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## Thinking out loud

*Speech disorders, common in Parkinson's disease (PD), can progressively diminish quality of life, but a specialist treatment therapy is giving people living with the condition something to talk about.*

Communication is a key element in quality of life and can assist in maintaining confidence and a positive sense of self as people with Parkinson's (PWP) deal with the challenges of the condition.

Research shows however, that 89 percent of PWP experience speech and voice disorders, including soft voice, monotone, breathiness, hoarse voice quality and imprecise articulation. As a result, PWP report they are less likely than healthy individuals in their age group to participate in conversations or to have confidence in social settings.

The recognition that speech therapy could be tailored to the specific problems of PWP led to the development of a method aimed at improving **vocal loudness**: the **Lee Silverman Voice Treatment (LSVT LOUD®)** method. This technique has helped many individuals with Parkinson's and speech problems, giving them new hope for improved communication for work, family and social activities.

There are several reasons why PWP experience speech and voice disorders. One is directly related to the *disordered motor system* that accompanies Parkinson's, including rigidity, slowness of movement and tremor. For example, the problem with muscle activation in Parkinson's can result in reduced movements of the respiratory system (reduced breath support), larynx (reduced vocal loudness) and articulation (reduced clarity of speech).

Clinical observations also suggest that people with PD may simply not be aware that their speech is getting softer and more difficult to understand. Furthermore, when asked to bring their voice to normal loudness, PWP can often feel as though they are shouting.

Another cause of this condition is that people with Parkinson's may have a problem with "cueing" themselves to produce speech with adequate loudness, although they respond well to external cues (e.g. an instruction from someone else to "speak loudly!"). Because of this, the family or carer may feel the person **could** be louder and clearer if they would only try harder.

These motor sensory and cueing problems have made people with PD particularly resistant to speech therapy.

Over the past 15 years, studies supported by the **National Institute for Deafness and other Communication Disorders (NIDCD) of the National Institutes of Health (US)** have demonstrated that LSVT LOUD® is an effective speech treatment for people with PD.

Those who have used it have improved vocal loudness, intonation and voice quality, and maintained these improvements for up to two years post treatment. Recent research studies have also documented the effectiveness of this therapy in meeting the common problems of disordered articulation, diminished facial expression and impaired swallowing.

LSVT LOUD® improves vocal loudness by stimulating the muscles of the voice box (larynx) and speech mechanism through a systematic hierarchy of exercises. Focused on a single goal – "speaking LOUD!" – the treatment improves respiratory, laryngeal and articulatory function to maximise speech intelligibility. It does **not** train people to shout or yell.

The program is administered in 16 sessions over a single month. This intensive mode of administration is critical to attaining optimal results.

In addition to stimulating the motor speech system, the treatment incorporates sensory awareness training to help individuals with PD to recognise that their voice is too soft, convincing them that the louder voice is within normal limits.

Patients are also trained to *internally cue* the adequate amount of loudness to make their speech understood.

While LSVT LOUD® has been successfully administered to individuals of all stages of PD, it has been most effective for those in the early stages of the condition.

LSVT LOUD® empowers people with PD to participate not only in their treatment management, but also in a wider range of social and interactive settings.

**Source: The Science and Practice of "Speaking LOUD" and "Moving BIG" by Lorraine Ramig, Ph.D, CCC-SLP, Cynthia Fox, Ph.D, CCC-SLP, and Becky Farley, Ph.D, PT.**

**If you are interested in learning more about LSVT LOUD®, have concerns about your ability to communicate, or would like a copy of the above article with references, please contact Parkinson's Victoria.**

# 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.

## Speaking your language

Information about Parkinson's is now available in 10 languages (right).

Bi-lingual booklets and Help Sheets have been produced in Arabic, Chinese (traditional), Croatian, Greek, Italian, Macedonian, Russian, Spanish, Turkish and Vietnamese, with English only versions also available.

A multi-lingual poster has also been produced for placement in community centres and health services. It encourages people to contact Parkinson's Australia for information and support and advises those who speak a language other than English to contact us using the Translation and Interpreting Service (TIS) on 131 450.

**For free copies of the brochures, Help Sheets or posters, contact Parkinson's Victoria: (03) 9551 1122 or download them from [www.parkinsonsvic.org.au/language.htm](http://www.parkinsonsvic.org.au/language.htm)**

**Organisations and health professionals can order bulk copies for distribution to community members using the order form on the above web site.**

## National Conference DVDs

Keynote presentations from last year's National Conference in Sydney are now available on DVD.

A set of presentations is \$35 and can be ordered through Parkinson's NSW. Contact Beulah Barker: pnsww@parkinsonsnsw.org.au or phone (02) 8875 8900.



A guest at the launch of our multi-lingual resources

## Tri-Turn sheets direct from suppliers

Parkinson's Victoria is no longer stocking Tri Turn sheets and pillowcases (cotton sheets that have a satin strip across the centre to assist people with mobility issues to manoeuvre in bed).

We currently have a limited supply, so please contact us to place your order. In the future, contact the manufacturers directly.

Satin Collections: (03) 9876 6444 or [teresa@satincollections.com](mailto:teresa@satincollections.com)

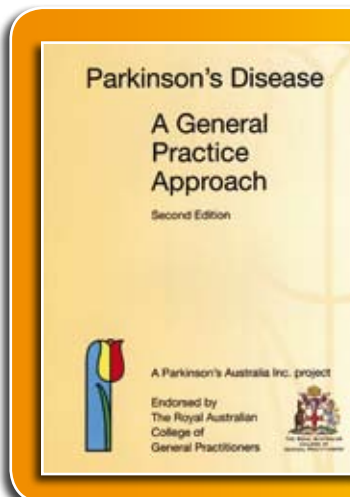
Easy Wear Australia: (08) 9445 2333 or [info@easywearaustralia.com.au](mailto:info@easywearaustralia.com.au)

## Enhancing GP knowledge

As recent readers of **Signpost** will be aware, the specialist publication **Parkinson's disease – A General Practice Approach** (below), was recently republished (2nd edition) by Parkinson's Australia, endorsed by the Royal College of Australian General Practitioners.

The manual is now being distributed to GPs throughout Australia, with the aim of ensuring every GP and/or clinic has access to a copy, enabling them to better understand, diagnose and treat Parkinson's.

**You can assist us in this aim:** Ask your GP during your next visit if they have a copy of the manual. If they do not, encourage them to contact Parkinson's Victoria to obtain their free copy.



## **Did you know that Parkinson's Victoria runs more than 45 Support Groups throughout the state?**

We would not be able to do this without the generous support and tireless work of our many volunteer Support Group Leaders, including members of the community, both people with Parkinson's and carers, and health professionals.

Unfortunately, several community health professionals are being asked to reduce their involvement with the support group in order to focus on other areas of their role, while encouraging groups to be "self-run".

While in many cases, the transition has had no negative impact, in other instances the group has suffered considerably. Without appropriate leadership or the availability of a suitable volunteer, some groups have been forced to halt meetings and disband, leaving members with little peer support.

Parkinson's Victoria is keen to provide support wherever possible to those leaders who might feel under pressure to cease their involvement with their group.

***In recent months we have contacted all Support Group leaders and written letters on their behalf supporting their involvement in the local group.***



*Leaders and members of the Portland Parkinson's Support Group, 2008. Photo courtesy of Portland Observer.*

### ***Take a seat***

Parkinson's Victoria currently has a number of second hand office-style chairs in pristine condition available for sale (\$30 each or nearest offer). The chairs would need to be collected from our office in Cheltenham.

For enquiries please phone: (03) 9551 1122.



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## **Get ready to walk**

***Australia's Unity Walk for Parkinson's  
Sunday 30th August 2009 Federation Square***

We invite people with Parkinson's, family members, friends and the general community to participate in Australia's Unity Walk for Parkinson's on the morning of Sunday 30 August 2009.



*Members of the Lower North Shore Parkinson's Support Group during Australia's 2008 Unity Walk in Sydney.*

Commencing at Federation Square, right in the heart of Melbourne, the four kilometre walk will follow the scenic path along the Yarra River, crossing historic Morrell Bridge, and finish back at Federation Square.

The Unity Walk will be held on the same day in Sydney, and it is envisaged that this will become a national event in years to come, with a walk in every state and territory.

***The objective of the day is to raise much needed funds, and to raise community awareness.***

According to John Silk, President of Parkinson's New South Wales, 1,000 people participated in their Unity Walk in 2008, with many people with Parkinson's, families, friends and Support Groups travelling from all parts of the state to participate. One of the highlights of the event was the opportunity that it gave people from the Parkinson's community to come together as one from all parts of NSW.

We will have further information, registration forms and details of our Unity Walk web site in the next edition of **Signpost**. For further information, and to register your interest in being sent further information, you can contact Judith Mooney at Parkinson's Victoria. [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au) or call our office (1800 633 189 country callers or (03) 9551 1122).

***This will be a great family fun day, so put the date in your diary, tell your family and friends, and plan to be a part of Australia's Unity Walk for Parkinson's.***

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# Ambassadors

*JOAN and GRAEME LONG, who was diagnosed with Parkinson's in 1994, became members of the Eltham Support Group in 2001 and were partners in everything, including being joint Ambassadors. Their presentation offered audiences a unique insight into what it is like to live with Parkinson's, from the perspective of one diagnosed and the partner/carer. Sadly Graeme passed away in 2007, however Joan continues her role as an Ambassador, and she is currently leader of the Eltham Support Group.*



## **How did you get involved in the Ambassador Program?**

My husband Graeme and I (pictured left) had always worked well and easily together, as a team during our long marriage. When Graeme was diagnosed

with Parkinson's, the teamwork just continued – we were on the journey together.

Being part of our local support group was an enabling, enriching and often enjoyable experience.

When a request for a speaker came to the group, we were a little apprehensive. However we felt it was important to help others learn about the experience of Parkinson's.

An important part of people's well being is the need to feel understood, to have a sense we still belong, and we are valued as people. Graeme and I felt that sharing our story would help people to understand.

We joined the Ambassador program in 2003.

## **What makes a good presentation?**

For me, a good presentation means the audience and I connected, and they understood my message. It takes some planning.

