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Express yourself

Anne Atkin, founder of the Painting for Parkinson's group, recently organised an exhibition of group member's artworks.

Expressions of Colour, was generously hosted by Libran Dogma Gallery, Narre Warren.

While the budding artists were considerably nervous about being "on show", the first-time exhibition of their work and the event overall was a great success, if the number in attendance and the number of SOLD stickers on various works was anything to go by.

Anne Atkin shares the experience...

"I have no doubt some of my students felt a bit self-conscious; after all, going to a studio and painting is one thing, but putting those paintings in the public arena is another thing altogether. And with a price tag!

But on the day I was stunned when people started arriving early. More people came. And more! The little gallery was full and then it happened...a RED DOT. A painting sold! I WAS RAPT.

My group stood and the word spread. Val sold a painting! Val got the giggles (not an unusual thing with Val). Then, Val sold another painting!

Parkinson's Victoria CEO, Glenn Mahoney was a guest, and like many people who see these paintings for the first time, he was taken by surprise by the bold colours and vibrancy of the paintings. So another painting sold.

Anthony Byrne, local Federal Member of Parliament for the seat of Holt, performed the official opening, and we were overwhelmed that Nancy Tingey, the founder of **Painting with Parkinson's ACT** came all the way from Canberra and gave a speech.

At the end of two hours, in between lots of food, champagne and red dots, a total of 13 paintings were sold!

As the opening of the exhibition wound up and the Narre Warren **Painting with Parkinson's** group finally left to go home, they did so with a smile on their faces, a glow in their hearts and the words of gallery owner, Di Lockwood, in their ears; that this had been a "ten out of ten opening!"

Keith, one of Anne's art students commented, "I have no previous experience of this area and it came as a pleasant surprise. It has shown me that even I, with no artistic background can contribute - particularly as a person with Parkinson's. Anne, you have helped me by providing tools that help me relax and reduce my tremor."

The **City of Casey Arts Newsletter** featured an article on the exhibition:

"Painting with Parkinson's is art therapy for Parkinson's. Parkinson's is a complex, progressive, chronic, incurable and often disabling condition that can make life so difficult that many simply withdraw from social activities.

Through careful, planned pre-painting activities and specially chosen materials, people living with Parkinson's can express their creativity in a way they would not have expected. It can help with relaxation, lowering stress levels, and help manage depression. It can also help give greater confidence and improve self-esteem.

Behind these paintings are many hours of experimenting with different art materials and learning that, while Parkinson's has taken so much from their lives, art can give it back in many different ways. This exhibition is a celebration, not only of the creativity this group has discovered about itself, but also of the beautiful expressions of color as seen through the eyes of people living with Parkinson's."

Expressions of Colour remained on show for the remainder of April. We congratulate Anne and her students on such a wonderful achievement and wish them continued colour and creativity in their lives! On their behalf, we also thank Di Lockwood of Libran Dogma Gallery, for her generous and ongoing support.

"During each session I am able to relax and put all of my thoughts into expressions of colour". Glensy Douglass, Painting for Parkinson's art group, pictured with Tony, who purchased one of her artworks.



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.

Here you'll find some of the latest and most important news and announcements affecting the Parkinson's community.

Drug therapy News Flash

Duodopa is a unique form of **Dopamine replacement therapy**, which comes in a gel form and is infused directly into the area of the intestine (the *jejunum*) where its uptake by the body is most effective.

Duodopa is best suited to people who have been living with Parkinson's for several years and who have difficulties with unpredictable motor fluctuations (referred to as "on/off" periods).

Duodopa is available in more than 30 countries worldwide, and in Great Britain, Sweden, the Netherlands and Germany it is available through the country's national health services.

Recently Solvay, the company that markets Duodopa in Australia, submitted an application to the government for the drug to be listed on the Pharmaceutical Benefits Scheme (PBS), thereby entitling consumers to a significant subsidy on prescriptions. Unfortunately, this application was not successful.

A representative from Solvay has confirmed to Parkinson's Victoria the company's commitment to Duodopa, and stated it will continue to support the **Compassionate Use** program, funding the medication for those who participated in the trial. It also intends to re-submit an application for PBS listing in the future.

PSP Australia seminar

In March this year, PSP Australia and Parkinson's Australia hosted **Insights into PSP**.

The event brought together 70 families who were keen to learn more about this poorly understood condition,

connect and share experiences with others who are living with PSP, and gain some valuable insights into how to best manage symptoms and maintain quality of life.

Keynote speaker, Associate Professor David Williams, had organized a "special guest" of his own and attendees were surprised and delighted when Professor Williams introduced, by phone link up, Dr John Steel.

Dr Steel, who is one of the primary researchers into PSP, answered questions about the condition from his base in Guam.

The event was moving, inspiring and supportive for all involved. A follow up seminar for allied health professionals who work with people with PSP is being planned for late 2009.

The majority of PSP information and support is currently generated by the PSP Support Group, based in Victoria, so it was not surprising to see guests arrive from interstate. As a result, and another positive outcome of the event, a PSP Support Group is now being established in South Australia (Adelaide).

Progressive Supranuclear Palsy (PSP) is a condition that affects nerves and causes problems with balance, speed of thinking and eye movements. Some of the symptoms are similar to those of Parkinson's, including a general sense of "slowing down", changes in hand writing, unsteady walking and loss of motivation. Although most patients with PSP do not develop tremor and do not improve with Parkinson's medications, many are misdiagnosed as having Parkinson's because of the similarity between the two conditions. PSP was first recognised as a disease in the 1950s by Dr J C Richardson.

For information and support about PSP, contact Parkinson's Victoria: 1800 644 189.

Parkinson's Australia and PSP Australia have recently released a new resource to assist people in understanding Progressive Supranuclear Palsy (PSP).

The booklet provides a basic introduction to the condition, and includes brief information on symptoms, treatments (although like Parkinson's, there is no treatment for the actual condition, only to alleviate some of the symptoms), statistics on prevalence, information for carers and where to find help.

In addition, a "first-of-its kind", comprehensive PSP resource kit is currently in production for Australians living with PSP. This will be available soon through the office of Parkinson's Victoria (for a nominal charge). PSP is a chronic, progressive neurological condition with a similar prevalence to Motor Neurone Disease, approximately 1300 Australians are currently diagnosed.

New resource for newly diagnosed

As a prelude to World Parkinson's Day (11 April), Parkinson's Victoria launched a new resource for newly diagnosed and their families on 2 April.

The Journey: Understanding and Learning to Live with Parkinson's combines a DVD with a series of Information Help Sheets, and aims to address questions and concerns most commonly raised by people recently diagnosed.

The DVD is a locally made product, featuring neurologists and health professionals, as well as personal stories from people who are living with Parkinson's and their partners.

The resource was launched during a community seminar held at the Florey Neuroscience Institutes to commemorate World Parkinson's Day. Prior to the launch, more than 100 guests had the opportunity to hear presentations from Professor Mal Horne and Dr Kate Kotschet on Parkinson's and stem cell research.

Production of the Journey DVD was made possible through a generous grant from Allens Arthur Robinson

If you or a family member has been recently diagnosed with Parkinson's, this resource is an ideal starting point for information, guidance and understanding. It provides sensitive, reliable and thoughtful information from both a professional and personal perspective. If you would like a copy of this free resource, please contact our office.



Alicia Silvio and Dominie Banfield from the Allens Arthur Robinson Charity Committee and Glenn Mahoney, Parkinson's Victoria CEO (centre left) and keynote speaker at The Journey launch Professor Mal Horne, from the Florey Neuroscience Institutes.



Participants from The Journey resource project who shared their stories in the DVD. From left: Peter Raymond, Anne Atkin, Shane Murphy, Marion Roberts, Brendan Lourey and Karyn Spielberg.

