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2010: Moving forward together

Happy New Year! The "noughties" are now behind us and we have a new and exciting decade ahead of us. We have much planned for 2010 and beyond, and look forward to working with you to reduce the impact of Parkinson's in Victoria.

State and Federal Elections

Victoria will be in election mode in 2010, with the state election scheduled for 27 November, and a Federal election more than likely in the second half of the year.

We will be creating a dedicated **2010 Election Section** of our website, which will contain an election "kit" with contact details for candidates, facts and figures about Parkinson's, and key messages about the need for improved services and support across the state.

The kit will also feature draft letters, electorate information, marginal seats and video interviews of people with Parkinson's sharing their story. This will include first hand accounts of where lack of understanding of Parkinson's in the health sector has caused distress (for example, poor medication management when someone with Parkinson's enters hospital).

You will be able to visit the web site, find your local candidates' contact details and use the information on the site to let politicians know that there are 15-20,000 voting Victorians with Parkinson's, and they have families and friends, making a voting population of over 100,000.

We live in a democracy and we have the opportunity to influence our elected representatives to respond to the need.

There will be more information relevant to the elections in the next edition of **Signpost**. You can also visit our website: www.parkinsonsvic.org.au

Harnessing the power of the Internet

On the topic of our website, we encourage you to visit the **Publications** section and click on the video link to a brand new section called "**Parkinson's TV**" to view our growing video and audio collection.

Catherine Watson from our Health Team has been busy uploading several of our public seminars to the Internet so that

anyone in the world can access this information; we have already had people from as far away as Spain contact us about our videos!

In addition, another team member, Jackie Jenkins has been uploading audio versions of Help Sheets, ideal for those who may have difficulty with the written word.

In the coming months, to ensure current, relevant information is more widely accessible, we will be further harnessing Internet technologies; producing more online interviews with health professionals and uploading information on symptom management, research and personal stories from people with Parkinson's and news about upcoming events.

Unite and Walk

Planning is already underway for **Victoria's 2010 Parkinson's Unity Walk** at **Federation Square on Sunday, 29 August**.

Please put this in your diary now: This is a fantastic opportunity to come together for Parkinson's in the centre of Melbourne, raising awareness and much needed funds to support research and services. Please tell your family and friends about the Walk and invite them to join you and – we hope – hundreds of other members of the community as we unite to raise awareness of Parkinson's.

Anniversary celebrations

Planning will begin this year for the 30th anniversary of Parkinson's Victoria in 2011.

In 1981, the **International Year of Disabled Persons**, four women with Parkinson's met and formed what was to be called the **Parkinson's Disease Association**.

In 2011 we will take the opportunity to celebrate the vision and commitment of the pioneers of Parkinson's Victoria, and to recognise the tremendous contribution made by people with Parkinson's, volunteers, staff, researchers, and supporters over the past 30 years.

Stay tuned for more details about how you can get involved in future editions of **Signpost**.

We wish you well in 2010

Glenn Mahoney
Chief Executive Officer

News & Highlights

New resources 'speak your language'

We are very pleased to announce that our series of multi-lingual information resources is now available in audio format and downloadable from our website. These are in addition to our multi-lingual Help Sheets and booklets.

Audio information is currently available in English, Greek, Italian, Vietnamese and Cantonese.

(Written information) is available in an additional five languages: Arabic, Croatian, Macedonian, Russian, Spanish and Turkish).

- To listen to the audio resources, visit www.parkinsonsvic.org.au/languages.htm or contact our office for CD copies.

The audio reads are particularly useful for people with limited reading skills or a vision impairment.

The non-English audio files have been professionally developed by SBS and we hope to expand the range of languages available in the future.

Brief radio announcements about Parkinson's have also been produced in Greek, Italian, Vietnamese and Cantonese, and are currently playing on SBS radio.

In addition, we have recently released a new multi-lingual booklet containing key Parkinson's information in the above 10 languages, including a section on *where to go for help*.

For free copies of the new multilingual booklet, bi-lingual **Understanding Parkinson's** booklets, or Help Sheets (available in 10 languages) please contact our office or visit our website (go to the languages section).

Annual General Meeting

Parkinson's Victoria held its 2008/09 Annual General Meeting on 27 November last year at the Kingston City Hall, Moorabbin.

The meeting was preceded by an excellent seminar on **Deep Brain Stimulation**, presented by neurosurgeon Dr Richard Bittar and neurologist Dr Richard Peppard. This seminar was recorded and is now available to view and download from our new **Parkinson's TV** website. We thank event sponsor Medtronic for their support of this seminar.

A highlight of our AGM is when we formally acknowledge the special efforts of our volunteers and present various awards. We were delighted to have Sir Zelman and Lady Cowen once again attend our AGM and participate in the awards ceremony. **The Sir Zelman Cowen Award** for outstanding volunteer contribution was awarded to Geoff Alexander, Shepparton and District Support Group Leader. You can read more about Geoff's achievement on page 13.

The formalities of the meeting included: Mary Jones and Peter Raymond being re-elected as members of the Board. Current Board members of Parkinson's Victoria are:

- Royce Pepin AM, MBE, GCSJ, Ph.C President
- Kate Brown Vice President
- Peter Walker Chairman Finance Committee
- Mary Jones
- Brendan Lourey
- Peter Raymond
- Fred Van Ross

Further, Bentleys were re-appointed as Parkinson's Victoria's auditors for the coming twelve months.

Amendments to the **Statement of Purposes** and **Rules of Parkinson's Victoria** were approved by members at the Annual General Meeting. These amendments were to ensure our statement of purposes and rules comply with current tax legislation, and to amend references to the "People Living with Parkinson's Advisory Group" and replace this with "Board Advisory Group". A further amendment ensures that a minimum of two Board Members are people living with Parkinson's. A copy of the Statement of Purposes and Rules of Parkinson's Victoria is available on request to members at our Cheltenham office.

Copies of the 2008/09 Annual Report were distributed during the AGM and more recently were posted to all Members. If you did not receive your copy or would like a copy, please contact our office. Alternatively, you can view the full report online at www.parkinsonsvic.org.au (go to the '**publications**' section).

Warrnambool celebrates 21 years

2009 marked the 21st anniversary of our Warrnambool Parkinson's Support Group and more than two decades of service to their local community by providing peer support to residents.

Members of the groups hosted a function in December, and dignitaries included the Hon. Denis Naphine, Mayor of Warrnambool, Mr Michael Neoh and Parkinson's Victoria President, Mr Royce Pepin.

Royce acknowledged the original foundation members and presented them with certificates, with a special Certificate of Appreciation to Support Group Leader Kieran Donlon recognising ten years of service.

