

If you haven't heard about the Team Parkinson's Challenge yet, you're missing out on being part of an exciting (and successful) fundraising and awareness raising initiative.

The **Team Parkinson's Challenge – Cycle Vietnam** invites participants to become Ambassadors for Parkinson's Victoria, and to commit their time and energy in order to achieve the Challenge goals. (Each participant also makes a personal financial contribution of \$550.)

Over a period of approximately 10 months, participants organise fun, community events that raise valuable funds (a minimum of \$6,000) and awareness within their network of family, friends, work mates and social groups.

Our team has been overwhelmed by the generosity of their supporters, but we are still a long way off our goal of \$120,000.

In addition to raising awareness and funds, participants take part in a 13-day trip/5-day bike ride challenge through the varied terrain of Vietnam.

The Challenge is proving to be a media hotspot, with several participants being featured in their local paper.

So far we have 18 Challengers across the state working hard to make a difference in the lives of those living with Parkinson's, but we're aiming for a team of 20! If you're interested in signing up, contact Chris Harrison from Memorable Challenges **today**: 0423 780 716 or email: [charrison@memorablechallenges.com](mailto:charrison@memorablechallenges.com) ([www.memorablechallenges.com](http://www.memorablechallenges.com)). Log onto [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) and follow the link to the Team Parkinson's Challenge to find out more!

You can also help Team Parkinson's 2009 toward its \$120,000 goal by sponsoring an individual team member or Team Parkinson's Challenge – Cycle Vietnam 2009 as a whole. All donations are tax deductible.

## *Honouring a loved one*

A donation to Parkinson's Victoria in memory of a family member or friend is a meaningful way for you to express your sympathy during a time of grief, and a thoughtful, tangible way of honoring the memory of someone who has touched your life.

These contributions go on to help support those living with Parkinson's, ensuring they have access to reliable information and support services, peer support and resources. Donations are also invested into research, advocacy and education initiatives.

Parkinson's Victoria will send a letter to the bereaved family acknowledging your thoughtful gesture, and you will receive a tax receipt and a note of thanks for your generosity. The amount of your donation is kept strictly confidential. In Memoriam envelopes are available to families requesting donations in lieu of flowers. Please contact Donna Willis at Parkinson's Victoria.

## *Calling for Volunteers!*

One of the major events in our Parkinson's Awareness Week calendar is our annual tin rattle at Connex city loop train stations.

Thanks to the generous support of Connex, we are once again seeking friendly volunteers who are able to "shake a tin" during peak hour train traffic on THURSDAY 4 SEPTEMBER, 2008, from 7-9.00am.

If you are interested and available to participate please contact Volunteer Coordinator Donna Willis: (03) 9551 112 or [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au). (Volunteers are not required to commit to the full 2-hour period.) Last year we raised \$3,713, and this year we hope to double that! More volunteers will help achieve this goal.

# Fundraising & events

## Message in a bottle

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

Purchase your wine from Alias Wines and 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.

Personalised and corporate labels are an ideal way to say Thank You or Congratulations, for birthday celebrations, weddings and other special occasions. Ask how your next special event can help support Parkinson's Victoria.



Sample corporate and personal labels from Alias Wines

*"Parkinson's Victoria makes sure that all the funds we receive through the alias wines community fundraising program, and alias wines customers, goes back into the community through our support services, assisting all those affected by Parkinson's."*  
Parkinson's Victoria CEO, Glenn Mahoney.

**Contact Kevin at Alias wines to discuss your needs: (03) 9769 6065 or visit the website: [aliaswines.com.au](http://aliaswines.com.au), and mention you'd like to support the Parkinson's Label Fundraiser. (Your label can include business logos, photos, graphics or special messages. Alias wines can even produce the artwork for you.)**

**\*Parkinson's Victoria receives a monthly account of exactly which individuals and businesses have supported its work through the alias wines community fundraising program.**

## Become an Everyday Hero

Parkinson's Victoria has recently become a registered charity partner as part of an exciting new online fundraising initiative.

Simply register your details online at [www.everydayhero.com.au](http://www.everydayhero.com.au) then create your own fundraising page, selecting Parkinson's Victoria as your nominated charity.

You can include a personal profile, photograph and details about the cause as well as information

about fundraising events you are hosting, activities you are getting involved in and any other way people can financially support or sponsor you. Receipts are issued automatically (online) by Everyday Hero.

Everyday Hero enables you to ask friends, near and far, to donate in lieu of gifts for your next birthday or celebration, or sponsor you for your next athletic event, such as a hike, bike ride or marathon – whether an organised event or simply a personal challenge you take on in your own time.

## Parkinson's National Conference

The Parkinson's Australia National Conference kicks off in Sydney in October.

With the slogan "Reaching our Goals" setting the agenda for the 2-day event (16-17th), guests will have the opportunity to hear from Australian and international keynote speakers on current news in relation to Parkinson's; the search for a cure, recent developments in symptom management and general advice for living with Parkinson's.

This event is aimed at people living with Parkinson's, their families and carers. Health providers will also benefit from this unique event which brings the community and professionals together.