Membership news

For the first time in seven years, the cost of Parkinson's Victoria's annual and lifetime membership subscriptions will increase.

From 1 June 2009, the annual membership subscription will increase from \$24 to \$30.

The corresponding financial life membership fee will increase from \$240 to \$300, from the same date.

While the organization has been able to bear the increased printing and postage costs of our newsletter and annual report over the past seven years, the Board has determined that we are no longer able to continue to absorb the increased costs.

We would like to highlight that Membership with Parkinson's Victoria is still excellent value, at just \$2.50 per month, and we encourage you to continue to support your peak organisation with ongoing membership. If you are not a member, please consider joining today.

Members receive four copies of Signpost magazine each year, are informed of upcoming seminars and events, receive a copy of our Annual Report, and importantly, become part of an organisation making a difference for people living with Parkinson's.

A message from our CEO

Information: Still a valued resource

Parkinson's Victoria CEO GLENN MAHONEY waxes lyrical about humble beginnings, the information age and being inspired to "always look up".

Recently, I had cause to try to find a computer that still accepted a floppy disk, to no avail. Do you remember floppy discs? In the 80s and early 90s we marvelled at the amount of information a floppy disk would hold. Today, my memory stick, which is smaller than my little finger, has a greater memory capacity than my first computer!

When Parkinson's Victoria was established in 1981, music was played on cassettes and records. The CD took over in 1982, and today we have the ipod.

We have seen an emergence of new technologies over the past decade like never before: Internet, Message Boards, Mobile phones, SMS, MP3 files, Torrents, Dongles, GPS, Youtube, Blu-ray, Blogs, Facebook, Twitter: What would they have thought we were talking about twenty years ago? In fact, some of you may be wondering what I am talking about right now!

Successful organisations harness new technologies: but technology is the tool, not the end in itself.

A lot has changed since our humble beginnings more than 25 years ago. Despite all of the changes, some things have remained the same. Our beginnings were based on a desire to make a positive difference in the lives of people living with Parkinson's - and that continues today.

We need your support to **continue** to make a difference. Today, I am asking you to help us by making a donation to Parkinson's Victoria. All donations over \$2 are tax deductible. If you are unable to make a donation, please consider making a gift that continues to give by remembering Parkinson's Victoria in your will. If you would like further details, please ring me on (03) 9551 1122.

A reply paid donation envelope is enclosed for your convenience.

Michael J Fox was recently interviewed by talk show host Oprah Winfrey on her program **Oprah**. The two were discussing his new book, **Always Looking Up: The Adventures of an Incurable Optimist**.

Excerpts of the interview were broadcast here in Australia on **A Current Affair** on 1 April. His outlook on life is an inspiration to all.

For those who may not know, Michael J Fox, now 47, was diagnosed with Parkinson's disease in 1991 at the age of 30. While he is now known for his work advocating and fundraising for Parkinson's research, Michael initially became a household name during his years as an actor, most notably in the hit sitcom **Family Ties** and the **Back to the Future** film series.

While there is insufficient room in this publication to allow the full transcript, several comments he made during the interview may be inspiring and insightful to **Signpost** readers.

Though Michael has learned to accept his illness and embrace life, he says there are still days when he thinks, "This sucks."

He goes on to say, "Having said that, somebody said to me one time that happiness grows in direct proportion to your acceptance and in inverse proportion to your expectations"...[In other words, I say] "Well, this is what I have today. Now, I didn't have a choice about this, but I have a million other choices I can make today: I can choose where I go, who I see, what I look at, what I take in. If I make good choices about all that, then I will be a happy person."

When he first made it big, Michael says he was "Michael, the actor". Then, he became "Michael, the actor with Parkinson's". When he left Hollywood, he wondered if he would just be "Michael, with Parkinson's". But, in fact he has become much more.

"Parkinson's is one fact of my life, but it's not the totality of my life: It doesn't define me. I am a father, a husband, an activist, a writer and I'm just a student of the world".

The transcript of the interview can be found at www.oprah.com and A Current Affair's nine minute excerpt of the interview is available at www.youtube.com.

Always Looking Up: The Adventures of an Incurable Optimist is available from Amazon.com and is now available in bookshops, published by Random House.

**Glenn Mahoney, CEO Parkinson's Victoria,
gmahoney@parkinsons-vic.org.au**

Challenge update

CATHERINE WATSON Parkinson's Victoria Community Development Worker and intrepid Team Parkinson's Challenge bike rider, shares some thoughts from her travel diary!

Well, what an experience the **Team Parkinson's Vietnam Challenge** has been! The many months of fundraising and cycling training certainly paid off as the team visited some incredible sights that constitute the beautiful country that is...Vietnam.

15 participants succeeded in the challenge to raise \$6,000, with many far surpassing this amount (the total so far is \$130,000 with donations still coming in!). On 7 March 2009, we were waved farewell and wished good-luck by several of our supporters, Parkinson's Victoria staff and family as we set off on the second part of the challenge – to cycle the length and breadth of Vietnam over 12 days.

The first few days were spent with our mouths agast as we witnessed the crazy local traffic and what seemed like thousands of motorbikes all navigating the roads in various directions at once. Road rules do exist in Vietnam – but one would question if they are merely a suggestion rather than an obligation! Our initial fear of crossing the road was soon overcome as we found ourselves on bicycles, riding amongst the traffic. In no time at all the group were experts in dodging everything from pot holes, rocks, oncoming buses, roaming cattle and everything in between.

The cycling component of the trip consisted of traveling around 60km per day. The riders were an eclectic bunch – from those with a great deal of confidence

on the bike who took it all in their stride, to those who rode less often and really pushed new personal boundaries in lasting the distance.

Everyone was able to experience the joy of riding through a vast array of landscapes: from fields, small villages and larger towns to rubber tree plantations, chaotic road work sites, past historic monuments, down mountains and through stunning valleys. Being greeted by children, waving and saying 'hey-lo' along the way was something the group never tired of.

The Team Parkinson's Vietnam Challenge can only be considered an incredible success as everyone achieved not only the official Challenge of fundraising, but also various personal challenges each had set for themselves, including the physical challenge of cycling through Vietnam (and it's weather, poor quality roads, traffic...) and being out of one's comfort zone.

To all those who supported the Challengers in their fundraising and awareness raising efforts, **Thank you.** The encouragement along the way meant a lot.

Putting on my Parkinson's Victoria hat, on behalf of the organisation, congratulations to all the challengers. Know that your hard work will make a real difference in the lives of people living with Parkinson's, through the work of Parkinson's Victoria.

Keep on peddalin'
Best wishes,
Catherine Watson
Parkinson's Victoria...and Team Parkinson's Challenger

Editor's note: The Team Parkinson's Challengers will be officially thanked and "Welcomed Home" during a special event in May.



The girls and tour guide "Hilly" get cosy in the cabin of a local train during an overnight trip.



The bike riders take a break from riding and take in the vista of the local countryside.



Team member Max is joined by some shy, but friendly school girls.



The Team, getting ready to set off again, stop for a group cheer.



The Team pose in front of the museum dedicated to the life and deeds of Ho Chi Minh. (Ho Chi Minh served as Prime Minister (1946–1955) and President (1946–1969) of the Democratic Republic of Vietnam (North Vietnam). The city formerly known as Saigon was re-named in his honour in 1975.)



Team member Nahid takes a break to pose with this almost life size stone elephant!

Parkinson's in the news

Making headlines

it hasn't been too hard to spot Parkinson's in the media spotlight lately, thanks to World Parkinson's Day, proactive supporters, exciting initiatives and some savvy media staff who realise the value in highlighting the many facets of Parkinson's.

Some media hits we've had recently include:

Highlighting our initiatives:

- **S2S HealthNews** highlighted the launch of our new multi-lingual Help Sheets, information brochures and posters.