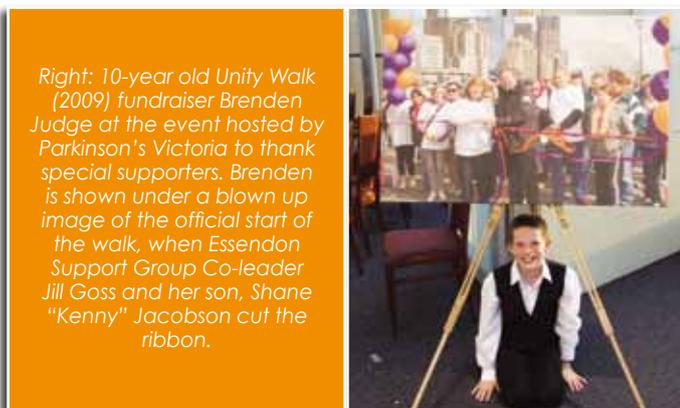
Congratulations to Members, past and present, of the Warrnambool Parkinson's Support Group. Thank you for all you do for your local community. You continue to make a significant contribution in the lives of those living with Parkinson's and to support our work.

Uniting to say 'thanks'

In October last year, Telstra, major sponsor of the Parkinson's Unity Walk (Victoria), kindly hosted our Thank You function at their Exhibition Street office. Invited were event sponsors, key supporters, volunteers and fundraisers.

During the evening, guests were treated to live entertainment from the Jazz Cats, who generously waived their performance fee, and President Royce Pepin presented prizes and awards, including a special **Certificate of Appreciation** to 10-year old Brendan Judge, who had raised almost \$1000.

One of the evening's highlights was the short video presentation of footage from the Walk. Thanks to Nerissa Mapes for her valuable assistance in coordinating this event.



Right: 10-year old Unity Walk (2009) fundraiser Brenden Judge at the event hosted by Parkinson's Victoria to thank special supporters. Brenden is shown under a blown up image of the official start of the walk, when Essendon Support Group Co-leader Jill Goss and her son, Shane "Kenny" Jacobson cut the ribbon.

New Year, new faces

Parkinson's Victoria is very pleased to welcome our newest member of staff to the Health Team.

Shelley Pollak is a qualified physiotherapist and for the past three years has worked closely with the Parkinson's community, particularly with in-patients at Elsternwick Private Hospital who were being treated by Professor Iansek in the hospital's Movement Disorders Program.

While in that role, Shelley was part of a team that included Neurology, occupational therapy, speech therapy, dietetics, social work and psychiatry. Together, these health and allied health specialists worked to address the many facets of the condition and improve quality of life.

Shelley's role was to provide a physical therapy approach to the management of mobility problems associated with Parkinson's. These problems are varied but are very common to most people with Parkinson's.

Shelley explains, "One area of my work centred on the difficulties of walking, getting on/off chairs, and moving in bed. My role was to teach strategies that patients could use to help them achieve "normal" movement, despite their symptoms.

Other common physical problems are loss of balance, stooped posture, loss of fitness, and pain.

These are all areas that I worked on with patients to help them improve their overall mobility and function, and therefore improve their independence and quality of life."

The following is based on a real-life case study of Shelley's and is a good example of how a physiotherapist might assist someone with Parkinson's who is experiencing mobility problems:

"Mrs B always needed her husband to assist her in getting in and out of bed, as she was moving so slowly at night and first thing in the morning. This was giving her husband a sore back, and Mrs B was very upset. Shelley was able to teach Mrs B a specific strategy which involved breaking up the movement sequence (getting off/on the bed) into separate tasks, and then only doing one task at a time. This strategy enabled Mrs B to move faster and importantly to move independently so that her husband no longer had to physically assist her."

This kind of strategy training is key in helping people with Parkinson's move with increased ease and independence.

During Shelley's time with Professor Iansek, she was also involved in research into treatment options for Parkinson's disease, and she recently presented a poster* outlining her research findings at the 2009 **Movement Disorders International Congress**, held in Paris. "This was an amazing opportunity for me to be exposed to the latest research and meet exceptional people who are treating and researching Parkinson's around the world", said Shelley. [Editor's note: Our Parkinson's Specialist Nurse Consultant Victor McConvey also attended this conference as a delegate and delivered an overview of content in the previous two editions of Signpost].

Shelley is very excited to be joining the team at Parkinson's Victoria and to have the opportunity to contribute in her area of specialty, which will greatly enhance our current services.

"I look forward to sharing my knowledge with you – the Parkinson's community - and continuing to develop my skills by working with the experienced team at Parkinson's Victoria".

***A scientific poster is a large document that can communicate a researcher's project and is typically displayed at a scientific meeting or conference.**

It is designed to be both a standalone document, which passersby can read, or which the researchers can 'speak to' as they address members of the public or conference.

Signpost is available by email

If you would like to receive this newsletter electronically, please email:
judith@parkinsons-vic.org.au.

Reflections

Parkinson's Gift: Michael J Fox's *Lucky Man* memoir and us

The value of writing of one's journey - as autobiography - and the lessons we can learn from sharing our own story, and in reading another's, is explored by JOHN GATT RUTTER. This article has been reprinted (unedited) with permission from the author.

I was diagnosed with Parkinson's disease, the shaking palsy, more familiarly known as Parky's, three years ago at the age of 65, and I have just read Michael J. Fox's 2002 autobiography, *Lucky Man*.

For those who haven't read it, this revolves around the author's experience of PD [Parkinson's], diagnosed, in his case, at the much earlier age of 38. Fox's book presents Parkinson's as a gift [6], a gift which saved him from the vortex of his life as a self-engrossed celebrity, submerged in inauthenticity and booze, wallowing in the fun-house of the entertainment industry centred on Hollywood. The ten years following that diagnosis, Fox writes, have been "the best ten years of my life – not in spite of my illness, but because of it." [5] "I am no longer the person described in the first few pages" Fox tells us, "and I am forever grateful for that." [7] That's why he calls himself a *lucky man*.

Fox's book is therefore clearly an implicit challenge to the reader to embrace any incurable and inexorably degenerative condition as an enhancement to our humanity, rather than a curtailment of it.

That's a big ask, and the stakes are raised by the ringing epigraph to the book – a quotation from Henry David Thoreau climaxing with the words: "In accumulating property for ourselves or our posterity, in founding a family or a state, or acquiring fame, even, we are mortal; but in dealing with truth we are immortal, and need fear no change nor accident."

This quintessentially humanistic affirmation invokes that most elusive of values – truth – from the perspective of our own mortality and immortality. An existential choice – a change of life-style and values, a personal transformation – embraced in view of mortality and immortality is presented as a truth claim, and *Lucky Man* comes across quite clearly as a conversion narrative – one of the classical paradigms of autobiography, and thus as a double success story – the central paradigm of autobiography: the story of a man who first

achieved fame as an actor, and then transcended that achievement by renouncing self-indulgence and becoming a model husband and father, an outstanding advocate on behalf of the Parkinson's community, and the author of first one best-selling autobiography and now, earlier this year, of a second autobiographical work, punningly titled *Always Looking up: The Adventures of an Incurable Optimist*: and all without wholly giving up his role in the world of film and television as actor and director, while the shaking palsy steadily extends its sway over his body.

Michael J. Fox as a Parkinson's Everyman? Someone with whom every Parkinson's bearer can empathize? Someone whose experience of life – and of Parkinson's – the non-Parkinsonian reader can vicariously share?