**The complete event program is available at: [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) (download brochure).**

## Party for Parkinson's

Keen to fundraise for Parkinson's but don't know where to start? How about hosting a **Party for Parkinson's?**

Party for Parkinson's is a novel concept where you organize your own event to raise awareness, raise money and have fun – all in the name of Parkinson's! Your party could be anything...from a coffee morning, movie night or work dinner – how about a casual day or Sunday BBQ?! Invite your work mates or neighbours, the local business community, friends and family to participate. Whatever the size, style, or location of your party, you'll be helping Parkinson's Victoria to help even more people living with Parkinson's.

**We would like to invite all our supporters to Party for Parkinson's!**

**The launch of this initiative will be during National Parkinson's Awareness – a great time to invite the local media along to cover your event!**

**For your FREE party pack, please contact Judith on: (03) 9551 1122 or email [judith@parkinson's-vic-org.au](mailto:judith@parkinson's-vic-org.au). (Packs include registration and donation forms, party ideas, awareness posters and information – everything you need to help get the party started!).**

# Reflections

## 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 of 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.

**Author's note: This poem is my first effort in the medium, written in August 2006. 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.**

## Art for Parkinson's



Members of the Art for Parkinson's group in the studio.

Where would you like to sit?

Art for Parkinson's is not about sitting in silence drawing the same vase as everybody else or painting the same thing over and over again. It's about, fun, camaraderie, support and having happy "accidents" with a variety of art materials.

**Ring Anne on 0409 188 317 and find out how research shows art activities encourage you to use both sides of your brain and helps with relaxation and depression.**

## Parkinson's - where are we headed?

Join us for a special presentation by eminent Parkinson's specialist neurologist Dr David Williams (Alfred Hospital) exploring current treatment options and what the future looks like for those living with Parkinson's. Tuesday 2, September (prior to the Parkinson's Victoria AGM).

**More information on page 8.**

## Beating the blues with books

*This edition's library update features a selection of books that can help individuals understand and manage depression in relation to Parkinson's. Parkinson's Victoria librarian, ANNE ATKIN also offers an insight into her own personal journey.*

"When I was diagnosed with Parkinson's three years ago, all I seemed to read about was how the condition was a **movement disorder**. But, over time, it dawned on me that there were non-movement symptoms too, and these are the ones that can (sometimes) make life a misery.

Two non-movement symptoms have dominated my life since diagnosis. The first, depression, invited itself to be part of my life fairly early on, and now I actually live with it in a fairly balanced way. I know it's there but most of the time, I just get on with life and keep it in a box tucked away.

The second, anxiety, leapt into my life with loud fanfare and made its presence felt in a very public place, a restaurant. It has been a long battle to keep it in its box. Every now and then my anxiety takes a peek around and I have to push it back.

Because of the emphasis on movement-based symptoms, anxiety and depression in relation to Parkinson's were two symptoms of the condition that I knew nothing about when first diagnosed. But, boy, do I know about them now!

For the past few months I have visited a psychologist every two weeks, learning about myself and why anxiety and depression managed to become such a big part of my life. I've also found the following books to be especially helpful in coping with these conditions."

### *New additions to the Parkinson's Victoria library*

**Making the connection between brain and behaviour: coping with Parkinson's Disease**, by Joseph H. Friedman

As one reviewer wrote, this book "...provides insights for the patient in a style that a non-medical person can understand..."

### *Promote your business HERE*

Are you looking for a unique opportunity to promote your product or service?

Signpost, a magazine for people living with Parkinson's, is seeking sponsors to assist in subsidizing the costs associated with producing and printing this vital information service.

We are now taking advertisements from a variety of retailers and service specialists. In return, Signpost offers a range of benefits, added value and exposure to a niche readership.

**To find out more, including rates, specifications, readership demographics, distribution and discount contract rates, contact the editor: [Judith@parkinsons-vic.org.au](mailto:Judith@parkinsons-vic.org.au).**

**Self-coaching: the powerful program to beat anxiety and depression**, by Joseph J. Luciani

**Healing from depression**, by Douglas Bloch

**Life in the balance: a physician's memoir of life, love and loss with Parkinson's Disease and dementia**, by Thomas Graboys

**Undoing depression**, by Richard O'Connor

**Panic free**, by Lynne Freeman

**Taking control of panic attacks**, by Reid Wilson

**Parkinson's Disease and other movement disorders**, by Mark Edwards

**Power over panic**, by Bronwyn Fox

**Client Services note: These books are designed to assist those who have been clinically diagnosed with depression and/or anxiety to understand and manage their condition (not for self-diagnosis). If you feel you may be experiencing either of these conditions, we encourage you to contact our team to discuss your concerns or speak with your neurologist or consulting doctor.**

### **A note from Anne**

"Recently the librarian at Vision Australia made a visit to our office as part of a series of visits to the libraries of different organisations, such as the MS Society and Diabetes Victoria. Vision Australia is keen to talk about the idea of introducing inter-library loans between organisations (we'll keep you posted on this idea).

During her visit, I found out that the Vision Australia resource library is open to the general public and you don't have to be assessed as legally blind in order to access the organisation's talking books and other reading aids.

Given that people with Parkinson's can experience difficulties with traditional reading materials - as a result of severe tremors which can make holding a book impossible, or problems with concentration and coordinating eye muscles - the services of Vision Australia's library may be the ideal solution.