The first step is to decide what the major points are and the different ways these can be reiterated during the talk. That way, at the very least, the major points are firmly planted in the minds of the audience.

It helps to know a little about the audience, so that you can tailor your presentation in a way that is hopefully appropriate to their level and their experience. It's important to talk to the audience rather than at them and, if you sense interest is flagging or something is not understood, responding in a flexible way.

It's important to focus on the message, not just the known facts about Parkinson's, but also the personal experience of day-to-day living with it.

I try to do this by relating to the audiences' own immediate experience. For example, taking for granted that there will be an automatic response

to the need to walk from the car park to the meeting room; that there will be an immediate response when the lights for a pedestrian crossing turn green; that in walking posture will be maintained; and so on. Then I compare and contrast this with the Parkinson's experience.

It's also important afterwards to meet with members of the audience to listen to their stories and answer questions, and to offer material they can take away and read.

## **How would you describe your presentation style?**

My aim in every presentation is to raise awareness. I try not to be too formal so that the audience feels they can interact or ask questions. I use overheads to underline or extend what I am saying. I involve the audience by asking questions and sometimes I might ask them to do something.

I am also flexible in my approach to content and style.

I try to relax the audience following heavier sections by adding humour (Graeme and I often found things to laugh about).

I also mention some positive aspects we were able to discover about living with Parkinson's, and that it is possible to continue for quite a while to be involved and find new and interesting things to do.

## **How do you know you've connected or made an impact?**

When the audience is responsive, looks interested and asks questions, especially perceptive questions that show they really listened and were inspired to learn more. Of course when people give unsolicited donations, that's usually a good sign too!

## **What have you gained from the program?**

There is great satisfaction knowing we have done something to raise people's awareness.

Being an Ambassador is an opportunity to promote the valuable role of the carer, as well as raising awareness about the complexities of Parkinson's and the multi-disciplinary needs of those living with the condition.

It's also very rewarding when audience members say that they now feel able to "support and help family or friends living with Parkinson's". That's when I feel I've made a difference for the Parkinson's community.

**In 2008, the dedicated volunteers of our Ambassadors of Hope community education program presented to more than 600 people, schools, workplaces, social clubs and community groups. Help spread the word! If your social, service, or sporting club or school is interested in an Ambassador presentation contact Parkinson's Victoria: (03) 9551 1122 or email [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au)**

## On Time, Every time

*In 2008, MOIRA LEWIS (diagnosed with Parkinson's in 2006) was sponsored by Parkinson's Victoria to take part in the Leadership Plus Program. Moira's project explored the issue of "getting medication on time" in aged care facilities.*

People with Parkinson's often rely on a number of drugs that are tailored and timed to their particular needs. These stimulate a complex, carefully timed release of chemicals in the brain, and as a result allow control of movement. With an uneven release of chemicals (namely dopamine), a person may suddenly not be able to move, get out of bed or walk down the corridor. People with Parkinson's need their medication on time – every time, whether they are at home, in hospital, respite or nursing home care.

If they are unable to access their medication on time, in addition to mobility issues arising, other problems can also occur: Sleep can become disturbed; bowel and kidney function and digestion can be affected; and mood swings can also be triggered. Once this balance of chemicals has been upset it may take hours, days or even weeks for a person's symptoms to stabilise, enabling them to get on with life again.

For people with Parkinson's who are in care or hospital, the issue becomes even more serious as failure to take medication on time can result in patients having to stay in hospital longer with symptoms worsening.

In 2006, Parkinson's Australia launched a major campaign addressing the issue of people with Parkinson's accessing medication on time in the hospital and health care setting. Our health team also conducts regular education to hospital and nursing home staff.

Unfortunately, in spite of the efforts of the organisation to increase awareness and education, the issue continues to be one of concern for patients in health and aged care facilities. Ongoing efforts are vital if we are to address and change this situation, and research

and initiatives such as Moira's enhance our efforts in this area.

### **Moira Lewis shares her experience:**

*"Leaders are everywhere, from people who are actively out in front with vision and mission blazing, to the more simple, yet effective leader who takes initiative to diffuse an argument between two people, solve a long standing problem or develop an innovative idea."\**

The **Leadership Plus Program** is an intensive program exposing participants to Victorian industry leaders and a diverse range of themes and ideas to stimulate discussion, thought and analysis.

At the commencement of the program it was rather daunting as I gathered with 27 other participants who were living with varying degrees of disabilities, but soon we became a cohesive group, disabilities becoming transparent.

I am currently employed as a Division One Nurse and I am also a person living with Parkinson's. As part of the Leadership Program participants take up the challenge to develop a community program to improve the lives of the community group they represent.

After discussion with Glenn Mahoney, CEO, Parkinson's Victoria, on issues of greatest concern to the Parkinson's community, I chose to take up the issue of "Get it on Time" for medication.

Being on both sides of the Parkinson's fence gives me drive and determination to assist both the person living with Parkinson's (PWP) and nursing staff. To this point in time, I have concentrated on the area of Aged Care, investigating what can be done to assist nursing staff to get medication on time to people in aged care facilities. As a result, a trial is currently underway in a Low Care and High Care Aged Care Facility, using both education and a timing device, specifically used by nursing staff.

The trial is due for completion in February, 2009. We will await the outcomes and feedback we receive from nursing staff involved before embarking further with improvements to "Get it on Time".

Victor McConvey, Parkinson's Nurse Specialist, Parkinson's Victoria, has been assisting with the education program for the trial, and I am grateful for his input.

My ultimate vision, along with the team at Parkinson's Victoria, is to develop a model of care which will assist nursing staff in the management of medication on time for PWP in health facilities.

**\*The Art of Networking**, Jennifer Harwood, 2007. Published by Direct Incite Pty Ltd.



*Parkinson's Victoria CEO Glenn Mahoney with Moira Lewis holding her Leadership Plus Graduation Certificate.*

# Fundraising & events

*Looking to get involved in some fun events and fundraising in 2009?*

*We're planning a range of events that focus on bringing the community together!*

**For more information about any of these fundraising events and initiatives, to register your interest to take part or request your free Party for Parkinson's kit, please contact our Marketing Coordinator, Judith: [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au).**

## KEY DIARY DATES FOR 2009

WORLD PARKINSON'S DAY

11 April

NATIONAL PARKINSON'S AWARENESS WEEK

30 August – 5 September

SEEKING VOLUNTEERS

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 from train commuters as part of our World Parkinson's Day and National Parkinson's Awareness Week tin rattles.



These important fundraising events are made possible with the generous support of Connex.

**If you are interested and available to "shake a tin", please contact our Volunteer Coordinator: (03) 9551 112 or [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au).**

## Time to Party

**Save the Date: World Parkinson's Day, 11 April, 2009 (Easter Saturday).**

Why not turn your holiday and Easter celebrations into a **Party for Parkinson's** with friends and family? You'll be helping to raise



awareness and vital funds to support those affected by Parkinson's.

## Join us for The Journey

A major event in the lead up to World Parkinson's Day will be the launch of 'The Journey'.

We'll be hosting a public seminar for the community to learn more about Parkinson's, which will include research updates from a leading Melbourne neurologist.

The event will culminate with the launch of our latest information and support resource for those newly diagnosed and their families, **The Journey – Understanding and Learning to Live with Parkinson's**.

This resource, which has been two years in the making, was made possible through a grant from Allens Arthur Robinson.

The highlight of the resource is a locally produced DVD featuring interviews with people with Parkinson's and carers from the Melbourne community who share their "journey with Parkinson's".

In addition, the DVD includes information, advice and tips from health and allied health specialists on how to cope with the diagnosis and live well with Parkinson's.

**Further details regarding location and time for the seminar/launch will be confirmed in coming weeks. To register your interest in attending or receiving The Journey resource, contact our office.**

## Australia's Unity Walk for Parkinson's to kick off National Awareness Week

Australia's Unity Walk will kick off this year's National Parkinson's Awareness Week for Victoria.

Taking place on Sunday 30 August, the same date as Parkinson's NSW's Unity Walk, we're hoping to see more than 1000 walkers from around the state (and beyond) join in the fun as they walk from Melbourne's iconic Federation Square along the scenic walking paths of the Yarra to Morrell Bridge and back.

In the lead up to the event, walkers will be asking friends, workmates and family to make donations and we aim to raise over \$50,000 to help fund Parkinson's Victoria information and support services.

The Unity Walk will be followed by a week of events designed to increase the profile of Parkinson's in the community and media. Members of the public and Parkinson's community will also have the opportunity to learn more about the condition at a number of seminars. Further details will be published online and in future editions of **Signpost**.

# Fundraising & events

**You can help raise awareness: Contact our Marketing Coordinator for brochures, posters and fact sheets you can display in your community (day care centres, church notice boards, shopping centres, social and clubs, chemists and local libraries).**

## *Pedal for Parkinson's*

On 14 February, a young Sydney University student and her college friends are setting off on a 1200km/13 day bike ride from Sydney to Melbourne to raise much needed awareness and funds for Parkinson's.

The riders will pass through and stop at Kiama, Mollymook, Lake Brou, Turra Beach, Alfred National Park, Cape Conran, Lakes Entrance, Maffra, Mirboo North, North Hastings and into Melbourne on 26 February. The full itinerary can be viewed on the Parkinson's Australia website.

If you live in these areas, we encourage you to come out and show your support to this dynamic group of people who want to make a difference.

Sarah and her friends hope to bring national attention to the need for specialist Parkinson's nurses, an area that has been poorly neglected in this country, compared to the UK and NZ. Donations can be made through Parkinson's Australia: [www.parkinsons.org.au](http://www.parkinsons.org.au)

## *Gearing up for the Challenge*

Over the past 13 or so months, a team of 14 inspiring people have joined together for the **Team Parkinson's Challenge**.

The Challenge is all about pushing personal boundaries and putting values into action to become an Ambassador for Parkinson's.

Together, the Challengers have hosted a wide range of fundraising events; from trivia and movie nights, to music concerts and luncheons, poker competitions, garage sales, sausage sizzles and dinner dances. They have spoken with community groups about Parkinson's and the need for increased funding. And, they have arranged media interviews with their local newspapers and encouraged family, friends, workmates and strangers to show their support by donating to Parkinson's Victoria.