The answer is clearly both yes and no. Yes: The engagingly comic and disarmingly unassuming personality is ever present in *Lucky Man*, busily crafting little tales within larger tales within the master-narrative which is his encounter with Parkinson's, the mysterious antagonist which could strike any of us.

Yes: Fox shares the experience with us in many vivid moments, the first being the mesmeric memory which opens the book with the little finger of the right hand moving, unbidden, all on its own as Fox emerges one morning from a beery slumber; another being that recounted in *Always Looking Up* of his apparently obscene groping to get his wallet out of his hip pocket with that uncontrollable tremor in his right hand.

The narrative *bravura* such reality effects is the petty cash of Fox's major investment in 'coming out' as a Parkinson's bearer, no longer hiding his condition from himself or the world, coming to terms with the insidious antagonist not only as an individual, but making common cause with Parkinsonians generally, and even more broadly with bearers of other disabling conditions in their shared interest in resourcing the search for a cure and mounting the political campaign to sanction the use of stem cells in that research.

Here too, then, the answer is yes: Fox conscripts his lively individuality into the collective interest. And yes: in *Lucky Man* Fox gives us a lively layman's exposition of what the shaking palsy is, its physiology and pathology and the pharmacy for treating it, he reports on his encounters with doctors, neurologists, psychiatrists. In all these ways, Fox – while focussing on his own particular case, his own story – relates it to

a paradigm involving all bearers of Parkinsonianism, and thus approaches the model which has come to be called autoethnography – that is, the description of a social group of which the author is himself or herself a member, and thus a participant observer.

If these are ways, then, in which Fox presents himself as one of us in his struggle with Parkinson's, first as a lucky man and then as an incurable optimist, there are ways in which he is clearly *not* your average Parkinsonian Everyman, who may be far less lucky and less incurably optimistic. Fox's celebrity status, with its attendant privileged social networks and financial resources, puts him well above the average. His fortunate family situation is likewise an advantage that not every Parkinsonian will enjoy. Those deprived of such resources, and faced with the prospect of diminishing returns and an eventual negative balance in their own lives, or of imposing a crippling burden on those dearest to them, may, of course, be tempted by an exit strategy.

This negative calculus may be repressed or tacitly implied in Fox's *Lucky Man* and *Always Looking Up*, but it is squarely faced in another Parkinsonian autobiography that coincidentally appeared in the same year as Fox's *Lucky Man*. This is more somberly titled *A Life Shaken: My Encounter with Parkinson's Disease*, though its author, Joel Havemann, is not much less lucky than Fox.

Havemann was diagnosed with Parkinson's at a relatively early age, though not as early as Fox. He was then a senior editor at *The Los Angeles Times*, and, like Fox, was able to continue in his prestigious career for several years after diagnosis, being in fact appointed European editor in Brussels for three years, and, like Fox, enjoyed a warm and supportive family life. Here is how Havemann sums up his reckoning with the shaking palsy:

"At first, I denied my fate. Now, thanks largely to preparing this book, I accept it for what it is – a life on the downward slide. What I don't accept is this: that such a life is no life at all. To accept that would be to quit living." [158]

And he returns to the topic:

"Parkinson's wins if it makes me focus on the long term – and give up. I set challenging short-term goals (finishing each chapter of this book provided a dozen of them) and strive to achieve them. I think not about what lies ahead for me but what awaits Anne, Margaret, and William, and now Evelyn and Audrey [his children and grandchildren]. Their future is my future. Their healthy bodies are my body. I live to enjoy their living." [158]

He goes on to ask, but not answer, a rhetorical question: "What if I had no children, no Judy?" [his wife] [159]

And he considers the alternative downside:

"I worry about the burden I might place on them if I become incapacitated for a long period of time but refuse to die. [159] ... I don't want them to sacrifice their best years for my worst." [160]

In lieu of answering the unanswerable, he ends the book with his declaration of faith, providing the uplift which is indispensable to the writing of biography and autobiography, which is always in some sense celebratory, a testimony to survival:

"Admiration for humanity. Reverence for nature. Love of family. These are my core beliefs. These are my religion. This I have learned from my disease. Parkinson's, do your worst. You can't rob me of that." [ENDS 161]

Life itself can be seen as a death sentence, and the diagnosis of a degenerative condition like Parkinson's serves to spell that out more concretely, and to concentrate the mind. Face the negatives, but focus on the positives, and live life as fully as possible – this unoriginal but hard-earned wisdom is the central message of both Fox and Havemann. Both claim to have reconstituted and fortified themselves as a result of that diagnosis, and to have done so largely through the autobiographical enterprise. The project and the act and the effort of writing is itself for them moreover a chunk of positive living. It is also offered as a service to others and with others.

Does this mean that other bearers of Parkinson's would also benefit from writing their own life story? Certainly, identifying positives and combating negatives through writing ourselves is worth trying. And we can certainly benefit from reading Fox's and Havemann's stories: published autobiographies mediate between individual and collective experience. We can be beguiled and fortified by the struggle of other selves against the Other which is in themselves – and in us.

This article has appeared previously in print and was originally presented by the author at the La Trobe Uni conference on Life Writing: Narratives of Ageing, Illness and Renewal. John Gatt-Rutter is an Honorary Associate at the La Trobe University (Melbourne) and Italian Australian Institute.

NB: The books referred to in this article can be purchase on amazon.com or from good bookstores, or they can be borrowed from our library.

Access, Advocacy & Assistance

Quality of taxi service survey

The Victorian Equal Opportunity and Human Rights Commission is undertaking research into the experience of people with a disability using taxi services in Victoria.

The survey will run from 5-26 February, 2010 and examines a range of issues relating to the quality of taxi services. (This follows a similar survey conducted in 2006, results of which were published in a report entitled, *Time to Respond* which made recommendations to government and the taxi industry about how to improve taxi services.)

We encourage our members and all members of the Parkinson's community to complete the survey, which we hope will help inform positive change for people with disability accessing the taxi services. Results will be included in a progress report due for release in June 2010.

How to complete the survey

- Forms are available in large font, in hard copy and electronic format. (Reply paid envelopes are provided to return the survey).
- Download a survey on line at www.humanrightscommission.vic.gov.au
- Or request a hard copy: Contact the Commission on: (03) 9032 3435 or email: liesl.l.oliver@veohrc.vic.gov.au. If you require an interpreter please call 1300 152 494 or TTY 1300 289 621.
- Assistance can also be provided to complete the survey over the telephone. Contact Liesl Oliver: (03) 9032 3435.

Disability networks are also assisting the Commission to distribute the survey throughout Victoria, so you may receive a copy of the survey this way. If not, please contact the Commission.

Please note: Information provided will be kept in strict confidence, in accordance with the Privacy Act. No individual responses will be identified and no names or addresses are required.

Centrelink Financial Information Services (FIS)

When you are looking at making financial plans and decisions about your future, you can make a free appointment with Centrelink, where a staff member will present a range of options and information.