S2S Health News is an online interactive noticeboard for health workers and professionals to share news, events, activities and education notices.

- **The Albury Wodonga Regional GP Network Newsletter** highlighted the re-release of **Parkinson's disease: A General Practitioner's Approach**, an initiative of Parkinson's Australia's, helping to increase the uptake of this critical resource.

Highlighting Parkinson's creativity and events

- Anne Atkin's **Painting with Parkinson's** group continues to be a drawcard for the media. Anne has conducted several sessions with Parkinson's Support Groups around Victoria and the **Mildura Weekly Times**, **Bairnsdale Advertiser** and **Berwick and District Journal** have all featured stories about the group, highlighting not only the artwork, but importantly the physical, mental and emotional benefits of this very creative 'therapy' for managing Parkinson's.
- **Expressions of Colour**, the Painting for Parkinson's art exhibition was also written up in the City of Casey Arts Newsletter. (Read more about the exhibition on page 1).
- In April, the **Waverley Leader** featured a story on a dynamic and creative young woman who has organized **Cure the Masquerade**, a cocktail party with all funds raised going to Parkinson's Victoria.

Vesna's mother Duja has Parkinson's, so she knows first hand the impact that the condition can have, not only on the individual, but also on family members.

Understanding that there is not enough support

for those living with Parkinson's, Vesna was inspired to "make a difference" with this creative event that highlights one of the common symptoms of the condition; "facial masking".

The party took place on 2 May at Arco Restaurant, Heatherton and, while the final figures are not yet in, Vesna hopes the event has raised close to \$14,000. We look forward to updating you in the next **Signpost**.

Editor's note: Vesna is one of several younger supporters who are keen to make a contribution but want to do so in their own way, rather than simply making a donation. If you would like to organize an event to raise money for Parkinson's Victoria or if you're keen to help but don't know where to start, please contact our Marketing Coordinator: judith@parkinsons-vic.org.au

- Tony Rowe, a talented local artist held his first exhibition in March at Brighton on Bay and was written up in the **Bayside Leader**. (Read more about Tony's exhibition on page 10).
- And Sarah MacDonald who "pedaled from Sydney to Melbourne for Parkinson's" in February was featured with the Sale Support Group in the local paper and on regional ABC radio.

Not forgetting the airwaves, Parkinson's Victoria was recently approached by two radio stations to discuss Parkinson's for the benefit of their listeners.

- On Monday, 9 March this year (Labor Day), Glenn Mahoney, CEO and Marketing Coordinator Judith Mooney joined presenter Keith Horner for his one hour program **The Disability Shop** to talk about Parkinson's, funding, Parkinson's Victoria's role and how the community can support our work. (**3RPP, Radio Port Phillip 98.7 FM.**)
- More recently, we coordinated an interview between Associate Professor David Williams and Dr John D'Arcy for the latter's **Health Matter's** radio program. The interview aired on 61 rural and regional stations nationally on the Macquarie Southern Cross network. Although this interview was only brief, we have since received a number of calls from the public, from as far as Queensland, requesting information about Parkinson's, specifically our recently launched resource **The Journey**, which Dr D'Arcy promoted during the interview.

- In March, Professor Mal Horne was also

Parkinson's in the news

interviewed for a segment on Parkinson's on 3AW's **Talking Health** program with host Sally Cockburn.

- And...earlier this year, we were able to secure advertising space in the **Melbourne Weekly Eastern**.

And, overseas...

- Michael J Fox has been on the publicity trail, promoting his new book **Always Looking Up**, as well as responding to US President Barack Obama's recent decision to lift the ban on embryonic stem cell research.

Have you seen or heard Parkinson's in the media lately? Drop us a line and let us know or post us the article: judith@parkinsons-vic.org.au or (03) 9551 1122, free call 1800 644 189 or post to: 20 Kingston Road Cheltenham, Victoria 3192.

And, keep an eye out for...Unity Walk and National Parkinson's Awareness Week (30 August - 5 September)

The main focus for National Parkinson's Awareness Week is to enhance our ongoing efforts to:

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

National Parkinson's Awareness Week provides Parkinson's Victoria with the opportunity to connect with the community, raise much needed funds to support our information and support initiatives, and to highlight Parkinson's and the needs of those living with the condition. We utilize the media and public forums to do so.

Awareness Week also provides members of the community with an ideal opportunity to make a contribution and to get involved in a wide range of activities.

Throughout Awareness Week, Parkinson's Victoria will host a number of events, including educational, fundraising, media, community and awareness activities. In addition, many of our affiliated Support Groups, located throughout Victoria, and a number of supporters, will be conducting fundraising and

awareness raising activities of their own in their local community, workplace and social network.

How will you celebrate and acknowledge National Parkinson's Awareness Week this year?

Start planning now! There are loads of different ideas for how you can support one of our organised events, or how you can create your own and get active promoting Parkinson's in your community.

- Organise a **Party for Parkinson's** to raise awareness and funds with your local community, workplace or social group.
- Organise a Team to join **Australia's Unity Walk for Parkinson's** on Sunday 30 August at Federation Square.
- Ask us for an Awareness Kit and approach local service providers or your workplace to ask if you can create a Parkinson's display.
- Contact your local media with a Parkinson's-related story idea.

To find out how you can raise awareness or fundraise for Parkinson's during National Awareness Week, or at any time, please contact Marketing Coordinator, Judith Mooney: (03) 9551 1122 or judith@parkinsons-vic.org.au

UNITY WALK FOR PARKINSON'S

Sunday 30th August 2009

Starting at Federation Square at 12 midday

Four kilometre walk along the scenic Yarra River walking paths (A two kilometre route is also available).

WE NEED YOUR HELP

We need sponsors: If you know of any companies willing to become a sponsor, please contact Judith Mooney judith@parkinsons-vic.org.au or (03) 9551 1122.

We need celebrities: Celebrity participation equates to media coverage. Who do you know? Contact Judith if you can assist.

We need participants: Please tell your friends and family about **Australia's Unity Walk for Parkinson's** and encourage them to participate.

Support Australia's Unity Walk for Parkinson's and help raise money for research and services.

Research

The path to discovery

Research into Parkinson's, including studies exploring the cause of the condition, quality of life and symptom management strategies, improved medication, and of course a cure, continue to take place around the world.

Parkinson's Victoria heads to Europe

This June, with the support of the Board of Parkinson's Victoria, our Parkinson's Specialist Nurse Consultant, Victor McConvey, will attend the **Movement Disorder Society** conference in Paris.

This conference, which focuses specifically on Parkinson's and other movement disorders, is acknowledged as the world's foremost opportunity to hear and participate in the debate over treatments and research about Parkinson's.

The benefits to be gained from a representative of Parkinson's Victoria attending this conference include engaging with leading Parkinson's health care professionals, and returning with the most up-to-date information about treatments, management and research supporting and involving people living with Parkinson's.

A note from Victor:

From a personal, professional perspective, attendance at this conference represents a significant contribution to my professional development, and I would like to take this opportunity to thank the Board of Parkinson's Victoria and in particular, President Royce Peppin, for their support in assisting me to attend this conference.

The Spring edition of *Signpost*, will include details for a special presentation by Victor, entitled *Postcards from Paris*, where he will share his learnings from the conference.

International congress

The World Federation of Neurology (WFN) **XVIII World Congress on Parkinson's Disease and Related Disorders** will be held on 13-16 December, 2009 in Miami, USA.

This year, the event celebrates half a century as a leading international summit for clinicians, researchers, and allied healthcare professionals worldwide seeking real solutions to improve the long-term outcomes for people living with Parkinson's.

Over 3,000 participants are expected to attend this biennial Parkinson's congress - the 18th organised by the WFN 'Research Group on Parkinsonism and Related Disorders.'