**Together they have raised more than \$95,000 so far!**

Next month they will be setting off for the second part of the Challenge – to cycle through Vietnam on a 12 day *ride of a lifetime!*

We thank them for their amazing and selfless efforts to make a difference for those living with Parkinson's, and wish them all the best as they head off for this exciting adventure.

We look forward to sharing their stories about the Challenge with you in the next edition of **Signpost**.

**Our Challengers are: Leanne Barnes, Maxwell Bradfield, Sue Dutton, Clare Eizenberg, Kim Harris, Nahid Jones, Brendan Lourey, Karyn Spilberg, Nicholas Taylor, Fred Van Ross, Christine Van Ross, Peter Walker, Catherine Watson and Jenny Young.**

## *Raise a glass to show your support*

Our Autumn 2009 wine drive is now on, with a delicious selection of red, white and bubbles available at great prices! **Remember, a percentage of the sale of every bottle goes straight back into our support and information services!**

Download an order form from [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) (go to the fundraising and merchandise section), choose your selection and send the form to our partner alias wines, together with your payment details (cheques payable to alias wines).

➤ **Thinking of hosting a Party for Parkinson's?** How about combining it with a special wine drive of your own and offer your guests another great way to support Parkinson's?

Ring Kevin at alias wines to discuss your ideas. You can even arrange a special label for your party wine!

**Ask Kevin at alias wines how your next special event can help support Parkinson's Victoria.**

**Alias wines: (03) 9769 6065;**

**[sales@aliaswines.com.au](mailto:sales@aliaswines.com.au) or visit the website: [aliaswines.com.au](http://aliaswines.com.au)**

## *Parkinson's takes centre stage at International congress*

The **2nd Asian and Oceanian Parkinson's disease and Movement Disorders Congress** will be held in New Delhi, India, 15-17 February, 2009. Parkinson's Australia hosted the 2005 Conference.

The meeting will provide an opportunity for young researchers to present their work and interact closely with world renowned speakers in the field of Parkinson's disease and Movement Disorders.

Concurrently, the **7th International Symposium of Asian and Pacific Parkinson's Association (APPA)** will take place from 15-16 February.

This is a forum especially for people with Parkinson's, caregivers, nurses, therapists and other allied health professions, with the aim of improving quality of life of persons with Parkinson's (PWP) through knowledge, research and information.

**For more information about the Society visit: <http://www.movementdisorders.org>**

# Symptom management

## Improving self management

*The diverse role and expertise of our health team ensures they are familiar with the wide range of Parkinson's symptoms and equally wide range of treatment therapies available to help individuals live well with Parkinson's.*

*Our Parkinson's Nurse Specialist VICTOR MCCONVEY shares some tips for improved management of Parkinson's, based on the team's experience.*

Our small team of health professionals is adept at multi-tasking as their role is a diverse one. Day-to-day tasks involve anything and everything from manning the information phone line and answering questions about symptoms and medication (remember there are no silly questions!), to heading out to work with people living with Parkinson's of all ages across the state. There's also education for health care professionals, public lectures and visiting support groups.

As we know, Parkinson's can affect people of any age, from young adults to people in their 90's. Every one is affected differently, and responds differently to treatments. The diverse work experience and expertise of our health team allows for a comprehensive understanding of how people living with Parkinson's manage their condition and how they deal with the daily challenges it can create. This understanding enables us to provide general and specific information and advice about the condition.

### See a neurologist

Regularly consulting a doctor who specialises in illnesses affecting the brain and spinal cord is important. If you can see a Neurologist, Rehabilitation Physician, or Geriatrician who specialises in movement disorders even better.

These doctors see a number of patients with similar conditions, enabling them to become experts in managing such illnesses and appropriate drug therapies. They are often involved in research studies and attend conferences to remain up-to-date with news on existing and new treatment options, and work with a multi-disciplinary team.

### Play an active role

Seeing a specialist is only part of achieving "improved management of Parkinson's". You also need to become an active participant in getting the most out of treatments, setting goals that are realistic, discussing these with your neurologist, and asking how he or she would like to be updated on your symptoms and response to medication.

*(A recent survey of Melbourne-based movement disorder neurologists found they prefer different methods for obtaining symptom/medication updates from their patients, ranging from a written diary to patient emails a few days prior to the consultation.)*

As someone living with Parkinson's (or any movement disorder), it is essential that you are an active participant in the management of your illness.

### Find a GP who can "work with" your specialist

While asking questions and keeping up-to-date with treatments is important, making sure your doctor is able to work with your specialist is essential.

Together, they should be able to discuss symptoms and your response to treatment (as well as alternative treatment options) and modify as needed.

Typically you will see your GP more regularly than your specialist, particularly if you live in the country and do not have easy access to a local or visiting neurologist, or if you find travelling to a major center difficult. Your GP will be able to provide your specialist with vital, detailed information about your health, which will assist the latter in reviewing management options.

*(Consulting both a GP and a specialist who work together managing your Parkinson's is recommended over a GP solely managing your condition. Parkinson's Victoria is able to provide a comprehensive list of neurologists, including Parkinson's specialists, as well as information on travel assistance schemes in the case of accessing Melbourne-based specialists).*

To enhance GP understanding of Parkinson's, Parkinson's Australia has recently updated the manual, **Parkinson's disease – A General Practice Approach**, and copies are currently being distributed to GPs through the local Divisions of General Practice. If your GP has not yet received a copy, encourage them to contact Parkinson's Victoria: (03) 9551 1122.

### Accessing information

Getting to know your symptoms is an important way of learning how you can best manage them.

There is a lot of information readily available on Parkinson's, its symptoms and treatments, and it's easy to feel overwhelmed. When seeking and reviewing information you should remember that you will not necessarily experience *all* of the symptoms you read about. Everyone's need for information is different and only you will know what is right or relevant for you.

# Symptom management

An excellent way to access current, credible and relevant information about the range of symptoms you may encounter is to utilise the information services of Parkinson's Victoria.

The health team of social work and nursing professionals are experienced in the specifics of managing Parkinson's.

In addition, our website contains loads of essential information on various aspects of the condition, including the latest developments in care and treatments, and various supports that may be helpful. Parkinson's information is also now available in 10 other languages.

We also offer a telephone information line and free 1800-number for country callers. Remember the information line is anonymous, so you are able to ask even those embarrassing questions!

## **Consult other health care (allied health) professionals**

It is often necessary and beneficial to see health care professionals, other than a neurologist, but exactly who you need to see will depend on the specific symptoms you are experiencing. For example, if you have difficulty moving or walking you may benefit from seeing a physiotherapist who will be able to address mobility issues.

Your local doctor is able to arrange appropriate referrals and you can access these professionals through the local community health care center, Community Based Rehabilitation centre (CBR) at your local hospital or privately.

Occasionally your neurologist or GP may ask you to see a psychologist or psychiatrist, particularly if they are concerned that you may be experiencing depression or developing side effects from Parkinson's medication. This is completely normal and done with your best interests in mind. Be assured that it is not because your doctors feel you have a mental illness.

Your GP may recommend an Enhanced Primary Care Plan. This program provides up to five visits to one of these health care professionals, which are eligible for a Medicare rebate. Be aware that there may be lengthy waiting lists to access these types of services and they are frequently only available for a period of up to six weeks.

You can access the entire Parkinson's health team through Movement Disorder Clinics. These are specialist programs offering the combined services of doctors, nurses, physiotherapists, speech therapists, social workers, occupational therapists and dieticians. Staff all offer expertise in managing Parkinson's, which means the clinics are able to

offer a comprehensive Parkinson's assessment and treatment plan.

Unfortunately there are currently only a few clinics operating in Victoria, although more are being developed in both metropolitan and rural areas. To find out more about these services contact our health team.

## **Helping yourself**

Maintaining or working to improve your general health is a very important part of managing and living well with Parkinson's.

Remaining positive, healthy eating and regular exercise will assist in promoting wellbeing.

Engaging in managing your illness is vital. Ensuring you take your medications as directed by your treating doctor, **on time, every time**, is an essential rule to live by. Many people report that using a prompt to remind them to take their medications is helpful (such as a pill timer or a mobile phone alarm). This means you don't have to concentrate on watching the clock.

Become a bit of a detective when considering a new medication or therapy. Do some research, read information about it and discuss it with your neurologist, especially the therapy's pros and cons. Similarly, if you are considering a complementary therapy, such as acupuncture, find out if there is any validated or independent evidence to support its use in relation to Parkinson's.

Your neurologist may discuss research studies with you or you may read about them in **Signpost**. Consider participating in these Parkinson's research opportunities, which may include diagnostic, new therapies or quality of life studies.

Research will aid in learning more about the mysteries of Parkinson's and the way it impacts upon all aspects of life. It will also assist in developing new treatments, and hopefully one day, in finding a cure. Comprehensive documents are available for you to read if you are considering research participation and will explain exactly what is involved. Our health team is also able to assist with information and advice.

**Remember our job is to assist you in managing and living well with Parkinson's. If you need help, advice or have a question about anything in relation to your Parkinson's, the staff at Parkinson's Victoria are here to help. In addition, the health team makes regular visits to communities and support groups across the state, ensuring we are able to recommend services in your area, or ways that you can access a metropolitan service.**

# Young Parkinson's

*During the 2008 Parkinson's Australia National Conference in Sydney, KATE WARD shared her inspiring story about living with Parkinson's. We are pleased to be able to publish her presentation in this edition of Signpost (with permission) and hope you too will be inspired by her words and actions.*

Let me tell you about one special day in my life and about my journey with Parkinson's disease.

My name is Kate Ward and I was diagnosed with Parkinson's in September 1999.

I am currently a committee member of **YOPSSA: Young Onset Parkinson's Support Group of South Australia**, and am working part time at Parkinson's SA as the Office Administrator.

Part of my job is answering calls from people recently diagnosed with or seeking information, direction or help on Parkinson's.

Because I have been involved personally and indirectly with people who have Parkinson's, I feel I have a unique perspective on what a person goes through when they are newly diagnosed.