This information may help in a number of ways. For example, it can:

- increase your confidence in dealing with investment-related financial issues
- help you to understand your financial affairs
- alert you to the levels of risk for each financial product type
- explain the roles of financial industry professionals
- help you to be discerning when choosing experts and how to use expert information
- explain the advantages of reducing personal debt
- help you to use credit in a sensible way
- help you to plan effectively for your retirement

Source: <http://www.centrelink.gov.au/internet/internet.nsf/services/fis.htm>

Please note: This service presents information about options available to the client, however it does not provide advice or recommendations. To make an appointment with your local FIS officer call: 13 2300. (The FIS officer may be also able to answer your questions over the phone).

Making Deep Brain Stimulation more accessible

The costs associated with Deep Brain Stimulation (DBS) surgery are significant, with only certain aspects covered by Medicare or the Victorian Health care service. The result is that patients are typically left with substantial out-of-pocket expenses.

However, there have been recent additions to items listed as covered under **casemix*** funding that has the potential to reduce some of these patient expenses (NB: the exact cost savings are unknown; the funding only applies to public hospitals; and the funding is likely to vary from hospital to hospital).

This is a positive move as it not only has the potential to reduce costs for the individual, but makes performing the DBS procedure more attractive for public hospitals.

***Casemix is a government initiative regarding subsidised funding for medical conditions. It uses a formula called *Diagnoses Related Groups*; a patient classification scheme that provides a clinically meaningful way of relating the types of patients treated in a hospital to the resources required by the hospital. The formula assigns certain diagnoses or procedures with a dollar value and the government then uses this system to provide the hospital with a rebate for managing or treating DRG conditions. www.health.vic.gov.au/casemix**

Young onset Parkinson's

During 2009, we were pleased to commence a unique project to identify the support needs and issues important to younger people in Australia who have been diagnosed with Parkinson's disease.

We engaged the professional services of Dr Chris Fyffe to coordinate the Young Onset Parkinson's Project. As part of the project, a questionnaire was distributed and completed by relevant individuals, and workshops were held to assist in gathering information. A report is now being finalised and will be made public in March this year.

This report will form part of a presentation at Parliament House (Canberra), which is being coordinated by Norman Marshall, CEO of Parkinson's Australia, to advocate for dedicated funding to support national young onset services.

We look forward to updating you on the outcome of the Parliamentary presentation in the next edition of **Signpost**.

We acknowledge the support of the **Parkies with a Purpose Support Group** for their support of this project.

For those who provided invaluable assistance by participating in the workshops and the questionnaire, Parkinson's Victoria will be holding a Thank You function at the Treacy Centre, 126 The Avenue (near the corner of Royal Parade and Walker Street) Parkville, on Sunday, 2 May from 10.30am – 1.00pm. A light luncheon will be provided as part of this event, where findings of the report will also be presented.

Dr Chris Fyffe and Parkinson's Victoria staff will be present to update you on the report and the outcome of the presentation in Canberra.

Please RSVP to Parkinson's Victoria by Wednesday, 21 April: info@parkinson-vic.org.au or (03) 9551 1122 or 1800 644 189.

Tulip tales - correction

Last year we were excited to announce that **Tulip Cocktails**, an event hosted by Julie Sewell and Jo Hill in August 2009, had been a wonderful success, raising \$4300.

We apologise that this was incorrect – and are pleased to now confirm that the actual amount raised was \$5600!

We thank Julie, Jo and their wonderful supporters and sponsors for their tremendous efforts in raising awareness and funds to support our work in the community.

Read more about what Julie and Jo have planned for 2010 on page 14.

Where to turn for support and information

Our Health Team can provide information and support on a broad range of topics related to Parkinson's. You do not have to wait until you are at a crisis point or only ring to discuss your medication questions.

Our Health Team can assist with answers and information regarding:

- Medication
- Symptoms and symptom management strategies
- Tips and advice for increasing your mobility and independence
- Information about new and alternative therapies
- Updates on research – did you read or hear something and want to know more?
- Information about research trials and participating
- Advice on referrals to allied health staff and other health professionals, including Movement Disorder Clinics
- Tips on getting the most out of your GP and neurologist appointments
- Information about your rights at work
- Information about financial matters
- Advice and information about 'strange' (seemingly unrelated) and embarrassing symptoms
- Travel and health insurance
- Information and guidance on eligibility for government subsidies and assistance schemes (help at home, travel, etc) – and help in accessing them
- Assistance and advice on how to share your diagnosis, feelings and situation with friends, family and work
- Tips and information for you to help a loved one cope with their diagnosis and move forward
- Information about support networks
- Information on topics such as...sexuality, continence, depression, exercise, diet and driving
- Information on mobility aids to enhance independence and personal safety

And much, much more!

Our free information and help phone line is open to ALL members of the community: You do not have to be a Parkinson's Victoria member or have Parkinson's to call us for advice or support. Most printed materials, fact sheets and a range of other resources are also all provided to the community at no charge. There is also a wealth of information on our website.

(Donations to ensure the ongoing provision of these free services to the community are greatly appreciated.)

Education & Information

Rural Health Conference held in Shepparton, an update by Moira Lewis

The **University of Melbourne Faculty of Medicine, Dentistry, and Health Sciences** held its 5th Annual School of Rural Health Research Conference in Shepparton, in November last year.

Anne Atkin, who developed the **Painting with Parkinson's** support group, was invited to deliver a presentation on her art program. Anne was also an event exhibitor and displayed some of her students' artwork, along with information about the program.

I was able to join Anne at her exhibit and had the opportunity to speak with conference participants around the issue of "medication on time", a project I had formally explored as part of the Leadership Plus Program I completed in 2009. (My project investigated the benefits of nursing staff using medication timing devices to ensure Parkinson's medications are administered on time). I was also pleased to have the opportunity to promote the services of Parkinson's Victoria.



Anne Atkin (left), *Painting with Parkinson's* Support Group leader and Moira Lewis, graduate of the Leadership Plus Program during the 5th Annual School of Rural Health Research Conference held in Shepparton last year.

Anne ignited audience interest in *Painting with Parkinson's* and spoke of the use of art as a therapy for managing the symptoms of Parkinson's.

Anne explained that creativity awareness assists in the functionality of the brains of those with Parkinson's, as during creative moments the brain is working subconsciously with low stress levels. Learning new skills also combats depression and improves mental health. Further, creating art provides an opportunity to exercise one's hands and eyes, improve eye-hand coordination and stimulates neurological pathways from the brain to the hands. Stress can intensify pain and other symptoms of Parkinson's, so stress reduction is also a significant benefit for those living with the condition.

There was a very positive response from attendees to Anne's address, with many program participants approaching our display table following the presentation.

The display of artwork from people in the *Painting with Parkinson's* group and the illustration of the **progress** they have made in regards to painting (and in many cases the improved ability over the course of a session, such as being able to move from drawing wobbly lines to smooth, flowing ones) made a significant impression on people.

The opening address at the conference was given by Mr Peter Green, CEO of Family Care. Peter gave a thought provoking address around the importance of our *social life* as a determinant on health outcomes. He addressed the importance of providing fresh water and sanitation and the significant effect this had on health outcomes, as opposed to medical intervention.