For more information about this event, details about registration and a comprehensive list of topics that

the congress will address, visit: <http://www2.kenes.com/parkinson/Pages/Home.aspx> or email: parkinson@kenes.com

Improving care in residential facilities

*Professor Bob Iansek and Margarita Makoutonina work extensively with people with Parkinson's (PWP) through **Elsternwick Private Hospital and the Clinical Research Centre for Movement Disorders and Gait.***

Aiming to improve the care of Parkinson's patients while in care, they recently conducted a pilot study in 9 facilities across Melbourne to determine whether (1) the knowledge base of staff in relation to Parkinson's issues could be improved and maintained, and (2) if so, what impact, if any, might this have on the level of care. (Specifically, "improved care" was determined in relation to mobility, mood, energy, ADL function (ability to perform general activities of daily living), quality of life and falls reduction.)

In developing their approach, Iansek and Makoutonina identified that the 5-7% prevalence of Parkinson's in nursing homes (relatively low), combined with the importance of expertise in the management of such a specialised condition (including medication issues and the benefits of complementary therapies such as physical therapy), expertise which may be lacking in some staff, may be factors which impact on the quality of life of residents, their dignity and self-esteem.

An education curriculum was developed for facility staff, based on the Victorian Comprehensive Parkinson Program (VCCP). The program emphasises the care needs of PWP and utilises a rehabilitation approach that enables PWP to undertake activities irrespective of medication effectiveness.

The program, which included a general knowledge component, rehabilitation strategies, and how to access relevant service expertise, was delivered on site to 118 staff and the results encouraging.

Assessment of the program, gained through resident (and family) and staff questionnaires, showed that not only was staff knowledge increased and patient care significantly improved as a result of the education program, but that the knowledge base and improved care was maintained over the following 12 months.

It is understood that this study is the first of its kind to address the issue of care provision in residential facilities for PWP, and the first to focus on staff education as a means to improving care in facilities. The researchers acknowledge that this study was limited and recommend that a randomised, controlled and 'blinded' trial be conducted to clinically validate their initial findings.

Participate for Parkinson's

Research opportunities

Participating in Parkinson's research is a unique way to assist further understanding of this complex and mysterious neurological condition. Research aims to improve the quality of life of those living with Parkinson's, and, ultimately, we anticipate, will lead to a cure being discovered.

Parkinson's, employment and quality of life

Researchers Louise Cooper, Dr Simon Knowles and Professor Susan Moore are currently seeking participants to take part in a research project investigating the experience of people with **Parkinson's in the workplace.**

If you are currently in full or part-time employment and have Parkinson's, you may be interested in participating. If you know of someone with Parkinson's who is currently working, you might like to let them know about this important research project.

Participation is voluntary and anonymous and involves the completion of a questionnaire that will take between 15 and 25 minutes. Questions relate to your experience of Parkinson's, your employment, and issues that may be of concern to you at work since diagnosis.

This project is the first to be undertaken in Australia exploring work-related issues that are faced by people with Parkinson's, and what effect these may have on a person's quality of life. It is hoped that data gained from this study will contribute to providing vital information for workers with Parkinson's, their employers and colleagues.

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

Alternatively, you can contact Louise Cooper to request a hard copy of the questionnaire: 0408 051 290 or lcooper@swin.edu.au

Home-based therapy program

Are you keen to stay active at home? Researchers at The University of Melbourne are currently undertaking a study entitled **Home based rehabilitation to reduce falls and disability in Parkinson Disease.** The study will explore the effectiveness of different therapies in preventing falls, improving mobility and quality of life.

Participants will be randomly allocated to one of two groups, both of which will receive therapy in their own homes, once a week for 6 weeks. The first group will receive strength training, movement strategies and a falls-prevention education program. The second group will participate in a "life-skills" education and social activity program.

Participants will be followed up over a period of 14 months, with assessments before and after the

completion of therapy, and then 12 months later.

All therapy and assessments will be conducted in the participant's home.

Am I eligible to participate?

You may be eligible to participate if you

- Have Parkinson's
- Do not have any medical conditions restricting you from participating in an exercise program
- Are willing to receive therapy in your home
- Live in metropolitan Melbourne.

If you are interested in participating in this research study or would like more information, contact Dr Clarissa Martin: (03) 8344 4118 or cmartin@unimelb.edu.au

Young Parkinson's

Are you passionate about issues faced by younger people living with Parkinson's?

Do you get frustrated when people think Parkinson's only affects people in their older years?

Are you interested and able to participate in a research study exploring issues faced by younger people with Parkinson's?

Dr Chris Fyffe is currently conducting a research study, which aims to identify the specific issues faced by younger people living with Parkinson's. The Support Group, Parkies with a Purpose and Parkinson's Victoria are collaborating on this project.

If you are a younger person with Parkinson's, or you care for a younger person with Parkinson's*, you may be interested in being part of our reference group, which will inform our wider research into the subject.

Being a part of the reference group will involve providing your opinion and feedback on different elements of the project. For example, we may ask your opinion on the types of questions that should be included in a survey to the wider community.

Participation may involve attending several meetings and providing phone or email feedback. If you are unable to attend meetings in person, but are still keen to participate, an alternative arrangement can be organised.

To find out more about this valuable and unique research study, please contact Amanda at Parkinson's Victoria: (03) 9551 1122.

*Health Team's note: The term younger in relation to Parkinson's is open to interpretation. "Younger" may mean you were diagnosed at a young age (regardless of your current age) or that you are currently of "working age". We encourage all those who feel they may be eligible to participate in this study, or if you are unsure about your eligibility, to contact Parkinson's Victoria.

Fundraising & Events

The first half of the year has been a busy one for events and fundraising for Parkinson's, and variety has been the name of the game!

Portrait of the artist

On 12 March, more than 120 guests attended the opening night of an exhibition of works by local artist, Tony Rowe, who was diagnosed with Parkinson's in 2000.

Space for the exhibition, **Maritime Expression**, was generously made available by the residents of the Brighton on Bay retirement resort.

"We first heard about Tony's search for an exhibition space late last year. The Brighton on Bay is a luxury retirement resort and a great venue – it sounded perfect for what he was looking for," said Lindy Pickersgill from The Brighton on Bay.

"We were thrilled when he accepted and are proud to have an association with Tony – he has a great talent and is an inspiration to many."

Tony's unique art style is known as figuratism and the exhibition featured a number of works that depict man at play in a maritime environment. The series was influenced by Tony's love for the beach, having spent 25 years as a Surf Life Saver with the Anglesea Life Saving Club.

Both Tony and Brighton on Bay were keen to support Parkinson's Victoria by including the organisation in the event. Parkinson's Victoria CEO, Glenn Mahoney addressed guests during the launch; information was available and on display during the exhibition; and guests were asked to make a donation to Parkinson's Victoria in lieu of an admission fee.

In addition, Tony generously donated the sale from the first artwork sold on the night, as well as proceeds from a raffle of wine from his personal cellar. The exhibition raised a total of \$1865.00 for Parkinson's Victoria, and was a wonderful opportunity to raise awareness of Parkinson's, while celebrating the talents of someone who is living with the daily challenges of the condition.

Tony's creative talent and passion for art is largely the result of a childhood spent in Flowerdale, an area patronised by many landscape artists, including Ambrose Griffin and Frank Kane.

"Artists would leave their oil paintings to dry on the backs of chairs in our lounge and from the age of six I would trot off with junior easel and palette in hand to learn from the masters," Tony said.

"I developed Parkinson's in 2000 and on some days the condition prevents me from being able to speak

so art has very much become my principal means of communication with the public.

"I'm extremely grateful to the residents and staff at The Brighton on Bay for opening their doors and giving me the chance to share my work with the local community. As my first exhibition, it's very exciting and I just want people to leave feeling happy."