Further information about Vision Australia library services is available from me on request."

**Anne**

# Symptom Management

## And so to sleep...

*VICTOR MCCONVEY identifies some of the Parkinson's-related sleep difficulties that individuals may experience, and suggests ways they can be managed.*

Sleep difficulties are often one of the more challenging symptoms of living with Parkinson's. There are many ways that sleep can be affected and, unfortunately, more than one sleep difficulty may be experienced at the same time.

Sleep difficulties are unpleasant and have the tendency to be disruptive for you and your bed partner. In addition, poor quality sleep will often make managing other Parkinson's symptoms during waking hours more difficult.

### *Difficulty in moving*

A common problem is having difficulty moving or repositioning yourself if you wake in the middle of the night. As Parkinson's medications are typically not taken over night (or are taken at much lower levels), you are in effect "off" during this time and certain Parkinson's symptoms can be at their worst (of course, if you were to sleep through the night you probably wouldn't notice).

Some simple measures can help to enhance mobility during this time. A satin bottom sheet, combined with satin pajamas will assist you in gliding over the mattress, making it easier to move, sit up or reposition. Sometimes also using a bed stick is helpful.

Discussing sleep difficulties with your neurologist is a good idea. They may suggest taking a long-acting Dopamine replacement medication (such as Sinamet CRT™ or Madopar HBS™), or incorporating a dopamine agonist into your medication regime to optimize the uptake of dopamine overnight.

### *Nightmares & vivid dreams*

Nightmares and very realistic dreams are often triggered by Parkinson's medications.

While it is commonly believed that **dopamine replacement therapy** triggers this type of reaction, many people also experience nightmares and vivid dreams when taking **dopamine agonists**. In addition, some reports indicate that those who experience nightmares are also more likely to experience hallucinations.

Experiencing nightmares and vivid dreams is very disruptive to your sleep pattern and often that of your bed partner. Often this is a minor disruption,

with the individual returning to sleep very quickly. However, if these symptoms are severely affecting your sleep and that of your partner, again discussing things with your neurologist is an ideal first step in managing the situation. Your neurologist may adjust your Parkinson's medications or introduce an additional medication.

### *Unexpected movements*

While sleeping is a time when we typically move very little, many people intermittently develop an **REM sleep disorder**, and this is particularly common if you have Parkinson's.

REM stands for **Rapid Eye Movement** which is the deepest sleep we achieve in our sleep cycle (dreaming occurs when we are in REM sleep). During this time we achieve a state of atonia (or mild paralysis).

An REM sleep disorder, combined with the tendency to have nightmares, may mean that you yell or punch out physically. This may wake you, and will most certainly wake your bed partner. It is interesting and somewhat ironic to note that people with Parkinson's and an REM sleep disorder will often have better motor coordination at this time as compared with when they are awake.

Your neurologist may suggest a sleep study to investigate your sleep cycle and pattern, and they may also review your medication and introduce other medications to assist in normalizing your REM sleep phase.

### *Nocturia*

Needing to go to the toilet frequently once you have retired to bed is a common symptom of Parkinson's.

The underlying reason for this is that many of the medications used to manage Parkinson's symptoms also have the effect of slightly lowering blood pressure (sometimes causing a symptom known as postural hypotension). Lowered blood pressure reduces blood flow to the kidneys, slightly reducing their function and urinary output during the day. When you lie down, blood pressure and flow of blood to the kidneys is normalized and urine production increases.

There are medications that increase bladder tone and when used will reduce the frequency of having to urinate. Your doctor may prescribe these, and, if you are taking anti-hypertensive medications for a past history of high blood pressure, they may reduce

# Symptom Management

your dosage. (NB: If you are a male over the age of 50, you should talk to your doctor about a prostate examination, to ensure that prostate problems are not contributing to Nocturia.)

## Insomnia

Many people living with Parkinson's may experience episodes of insomnia on occasions. Insomnia is a difficulty in getting to sleep, or resuming sleep once you wake. Insomnia is a very difficult symptom to live with as we all need a certain amount of quality sleep to function normally. Practicing good bed time habits (what the experts refer to as "sleep hygiene") is important if you are having difficulties getting to sleep. These habits include:

- Winding down and having some quiet time before going to bed
- Avoiding watching TV or using your computer prior to bedtime (as these are both visually stimulating and may keep your brain working when you're trying to "switch off". Reading a magazine can have the same effect).
- Avoiding alcohol, caffeinated and high sugar drinks within an hour of going to bed. Consider a warm glass of milk or herbal tea instead.
- Learning some relaxation techniques (deep breathing, meditation) and incorporating them into your bedtime ritual should also be considered.

Most doctors will be reluctant to prescribe sleeping tablets and while most of these drugs are safe to take if you have Parkinson's, prolonged use should be avoided.

## Depression

Unfortunately, depression is a common symptom of people living with Parkinson's, and one sign of depression is difficulty getting to sleep.

Depression is often associated with concerns and worries which make it difficult to relax, mentally switch off and allow your brain and body to move into REM sleep. However, depression is also related to a decrease in the production of a brain chemical called **Serotonin**, which stabilizes our mood and helps us sleep.