What I hope to impart today is that people who are newly diagnosed need to be given some direction, hope and help in establishing where they go from here whilst they are reacting emotionally to the diagnosis.

Advising a patient of the diagnosis can be challenging to professionals, who are working within tight time constraints and are aware that the diagnosis itself can make it difficult for people with Parkinson's (PWP) to assimilate a lot of information. Some professionals are able to do this with care and understanding, but in my experience, and from talking to other PWP, a lot of professionals struggle.

To make this clearer, I would like to give you a personal example of what happened to me on the **"Day that turned out nothing like I planned"**.

I went to the local doctor because I was having severe migraines due to menopause, and happened to mention that at night, while sitting down watching TV or reading a book, the little finger on my right hand "twitched".

The doctor directed me to a neurologist, "*Just to check out what was going on*". (We'll call the neurologist "Dr X" for the purposes of this discussion).

After doing some finger exercises, walking up and down, tapping toes etc, Dr X gave me an "in depth" description of Parkinson's disease, *including the stantia nigra, corpus striatum, dopamine receptors*

*and neurons, most of which went over my head, and as you probably noticed - I can't even say properly!*

I was speechless. I thought Parkinson's was an old person's disease and really knew nothing about it! I was only 49 years old for goodness sake! My mind went blank whilst at the same time raced around a million miles an hour.

Dr X talked for about 20 to 30 minutes, and to be honest, I was *floored* (so to speak) and took in almost nothing regarding "the diagnosis" ... until near the end, when Dr X advised me of 3 things:

1. I had approximately 5 – 10 "good" years left.
2. I should go home and get my "things in order"
3. I would probably end up with dementia. \*\*\*

Dr X said I did not need medication at this time, so I should make an appointment to come back in 6 months time to "review the situation" - and then he walked me to the door!

He gave me no written information, nor did he direct me to a support group or the local Parkinson's association. And, I remember the words that stuck in my mind were "degenerative disease" and "no cure".

How can a so-called specialist do that to a person, and not give them something to hold onto? This is a thought I continue to wonder about when I hear similar stories over and over again.

I drove home that day, but I don't know how I got there. I just remember thinking, "I'll have to divorce Tony. He's too young to be saddled with a person who is going to get dementia." (And by the time I got home I'd convinced myself that I could already see the signs, after all, I couldn't remember driving home!)

What about my children? I'd decided that we would move to a smaller house where there wouldn't be enough room for them so they wouldn't be lumbered with a sick and ageing parent (I guess the divorce was off at this point!).

My life, in the space of 2 hours, had been totally turned around, and I had begun what was to be an emotional rollercoaster ride, guided by no-one and driven by a crazy person who was in complete emotional chaos!

I pulled up in the driveway and looked out the front of the car. Tony was working on his Holden, pulling out an engine. He took one look at me and dropped the engine back into the car, and with that one look I was a blubbering mess.

"What's wrong?" he said over and over again. I couldn't bring myself to talk coherently and it was about 30 minutes before I spilled it all out.

Neither of us was prepared for such a bombshell, and neither of us knew how to cope. After all, the neurologist said to come back in 6 months and all I was equipped with was a few sentences I remembered him telling me.

We decided not to tell my family until we got a handle on it, but later that day I rang my brother Ed (whom I am very close to) and the minute I heard his voice I broke down and cried. He was a rock, but his wife Mel said that when he had finished talking to me, he cried too.

You can probably imagine the state I was in, and all I can say is that it took me a 2-year journey before I approached Parkinson's South Australia and subsequently **YOPSSA**, and finally took control of my life as a person living with Parkinson's.

I was lucky my whole family were so supportive, loving, understanding and caring in all that I was going through.

It has only taken minutes to relate to you two years of emotional hell, which I believe many, many PWP have also experienced.

I haven't told you my story to make you feel sorry for me, but as I mentioned before, I have spoken to others who have experienced similar situations, particularly with regard to "what to do next?" and this is what I would like to focus on.

In reflecting on my experience I realize that I was in no fit state to retain any of the information imparted to me by Dr X and had I received:

- written literature on Parkinson's with some direction as to making contact with an association (such as Parkinson's South Australia),
- recommendation of continuing (or beginning) a fitness program and its benefits,
- suggestion of joining a support group,
- details regarding specialist services such as physiotherapy, exercise groups and massage, and lastly,
- information about Parkinson's disease, possible medications and their benefits and pitfalls ...

Then I probably would have handled being diagnosed with Parkinson's a whole lot differently.

You are probably aware that Parkinson's associations throughout Australia receive little, if any, government funding.

Most of you here today are either a PWP, a family member and/or carer, or a professional. You are somehow "touched" by Parkinson's, so you know that more needs to be done, funding needs to be found and government backing and support needs to be had.

"But, what more can I do?" you might ask yourself. "Oh no!" you might be thinking; "I'm going to be asked to volunteer/donate/work more. How do I get out of this hall without being seen?!"

Not at all, there are a couple of simple things you can continually do such as:

**Every time** you see your neurologist ask them if they have brochures to hand out on Parkinson's disease and suggest they contact their local Parkinson's office to obtain some. Perhaps relate your experience (or feel free to relate mine) or you could take a current brochure from your local Parkinson's office along for them to peruse (and let them know how useful it has been to you).

You can pressure your representative in Parliament for their support and more government funding. Just talk to your local Parkinson's office and they can direct you on what they are doing so you can support their efforts.

It must be **our** voice who complains, whinges, wheedles and coerces to have our plight heard, just to be treated equally and along the lines of other debilitating illnesses.

***The more proactive we are now the easier the journey will be for those who follow us, remembering those who follow might be our family or friends.***

We here today can choose the path of least resistance, or we can go out screaming and kicking. I know which one I'm going to do. So don't just sit there and do nothing. Make your voice count!

Thank you for listening.

**Kate Ward can be contacted at:**  
[office@wardscm.com](mailto:office@wardscm.com)

***Want to know more about how you can make your voice count? Contact Parkinson's Victoria or consider becoming a registered member of the organisation.***

***\*\*\* Health team's note: Parkinson's is a movement disorder and does not mean individuals will also be diagnosed with dementia. With support, information and specialist treatment, people with Parkinson's can continue to enjoy a long and productive life.***

# Access, Advocacy & Assistance

The “Triple A – Access, Advocacy and Assistance” assist individuals and families to **live well with Parkinson’s**. This includes knowing your rights, being able to access financial, peer and professional support, and making the most of available assistance. It also means empowering you to play an active part in managing your condition, providing you with opportunities to have your voice heard, and influencing decision makers and the community at large to ensure greater understanding and support for the Parkinson’s community.

## Staying in touch

If you have a disability and are unable to access the standard telephone handset, you may be eligible for specialist equipment from **Telstra’s Disability Equipment Program**. (Most products can be rented for the same annual rental charge as a standard telephone handset).

For example they have a big button/multi-purpose phone designed for those with a vision or dexterity impairment. This phone is ideal for people who have difficulty holding a telephone handset, reading or dialling numbers, or being heard over the phone.

The phone features buttons which are double the size of a standard phone and a flashing light for incoming calls. There is also an adjustable voice aid to amplify **outgoing and incoming** speech.

**For more information about the big button phone or other products from the Telstra Disability Equipment Program, or to find out if you are eligible to access this service, contact Telstra’s Disability Enquiry Hotline: 1800 068 424.**

## Carer financial support

### What is the Carer Allowance?

The **Carer Allowance** is a fortnightly payment paid to carers who provide daily care and attention for an adult who is frail aged or has a disability or severe medical condition.

The Carer Allowance is not subject to the Income and Assets Test and is not taxable. It may be paid in addition to a Carer Payment (see below) or another pension or benefit such as the Aged Pension.

### What is the Carer Payment?

The **Carer Payment** is an income security payment paid to carers who are unable to support themselves through work, as a result of their caring

## Breaking down the myths

A simple but effective way to advocate for Parkinson’s is to help dispel some of the most common misconceptions.

### Myth: Only old people get Parkinson’s

Fact: Parkinson’s affects up to 20,000 adults of all ages in Victoria, and approximately 80,000 nationally. Nearly 20 percent of those diagnosed will be of working age.

### Myth: It’s just the shakes

Fact: Parkinson’s is more than just the shakes. In fact, 30 percent of people diagnosed experience no tremor at all. While tremor is a common symptom, other major symptoms include stiffness, sore muscles, and slowness of movement or changes to walking. Other symptoms can include sleep disruption, changes to handwriting, anxiety and depression. The wide range of Parkinson’s symptoms means a doctor may miss the signs of Parkinson’s when they

present and as a result the condition may go undiagnosed or be misdiagnosed for months or even years.

### Myth: People with Parkinson’s also get dementia

Fact: Parkinson’s is a **movement disorder** that affects the brain’s ability to co-ordinate smooth movement. People with Parkinson’s are still able to think and make decisions about their life. Parkinson’s can, however, affect how quickly or loudly a person can communicate.

Having a diagnosis of Parkinson’s also does not make you immune to other conditions such as dementia and unfortunately, some people are diagnosed with both.

### Myth: People with Parkinson’s can control their symptoms

Fact: Parkinson’s symptoms can fluctuate throughout the day according to medication absorption and cycles.

**People are not able to control when this**

# Access, Advocacy & Assistance

role. People who receive a full or part Carer Payment get the same concessions as other pensioners, including the Health Concession Card. The Carer Payment is means and assets tested.

Not all carers are eligible for the Carer Allowance and/or Carer Payment.

**For further information, to find out if you are eligible or to apply for the Carer Allowance or Carer Payment contact Centrelink: 132 717.**

**Alternatively, contact Carers Victoria who can also advise on applying and appealing decisions: 1800 242 636.**

## Government Concessions

Did you know that the Victorian Government offers a range of concessions that make key services more affordable to low income households?

Most State Government concessions are available to individuals and families who receive income support payments from the Commonwealth Government and who have an appropriate Commonwealth concession card such as a Pensioner Concession Card, Health Care Card or an appropriate Department of Veterans' Affairs Gold Card.

For example, the **Medical Cooling Concession** provides a 17.5 percent discount off electricity costs over a six month period from 1 November to 30 April each year.