Following the opening night launch, Tony's art remained on display and open to the public throughout March.

Parkinson's Victoria would like to congratulate Tony Rowe on his exhibition *Maritime Expression*, and thank him and the residents of The Brighton on Bay for their generous and thoughtful support of the work of Parkinson's Victoria and the Parkinson's community.



Artist Tony Rowe poses in front of one of the works from his Maritime Expressions exhibition.



From left, Charles Lyne, Kevin McKenna, National Sales Manager, Lend Lease Primelife, Tony Rowe with friend and Glenn Mahoney, Parkinson's Victoria CEO.

Fundraising & Events

Get your walking shoes ready!

Could you be a "Walker **Talker**"? **Australia's Unity Walk for Parkinson's will be held at Federation Square on Sunday 30 August.** Over the next few months, we'll be heavily promoting the walk to the wider community.

Registration will be available through a dedicated website and promotional materials will be distributed throughout the state. We are asking all our supporters to engage with their networks to promote the Walk and get behind this wonderful community event!

Please encourage your friends, family, neighbours, school mates, teachers, colleagues, social networks and local business to register to walk or sponsor those who are walking. Why not ask your employer to match the donations you raise!?

You can donate in honour, support or memory of someone, or make a general donation. You can also walk in honour or memory of someone, and the opportunity to create a sign to wear or carry will be available on the day.

Check out Unity Walk New York:
www.unitywalk.org (Youtube Video).

Interested in finding out more about Unity Walk?
Contact judith@parkinsons-vic.org.au
or call (03) 9551 1122.

City commuters reach deep

On Thursday 9 April, staff from Parkinson's Victoria and 35 wonderful volunteers from various walks of life joined forces to collect donations from the general public at Melbourne's city loop train stations.

This year, in just two hours, we collected over \$5800! This is a record for our tin rattle – even beating last year's amazing effort of \$4300! Many donors stopped to chat, ask questions about Parkinson's or share why they were donating; because a family member or friend was living with the condition.

Thank you to our enthusiastic and friendly volunteers and many supporters for their donations.

If you're interested and able to volunteer for our second tin rattle for 2009, which takes place during National Parkinson's Awareness Week on Wednesday, 2 September (also at Melbourne's city loop train stations between 7-9.00am), please contact our office. Experience has shown that the more volunteers we have on hand, the more donations we collect!

Movie magic

Parkinson's Victoria has again partnered with the Classic cinema in Elsternwick to bring you one of the year's most anticipated films!

In May, we're hosting a charity screening of **Angels & Demons**, the sequel to the **Da Vinci Code**. Bring along your friends for a great night out and help raise funds for Parkinson's Victoria.

Event details:

Date: Thursday 14 May, 2009, 8.00pm for 8.45 screening.

Tickets: \$25 (includes pre-film nibbles and wine tasting, popcorn and a soft drink).

Venue: The Classic, 9 Gordon Street Elsternwick 3185

Reserve your seats today by emailing judith@parkinsons-vic.org.au or phoning (03) 9551 1122.

You can also register your details with Judith to receive updates on our Movie Club events straight to your email!

Party for Parkinson's

Party for Parkinson's is a major awareness and fundraising initiative of Parkinson's Victoria that people from all walks of life and ages can get involved in.

Party for Parkinson's has two very important goals and as a host, you will play a vital role in helping us to reach them.

Firstly, you'll help to increase awareness of Parkinson's and to publicise the work of Parkinson's Victoria. Secondly, you'll help raise much needed funds that will ensure people living with Parkinson's have access to the support and information they need.

The funds your Party raises will help Parkinson's Victoria to deliver and develop support and information programs, resources and services. They will also go towards research into the cause and a cure for Parkinson's, and into improving symptom management and medication therapy that will enhance the quality of life of people living with Parkinson's.

If you'd like to host a Party for Parkinson's, contact judith@parkinsons-vic.org.au to obtain you free party kit, filled with everything you'll need to create a fun and successful party!

What do you do?

What do you do when words won't come?
When all inside is pressed down – compact,
Heavy – tight – emotions numbed beyond
Pain.

Tears of long ago could bring relief – but even
tears end, and hopelessness slips into endless
shadows descending...

Joyce Aslangul

Education

Staying informed

Ensuring the community and health professionals have access to credible, current and comprehensive information about Parkinson's is one of our top priorities.

Every year, in addition to our information initiatives and resources, our team conducts a range of education events throughout the state. Often these take the form of community seminars open to the general public, but we also join Support Groups to conduct information sessions, deliver professional development sessions to health and allied health professionals, and facilitate education dinners for GPs around Victoria.

If you are looking for an opportunity to meet our health team, learn more about Parkinson's and symptom management strategies, network with others from the Parkinson's community and hear from some of Melbourne's leading specialists in the field of Parkinson's and neurology then make one of our upcoming events a "must-attend" in 2009.

Regional seminar

In 2009, our annual regional Parkinson's education forums will take place in Ballarat.

In previous years, these forums have been conducted in Wangaratta, Shepparton, Horsham, Traralgon and Gippsland. The forums combine a community (public) education component with an evening session for GPs from the local and surrounding areas.

Regional areas have traditionally been targeted for our professional and community seminars, due to the limited availability of Parkinson's-specific services and resources in these areas, as well as residents' limited access to professional and specialist health expertise.

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

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

As a result, many people feel isolated and alone in their experience of Parkinson's.

In addition, regional-based GPs are often required to manage complex Parkinson's patients and as such, are keen to learn the latest strategies that will assist them in this role.

Our education program for regional areas, combined with the work of our regional Support

Groups, aim to address this gap in the provision of support and information.

The keynote speaker for both the community and GP sessions will be Associate Professor David Williams. He will be joined for the community seminar by a member of the Parkinson's Victoria health team and together they will deliver a wide range of Parkinson's-related information, including advice, research updates and symptom management strategies.

Registration for the free community seminar is essential. Please register your interest today by contacting Parkinson's Victoria: 1800 644 189 or info@parkinsons-vic.org.au

Event details:

Ballarat community seminar

Date/Time: 27 August, 12-2.30pm

Location: Ballarat University

NB: The GP evening session will take place on 26 August, 6.30pm at the Heritage on Lydiard, and a special session for local medical and nursing students will take place on 27 August, at Ballarat University.

These education events have been made possible with the generous support of Novartis Pharmaceuticals.

Metro seminars

This year, for the first time, Parkinson's Victoria will also host a series of metro-based, community and health professional education seminars.

These events will augment our recently diagnosed seminar.

The metro community seminars will be an ideal forum for those diagnosed with Parkinson's, family members and/or carers to learn more about the condition, and will be especially beneficial for those not yet linked in with local support and information networks.

The seminars are primarily designed to increase awareness and understanding of Parkinson's in the community, as well as enhancing the individual's knowledge of symptom management options and support services. The core aim of the community metro seminars is to empower individuals to participate in their own care and decision making.

The metro seminars will also offer a dedicated evening session for local GPs.

Event details:

Central Melbourne community seminar

Date/Time: 29 June, 2-4.00pm

Location: The Treacy Centre, Parkville

NB: This will be followed with a GP evening session.

These events are made possible with the generous support of Medtronic.

Event details:

Dandenong community seminar

Date/Time: 19 October, 2-4.00pm

Location: The Mulgrave Country Club

NB: This will be followed by a dedicated GP evening session.

These events are made possible with the generous support of Novartis.

Keynote speaker for our metro seminars is Associate Professor David Williams.

Book your seat to attend one of our metro community seminars today. Contact Parkinson's Victoria: 1800 644 189 or email: info@parkinsons-vic.org.au

Our metro and regional community events are free to attend for the general public, thanks to the generous support of our sponsors. Donations to Parkinson's Victoria on the day to further enhance our information and support programs would be appreciated.