In Parkinson's, the decreased dopamine production is accompanied by a decrease in the production of Serotonin. The result typically causes depression and impacts on the individual's sleep. Treating

depression will usually resolve sleep difficulties in this instance.

## Night time anxieties

Many people with Parkinson's encounter feelings of anxiety at night, which may be heightened if the individual is also experiencing problems with poor sleep and/or nightmares.

Feeling anxious, which can progress to an actual anxiety attack, is often a response to (symptom of) lower levels of medication or "wearing off".

If you are feeling anxious overnight, learning some relaxation techniques is a good first step to overcoming it. You may also wish to talk with your neurologist who may look at your medications and adjust them to minimize wearing off overnight.

## Day time sleepiness

Sleep difficulties don't always manifest as a problem in getting **to** sleep, but can be related to experiencing a "sleep attack".

Sleep attacks, where you suddenly and unpredictably fall asleep during the day, may be a side effect of dopamine agonist medication, and can be more common in those who are having problems sleeping during the night. Sleep attacks are often more an inconvenience, however they can be dangerous if they occur while you are driving or operating machinery.

It is important to note that not all sleep difficulties are related to Parkinson's and most people will experience these sorts of problems from time to time. However, sleep difficulties will have notable impact on Parkinson's symptoms, and will worsen fatigue and make managing symptoms and performing daily activities more difficult.

**If you are having trouble sleeping or are experiencing sleep related-issues and the problem lasts longer than a week, it is advised that you speak with your GP or neurologist. The client services team at Parkinson's Victoria is also able to discuss your concerns, and provide suitable information, advice and referrals that can help.**

## Parkinson's Awareness Week: 1 - 7 September

If you're interested in raising awareness in your community, workplace, social club or wider network, contact Judith Mooney for a FREE Parkinson's Awareness kit: (03) 9551 1122 or email [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au).

# Access, Advocacy & Assistance

## Enhancing nursing care

**Guidelines for Nursing Practice in Caring for People with Parkinson's Disease** (Revised edition, 2007) by Doherty, J (RN Cert. Gerontology B.N. M Nurse), has recently been published, an initiative of the Research Sub-Committee of Parkinson's Western Australia (PWA).

The publication provides a user friendly reference for nurses caring for people with Parkinson's and aims to bridge any theory and experience gap, guiding nurses in understanding and anticipating the care needs of the patient or resident who has Parkinson's.

The editors are Parkinson's Nurse Specialists with several years of experience in managing the condition and the information and advice is based on knowledge current at time of publication. References are included for those who wish to pursue more detailed information.

**The publication (\$110, plus postage) is available from Parkinson's WA, [www.parkinsonswa.org.au](http://www.parkinsonswa.org.au).**

**This publication is aimed at nursing professionals and not the general consumer. If you are a person with Parkinson's or carer and know someone who might benefit from the guide, please contact Parkinson's Victoria with details.**

## Aged care advocacy

**Elder Rights Advocacy** is part of the **National Aged Care Advocacy Program** and is funded by the Australian Government Department of Health and Ageing.

Elder Rights Advocacy promotes and upholds the rights of older people receiving aged care services. It is a free and confidential service, providing support to people receiving Commonwealth-funded services and their carers.

### Who can access the services of the ERA?

The ERA's services are available to any Victorian resident receiving an Australian Government subsidised aged care service.

This includes people who:

- Live in an aged care home (high or low care)
- Receive a community aged care package (CACP) or (EACH)
- Receive flexible care services

- Have been assessed by an Aged Care Assessment Service (ACAS)
  - Used to receive aged care services
- or
- Are representing the interests of the person receiving aged care services

### How can ERA assist you? We can

- Support you to speak out on your own behalf
- Help you to have your complaints addressed
- Speak for you to service providers and other agencies
- Refer you to other agencies when needed
- Assist you with the Complaints Investigation Scheme

### How to contact ERA

You can contact the advocacy service by phoning: Free call: 1800 700 600

## It's all about you

Recent government changes to disability supports means greater flexibility and tailoring of services.

A priority strategy of the *Victorian State Disability Plan 2002-2012* is to reorient disability supports to be more flexible, to work with people as partners and respond to individual needs. The introduction of an individualised planning and support approach is part of this strategy and aims to ensure that supports are provided based on people's needs, aspirations and choices that they make about their lives.

Individualised Support Packages relevant to this are **Support & Choice, HomeFirst, Community Options** and **Futures for Young Adults, Years 1-8**. These packages are currently individually attached and enable choice of service provider.

### What are Individualised Support Packages?

Individualised Support Packages are Disability Services funds that are allocated to a person for support towards meeting their disability related support needs. The funds may be used to buy a range of supports chosen by the person to assist them to achieve their goals. This may include individually delivered supports and/or group based supports such as a day service.

# Access, Advocacy & Assistance

An individualised planning process will assist the person and their family to consider how their support needs may be met and to develop the person's support plan.

## **What is meant by 'streamlining Individualised Support Packages'?**

Currently, the packages operate under different guidelines. Some people also get some funds from more than one of these packages for different types of support. This means they have different rules for different parts of their funding. Users want disability funded supports to be simpler, with clear guidelines and to be more responsive and flexible.