To be eligible, a member of a household must have a condition that impairs the body's ability to regulate its own temperature. (Parkinson's is recognized as such a condition), and has either a Pensioner Concession Card, Health Care Card or Veterans' Affairs Gold Card.

**For a copy of the publication *State Concessions: Your Entitlement*, which provides a comprehensive overview of all available concessions (including those affecting utilities, public transport, hearing, taxi services and municipal rates), eligibility and application processes,**

**phone: 1800 658 521**

**or email: [concessions@dhs.vic.gov.au](mailto:concessions@dhs.vic.gov.au)**

**The publication can also be viewed and downloaded online at:**

**[www.cyf.vic.gov.au/concessions](http://www.cyf.vic.gov.au/concessions)**

**Editor's note: Information regarding *State Concessions* has been reprinted from the above publication.**

***happens and therefore cannot control their symptoms.*** (Taking medication **on time, every time** can help make this pattern more predictable).

### **Myth: Parkinson's is fatal**

**Fact:** Parkinson's is not fatal. It is a progressive condition with symptoms worsening over time. However, new treatments are constantly being discovered to help improve quality of life. With support, information and specialist treatment, such as physiotherapy, speech therapy and allied health services, people can live a long, productive life.

For a copy of the fast fact sheets ***Living with Parkinson's – The Challenge*** or ***Living with Parkinson's in Multicultural Australia***, contact Parkinson's Victoria. For more information about Parkinson's in Australia facts, figures and funding, visit the **Media and Advocacy** section at: [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au)

## Make sure your voice is heard

Become a member of Parkinson's Victoria and be counted when it comes to lobbying Government for improved services and funding. You'll also become part of a unique and supportive community.

Membership entitles you to receive your own copy of our quarterly newsletter Signpost; free access to our library resources (books, DVDs, videos) and discounted tickets to attend various functions throughout the year.

Most importantly, registering as a member provides us with valuable statistics about the prevalence (incidence and demographics) of Parkinson's in Victoria, which are vital when lobbying Government for improved services on your behalf.

**Contact our office to join up today.**

# Research

## Can a sleep disorder predict Parkinson's?

*There is expanding clinical and research interest in the association between Parkinson's and sleep disorders. Neurologist KATYA KOTSCHET explains.*

Research studies have shown that some features of Parkinson's, such as sleep disturbance and altered sensation of smell, may develop several years before the clinical diagnosis of Parkinson's can be made. In the future, these could be important markers that enable an earlier diagnosis of the condition, which will be important as neuroprotective treatments are developed and become available.

One of the most common sleep disorders associated with Parkinson's is REM sleep behavioural disorder (RBD), where there is lack of muscle paralysis that

usually occurs during REM sleep (or 'dream' sleep). This means that dreams may be acted out, with kicking and shouting out. A recent study (*refer to article on this page: New Research into Sleep Disorders & Parkinson's*) reviewed the risk of developing a neurodegenerative condition, such as Parkinson's, after a diagnosis of RBD has been made, and considered the risk to be as high as 40% after 10 years. Unfortunately, we are still unable to predict which patients with RBD are more likely to go on to develop Parkinson's, but this remains an important area of ongoing research.

Interestingly, patients with RBD are noted during their dream sleep to have minimal "parkinsonism", with their movements being faster and smoother, and their speech being louder and clearer, than during their awake state. This provides interesting insight into brain connectivity and regulation in Parkinson's.

## New research into sleep disorders & Parkinson's

Scientists at Sacre-Coeur Hospital at the University of Montreal believe that increased risk of Parkinson's can be predicted relatively accurately up to 12 years before the first muscle tremors appear, in **some** individuals who experience a particular sleep condition. (Based on research they conducted, results published in the journal **Neurology**)

People diagnosed with an unusual sleep condition called REM sleep disorder...physically act out their dreams by kicking, screaming and even harming themselves and others lying next to them...

"We have been aware of the potential connection between REM sleep disorder and these diseases for some time, but this is the largest and longest study to estimate the true risk of getting Parkinson's and other neurodegenerative diseases if someone has the sleep disorder," says Dr. Ron Postuma, the study's author and a neurologist at Montreal General Hospital.

The trial involved nearly 100 men and women with an average age of 65, all diagnosed with REM sleep disorder.

During normal sleep, our muscles become paralyzed when we enter the REM, or dream state, which explains why inside our dreams, we occasionally feel as if we can't move or are operating in slow motion. People with REM sleep disorder, however, never achieve this muscle relaxation, and researchers now believe that this could be the first sign of Parkinson's. The latest thinking on the disease holds that the uncontrolled movements that are the hallmark of Parkinson's

are only the latest and most advanced sign of the disease, the final stage of a 10- or 20-year gradual decline in nerve function.

In fact, experts believe that the condition actually begins with a loss of smell and a degeneration of nerves in the olfactory tract, then proceeds to the gut and brain stem. At some point along this march, the nerve damage hits the pons, a region in the brain that regulates sleep. "So in Parkinson's, there is a period that we don't know how long it lasts, in which the neurons are dying in the brain, just not in the motor areas," says Postuma. "And sleep is an area where this degeneration occurs, indicating that the process of Parkinson's has started."

Postuma stresses that **REM sleep disorder is a rare condition not to be confused with the tossing and turning that most of us do every night.** People with the condition have vivid movements nearly every night, and unlike those who sleepwalk or sleeptalk and remain confused for a bit after they awake, these patients are completely alert and oriented once they wake up.

REM sleep disorder itself can be treated with medications, but those drugs won't slow the decline in nerve function that's responsible for Parkinson's. But identifying the disease at this earlier stage may help scientists come up with newer ways of protecting the motor neurons from further damage. "We don't have agents now to stop the degeneration of Parkinson's," says Postuma. "But once we have those agents, as far as I'm concerned, every patient with REM sleep disorder should be taking it."

**Source:** <http://www.time.com/time/health/article/0,8599,1868646,00.html>

## Calling volunteers

Research study seeks volunteers to join an exercise trial for the Michael J Fox Foundation research grant.

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 Essendon commencing in March or April 2009.

Physiotherapy, occupational therapy and social groups are being offered at these centres as part of this research project.

People attend once per week for a two hour therapy session for 8 consecutive weeks and are measured before and after therapy, three months later and 12 months later.

**If you would like further information please contact Mary Danoudis or Illy at the University of Melbourne: 1800 428 688 or (03) 8344 7715.**

## 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 living with Parkinson's to be part of the control group).

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](mailto: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).**

**Q: My neurologist has recently reviewed my Parkinson's medication and replaced Cabaser with Sifrol. I have noticed my health has deteriorated as a result. What should I do?**

**A:** Many people with Parkinson's have recently experienced this medication "swap" of dopamine agonists\*, from Cabaser to Sifrol by their neurologist.

The most likely reason for the neurologist making this change is that the latter has been identified as a safer option. Sifrol is non-ergot derived and avoids side effects associated with Cabaser, which can cause some changes to the tissues in the heart and lungs.

In addition, Sifrol has different dosing schedules and can be administered up to 3 times a day (Cabaser dose is once a day), depending on what your neurologist recommends.

Typically, new medications are introduced gradually, increasing doses over time until the correct (effective) dose is achieved. This may take some days or weeks. During the transition to Sifrol, you may initially notice an increase in the severity of Parkinson's symptoms, however this should subside once you reach the prescribed dose.

**Changes to medication can take up to 6 weeks to take full effect**, so try to be patient. If you find that after this time you are still not functioning as well as you were on your previous medication, speak to your neurologist. They may need to make some simple changes to your medication regime.

In addition, during the transition phase you may wish to scale down certain activities and take some precautionary measures such as avoiding long drives, and being aware of your medication cycle and "on" and "off" times.

However, if you notice any adverse reactions such as rash, significant worsening of symptoms or pain, you should contact your neurologist as soon as possible.

If you have any other concerns, feel free to give Parkinson's Victoria a call to discuss your situation.

\* **Dopamine Agonists** work by stimulating the parts of the brain where dopamine works, and unlike levodopa medications, do not require conversion by the brain cells first.

**Do you have a question about Parkinson's? We welcome questions from people living with Parkinson's, carers, family members or health professionals, about anything from diet, medication and mobility aids, to symptoms and side effects, access and assistance or lifestyle.**

**Send your question to: [amanda@parkinsons-vic.org.au](mailto:amanda@parkinsons-vic.org.au). Names will not be published.**

# Tulip Tributes

## Thanks to a valued leader

Parkinson's Victoria would like to thank Jan Hickmott who generously put her hand up to assist in establishing Swan Hill's first Parkinson's Support Group, two and a half years ago.

Jan worked at the Carer Support Service and added leadership of the Support Group to her role. Unfortunately, Jan has recently had to resign from her position as Carer Support Worker.

We are pleased to announce however that the Swan Hill group will continue. (Carer Support Service Site Leader Joanne O'Rourke has agreed to be the interim contact person for the group until a new leader has been appointed).

**We would like to formally acknowledge and thank Jan and Jo for their ongoing support.**

## Italian hospitality

In December last year, our Client Services Coordinator, Amanda Spillare, was privileged to attend a presentation hosted by the Italian-Australian Club, **Villa Adriana**.

The meeting brought together more than 70 people from the local Italian community and gave Parkinson's Victoria the opportunity to introduce our new multilingual resources.

Amanda offered the audience an overview of Parkinson's and our services and Ginetta Bianchin gave a moving speech about the personal affect Parkinson's has had on her as a carer and her family.

**We would like to thank the club for their fundraising efforts and contribution towards raising awareness and understanding of Parkinson's in the community.**



Villa Adriana members Ginetta Bianchin (centre) and Lynette De Bona (far right) presented Amanda Spillare with a cheque for \$750 to support the work of Parkinson's Victoria.

## Singing their praises

There could have been no more appropriate atmosphere for the launch of our Parkinson's multi-lingual resources than that created by Julian Yu playing the **Erhu** (a traditional Chinese two-stringed instrument), accompanied by his partner Marion Gray on piano (shown top right performing during the launch). The launch took place at the Melbourne Town Hall in November, 2008.