Health Team's note: Local GPs will receive an invitation to attend the regional and metro GP evening sessions, however we recommend that you speak with your GP about these unique events and encourage them to attend the one taking place in their local area.

In addition, GPs attending the education sessions will receive their own copy of the recently revised manual, **Parkinson's disease: A General Practice Approach**, a Parkinson's Australia project, endorsed by the Royal Australian College of General Practitioners. The manual is currently being distributed to all practitioners across the country.

Managing advanced Parkinson's

On 16 March, more than 75 health and medical professionals attended a dedicated education seminar to learn about working with and assisting those facing the challenges of advanced Parkinson's.

Keynote speaker Professor Robert Iansek discussed the medical management of the condition, and later-stage interventions, such as the introduction of liquid Sinemet, Apomorphine, and Deep Brain Stimulation Surgery.

Victor McConvey from our health team also presented, discussing nursing considerations.

The event was hosted by the Kingston Centre's Movement Disorders Clinic.

Given the positive response from the professional sector on this subject matter (including a maximum capacity attendance), and the general need for this kind of information and improved management of late stage Parkinson's patients, we anticipate conducting more seminars of this nature in the future.

Thanks a bunch

Earlier this year, Parkinson's Victoria President, Royce Pepin and CEO, Glenn Mahoney were delighted to accept a cheque for \$34,900 from Tulip Ball co-organisers, mother and daughter, Julie Sewell and Jo Hill.

The inaugural Tulip Ball was hosted in November 2008 and proceeds from the event will make a significant contribution to helping fund the delivery and development of our information and service programs.

Following this wonderful and extremely successful event, we are pleased to confirm that Julie and Jo are currently working on another "Tulip" event for late 2009. We are sure it will be an equally fun and engaging event, with the same attention to detail and emphasis on the "supporting Parkinson's" message. Stay tuned for further details!



John and Julie Sewell, with daughter Jo Hill (John has Parkinson's and was the inspiration behind the Tulip Ball), Parkinson's Victoria President, Royce Pepin and Glenn Mahoney.



Associate Professor David Williams with Cynthia Hicks an avid Geelong supporter.

Celebrating Support

As the Horsham Support Group gears up to celebrate 20 years of service and support for the local Parkinson's community, Parkinson's Victoria would like to send a HUGE Tulip Tribute to Support Group leader Cynthia Hicks.

Cynthia, renowned for her caring and personal approach, has been with the group since the beginning, when she joined as a carer of a family member with Parkinson's.

Cynthia ensures group members always feel welcome and involved, hand writing personal letters to each member following meetings, which is a wonderful way to make sure those who were unable to make the meeting still feel included and up-to-date on news.

Cynthia has also been extremely active advocating for the rights of people with Parkinson's by contacting local government.

The local carer respite centre has sponsored a celebratory lunch to take place in August, and Victor McConvey will be the group's guest speaker for the occasion.

Congratulations to all members – what a fantastic accomplishment!

Health & Symptom Management

Surviving Hospital

Going into hospital, whether planned or unplanned is never easy and living with Parkinson's has the potential to make it even more difficult. Parkinson's Specialist Nurse Consultant VICTOR MCCONVEY offers some advice to help reduce the chance of unnecessary problems or side effects occurring during your stay.

We now know that Parkinson's is "surprisingly prevalent". It is the second most common neurological condition affecting Australians (after dementia)*. In spite of this, there is a significant lack of familiarity with the condition and its nuances amongst hospital staff.

While Parkinson's is not an illness commonly associated with needing to be hospitalised, needless to say, many people with Parkinson's **are** admitted to hospital, whether in relation to their illness or for other reasons. Their anecdotal experiences attest to this lack of understanding of the condition, including medication and side effects.

The difficulties encountered by people with Parkinson's who are admitted to hospital are many and varied. This article explores just a few of the challenges and ways in which they can be minimized and/or managed.

Medication management

One of the most common problems experienced by people with Parkinson's in hospital is not getting their medication on time. (**Medication on time, every time** is essential to managing Parkinson's symptoms.)

In a hospital environment, all medications are typically administered at the one particular time. Failure to administer Parkinson's medication at the appropriate time for each Parkinson's patient may simply be a result of that 'time' being outside the normal medication rounds. Alternatively, the need to administer Parkinson's medication at a particular time may have been forgotten by staff, ordered incorrectly by the doctor filling in the medication chart, or the medication may be unavailable from the hospital supply.

Beginning your stay in hospital with your medication administered on time will help reduce the chance of medication mismanagement occurring later in your stay, which may result in additional health problems and perhaps even extend your time in hospital.

One way of ensuring this happens is by advising the doctor of the times you take your medications. Remember: Hospitals work on a 24-hour clock, and will prescribe medication accordingly. For example, if you take the drug Sinemet three times a day at 8, 12 and 4, the doctor could interpret a "three times daily medication" regimen as being due at 6, 2 and 10.

The best way to manage medication and ensure it is administered on time, every time, is to ask hospital staff if self administration is possible.

Self administration is where you take responsibility for your usual medication and the nurse simply asks whether or not you have taken it and then ticks it off your chart.

If you are able to self administer, keep using all the normal cues that you use at home to make sure that you take your medication at the correct time.

If self administration is not an option, it is a good idea to talk to the nursing staff about what **is** possible to help you access your medication on time. Nurses will often try to incorporate the importance of getting medication on time into your care plan, in a similar way that they would highlight if you had a wound that needed dressing.

Please remember: Hospitals are busy places and when emergencies occur all available staff are often called upon to assist. There may be occasions when "on time, every time" doesn't occur, so try and be patient. You may be able to assist staff by keeping track of when your medications are due and asking for them.

At the time your doctor is admitting you into hospital, it is worth checking that the ward has a supply of your particular Parkinson's medications in stock. Most hospitals will not automatically have supplies of all medications and will have to order them from the on-site pharmacy. In small hospitals they may have to be ordered from an outside supplier. You may even have to use your own supply until the order has arrived. In private hospitals, patients generally use their own supply of medications, so keep check on how much you have left, particularly at the end of your stay as you may need to get a new prescription filled.

Editor's note: The issues around administering Parkinson's medications on time in a hospital or other care facility were recently explored by

Health & Symptom Management

Moira Lewis as part of her **Leadership Plus** project (highlighted in **Signpost**, Autumn 2009).

With assistance from Parkinson's Specialist Nurse Consultant Victor McConvey, Ms Lewis conducted a trial on the impact medication timers had on nursing staff's ability to administer medication on time. (The Cadex™ watches, which were supplied by Medtex, signaled when medications were due). The project results indicated consistent, significant improvement in the delivery of medication on time to Parkinson's patients, ultimately improving their hospital stay experience and significantly reducing the occurrence of unrelated health/mobility problems.

Parkinson's, what's that?

Another challenge experienced by people with Parkinson's in a hospital environment is the lack of awareness regarding the most common and/or variety of Parkinson's symptoms amongst general hospital staff, who have likely received little information about the condition during their training.

As the symptoms of Parkinson's – and therefore medication regimens – tend to be highly individual, it is easy to appreciate that some hospital staff struggle to understand the illness, let alone the importance of medication on a case by case basis. Typically, every Parkinson's patient they have cared for was, and will be, different.

To assist staff to better understand Parkinson's – and *your* particular Parkinson's – it's a good idea to provide them with information about the condition.

A range of information materials are available from Parkinson's Victoria, including a Hospital Kit, multi-lingual information, and information online which can be downloaded.

To support this *general* information, we encourage you to share what living with Parkinson's is like **for you**, and some of the daily challenges you face. You may draw their attention to your experience of freezing, dyskinesia (abnormal movement of voluntary muscles) or hallucinations.