In his address, Mr Green often made reference to philosopher Ivan Illich and the Ottawa Charter.

Illich was an Austrian philosopher who wrote extensively about the health system and society's attitude to death and the preservation of life. Illich wrote about society experiencing pain and ill health, but that society also hopes, laughs, celebrates, and to also know the joy of caring for one another. The **Ottawa Charter** was adopted at an International Conference on Health Promotion in November 1986 in Ottawa, Ontario, Canada. The Ottawa Charter made much reference to the importance of people as the main health resource; to support and enable them to keep themselves, their families and friends healthy through financial and other means, and to accept the community as the essential voice in matters of its health, living conditions and well being. Parkinson's Victoria is an example of the Ottawa Charter in action.

There were displays from other exhibitors and of other projects being undertaken by allied health and community groups, such as **Taking action on Diabetes**, **Farm Gate Calling: An outreach strategy**, **Mental Health Service from Wangaratta** and a **Labyrinth** workshop by Reverend Dr Helen Malcolm.

Overall the Shepparton conference was a great opportunity to showcase the positive things happening around Parkinson's.

Recently in Echuca Moira attended the Aged Care Expo, where she again had the opportunity to promote the resources and services of Parkinson's Victoria to various members of the community and allied health providers.

Health Team note: We thank Moira and Anne for their ongoing work in the community to raise awareness of Parkinson's and related issues, to promote the

importance of 'living well' with Parkinson's, and in highlighting our services to those who need us most.

Anne was officially recognized for her outstanding contribution to the Parkinson's community, through her Painting with Parkinson's workshops, during our 2009 AGM, where she was presented with a Certificate of Appreciation.

Regional Education Program

Community Rehabilitation Services (CRS) at Latrobe Regional Hospital (Traralgon) is offering the community an education and exercise program called **The Parkinson's Group**.

The program involves education sessions to increase participant's knowledge of their condition as well as exercise sessions that aim to improve their physical function.

The program is specifically designed for those diagnosed with Parkinson's, however carers are also welcome. (Potential clients need to be medically stable to attend this group.)

What are the benefits?

People who attend **The Parkinson's Group** will gain:

- a broader knowledge of how the condition affects them
- an understanding of strategies that may assist with the management of the condition
- knowledge of how health practitioners can help
- information about current equipment that may help with daily functioning
- information about community services which may be beneficial

What's involved?

The Parkinson's Group is an eight (8) week/once-a-week program of exercise and education sessions with a multi-disciplinary team that includes: a Physiotherapist, Occupational Therapist, Social Worker, Speech Therapist, Dietitian, Pharmacist and a Rehabilitation Physician.

Before starting the program each client has an initial assessment with the Physiotherapist, which is repeated on completion of the program to monitor improvements.

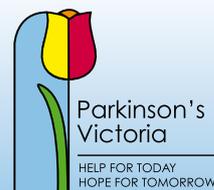
The first group begins on Wednesday 14 April 9-11.30am (this will be the regular day/time). If you would like further information contact The Clinical Coordinator, Ambulatory Care: 5173 8383 or Nicki Cann, Occupational Therapist Community Rehabilitation Service: 5173 8383.

Bequests

Please consider leaving a bequest to Parkinson's Victoria in your will. It is the ultimate gift you can make: to leave a lasting legacy in perpetuity and to assist those living with Parkinson's in the future.

Bequests make a real and lasting difference to our work. They greatly assist us in planning for financial sustainability to ensure we can continue to provide for those in need.

If you would like to know more about remembering Parkinson's Victoria in your will please contact our CEO, Glenn Mahoney. If you have already remembered Parkinson's Victoria in your will, please let us know as this enables us to acknowledge your generous support today.



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Health & Symptom Management

Getting Medications on time

*Parkinson's and medication are practically synonymous. Medication often starts early after diagnosis and remains an ongoing – and relatively effective – treatment in managing Parkinson's symptoms. Our Parkinson's Specialist Nurse Consultant VICTOR MCCONVEY explains the important and varied roles of Parkinson's medications and highlights the common denominator in achieving optimal results – GET "IT" ON TIME**

At some point, everyone living with Parkinson's will need to take medication for the condition on a regular basis, and one of the most troublesome aspects of this fact is the need to take medication on time. Of course, the *other* troublesome thing is trying to remember to take it on time!

The underlying cause of Parkinson's, where the brain produces less dopamine than what is required to ensure smooth functioning of the body's muscles, results in a range of related symptoms, such as slowness of movement and the inability to control one's movements. Through the use of certain medications we aim to combat this reduction in the all-important 'brain fuel' called dopamine and thereby reduce the various symptoms. Your doctor will commonly refer to this as *dopaminergic stimulation*.

To maintain a constant level of **dopaminergic stimulation**, and thereby reduce the impact of symptoms, individuals need to take medications at regular intervals throughout the day. A good analogy is to liken dopamine in the human body to the role fuel has in a car. Without fuel [dopamine], the car [body] simply won't go.

In early Parkinson's, medication may be required only a couple of times a day, however as the condition progresses (and symptoms worsen) medications will need to be taken at more frequent intervals to maintain an effective level of dopamine.

To confuse the issue, there are a number of different medications that are used to treat the symptoms of Parkinson's, which - in varying ways - all aim to increase the level of dopamine in the brain.

- The most common form of medication is **dopamine replacement therapy**, sometimes referred to as Levodopa. These mimic the effect of natural dopamine and are designed to maintain a constant level of dopamine in the system. (These drugs include Madopar, Sinamet and Kinson and come in tablet form).
- The other commonly prescribed class of medication are **dopamine agonists**. These drugs increase the effectiveness of the cells in the brain called *Dopamine receptor cells*, enhancing the uptake of dopamine that is either still being produced by the brain or that comes from the tablets. Examples of these drugs are

Sifrol, Cabaser, Parlodel, and Permax which come in tablet form.

Other Dopamine agonists include Apomine, which is an injection or infusion based drug, and Neu-pro, which is a stick-on the skin patch. (The tablet form drugs are the most common and the patch is only available under private prescription). Dopamine Agonists are commonly administered *with* Levodopa and are typically taken two or three times daily.

- Other categories of medication include **MAO-B inhibitors**, such as Selegiline or Elderpryl and **COMT inhibitors**, such as Comtan.

These drugs work in a similar way by either blocking the metabolism of dopamine or by reducing the production of the natural enzyme that breaks dopamine down. These types of medications may need to be taken once daily or with every dose of Levodopa taken, depending on the drug used.

To further complicate matters it is common that you will need to take several different medications as part of your drug regimen, that all have a slightly different role to play, but with the shared aim of "maintaining a constant level of dopamine". An example might be:

- 1 Madopar every three hours
- 1 Comtan every three hours,
- Sifrol three times daily and
- 1 Elderpryl in the morning

It is understandable that remembering to take medications on time while balancing out the demands of life - especially when living with Parkinson's - means you will need to concentrate more and it can be very easy to lose track of time.