Julian, diagnosed with Parkinson's four years ago, is an accomplished composer, whose work featured in the Beijing Olympics opening ceremony. He and Marion also assisted in the development of the new resources.



**We thank them for their contribution to the project and the launch and for their music on the day.**

## Sharing the message

As part of our mission to **Bridge the Gaps** by providing Parkinson's information in languages other than English, we have begun presenting a series of information sessions to people from specific cultural and language groups in Victoria.

The first of these targeted the Arabic speaking community. Organised in conjunction with Arabic Social Services, around 50 men and women of all ages gave Parkinson's Victoria staff and Ambassadors a very warm welcome.

Attendees were particularly appreciative of our two Ambassadors, Fred Van Ross and Jill Goss, and commented that they gave hope and encouragement to people with a range of illnesses.

Fred also shared his personal story with approximately 70 members of the Russian-speaking Jewish community at a separate event.

**Thank you Fred and Jill for sharing your journeys.**



Staff and Ambassadors from Parkinson's Victoria, staff from Arabic Social Services and the local community showcase our new multilingual resources.

## Lending a hand

Anne Atkin from the **Painting for Parkinson's** art group and members of the **Narre Warren Painting with Parkinson's** group would like to give Jeremy and Andrea Hrubos a big Tulip Tribute for their recent support.

# Tulip Tributes

Jeremy, a picture framer with a stall at the Acoonah Park Market (Berwick), has offered his creative and professional skills to the group at a greatly reduced rate and creates stunning frames and backdrops for the group's growing collection of "masterpieces".

## *Extra assistance always appreciated*

A special thanks goes to Marion Roberts, who has been instrumental in distributing copies of the re-published GP manual to GPs and clinics in her local area.

Marion has spent recent months personally visiting clinics to hand deliver the manual. **Marion, thank you for your ongoing support and encouragement, and your enthusiasm to make a difference in whatever way you can!**

## *Inspired to give... Thanks!*

Late last year, staff from Aviva's Protection First team presented Parkinson's Victoria with a generous cheque for \$1500, as part of the company's **Inspire to Give** project. **On behalf of all those who benefit from our programs, which donations such as these help fund, a BIG Tulip Tribute to the Protection First Team!**



Aviva's Protection First Team present Victor McConvey from our team (centre) with a cheque for \$1500 to help fund our support and information programs.

## *Ovation for two special women*

In November 2008, the inaugural Tulip Ball was hosted by two amazing women – mother and daughter team Julie Sewell and Jo Hill.

Earlier in the year, Julie and Jo approached Parkinson's Victoria with their idea to create a special event that would raise funds and understanding about a cause close to their hearts: Julie's husband John, Jo's father, was diagnosed with Parkinson's in 2000.

And what an incredible success it was. The event raised more than \$36,000, funds that will go directly towards our support and information programs. Julie and Jo put together a wonderful program to both move and educate people about what it is

like to live with Parkinson's, ensuring the cause they were there to support was never far from their minds.

The event was attended by Glenn Mahoney, CEO Parkinson's Victoria and Marketing Coordinator, Judith Mooney, Board member and our Ambassador Coordinator Peter Raymond gave a moving and entertaining speech about his own journey with the condition, which had a powerful effect on all guests.

Julie, Jo and their network of helpers went to incredible lengths to create an amazing experience for guests; from the WOW factor of the beautifully decorated South Yarra Tennis Club to the fantastic array of donated prizes, right through to the great music and delicious food! Each guest also received a "goodie bag" filled with treats and information about Parkinson's.

Events such as this take a lot of hard work to make happen. Julie and Jo dove into the task with a sense of creativity, fun, professionalism, sensitivity and commitment to ensure the event was enjoyable and successful one for all involved.

**Thank you Julie and Jo, and to your team of helpers! Your support is a most valued contribution to our work in the community, and your energy and efforts are inspiring!**



From left: John and Julie Sewell, Glenn Mahoney, Judith Mooney, Peter Raymond and Jo Hill.

## *Parkinson's Victoria Movie Club*

Do you love going to the movies? Are you keen to support Parkinson's while having a great night out with family and friends?

Register to become a **Parkinson's Victoria Movie Club Member** today and receive invitations to attend special Charity Screenings of the latest and greatest releases for 2009.

These special fundraising events will help raise funds to support our information and support services. Tickets \$20 will include nibbles.

**Upcoming movies: The Reader, mid-February screening (Actress Kate Winslet is up for an Oscar for her performance) and Angels and Demons, May screening (Tom Hanks stars again in this sequel to The DaVinci Code).**

**Contact Judith: (03) 9551 1122 or email [judith@parkinsons-vic.org.au](mailto:judith@parkinsons-vic.org.au)**

## Living well & running hard

*JOHN BALL was diagnosed with Parkinson's at 39 years of age. He is now 64, and has recently completed his 20th marathon. John co chairs 'Team Parkinson' in America, raising awareness and funds for Parkinson's research.*

*The following is an extract from John Ball's keynote presentation to the Parkinson's Australia National Conference in October 2008.*

I've lived with Parkinson's for over half my life, so what have I learned from it?

**Lesson number 1:** I am not defined by my disease. I have Parkinson's. It doesn't have me. It's just something that happened to me, like having blue eyes or losing my hair. I don't believe that God designed it as a punishment for my shortcomings or a test of my character. It is just an obstacle to be overcome, and I choose whether to be a victim or a victor.

As I was preparing to retire from my career as a training manager at American Honda, someone asked me why I got Parkinson's. I tried to explain that scientists are still looking for the cause of PD when she stopped me and said, "I know why you got it." I looked at her and said, "Then would you please tell me." She said, "Because you're going to do something about it." That brought me to a complete stop. Even if she was right – the question remained: what could I do about it?

Here's what I decided to do:

Take care of myself first. I know that sounds selfish, but it's like they say on the airlines about the oxygen mask. You won't be able to take care of others if you don't take care of yourself first. That means living a healthy lifestyle. A healthy lifestyle includes eating a good diet, balanced nutritional value, not overeating, not drinking to excess, getting as much sleep as possible, keeping stress to a minimum and all the other good habits that healthy people live by. It also means learning which foods impact my medications, and when to take my meals so they do not interfere with my medications. And, most importantly, it means paying attention to my level of fitness and staying strong.

Fitness and strength are huge assets when it comes to dealing with Parkinson's symptoms. I know that my fitness level controls how much I can do and

how much I have to off-load to family, friends or caregivers. I can be a lot less burdensome to others if I take care of myself first. I have to be willing to put in the hard physical work required to stay in top shape. For me that means running between 5 and 10 miles regularly, riding my bike, doing my back and upper-body exercises because if I just let it slide, even for a short time, I know I'll get injured and I know I'll be in pain. (Hey, did you notice in the news a couple of weeks ago? Doctors have recently discovered through a large scale survey of PD patients that there is pain associated with PD! Can you believe this is news to anybody?) Believe me the pain of injury is far greater than the pain of working out. And the time I spend on my exercise is more than paid back by the strength I have as a result and the things it allows me to get done. And, to be honest, running and riding also allow me to satisfy some of my social and competitive needs as well. One more thing: it's the only thing that is entirely under our own control. As far as which exercise is best for Parkinson's; it's the one you like the best and will do most often. A good exercise for PD will include duration, complexity and intensity. That can be anything from swimming to weight lifting, tai chi to tango.

I also decided to become part of a community. This took me some time to figure out, because I thought I was quite successful in dealing with my Parkinson's by myself. It took me several years to figure out that I really wasn't dealing with it by myself. Everyone around me at home and at work was dealing with it as well. None of us with chronic illness can deal with it in isolation because it affects everyone around us, particularly those closest to us. I am not a big worrier about the future, but does that mean my kids weren't worried about how long their Dad would be able to work, whether there would be money enough for college, whether I will need a lot of care on their part as I grow older? There are so many questions that they were probably afraid to ask. And how about those who depended on me at work? How much trust could they extend when PD made it difficult to predict how much I could get done day-to-day? Or how long I would remain at work? So I had a lot to learn about how my Parkinson's affected those around me, and I didn't really learn that until I connected with others living with this disease.

I went more than 10 years after my diagnosis before

I attended my first support group meeting. And I went, finally, not because I thought I needed something, but because I was invited to speak about running the marathon. I thought I had something to teach, and what I discovered was that I had so much more to learn. Once I connected to the patient community, I began to truly learn how complicated it is to live successfully with this condition.

The third thing I did was to identify Parkinson's as a cause worth living for and dedicating myself to. It wasn't enough for me just to join the community - I needed to become an advocate for it. I believe that you really can't make a difference if you don't show up...So I try to be a part of everything that has a bearing on the PD community. I go to every meeting or support group I can. If I can get there I'll be there. I have called on the US Congress each of the last ten years with the Parkinson's Action Network (PAN) to put a face to this disease and made sure that my voice was there to be heard. That's also why I've I'm happy to be here today, because I know I can't make a difference if I don't show up.

In 1999, it was that same sense of commitment to a cause that led Mary Yost and a few friends, including Edna and me, to form Team Parkinson. Team Parkinson was created to serve two goals: to raise awareness of the impact Parkinson's disease has on society, and to help raise the money needed to find a cure. In addition, it's become an opportunity to inspire others to take on challenges of their own. I think we're doing that with some success. We have been an official charity of the LA Marathon for 9 years, and in that time we have raised over \$1.5 million dollars for research. Oh yes, we've also had 15 people with Parkinson's finish the full 26.2 mile marathon. This March we had five PWP finishers for the second time.

**Lesson number 2:** I also learned to decide for myself what's really important for me to keep in my life and what to be willing to give up. I loved riding motorcycles and flying airplanes for example. And when I was diagnosed with Parkinson's the doctor said I had to give up my aircraft medical certificate and he told me to get rid of the motorcycle. I did so because I didn't know any better. I went ten years without riding or flying, and then learned that I didn't really need to. Ten years after my diagnosis of Parkinson's I was still able to pass a flight medical

exam and my flying privileges were restored. I had to learn the hard way that many times people will recommend that you give up the more challenging aspects of your life, and think they are being kind to you, when in reality they may be taking much of the joy from your life. I learned to decide for myself what I can or can't do. That doesn't mean I just ignore the advice of my doctors or my family when they say I shouldn't do something, because some things are genuinely risky because of PD, like wood working. Yes, I lost part of my thumb, but I'm going to keep my woodshop going as long as possible.