From 1 July 2008, the different packages will be streamlined into one Individualised Support Package with a single set of guidelines and processes.

What does the change mean for you?

If you currently access one or more of the existing funding packages above, you will continue to receive the same funding allocation and supports until the next time they come up for review. A User Manual is available to help people with a disability find out about the changes and what their options are so they can make decisions about their future supports.

**If you would like more information or have questions, contact your Disability Services Intake and Response team on:  
1800 783 783 or TTY 1800 008 149.**

**(Editor's note: Information on Individualised planning and support is taken from information sheets issued by the Department of Human services)**

## **Keeping track of Medicare claims**

Did you know that Medicare Australia has developed a secure site where information about your family's Medicare Claims history is stored? You can also view your Medicare Safety Net balance and Medicare tax statement. To access these services you need to go on-line and register, you'll then be issued with a password. A secure history of an individual's PBS medications usage will also be made available soon.

[www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au)

## **Online professional education**

Parkinson's Australia recently announced a joint collaboration between the Australian and New South Wales Governments to fund the development

and implementation of an online professional education and support program. The program will be accessible to all health professionals, including those in regional and remote Australia, and will be provided free-of-charge to medical practitioners and nurses, with the aim of equipping them to better diagnose Parkinson's and more effectively treat their patients.

Another joint venture, this time for the schools of Nursing in Sydney and Freemantle, has resulted in the University Of Notre Dame, Australia's proposal to offer a Graduate Certificate in Clinical Nursing (Neurological Disorders).

Parkinson's Australia has been integral to the development of components within the graduate certificate, and the Australasian Neurological Nurses Association has also been consulted for its expertise in the area of neurological nursing.

This new graduate certificate, beginning 2009, comprises four units of study:

1. Advanced Nursing Assessment
2. Clinical Governance and Leadership
3. Clinical Therapeutics - Neurodegenerative Disorders
4. Neurodegenerative Conditions and Care

### **Enhancing GP knowledge**

The publication, **Parkinson's Disease – A General Practice Approach**, is an initiative of Parkinson's Australia, in conjunction with the Royal Australian College of General Practitioners.

The manual, which has just been revised and re-printed, aims to assist general practitioners by presenting current information on the diagnosis, medical management and treatment of Parkinson's. It provides advice on the management of early and advanced PD, the problems that may arise, and the drugs that are available, as well as the drugs that should be given with caution. Suggestions are offered on the help that can be gained by a GP from specialists and allied health professionals, and there is a section on patient self-help and information.

**Parkinson's Australia aims to have a copy of the manual in the office of every GP across the country. The publication is free to General Practitioners and Parkinson's Victoria is currently seeking support to assist with distribution of the manual to all Victorian GPs.**

# Participate for Parkinson's

*One of the most exciting things about research into Parkinson's is that several studies are being conducted right here in Melbourne! This means people with Parkinson's have the chance to play an active role in the research studies; sharing their experiences, trialling new medications and benefiting from the latest developments in symptom management, all while contributing to advances in understanding and managing the condition.*

## Get moving with Fox

Did you know that movement rehabilitation strategies and muscle strengthening are believed to improve mobility and assist with falls prevention in people with Parkinson's? This is your chance to help prove the theory!

Healthy men and women who have Parkinson's are invited to participate in a large research project, funded by the Michael J Fox Foundation.

Physiotherapy, occupational therapy and social groups are offered at these centres as part of the research project. Participants will be required to attend a two hour therapy session, once a week for 8 consecutive weeks. Their responses will be measured before and after therapy, with follow up assessments at three and 12 month intervals.

**If you are interested in participating, or would like further information, contact Professor Meg Morris, or her assistant Illy, at the University of Melbourne: 1800 428 688 or (03) 8344 7715.**

## Parkinson's and driving

In association with Monash University and Southern Health, research is currently being conducted by Karen Scally into driving performance in Parkinson's, as part of her doctorate in Clinical Neuropsychology.

Research has shown that at least some individuals with Parkinson's experience difficulties with particular driving tasks, such as turning across traffic and driving in peak traffic flow.

The aim of this study is to look at driving performance in Parkinson's and investigate what factors are causing driving difficulties for some individuals. Researchers also hope to devise strategies for such people to improve their driving and keep them driving for longer.

The study is currently seeking participants to assist in research, specifically, people with and without Parkinson's who are 50 – 78 years of age and are current drivers (drive at least once per week).

### Participation involves:

- A one-hour session in the participant's own home in which they would complete some screening tasks and a short computer task.
- A two-hour session at the Accident Research Centre, Monash University Clayton campus in which they would complete some driving tasks on the driving simulator.

A taxi will be arranged and paid for by the researchers for participants' travel to and from Monash University.

PLEASE NOTE: Participation in this study will not affect your driving licence status in any way. Your performance on all tasks will be kept strictly confidential. Feedback on your driving will not, under any circumstances, be given to any clinicians or licensing authorities.

**If you are interested in participating, please contact Karen Scally: (03) 9905 3958 or 0408 170 364.**

## Carers experience of DLB research

Dementia with Lewy bodies (DLB) is a condition that is not well recognised and is difficult to diagnose, particularly in the early stages.