To assist in remembering to take medications 'on time – every time', it is often worthwhile to develop some sort of strategy. It might be as simple as putting a reminder into your mobile phone (alarm) or investing in a commercially produced pill timer.

There are currently a great variety of pill timers on the market, including pill boxes with timers on them and wrist watches with an alarm.

It is important to find a device or system that is right for **you**. For example, if you spend a lot of time away from home, a medication pill box timer may be the best option: These have the capacity to hold a small quantity of medication (to last a few days) and will prompt you (by alarm) to take your medication on time.

Why is it so important to get Parkinson's medication on time?

Each of these medications is trying to do what your body can no longer do on its own: maintain a consistent level of dopamine in the brain, which helps to reduce or negate the symptoms

Health & Symptom Management

of Parkinson's. As outlined above, the medication works to either prolong the effect of naturally occurring dopamine and/or *mimic* real dopamine and increase uptake of dopamine.

One of the most important things that we have learnt over time is that medication continues to be effective in treating the symptoms of Parkinson's, regardless of how long the individual has been taking it: there is no need to fear becoming addicted or that at some point the drugs will cease to work. **While it is up to the individual to choose when they will begin taking medication, there are no benefits to be gained in delaying taking medication.** If the symptoms of Parkinson's have begun to impact on your quality of life or your ability to do the things you love – or even day-to-day things - it is recommended you consult your neurologist who will determine an initial medication strategy unique to your needs.

Getting into the habit of taking your medication on time, as your doctor or Neurologist prescribed, gives the best indication of how progressive your Parkinson's is and how effective that particular drug regimen is in managing your symptoms. It also allows your doctor to refine the treatment to achieve optimal symptom control. As such, it is important to always let your doctor know what medications you are taking and when (both Parkinson's and non-Parkinson's, as some medications can impact on the effectiveness of others, or have severe side effects when taken together).

Developing good medication habits will also help to minimise motor fluctuations. Motor fluctuations are symptoms such as *Wearing off* or *Dyskinesia*. A classic indication of "wearing off" is if you notice your medication isn't quite lasting as long as it normally does (for example you're due to take your next dose in four hours, but your symptoms have started reappearing after three).

There are many symptoms specific to "wearing off", which can include increasing muscular stiffness, poor balance and tremor. They may also include feelings of sadness or depression and anxiety, reduced bladder control and pain.

If you have been taking your medication at regular intervals it will not only be easier to identify when you are experiencing "wearing off" and but it will be easier for your doctor to treat (typically by altering your medication regimen).

Dyskinesia, which is another motor fluctuation, is an involuntary movement of the muscles, which may involve twitching, fidgeting or a writhing movement (often referred to as 'wriggling').

While the cause is not fully understood, dyskinesia seems to be related to excessive dopaminergic stimulation. Some people experience dyskinesia when they have taken doses of Levodopa (such as Sinemet or Madopar) too close together. This

is another reason to ensure you are taking your medications on time, as prescribed, to avoid over dosing. Unfortunately, individuals may still experience motor fluctuations even if they have good medication habits. Your doctor or Neurologist can usually address this simply by adjusting your medication or its timing.

If you are noticing some "strange" symptoms (regardless of whether you feel they are related to your Parkinson's), we encourage you to make an appointment with your Neurologist. At the same time, it is a good idea to keep a diary of when you take your medication, and if and when you are experiencing motor fluctuations or any other symptoms. This will help you to monitor your symptoms and the effects of medication and will greatly assist your doctor as you work together towards optimal symptom management.

Of course, accidents do occur; you may forget to take your medication or over-sleep and start taking medications later in the day. Asking your neurologist what to do in this instance is a good idea so you can be prepared. However, the most important thing is not to panic.

If you do forget to take a dose of medication, take it as soon as you remember (you are likely to be experiencing a "wearing off" sensation). For the remainder of the day, you may need to reduce the time between doses, but be mindful not to take doses of medication too close together. If you start late, simply maintain your regular interval between doses, though you may need to omit a dose if you take medication at very frequent intervals.

Getting into good habits with your medication is important in achieving the best degree of symptom control possible **for you** and will help your medical team in determining how Parkinson's is affecting you, and how best to manage it. Good medication management is also the most effective way of minimising motor fluctuations. Maintaining good communication with your treating doctors about the effectiveness of the medications and any other symptoms you experience is also important.

To help in achieving good medication management there are lots of strategies and devices available. Our Health Team is able to assist with information and advice on strategies, timers and keeping a diary. We also have information designed specifically to assist you – and staff - if you are going into a health care facility.

*** *Get it on Time* is a campaign launched by Parkinson's Victoria to highlight the importance of Parkinson's medications being administered on time, every time according to the individual's drug regimen.**

For a copy of Parkinson's Victoria's *Get it on Time* or *Hospital Kit* contact our office and speak to a Health Care team member.

Tulip Tributes

Passionate pedaling

Sarah McDonald is a passionate and driven young woman on her way to completing a degree in Engineering at Sydney University. In 2009, she established the **Pedal for Parkinson's** bike ride from Sydney to Melbourne. Last month, she hit the road to repeat her trip (with a few tweaks to the itinerary) and carry on her mission to raise awareness and funds in support of Parkinson's.

Local support groups across NSW, the ACT and Victoria loved meeting up Sarah and her support crew - Warwick, Sri, and Jimmy - and several local radio stations and newspapers ran interviews covering Sarah's journey and highlighting key messages about Parkinson's and local support.

We commend Sarah on undertaking this personal and difficult challenge, inspired by her father's own challenge of living with Parkinson's. Not even a serious tumble on the road just days out from arriving at Federation Square (her self-elected finish line) could keep her down: While a broken rib or two and some serious bruising forced Sarah into the support van for the last two days -she valiantly ran the last 4kms into Melbourne city, with a smile on her face and no dint in her boundless energy and enthusiasm. Check out Sarah's blog: www.pedal4parkinsons2010.blogspot.com

Congratulations on such an amazing effort Sarah, and to your wonderful support crew. We also thank those Parkinson's Support Groups who came out to welcome you to their neighbourhood. We hope you are fully recovered and back on two wheels very soon!



Federation finish line: Pedal for Parkinson's riders with members of our very own Team Parkinson's Challenge - cycle Vietnam 2009 (who joined Sarah and her crew for the last 40kms into Melbourne). From Left: Sri and Jimmy (both members of Sarah's support crew), Karyn (Vic), Sarah, Ingrid (Vic), Brendan (Vic), and Warwick (support crew).

Celebrating a Milestone

Last year, John Vaughan-Fowler, set himself a challenge to cycle from Darwin to Melbourne - in time to celebrate his 50th birthday at Federation Square on December 19. That's the same as travelling from London to Paris 10 times!) But, first of all, he had to get here all the way from the UK! He then set off on a grueling 30 day journey from 'top to bottom' across our sunburnt country.