This can be of particular importance if you have symptoms that are significantly worse during "OFF" periods. (ON/OFF periods are defined as fluctuations that occur in response to levodopa therapy, in which the person's mobility changes suddenly and unpredictably from a good response

(on) to a poor response (off)). For example, some people find that swallowing is more difficult during "off" times, so eating and drinking should be avoided at this time.

Sometimes a letter from your neurologist, GP or Parkinson's nurse outlining your symptoms can also help when briefing staff about your condition and "handing over" (relinquishing) some of the care related to your Parkinson's.

There is no doubt that when staff learn how Parkinson's affects you, (whether through general information or hearing your personal experience), it makes it easier for them to plan your care, and of course you, the patient, benefit from this.

Keep in mind that you may need to tell your story a number of times to a number of staff during your stay, as even with short hospital admissions, you are likely to have a number of nurses and other staff looking after you.

When you have to halt your medication

Many people living with Parkinson's, at some stage, will need to be admitted to hospital for a review of their Parkinson's symptoms or when a new medication is being added to their existing regimen (to monitor its effects).

When this occurs, it is common to have your medications withheld for a period of time so that the physician can obtain a clear picture of how Parkinson's is currently affecting you and the impact of any new treatment that is being commenced. Unfortunately, this will result in you experiencing more Parkinson's symptoms than you normally would, and you may experience some associated discomfort. However, this assessment is typically carried out in Neuroscience or movement disorder units, where nursing staff will do their best to keep you as comfortable as possible. **This is one of the few occasions that it is okay to halt your Parkinson's medications.**

If you need to fast for a medical procedure, discuss whether or not you are still able to take your Parkinson's medication. While medical and anesthetic staff often allow tablets with a sip of water for most procedures, you **must** discuss this with them. This will help ensure they are aware of what Parkinson's-related symptoms you experience and your need for medication.

If you are having major surgery or an operation where you are unable to take your medication,

Access, Advocacy & Assistance

Making the most of support

The “Triple A – Access, Advocacy and Assistance” helps 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.

Medical Cooling Concession

In previous editions of our newsletter, we have highlighted the Department of Human Services (DHS) **Medical Cooling Concession**, which applies to eligible people living with Parkinson’s. This concession was previously known as the MS Summer Energy Concession.

It is well documented that people with Parkinson’s can experience a reduced ability to regulate their internal temperature. This often leads them to run their home air conditioning more than usual, resulting in a significant increase in energy bills.

The government concession offers 17.5 percent off an individual’s energy bill and is available to people with Parkinson’s who also hold a Pensioner Concession Card, Gold Card or Health Care Card. If you are eligible and would like to apply for the concession, please call Parkinson’s Victoria for an application form.

Health Team’s note:

Most people are able to access this concession with little to no hassle. Unfortunately however, Parkinson’s Victoria is aware of instances where people with Parkinson’s have had difficulty obtaining the Medical Cooling Concession through their energy supplier (in other words, the supplier has failed to recognise their eligibility and subsequently failed to deduct the concession amount from the account).

If you have experienced, or are currently experiencing, a similar problem, we encourage you to try and resolve the issue directly with your service provider. You can do this by calling the provider’s customer service line and speaking with a customer service representative. If, however, you are still unsatisfied with the outcome, you can

lodge a complaint with the Energy and Water Ombudsman of Victoria (EWOV) who will allocate a representative to investigate on your behalf. There is no charge for this service.

You can contact EWOV online at:

<http://www.ewov.com.au/>

or free call: 1800 500 509.

Alternatively, you can write to:

Energy and Water Ombudsman (Victoria) Ltd

GPO Box 469D

Melbourne VIC 3001

Keeping Parkinson’s TOP OF MIND

Increasing awareness about Parkinson’s is essential in our fight to reduce the impact of the condition, enhance quality of life, and increase support, services and funding.

Everyone knows the saying “out of sight, out of mind”...Right? Well, the phrase “**Top of Mind**” traditionally refers to a marketing concept that means a product or brand is the first thing that springs to mind when you think of a particular thing. For example, many people will think of ‘Kleenex’ when you mention ‘tissue’. Being **top of mind** means **never** being out of sight.

At Parkinson’s Victoria we consistently work to raise the profile of Parkinson’s so it is **top of mind** for the community, government, decision makers, corporate Australia, health providers, schools, grant makers and sponsors.

When people think about a worthy cause, a cause they should support, sponsor or write a media story about, we want to ensure Parkinson’s is **top of mind**.

When people think about the most common neurological conditions affecting Australians, we want them to keep Parkinson’s top of mind.

How do we keep Parkinson’s TOP OF MIND? We keep talking about it!

While we work to support people living

Access, Advocacy & Assistance

with Parkinson's, we are also working towards greater understanding of the condition in a general sense, so that more and more people can readily identify the cause and understand what the condition involves.

AWARENESS: Throughout the year, Parkinson's Victoria and our 50 affiliated Support Groups initiate and respond to requests from the community for information and materials to increase awareness and understanding of Parkinson's.

You can help! The next time you visit your local library, pharmacy, church group, social club or other community centre, ask them if they would like information about Parkinson's to display. We can send them a free kit of brochures, posters and other materials. Your work place might also be happy to help by putting up a poster, especially if they know it's a cause close to your heart!

MEDIA: We also initiate and respond to requests from the media. We've found local media groups are especially supportive of local stories — *this makes sense!*

How can you help? Many Parkinson's Support Groups and members have approached their local newspaper or radio station to share their Parkinson's story.

Have you thought about phoning or writing to your local paper to suggest a story about Parkinson's? It's great if you can offer a personal or interesting angle: If you have Parkinson's, let them know that you're celebrating a milestone of some sort (such as a wedding anniversary or personal achievement); remind them (when the time comes) that it's National Parkinson's Awareness Week and you'd like to offer a personal perspective; or you might like to share the powerful and positive impact the local support group has had helping you cope with

your diagnosis and live well with with Parkinson's.

If you're a Parkinson's supporter, organise a **Party for Parkinson's** and let your local newspaper or radio station know! Promote the fact you're getting local business involved and why you're passionate about supporting Parkinson's. (Find out how you can **Party for Parkinson's** on page 10)!

If you'd like to discuss ideas for a media story, or would like information on how to work with local media to help raise awareness of Parkinson's and keep it "top of mind", contact Judith our Marketing Coordinator.

We also have a great "fast facts" sheet about Parkinson's, which is a summary of the condition, funding needs, prevalence and statistics in an Australian context, perfect for forwarding to the media to complement your personal story.

ADVOCACY: Advocating for Parkinson's is a top priority as well. To advocate is "to speak or write in favor of; support or urge by argument; or recommend publicly" (dictionary.com).

At a state and national level, Parkinson's organisations are urging government decision makers to listen and take action in support of those living with Parkinson's, including those who have been diagnosed, carers, health and allied health professionals, family members, employers and service providers.

If you would like to play a greater role advocating for Parkinson's by contacting your local government, but don't know where to start, Parkinson's Victoria CEO Glenn Mahoney can help: gmahoney@parkinsons-vic.org.au

We also have up-to-date statistics and information about funding and prevalence, as well as the top funding priorities in relation to Parkinson's in Australia.

More fundraising & events

Pedal for Parkinson's

Just before our own Team Parkinson's Challenge bike riders departed for their big adventure to Vietnam (having raised more than \$130,000!), another keen cyclist, Sarah MacDonald, undertook her own challenge to ride from Sydney to Melbourne, while raising funds and awareness for Parkinson's.

Sarah, a young student from NSW whose father has Parkinson's, took 2 weeks to complete the ride, often covering more than 100km a day.

Along the way Sarah and her support team – boyfriend Adam – passed through regional towns and were greeted by local support groups who showed their support and encouragement. The Sale Support Group even organised an interview with the local paper to promote Sarah and her ride, their group, and Parkinson's in general.