A research study is currently underway into the experience of carers of people with DLB, titled **Dementia with Lewy Bodies: Evaluating Carers' Experiences.**

There is some evidence to suggest that people with the condition may have been initially told they have either Alzheimer's or Parkinson's, with the diagnosis of DLB given after an adverse event.

Researchers are keen to talk with carers about their early experience of caring for people with the condition, and to raise the profile of DLB.

The research will be conducted through the University of Melbourne by Kathryn Nicholson (Doctor of Philosophy candidate), under the supervision of Dr P St Leger and Professor D Ames.

The study is currently seeking primary carers (preferably spouses or partners) of people with dementia with Lewy bodies. Participation involves a 20 minute telephone survey, a 60-90 minute face-to-face interview and participation in a discussion over lunch and focus group. All information provided will be treated with the highest confidentiality, results will remain

# Participate for Parkinson's

anonymous and the data stored and destroyed in accordance with the University's requirements. The results may be presented at conferences and in journal articles.

**If you are interested in contributing to this research project, contact Kathryn Nicholson: 0412 051 749 or (03) 5427 0153 or email [Kathryn.nicholson@ihsipl.com.au](mailto:Kathryn.nicholson@ihsipl.com.au).**

## *Could you be a "Face of Parkinson's Victoria"?*

We're looking for enthusiastic and friendly volunteers to represent Parkinson's Victoria and collect donations as part of our annual Awareness Week tin rattle on THURSDAY 4 SEPTEMBER at Connex city loop train stations from 7-9.00am.

This initiative is made possible with the generous support of Connex.

**Find out more on page 8.**

## The Parkinson's Victoria research registry

The research registry is an exciting, collaborative project between the Howard Florey Institute and Parkinson's Victoria to establish a registry of people with Parkinson's who have been very carefully assessed and who are willing to participate in research. The registry will be a rich resource of information to improve our understanding of the condition and as a further resource for improving treatment and symptom control.

### **What would happen if I participated?**

- A detailed history would be compiled of your experience of Parkinson's, based on an assessment at St Vincent's Hospital (Melbourne). The assessment, which will take approximately 1 hour, will include a range of tests to assess severity and signs/symptoms of the condition. It may also include videotaping, scans and a history of medications.
- Blood would be taken for genetic testing and other blood tests.
- You would be asked to participate in various research trials.

### **How often would I have to participate?**

- An examination would take place on entry and then every three years.
- You will be invited to participate in various research studies (with various time frames). (This may occur as frequently as several times a year.) You choose which ones you wish to participate in. (The reason for joining the register is to be readily identified as being suitable to participate in research studies, however this is not a binding obligation.)

### **Am I eligible?**

You are eligible if you meet the following criteria:

### **People with Parkinson's group - OPTION (1)**

1. Do you have Parkinson's? While the examination will go over this information in detail, we are looking to register people with Parkinson's (disease) proper and not one of its related "cousins" (such as Multiple System Atrophy or Progressive Supranuclear Palsy (PSP). If you are not sure, ask your neurologist. (It is advised that you gain your neurologist's approval before you participate in the registry.)
2. Are you able to get to St Vincent's hospital to have a 1- 1½ hour examination every 3 years?
3. Will you be able to participate in research programs? For example, if you come from the country will it be realistic for you to make the trip down to Melbourne?

*If you answer say "yes" to questions 1 AND 2 AND 3, then you may be eligible to participate.*

### **Control group - OPTION (2)**

The registry also requires "control" subjects (those who do not have Parkinson's or a 'cousin' condition) and we need approximately equal numbers of people of the same age and gender as those with Parkinson's.

### **How do I indicate my interest in participating in option (1) or (2)?**

Email [gmahoney@parkinsons-vic.org.au](mailto:gmahoney@parkinsons-vic.org.au) or send a letter expressing your interest to: Parkinson's Victoria Research Registry, 20 Kingston Rd 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). Your expression of interest will then be passed on to the project team at the Howard Florey Institute who will be in contact with you to follow up.

## Regional seminars

For many people living in country Victoria, support and information on Parkinson's is very difficult to access, particularly when you consider the associated costs, specialist expertise and efficiency in delivery.

With shortages of country GPs and sometimes no visiting neurologist in the area, options around Parkinson's treatment are extremely limited for those living in regional Victoria. Often it is necessary for individuals to travel to Melbourne with their carer for treatment.

In order to address this issue, Parkinson's Victoria established its regional forums program, conducting two seminars in different regions each year.

The Regional Seminars are primarily aimed at locating and targeting isolated communities affected by Parkinson's throughout Victoria. The secondary aim is to enhance medical professionals/ GPs' understanding and management of Parkinson's.

The forums are also a great opportunity to promote Parkinson's support services to local service providers and create general awareness of the condition and its impact.