Along the way, John raised an incredible \$6750 for Parkinson's Victoria (and a further £9895 for Parkinson's Disease Society (UK) and £11772 for the Roald Dahl Foundation). Check out his blog for a fantastic and enlightening read about his amazing experience. www.top2bottomdownunder.com



John surrounded by supporters celebrates the finish of his 3935km bike ride - and his 50th Birthday! Despite leaving on 18 November, John 'enjoyed' a total of 9 days rest (including when his wife Kate and 4 daughters, Emily-Rose, Alice, Tilly and Kitty, flew out to join him midway). This meant he actually covered the total distance in 23 days at an average of 171kms (107 miles) per day (when cycling).

Thank you for taking on such a phenomenal challenge John, and garnering such incredible support. You have made an amazing contribution to support our work here in Victoria. Thank you also to your wonderful friends and family who provided invaluable support! And, Happy Birthday!

Let's get physical

On Sunday, 8 November last year, clients and staff of WAM Personal Training, Narre Warren, joined together for their annual 5km fun run/walk fundraiser, this time in support of Parkinson's Victoria.

Approximately 30 participants enjoyed a walk/run in the early morning sun, some indulging their competitive spirit while others took in the scenery and the chance to get to know each other. Once they hit the finish line it was delicious pancakes, coffee and juice all round!

Thank you to the team at WAM Personal Training, and their clients and friends who came together to raise \$220



Participants from the 2009 WAM Personal Training Fun Run/Walk (Judith Mooney, our Marketing & Fundraising Coordinator joined in the fun (walking, not running!), seen middle row, in black baseball cap).

Tulip Tributes

Summer sizzler

Thanks to Bunnings Moorabbin for generously providing us with access to their BBQ facilities on Saturday 2 January. As a result we were able to get our 2010 fundraising off to a brilliant start – raising just over \$1500 for the day!

Events such as these take a lot of coordination and teamwork, so we especially acknowledge our awesome volunteers and corporate supporters.

Our volunteers who helped make the day such a success with their friendly smiles and barbeque brilliance were: Lesley, Cathy, Kieran, Angela, Liz, Jane, Peter, David and Leanne (who came all the way from Portarlington).

And, our generous corporate supporters who assisted with the donation of goods were: Baker's Delight (Glen Waverley, The Glen), Morris Meats (Mentone), Coles (Mentone), Scicluna's (Mentone), Sape & Sons (Specialist Sausage Manufactures), Heinz and Cold Express.



Some of our wonderful volunteers take a well earned break in the midst of all the action during our Bunnings Moorabbin charity sausage sizzle.

We will be hosting another fundraising BBQ on Sunday 4 July, also thanks to Bunnings Moorabbin. If you would like to support by volunteering on the day, or can assist in helping us to secure donated goods (sausages, onions, cold drinks, napkins etc) please contact Judith, our Marketing & Fundraising Coordinator: judith@parkinson-vic.org.au or call our office.

Team spirit



Members of Beta Sigma Phi (Victoria), a "friendship organization for women worldwide", with a cheque for \$2000 which they presented to Catherine Watson (a member of our Health Team), on behalf of Parkinson's Victoria.

2009 Sir Zelman Cowen Award



Clockwise from back left: Parkinson's Victoria President Mr Royce Pepin, Geoff Alexander, Geoff's wife Margret, Parkinson's Nurse Specialist Mary Jones, Sir Zelman and Lady Anna Cowen.

Geoff Alexander was formally acknowledged by Parkinson's Victoria during our 2009 AGM with a special award for his years of service to the local Parkinson's community.

The Sir Zelman Cowen Award for Outstanding Service to the Parkinson's Community was officially presented by the award's namesake, Sir Zelman Cowen, who was diagnosed with Parkinson's in the early 1990s.

Geoff has held the position of group leader of the Shepparton and Districts Parkinson's Support Group for the past 16 years.

Geoff was diagnosed with Parkinson's while seeking treatment for pain following a serious farming accident. Not long after, he joined the local support group and took on the leadership role.

Having had little understanding of the condition when he was diagnosed, Geoff believes access to correct and timely information is vital in learning to 'live well' with Parkinson's, as is being able to hear from others who are going through similar circumstances, sharing experiences and knowing that one can speak candidly and in confidence.

Despite very serious health problems over the years, Geoff spends many hours on the phone to maintain a connection with members who have been unable to attend meetings, including those based in Strathbogrie, Nagambie, Euroa.

Geoff is also active in ensuring local doctors, community health professionals, chemists and hospital staff are "Parkinson's aware", and spends time speaking with the media to highlight the existence and role of the local support group and Parkinson's in general.

As support group members say, "Geoff does many things to benefit our group and Parkinson's in general. He is a man of great warmth and compassion whose aim is to make the plight of people living with Parkinson's all the better. He is an inspiration to us, and we have the greatest respect and admiration for him".

It was fantastic to see Geoff's achievement being recognized by the two major Shepparton newspapers late last year, and we thank **The Shepparton Advisor and **The Shepparton News** for their support.**

Parkinson's Victoria again congratulates Geoff on his achievement.

Fundraising & events

2010 is jam packed with events and activities for all members of the community to get involved in.

Whether you're looking for a social outing or a chance to show your support for the cause; if you want to assist with raising much needed funds, or you're simply keen to join with others who want to make a positive difference for those living with Parkinson's - you'll find the perfect solution here!

Don't forget to share news about Parkinson's events and activities with your friends, family, workmates and social group - you'll be surprised how many people in your network are keen to support "you" by getting involved!

For information about any of the following events or to register your interest please contact our Marketing & Fundraising Coordinator, Judith at Parkinson's Victoria: (03) 9551 1122 or judith@parkinsons-vic.org.au

Gala Tulip Ball 2010

Mother and daughter team - Julie Sewell and Jo Hill - have begun planning for the 2nd Gala **Tulip Ball**® and its shaping up to be even bigger and better than the inaugural event, held in 2008.

The evening will be a black tie affair, with a 3-course dinner, speakers, dancing and auction items all on offer in the name of Parkinson's. The finer details (such as date: either Saturday 13 or 20 November 2010), are yet to be finalised, but we anticipate this will be another sell out "Tulip" event hosted by Julie and Jo.

Since November 2008, Julie and Jo's "Tulip Events" have raised approximately \$41,000, with all proceeds donated to support the work of Parkinson's Victoria. This year they hope to continue to make a difference for the Parkinson's community. Their motivation is John Sewell, Julie's husband and Jo's father. John was diagnosed 10 years ago and the girls remain optimistic that progress is being made to improve quality of life.

Julie and Jo are currently negotiating with potential sponsors, and are seeking to partner with others. If you or someone you know is interested in sponsoring the TULIP BALL®, they would love to hear from you!

Final details for the 2010 Tulip Ball will be advised in the next edition of Signpost (May/Winter) and all Members, readers, their family and friends are invited to attend. Come on your own or make up a table: Don't be shy. Everyone will be there for the same cause! For further information or to speak with Jo and Julie regarding sponsorship opportunities or tickets, please phone: 0417 384 954 or email: sewelljd@bigpond.com or johill@interchem.com.au

Raise a glass to show your support

Thank you to everyone who has been purchasing their wine from our charity partner alias wines!