**Lesson number 3:** I learned how to adjust my targets and expectations as my capabilities change. I know that Parkinson's has eaten away at my productivity. I know I'm no longer able to multi-task like I used to. I recognize that I am less able to get everything done in a day than I was 10 or 15 years ago. Hey, I can blame it on PD or I can blame it on being 64, but it doesn't make any difference; nor does it do any good to shift away the responsibility. If I think something is important, then I need to make sure it gets done. That doesn't necessarily mean I have to do it myself...it may mean that I have to empower someone else to do it. It may mean that I have to give that person absolutely clear instructions and a good reason to want to take care of it. It may also mean that I have to be honest with myself and ask for help when I need it. In other words I have to look at my total resources available to get the important things done. And I have to deploy those resources like a good manager to make sure that the goals are achieved. I may have Parkinson's, but that doesn't mean I have nothing more to do in life.

**Lesson number 4:** I need to keep growing and taking on new skills and new challenges. Our world is changing all around us constantly, and I want to be able to grow with those changes. Not only that, but my Parkinson's symptoms are constantly changing as well. I have to be prepared to adapt my ways of doing things as my condition changes. That means I have to have the right tools in my tool kit. What I mean is that we have all assembled over the course of our lives the habits of thought and action that make us comfortable in handling life on a daily basis. Just like my garage and workroom are full of hand tools for my woodworking and model airplane building, my head is full of tools for managing work that can be applied to dealing

with PD. Primary tools include problem solving and decision making skills learned in flight training and business management courses; my strength and fitness; my wonderful wife and kids; and my leadership skills acquired over a lifetime of work. Those skills work just as well at managing PD as they did at managing a department. My tool kit also includes my neurologist, Doctor Mark Lew, and a wonderful team of support personnel, including the physical therapists, exercise physiologists, and Lori, my masseuse.

Another powerful set of tools in my kit are my medications and my understanding of how they work. I have developed my personal cocktail of Sinemet, Comtan, Zelapar, Mirapex and Amantadine. I wouldn't recommend it for anyone else in particular, but it works for me. Another vital tool is my knowledge of this disease, because I think it is important to know as much as I can about this Parkie that lives within me. That's why I say, "It's not the guy with the most toys that wins; it's the guy with the most tools." If I keep all these tools at my fingertips, and keep them sharp and ready to use, how can I not succeed?

**Lesson number 5:** Parkie can be a devious companion to deal with, and he doesn't always come straight at you. I'm talking about depression. It's part of PD, and for many of us, it is part of life. I'm not just talking about having the blues; I'm talking about being clinically, and chronically sick. Depression can strip you of your most comfortable tools. It can take away your logic and fog your perception of reality. It can dull your senses and blur your feelings to such an extent that you mistake pain for pleasure and abuse for love. It can make you hate this life you normally love. It can also make you terribly ineffective at work and unable to achieve the goals you set or those your management sets. I have been there. I have felt the urge to give up, to give in to the longing for release and take that swan-dive from someplace high. Don't let it do that. I did recover...it just took some new tools in my kit. I found I needed to expand my doctors' circle to include a psychologist, and needed to include an anti-depressant in my medications list for a while. I also enlisted the help of friends and family to correct my misimpressions and help me see reality. I also needed to cast aside those feelings of guilt and unworthiness. It wasn't my fault for having PD, and I wasn't to blame for being depressed. It's just another symptom of this

disease. It isn't our fault for being sick, but we do have to take responsibility for our recovery. We are each responsible for our own happiness, and we are each responsible for making our lives worthy of the gifts we've been given. I tried to do that in my working career, and I'm still trying to do that through Team Parkinson. I'm still fundraising, and training hard for my next marathon, which will be my 20th overall and my fourth this year, on November 16th in Pasadena.

**Lesson number 6:** Looking at it realistically, I would have to admit that the challenge of Parkinson's disease is a mixed blessing. Yes, it's a sly and challenging companion to live with, and a constant threat to wreak havoc on my future, but I have learned so many things I might have missed had it not slowed me down and made me aware of what was at stake. I might have missed the many incredible friendships and the truly wonderful people I have met because of it. A year ago, I gave a lecture on PD at Whittier College, and afterward a student asked if I thought my life was better or worse because of Parkinson's. I had to admit that I am very happy with my life, and I believe it is richer and more meaningful because I have found a community to care about and focus on.

It has taken me more than a dozen years to put all these thoughts together in a book about this experience. It's called **Living Well, Running Hard: Lessons Learned from Living with Parkinson's disease**. It goes into a great deal more depth and detail about running and hiking and living this experience. It's available through the publisher, Author House, and through retailers on the web like Amazon and Barnes and Noble

Let me finish by reminding you of something I learned in Boy Scouts. My scoutmaster always said "Leave the campsite cleaner than you found it." ...Well, I've both simplified that, and expanded it. My goal in life is to leave this world a better place than I found it. That's easy to say, but a lot harder to accomplish... It's kind of like running the marathon, it takes lots of practice and preparation, and even when you think you're ready, there is still a lot of work to be done, but I think it's worth the effort.

**John Ball**

**The complete speech can be viewed at the Team Parkinson website:**

**<http://www.team-parkinson.org/news.php?ID=39>**

*Our volunteer librarian ANNE ATKIN, who was diagnosed with Parkinson's in 2005, reviews some of the most popular books on our resource shelves.*

We've had some excellent new additions to our library at Parkinson's Victoria in recent months, but in this edition's library column, I've decided to revisit some classics which have stood the test of time.

### ***Eat well, stay well***

This is a brilliant book when it comes to nutrition and what to eat when Parkinson's gives you such a variety of symptoms and problems.

It's easy to read, easy to understand and the advice offered is easy to follow. Never read it? Good heavens! Ring me now and I'll send it out to you! It's also well worth having your own copy (contact the office to order).

### ***Parkinson's at your fingertips, Parkinson's disease: a team approach and Moving ahead with Parkinson's***

These three titles have one thing in common... actually two: Professors Meg Morris and Robert Iansek.

When you see a book with those two names you just **know** you are about to read something that will actually help you!

They are books you don't have to read from cover to cover. You can simply 'dip' into them and find some little piece of information that grabs you. For example, I no longer try to carry too many things in my arms (resulting in falls and pulled muscles). Now, I carry everything I want in a backpack or a "bum bag" (which I actually wear on the front). They keep my arms free and I keep better balance.

***If you're interested in borrowing any of these titles you can contact Anne at Parkinson's Victoria on Thursday mornings.***

### ***The Icecream Boy***

Peter Dawkins, whom many Australians will know from his stellar career in the local music production scene, has lived with Parkinson's for some 20 years. Peter was appointed the first CEO of Parkinson's NSW in 1994, and held the position for six years.

***The Icecream Boy*** is Peter's first-hand account of his fight to keep working in the face of increasingly severe symptoms, a fight he eventually lost when forced to retire early.

Peter also recounts his experience as one of Australia's first patients to undergo deep brain stimulation (DBS) to combat Parkinson's symptoms.

***The Icecream Boy*** is available through Parkinson's NSW (\$24.95 + \$6 postage). A CD compilation of some of Peter's most well-known music productions is included. (02) 8875 8900 or email: pnsw@parkinsonsnsw.org.au

### ***Australia Day Honours for Parkinson's Volunteer***

Congratulations to Anne Atkin, our resident librarian, founder of the Narre Warren **Painting with Parkinson's** art group and workshops, and tireless Ambassador for Parkinson's, whose voluntary service to the community was recently acknowledged with a **2009 Holt Australia Day Award**.

The Holt Australia Day Awards recognise the significant contribution that volunteers make to the community, sporting and service organisations in the local area and surrounding region.

The Federal Member for Holt and Parliamentary Secretary, Anthony Byrne MP, stated in a letter to Anne: "I would like to officially recognise your work and thank you for the role you play, volunteering your time and making such a valuable contribution to the local community. It is through the work of volunteers that many of our local community, service and sporting organisations exist and you join a long line of outstanding recipients."

Anne was invited to attend the City of Casey Australia Day celebrations in Doveton, where she and other recipients of the award were presented with their certificates.

***Congratulations Anne! And thank you for all you do in support of people with Parkinson's and on behalf of Parkinson's Victoria.***

### ***Upcoming Parkinson's Art Exhibition***

***Expressions of Colour*** is an exhibition of the work from students of the Narre Warren Painting with Parkinson's Art Group.

The opening will take place at **Libra Dogma Gallery**, Abeckett Road, Narre Warren North (look out for the gallery's street sign) on Saturday 4 April at 2.00pm. All welcome.

Viewing times will then be Fridays, Saturdays and Sundays through the month of April 2009.



***Above: Anne Atkin with Anthony Byrne MP during the 2009 Holt Australia Day Award ceremony.***

# Our Supporters

Thank you to our supporters who generously made donations in recent months. Listed below are the names of those who kindly donated \$200 or more between 16 October (2008) and 12 January (2009), 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.

## Donations \$200 and over (individual)

Roy Allen  
Bronwyn Andrews  
Stephen Brown  
Mark Busby  
Donald Collins  
Richard Court  
Andrew Edis  
John & Jane Edwards  
Bill Esman  
Robyn Gooley  
Doris Grinlington  
Mario Grollo  
Warwick Hall  
Elva Hosken  
John Howden  
N & Y Lancaster  
Fiona Lourey  
Tom Matthews  
John McCarthy  
J McDonald  
Christopher McEvoy  
Norman McKendrick  
Gagandeep Kaur  
Moorad  
D & J Morrison  
KG & BAM Neill  
Roger Nixon  
Mrs Odgers  
Andrew Padula  
JD Perkins  
June Pigott  
John Shawley  
Alan Stevens  
Bob & Barbara Swift  
Takako Subocz  
Leslie Trickey  
Jack & Joan Wallis  
Lee Webster  
Brian & Margaret Weeks  
Stuart Westerman  
Valerie Young

## In Memory of...

Lina Armato  
June Bollard  
Shiela Broydell  
Dulcie Campbell  
Rita Chivers  
Sylvia Christensen  
Margaret Collins  
Bill Deneys  
Geoff Dunmill  
Coral Edis

Don Gillon  
Rob Hicks  
Joe Hughes  
Roy Hunt  
Maria La Francesca  
George Laband  
Betty Lawson  
Alan Leslie  
Kenneth Lipzker  
Carol Milan  
Joan Miller  
John Odgers  
Anthony Ord  
Betty Price  
Kate Sangaletti  
Vin Sier  
Miriam Stubbey  
Franciscus Van Den Boom  
Ralph Varnes  
Margaret Williams  
Charles White

## Team Parkinson's Challengers

The following members of the Challenge have already raised more than \$92,000!