***This year's Regional Community Seminars will take place in Geelong and Traralgon and Parkinson's specialist neurologist Dr David Williams has been confirmed as the keynote speaker. We gratefully acknowledge our sponsor Novartis, which has made the seminars possible.***

### GEELONG SEMINAR

Date: Monday 22 September, 2008

Venue: The Geelong Conference Centre, Adams Court, Eastern Park, East Geelong

Time: Registration from 1.00pm. Event begins 1.30pm (Afternoon tea will be served during the break)

### TRARALGON SEMINAR

Date: Monday 20 October, 2008

Venue: Traralgon Hospital Auditorium, LaTrobe Regional Hospital, Centre for Rural Health, Princes Highway, Traralgon West, Victoria, 3844

Time: Registration from 10.00am. Event begins 11.00am (Lunch will be served at the conclusion of the presentations)

RSVPs are essential and places are limited. Reserve your place today by contacting Donna Willis: (03) 9551 1122 or email [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au). Please promote the forum to your local community. Flyers are available for distribution to your community.

*Coming to terms with a diagnosis of Parkinson's can be challenging – coming to terms with the reaction of others is another story. Sharing diagnosis with friends, family, partners, work mates and even strangers can have positive benefits for everyone, but it is the right of every individual living with Parkinson's to choose when and how they will let people know about their condition. The following information may help when the time comes.*

- Timing is important. If you wait too long, people may feel betrayed. If you tell a new acquaintance too soon, you may turn them off before they get a chance to know you. If you bring it up when you're distraught you're likely to get a far different reaction from when you're in more control.
- Decide who you need to tell personally. If there are some people who should be told but don't need to hear it from you directly, ask a close friend or relative to tell them. If you're planning to tell co-workers, tell your supervisors first so they won't find out from someone else.
- Try to anticipate how the person will react. You're better off not being caught completely off-guard by negative reactions. Self-help groups or counseling can help you sort out what the range of reactions might be.
- Think about what you want or need from the person you're telling. Do you want time off from work? A shoulder to cry on? Help with chores? State your needs as clearly as you can; it will guide friends, relatives and co-workers toward a positive reaction.
- Guide people to sources of information. People may not want to burden you with questions or may be too confused or worried to ask. Bring educational materials with you from [Parkinson's Victoria] or elsewhere that may help.
- Accepting on an emotional level the fact that you or someone you love has a chronic illness is a never ending process.

***The above information is from the book, Parkinson's Disease: the complete guide for patients and caregivers, by Lieberman MD, Abraham N and Williams Frank L. The excerpt is from the chapter Coming to Terms with Chronic Illness.***

# Our Supporters

Thank you to all our supporters who generously made a donation in recent months, whether general donations or specifically for education or research.

Listed below are the names of those who kindly donated more than \$200 between 25 April and 17 July (2008), 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 all those who have donated but wish to remain anonymous.

## Donations (individual)

Desmond Alach  
Rowena Armstrong  
Daniel Atkin  
Lurline Atkin  
Paul Atkinson  
Ray & Liz Bisset  
Jean Bowels  
Su Bradfield  
Mary Bradfield  
Karen Branch  
Adam Broadway  
Richard Court  
Morris Craig  
Marjorie Crotty  
Stuart Cumming  
R Dunn  
Diane Gott  
Frank Hambridge  
WD Hardley  
Y Hayes  
Sue Hayes  
Judith Hedstrom  
Beryl J Height  
GA (Wendy) Heisler  
Trevor Hewitt  
John Howden  
Mary Kentish  
Janice Knox  
Arthur & Doreen Korfiatis  
Peter Kostaridis  
Ray & Esma Lawley  
John Lessels  
Fiona Lourey  
Christina MacGregor  
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Bruce Mathewson  
Peter McGregor  
Alan Michael  
Margaret Michelmore  
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Lynda O'Brien  
Allan Penney  
JD Perkins  
Annette Pijpstra  
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Graeme Pitfield  
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Joe Rhoddy  
Keith & Ann Robinson  
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Stuart Rowley  
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John Sewell  
John Shawley  
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David & Mary Shuttle  
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JW & JE Sutton  
Joe Tedesco  
G Timewell  
Noel Turnbull  
Justine Ward  
Adrian Warwick  
Paul White  
Helen Wilkinson  
Keith Williams  
Barry Williams

## In Memory of...

Maurice Cummings  
Joseph Depares  
Richard Gutteridge  
Salvatore Princi  
Julie Shawley  
John Anderson  
Noel Alfred Ashby  
Joel Belkin  
Margery Constance Best  
Ian Bowditch  
Glyn Broadbent  
John Burke  
Donald Coulsell  
Ron Dawson  
John Edwards  
Filo Farrelly  
Sylvia Farrugia  
Ronald Giblett  
Margaret Greening  
Pat Hambridge  
Douglas Thomas Hardley  
Geoffrey Hayes  
Noel Horsburgh  
Arthur Johnstone  
George Kostaridis  
Jeanie Lowe  
Athole Macpherson  
Isabel Mansfield  
Bruce A Marston  
Fred Moylon  
Calvin Naylor  
Valerie O'Leary  
Albert Penny  
Giuseppe Saias  
Kata Sangaletti  
Eva Searle  
Graeme Sibley  
Shirley Stewart  
Jean Stopford  
John Styles  
Claude Victor Swinson  
Keith Tilley  
Arie Van De Donk

Jannetje Vis  
Kerstin Von Strokirch  
Robert Ian Ward  
Peter Warwick  
Majorie Williams  
Hilda Joan Wills  
Edward Wilson