Sarah received an inspiring message via email from Anna Meares OAM, who returned from injury to take the Silver medal in track cycling during the 2008 Beijing Olympics.

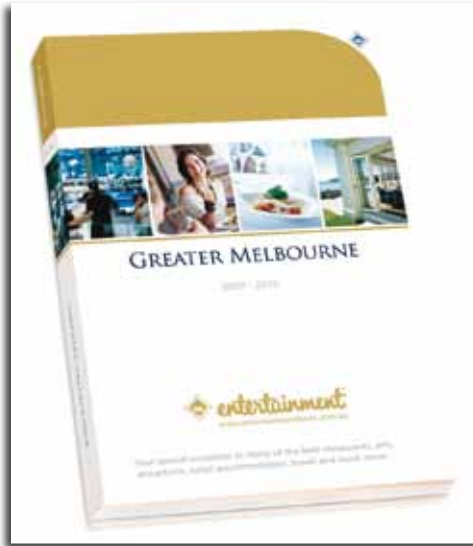
Sarah was welcomed across the 'official finish line' at Federation Square on 26 February by Parkinson's Victoria CEO, Glenn Mahoney and Catherine Watson from our health team and also one of our Team Parkinson's Challenge bike riders. Max Bradfield, another Team Parkinson's bike rider, joined Sarah to accompany her on the last few kilometres into Melbourne.



From left: Adam and Sarah with Parkinson's Victoria CEO Glenn Mahoney, and Team Parkinson's Challenge bike rider, Max Bradfield, pictured at Melbourne's iconic Federation Square.

Eat, drink and fundraise!

Love eating out? The brand new 2009/2010 Entertainment™ Book for Greater Melbourne – out now – means you can indulge without breaking the bank AND help fundraise for Parkinson's!



The Entertainment™ Book (above) is your guide to the best restaurants, hotel accommodation, attractions, sports and leisure activities, as well as casual and family dining and informal and take-away outlets. All outlets featured in the Book carry "25-50 percent off" or "2-for-1" offers.

Books cost \$65 each, with \$13 going directly to Parkinson's Victoria.

To purchase your 2009/10 Entertainment™ Book contact:

Parkinson's Victoria: (03) 95511 122 or judith@parkinsons-vic.org.au. Order forms can be downloaded from our website: www.parkinsonsvic.org.au

Books can also be purchased direct from the office of Parkinson's Victoria: Corner Warrigal and Kingston Roads, Cheltenham (Enter off Warrigal, at the entrance to the Kingston Centre). Office hours Monday-Friday, 9–5.00pm.

For more information about the Entertainment Book, contact Karyn Spilberg, Young at Park Support Group Coordinator: curlyaussie@optusnet.com.au

A day on the green

Whether you're a keen golfer, looking for an opportunity to network with current or prospective clients, or you simply want to enjoy a fantastic charity event at one of Melbourne's prestigious golf courses, you won't want to miss the 2009 Spring Valley Charity Golf Day.

More fundraising & events

For the second year in a row, Parkinson's Victoria is proud to announce that it has been chosen as the recipient of funds raised from this event, an honour again shared with the Kingston Charitable Trust.

Last year, the event raised just over \$8,000 for Parkinson's Victoria and this year the committee hopes to double that effort.

Event details:

Spring Valley Mixed Charity Golf Day

Date/Time: Friday 29 May, Registration 8.00am, shotgun start at 9.00am.

Location: Spring Valley Golf Club, Heatherton Road, Clayton South.

Entry Fee: \$60 per person (includes game, entry into the main 4BBB Stableford competition, and a light lunch).

To register as an individual or team, download a form from www.springvalleygolf.com.au or www.parkinsonsvic.org.au

Registrations close Monday 18 May or when field capacity is reached.

Enquiries: Spring Valley Golf Club (03) 9562 3811.



Guests get into the spirit of things during the 2008 Spring Valley Charity Golf Day: During the luncheon, guests had the opportunity to win a range of fantastic raffle and auction items, including this one being paraded through the crowd, a framed tournament T-Shirt worn by Karrie Webb.

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make sure your neurologist or treating Parkinson's doctor is aware of this. They will be able to put a plan in place to manage your Parkinson's symptoms post procedure, and to gently re-introduce medication with the least amount of side effects possible. They will also communicate with the nurses looking after you that you may have some additional needs post procedure, such as medication or personal care needs.

While they are rarely pleasant, with good management and some pre-planning, hospital stays can be made less difficult, ensuring the reason you were admitted in the first place is addressed effectively and efficiently without being compromised or complicated by unrelated issues.

For more information or assistance with planning your hospital visit or if you require assistance during your stay, contact the Parkinson's Victoria Health Team.

Quick tips for "surviving hospital"

- Check with hospital staff to find out if self-administration of medication is possible during your stay.
- Use prompts to ask for medication when it's due (for example your pill timer)
- Provide the hospital staff with relevant, reliable information to help them understand Parkinson's.
- Communicate with your doctor/s about your Parkinson's, your symptoms and medication regimen (and any other treatment management strategies you currently employ).
- Encourage your doctor/s to talk with each other, and other treating staff to ensure that they have a plan to manage your Parkinson's and your hospital stay.

* Access Economics, 2007

Our Supporters

Thank you to our supporters who generously made donations in recent months. Listed below are the names of individuals, businesses and community groups who kindly donated between 13 January and 14 April, 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)

Daniel Atkin
Valerie Audsley
P Aughterson
Betty Blake
K & N Bruhn
Angie Carter
John Cary
Julius Coleman
Deirdre Collier
Andrea Davis
Peter & Lesley Dyer
David Garrioch
Peter & Rosie Gates
Baldeep Gill
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Sidney Savage
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Barry Williams
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In Memory of...

Thomas Allsop
Bronwyn Andrews
Norman Bedingham
Harold Blake
Felice Blake
Franis Caspersz
Angela Commisso
Betty Chrichton
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Marjorie Greig

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Alison Patrick
Marie Ricketts
Derick Senior
Peter Sullivan
Elizabeth Taylor
Brian Tupper
Robert Weekes
Charles White
Dennis Wooton

In Celebration of...

Ron Baincridge
(60th Birthday)
Rosemary Piper
(60th Birthday)
Ella Goldberg
(B'at Mitzvah)

Team Parkinson's Challengers

Together the Team has raised in excess of \$130,000

Leanne Barnes
Edward Beesley
Helen Bignell
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

Bergent Research
Brighton on Bay
Burhadon
CAF Community Fund/
Fosters in the Community
Connex
Country Womens
Association (Berwick)
Doctors of Ivanhoe
Goldman Sachs JB Were
Health Matters (radio
program)
Interchem
Leongatha Anglican
Opportunity Shop
Committee
Lions Club of
Greensborough
Melbourne Eastern
Weekly
Midwood Roses (Treloar
Roses)
Mount Scopus College
Nambucca Valley
Parkinson's Support
Group
National Poker League
Novartis
Order of Ahepa
Powercor Australia
Reading Cinemas (The
Classic)
The Disability Shop (3RPP,
Radio Port Phillip)
Victorian Calisthenics
Coaches Association
Villa Adriana Function
Centre
Williamstown Motorcycle
Club
Woolworths/Safeway

Team Parkinson's - Auxiliary Fundraisers

Sarah MacDonald

Bequests

The Estate of the Late
Marjorie Craig

We would also like to thank all those who supported our World Parkinson's Day tin rattle at Flagstaff, Parliament, Melbourne Central and Flinders Street train stations, conducted during peak hours on the morning of 2 April. Also those who have made donations but wish to remain anonymous.

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

We conduct only two official fundraising appeals annually and this edition of Signpost includes our annual mid-year appeal. Whatever amount you are able to put towards the fight will make a difference.

If you have recently made a donation, thank you for your generosity and ongoing support.

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