Leanne Barnes  
Edward Beesley  
Maxwell Bradfield  
Sue Dutton  
Clare Eizenberg  
David Gibson  
Kim Harris  
Nahid Jones  
Brendan Lourey  
Karyn Spielberg  
Nicholas Taylor  
Fred Van Ross  
Christine Van Ross  
Catherine Watson  
Jenny Young

## Corporate, Community & Other Donations & Support

Alliance Australia Insurance Ltd  
Australian Air Express  
Aviva  
Beaconhills Christian College Ltd  
BKB Environtech

BKB Pumps & Tanks Pty Ltd  
Bunnings (Moorabbin)  
Charity Greeting Cards  
City of Casey  
CommInsure  
Dallas Primary School  
Doctors of Ivanhoe Pty Ltd  
EyeConnect Pty Ltd  
First Valuation Group  
Handorf's Fine Chocolates (Black Rock)  
Her Majesty's Theatre  
Industrial Supply Group Pty Ltd  
Link Pumps  
Lions Club,  
Broadmeadows  
Lions Club, Coburg  
Lions Club, Footscray  
Maroondah City Council  
Meadow Heights  
Learning Shop (Visy Cares)  
Melbourne Welsh Church  
Memorable Challenges  
Shepparton South Rotary Club  
St Andrew Opportunity Shop  
Ticketek  
Treloar Roses  
Villa Adriana  
Waverley Apex Club  
World Expeditions

We also thank those who supported our 2008 Christmas card Campaign by purchasing our cards, and especially the

following businesses for purchasing corporate Christmas cards:

Complete Mailing; Florey Neuroscience Institutes; Imagine - Accounting & Finance Resourcing (AFR); and Maroota Printing; and

Thanks also to the following community groups who assisted in selling our Christmas cards in 2008:

Camberwell Combined

Charities Christmas Card Shop (CAMCARE); Kingston Centre Gift Shop; Mornington Community Information & Support Centre; St Paul's Combined Charities Christmas Card Shop; and the Shepparton Parkinson's Support Group.

## Team Parkinson's (Auxilliary Fundraisers)

The Tulip Ball (organizers: Julie Sewell & Jo Hill)

## Grants, Trusts & Foundations

The William Angliss (Vic) Charitable Fund

## Bequests

The Estate of the late Ellen Ethel Wilson

The Estate of the late Suzan Winifred Johnston

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

In addition, we would like to thank all those who generously supported our 2008 Annual End of Year Appeal.

If you would like to make a tax deductible donation today, please contact our office or donate securely online at [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au)

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

## Let's talk about it

*Many people find that speaking to others about their experience of Parkinson's can be an invaluable and enriching experience. Not only can it help to verbalise some of those questions that linger in the back of your mind, but it can also offer other people valuable insights into coping that they may not have considered.*

Our 47 affiliated Support Groups are a forum for meeting with other people living with Parkinson's. They are run by volunteers who may be a health professional or person living with Parkinson's.

Guest speakers are often arranged to speak on a topic of interest and benefit to the group, but the best learning point is from speaking to other people facing the same situation as you!

Support Group meetings are typically informal and there is plenty of time to ask questions of the speaker and mingle with the others.

You may also meet people in the group who have had Parkinson's a lot longer than you, or who have different symptoms than you. Don't be afraid. No two people with Parkinson's are ever the same and it is important to remember that everyone's journey is unique.

Joining a support group can be a good way to share information, make friends and hear advice. Parkinson's Victoria runs support groups for people living with Parkinson's, their carers and friends all across Victoria.

**If you are interested in attending a support group in your area, or would like to find out more about support groups and the value of peer support, contact our health team: (03) 9551 1122 or 1800 644 189 (country callers).**

## Caring for Carers

*Anyone, anytime could become a carer and there is help, advice and support available to assist in this role.*

Caring for a person who is frail or aged, or for someone who has a disability or a mental health issue involves many ordinary people doing extraordinary things.

The caring role can be compounded by lack of information and limited knowledge of what assistance is available.

Empowering carers to make realistic, informed decisions, knowing what is available and what to expect in the role, can help and enhance the caring experience for all involved.

Carers Victoria has developed a wide range of workshops which provide carers with:

- Information sessions about "navigating the (support) system"
- Wellbeing sessions exploring the importance of caring for yourself
- Advocacy sessions highlighting assertiveness and having your say
- Sessions about the journey in caring and strategies to support them in their caring role.

**If you would like a brochure on Carer Victoria's Calendar of Events for 2009, or for more information contact Carers Victoria: (03) 9396 9500 or freecall 1800 242 636. Alternatively, email: [carereducation@carersvic.org.au](mailto:carereducation@carersvic.org.au) or visit the website: [www.carersvic.org.au](http://www.carersvic.org.au)**



*Rhonda Kennedy (front row with flowers) with members of her family and the Bendigo Support Group.*

## Farewell to a favourite

Parkinson's Victoria is sad to say goodbye to Rhonda Kennedy, a very valued friend, volunteer and 2007 **Sir Zelman Award Winner** for service to the Parkinson's community.

Rhonda has been the dedicated Leader of the Bendigo support group for the past 20 years, coordinating group meetings, outings, speakers and special events. Glenn Mahoney, Parkinson's Victoria CEO, who attended Rhonda's farewell in December 2008, said the admiration for Rhonda among the support group members was clearly evident.

Rhonda has had to retire from her role due to personal reasons, and will be greatly missed by group members and staff of Parkinson's Victoria.

The group will continue to meet, no doubt with Rhonda never too far from their thoughts and actions!

We wish Rhonda our best wishes and hope her health improves quickly.

**Good luck Rhonda!**

# Education & Information

*Get your diaries ready: Parkinson's Victoria is coming to a location near you in 2009.*

## *Health Team road trips*

Every year, our health team visits members of our 47 affiliated support groups during their monthly meetings.

These visits are a great opportunity for interested members of the community to meet and speak with our health team, and to hear a special presentation.

If you are not currently a member of a Parkinson's Support Group and would like to experience a meeting, or simply want to learn more about the condition and meet with others in a similar situation, all in the convenience of your local community, this is a great time to do so.

**To find out when our team is visiting your nearest Support Group (from the list below) contact our office, speak to one of our health professionals and register your interest to attend. They'll be able to confirm dates and further details with you.**

## **Health Team 2009 Support Group Visits**

### **Metropolitan:**

- Bentleigh
- Camberwell
- Eltham
- Essendon
- Frankston
- Monash/Glen Waverley
- Werribee
- Box Hill
- Cranbourne
- Epping
- Forest Hill
- Melton
- Ringwood
- Young at Park

### **Rural:**

- Bairnsdale
- Bellarine Peninsula
- Bendigo
- Charlton
- Colac
- Geelong
- Horsham
- Lakes Entrance
- Mildura
- Orbost
- Rosebud
- San Remo
- South Gippsland (Leongatha)
- Stawell
- Wangaratta
- Warrnambool
- Yarrawonga
- Ballarat
- Benalla
- Bright
- Cohuna
- Echuca
- Hamilton
- Kyneton
- Mansfield
- Moe
- Portland
- Sale/Maffra
- Shepparton
- Swan Hill
- Warragul
- Yarra Valley

## *Community seminars & research updates*

Major seminars will take place for the first time in 2009 throughout metro Melbourne, and our annual regional seminar is scheduled for Ballarat in September.

These seminars will feature presentations from Associate Professor David Williams and members of our health team.

Our annual research update from a leading Melbourne neurologist (as part of our Annual General Meeting) is also a popular event.

A must-attend event for those diagnosed with Parkinson's in the past five years, as well as their family is the **Parkinson's Victoria Recently Diagnosed Seminar**. In 2009, it will again take place during National Parkinson's Awareness Week (31 August – 6 September).

This is an in depth but sensitive introduction to Parkinson's. Come along and learn more about the condition, treatment therapies and how to 'live well' with Parkinson's. Hear and talk with experts from the health industry, including neurologists, and meet other members of the Parkinson's community.

**Further details regarding locations, dates and registration for our community seminars will be published online at [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) and in future editions of Signpost. If you would like to register your interest today, please contact our health team.**

## *Upcoming PSP seminar*

Have you or a family member been diagnosed with Progressive Supranuclear Palsy (PSP)? Would you like to meet other people living with PSP, develop support networks and hear the latest in research and treatment therapies from a range of specialists?

**INSIGHTS into PSP**, a free community event, will provide you with credible and useful information and answers about this poorly understood neurological condition.

Event details: **Insights into PSP**

Date/Time: Wednesday 4 March, 2009.  
10.00AM – 2.00PM

Venue: Bethlehem Hospital, Conference Room (3rd Floor) 476 Kooyong Road South Caulfield (Melway reference: 67 J7). Free parking available on the corner of Saturn Street and Kooyong Road.

RSVP: 19 February, 2009

Numbers are limited and registrations are essential. Please register your attendance by contacting Parkinson's Victoria: (03) 9551 1122 or [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au)

**Looking for PSP support?** PSP Australia provides advice, group meetings, advocacy and fundraising for PSP research. To find out about their next meeting at our office,

contact Anne: [damooney@bigpond.com](mailto:damooney@bigpond.com) or email [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au)

**What is PSP?** PSP was first recognised as a disease in the 1960s by Dr J C Richardson. The condition affects nerves and causes problems with balance, speed of thinking and eye movements. Some of the symptoms are similar to those of Parkinson's