## In Celebration of

Robert Berry  
Peter Bollen  
Alfred Goldschagers  
Brian Hartshorn  
Merle Rapley  
Trevor & Pearl White

## Team Parkinson's Challenge Participants

Leanne Barnes  
Edward Beesley  
Maxwell Bradfield  
David Gibson  
Kim Harris  
Brendan Lourey  
Kim Nicholson  
Karyn Spilberg  
Nicholas Taylor  
Fred Van Ross  
Christine Van Ross  
Catherine Watson  
Jenny Young

## Bequests

Joe White

## Corporate & Community Donations & Support

Abbin Engineering  
Alias Wines  
All Souls Opportunity Shop  
Alucobond Architectural  
AMG Distributors  
Black Dog Books  
Burra Foods  
Casama/Endeavour Wines  
Caulfield Hospital (Health Information Services)  
Claytons Kitchen  
Dealer Solutions  
Donation Home Loans  
Essendon Choral Society Inc  
Glyde Metal Industries  
Health Recruitment Specialists  
Holbrew Nominees  
Insurance House Group  
ITW Buildex

Jo Harkin Photography  
John Hossack Funeral Services  
Ladies Guild of the United Churches of Dumbalk  
Lions Club of Moe  
LKD Livestock  
Loose Nuts 4WD Club  
Lyon Architects  
Mackay Consolidated Industries  
Mitchell Community Health  
Mitek Australia Pty Ltd  
Mutual Trust  
Premier Network Support Management  
Rapley, Bassett & Associates Pty Ltd  
Ritchies  
RMIT Division of Psychology, city campus  
Silvio Bordignon Financial Services  
Spring Valley Golf Club  
St John's Uniting Church - Ladies Guild  
Steve Fretwell Design  
Taylors Hill Retirement Village  
The Ex RAAF Nursing Service Association  
The Hamilton and Alexandra College  
Victoria Council of Social Service  
Village Roadshow  
Westfield (Southland)

## Grants, Trusts & Foundations

Handelsman Charitable Trust  
Kingston Charitable Trust  
Lord Mayor's Charitable Fund

## Parkinson's Victoria Support Groups

Frankston Parkinson's Support Group

**We have also received 63 generous donations from supporters who wish to remain anonymous.**

# Tulip Tributes

## Putting for Parkinson's update



City of Kingston Mayor Bill Nixon, Spring Valley Golf Club President John Philp, Charity Golf Day committee member Sue Semmons and Parkinson's Victoria board member and Ambassador Coordinator Peter Raymond.

On Friday 16 May, Spring Valley Golf Club held its annual Charity Golf Day. The day was a huge success, raising more than \$16,000 to support the work of local charities, with Parkinson's Victoria receiving \$8,250!

Approximately 150 players joined in the 4BBB competition and each received a gift bag filled with information and goodies from sponsors, as well as information about Parkinson's. They later enjoyed lunch while trying their luck in the Spin-the-Wheel raffle and fast-paced auction.

We gratefully acknowledge the generous support of the Spring Valley Golf Club for nominating Parkinson's Victoria as a recipient of funds from the event, and the Golf Club's Charity Day committee, particularly Ms Terri Farrell. We would also like to thank the Kingston Charitable Trust, and our sponsors who contributed to the event's success by donating prizes for the day: Village Roadshow, Alias wines, Westfield (Southland), Patchwork Gallery, Casama and Endeavour Vineyards.

## Mid-year appeal makes a big difference

Parkinson's Victoria conducts just two public appeals annually, when we actively seek financial support from the community.

Our recent mid-year appeal gave us a chance to connect with supporters and update them on our work as well as the need for improved services and funding. Non-members received a special mailout with a story from "Brendan", diagnosed at the age of 52. Brendan shared how Parkinson's had impacted on him and his family, but also spoke about how Parkinson's Victoria had helped with information and support.

We'd like to thank Brendan for sharing his story and all our members and supporters who made such a valuable contribution to our mid-year appeal, helping us raise just over \$22,000.

If you missed the opportunity to contribute to our appeal but would like to make a donation now, please contact our office or you can make a secure online donation via our website: [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au).

## World Parkinson's Day Volunteers

We'd like to give a BIG Tulip Tribute to the wonderful volunteers who generously gave their time to assist us during our World Parkinson's Day special events.

A number of enthusiastic volunteers headed into town for morning and afternoon "tin rattle" shifts at Connex city loop train stations to collect donations from commuters. In just 4 hours (7-9am and 4-6pm) we raised just over \$3,100! A fantastic effort. It's amazing what impact a friendly smile and a great cause can have.



Two of our World Parkinson's Day tin rattle volunteers, Marion and Michael, with Donna Willis, Parkinson's Victoria Administration Officer (and Volunteer Coordinator).

Also on World Parkinson's Day, we hosted a major community seminar, addressing the issue of Depression and Parkinson's. Volunteers played a valuable role directing traffic and attendees into the venue, and ensured guests were greeted with a warm and friendly face! We are grateful for their assistance in helping the day run smoothly and for creating such a welcoming environment for all who attended.



Some of our World Parkinson's Day Depression Seminar volunteers; Norma and Carolyn, Anne and Neil.