Proceeds from the sale of every bottle go straight into funding our support and information services.

Our Autumn 2010 wine drive is on now: Download an order form from www.parkinsonsvic.org.au (go to the **fundraising and merchandise** section), choose your selection and then send the form to our partner **alias wines**, together with your payment details (**Please make all cheques payable to alias wines**).

Fundraising BBQ

We will be hosting a fundraising BBQ on Sunday 4 July at Bunnings Moorabbin (corner of Warrigal Road and Fairchild Street, just down from South Road).

If you would like to support by volunteering on the day, or can assist by helping us secure donated goods (sausages, onions, cold drinks, napkins etc) please contact us!

Painting for Parkinson's

Beyond the Mask II - an art exhibition showcasing the talents of artists who are living with Parkinson's from around the state - will take place as part of National Parkinson's Awareness Week, from 27 August - 14 September at Kingston Art Centre Gallery (979 Nepean Highway, Moorabbin).

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

For further information, contact Parkies with a Purpose: Vanessa (03) 9585 2402 or Ursula (03) 9557 5153.

What goes around

Don't just throw away your old ink cartridges and toners! Donate them to Parkinson's Victoria. Thanks to a 'buy back' scheme with Mammoth Recycling we will receive a "donation" for boxes of HP, Canon, Lexmark, Brother and IBM cartridges.

Cartridges must be delivered to the office of Parkinson's Victoria: C/- Kingston Centre, Corner of Kingston and Warrigal Roads, Heatherton, 3202. Office hours are Monday to Friday 9am-5pm.

Up, Up and Away

We have 4 Challengers heading off to Vietnam in March after having raised more than \$33,000! **Congratulations to Ed, David, Matthew and Dean for a fantastic effort. Bon Voyage! We look forward to sharing the photos and stories from their trip in the next edition of Signpost.**

October Charity Challenge announced!

We are excited to confirm that we are now taking registrations for our October 2010 trip (departing Melbourne 31 October, and returning on 12 November). Of course, the adventure begins as soon as you register, with planning for your fundraising activities and preparing for the bike ride.

Fundraising & events

If you're passionate about making a difference; if you love to travel and experience the colourful culture of exotic destinations; if you're keen to support people living with Parkinson's...then the Team Parkinson's Challenge is for you!

You'll be surprised who might be keen to take on our next Charity Challenge and support Parkinson's.

Perhaps you have a workmate, daughter, son, or even grandchild, niece or nephew who might love the idea of this Challenge and helping to support this worthy cause. They might love bike riding, love to travel or simply love a new personal challenge and adventure. Please tell **everyone** you know about this amazing opportunity to make a difference in the lives of people with Parkinson's.

A flyer explaining the Challenge is enclosed in this edition of **Signpost** and more flyers are available for you to pass on to a friend or family member or to put up in your local shopping centre or club.

Keen to know more about our October Charity Challenge? Contact Judith, our Marketing & Fundraising Coordinator: (03) 9551 1122 or email judith@parkinsons-vic.org.au. Or log onto www.parkinsons-vic.org.au to read more!

Shake a tin for Parkinson's

We're looking for enthusiastic and friendly volunteers to represent Parkinson's Victoria and collect donations from train commuters as part of our annual April tin rattle, to coincide with World Parkinson's Day (date to be confirmed).

If a family member, friend or workmate is interested in volunteering please contact us as soon as possible. (Volunteers are not required to commit to the full 2-hour period.)

Stamp of approval

Our colleagues at **Parkinson's NSW** run a fantastic fundraising activity where volunteers of the organisation collect used stamps and then package them up and sell them to collectors. Last year, this seemingly inconsequential activity raised \$3000!

We would be very interested to hear from individuals who would be able to do the same as a fundraiser for Parkinson's Victoria.

Country artist comes to town

The Kingston Arts Centre Gallery is hosting a special exhibition in April of work by NSW artist Harley Gale, who was diagnosed with Parkinson's in recent years. Gale's latest exhibition **Phoenix Rising** follows on from his 1972 exhibitions **A Sail in Time and Space**

and **The Garden of Earthly Delights**.

Gale, who actually hails from Goonengerry in Northern NSW, uses colourfield, action painting and the happy accident to illustrate the Chinese belief that 'the universe is in my heart and the heart is in my universe'.

The Kingston Arts Centre Gallery is located at 979 Nepean Highway, Moorabbin. The Exhibition will be launched on Thursday, 8 April, 6, and will continue from 9 to 20 April (gallery hours are 9-5pm).

SPECIAL EVENTS DIARY DATES

We encourage you to let your friends and family know about these events and activities and give them the opportunity to get involved in supporting Parkinson's. We have heard many stories from relatives and friends of people with Parkinson's who would love to have done this or that to show their support for a loved one... if only they'd known about it in time.

- Thursday 11 February Movie Club Fundraiser: Opening Night screening of the movie "Valentine's Day" at Dendy cinemas in Brighton (tickets \$25)
- Saturday 13 March our Team of Charity Challengers depart from Melbourne for Vietnam
- Sunday 11 April World Parkinson's Day: get your free Awareness Kit today!
- (second week of April, date to be confirmed) Metro Trains city loop train station tin rattle
- 20 April Haley Gale Art Exhibition
- Sunday 2 May Young Onset Parkinson' Project Launch
- Sunday 4 July Bunnings Moorabbin Charity Sausage Sizzle for Parkinson's
- 27 August – 14 September Beyond the Mask II art exhibition (at Kingston Arts Centre Gallery)
- Sunday 29 August Parkinson's Unity Walk Victoria (Federation Square)
- Sunday October 31 our Charity Challengers depart from Melbourne for Vietnam
- 13 or 20 November Gala Tulip Ball

Stay tuned for more information and details about new events over the coming months and keep an eye on our website.

Participate for Parkinson's

Research to find the cause and a cure for Parkinson's is taking place around the world. Important research is also being conducted into improved symptom management strategies and quality of life.

The fact that research is taking place here in Melbourne means that people living with Parkinson's from the local community have the chance to play an active role in these studies; sharing their experiences, trialling new medications and benefiting from the latest developments in symptom management, all while contributing to advances in understanding and managing the condition.

Research study attempts to gauge quality of life

Melbourne University researchers are currently seeking volunteers for a research project titled **Health-related quality of life of Australians with Parkinson's disease**.

The study aims to explore the quality of life of people with Parkinson's who are living in both metropolitan and rural areas of Australia.

If you have Parkinson's, live in rural Victoria and are interested in participating in this study, the researchers would like to hear from you.

Participation requires individuals to attend one assessment session at a mutually convenient location. You will also be asked to complete three questionnaires about your quality of life as a result of having Parkinson's. The questionnaires should take approximately 30 minutes to complete.

If you are interesting in participating in this research study or would like more information, please contact Sze-Eh Soh (pronounced Sue-Ee) at the University of Melbourne: (03) 8344 0486.

Painting with Parkinson's

Anne Atkin, an artist and teacher who diagnosed with Parkinson's in 2005, pioneered the **Painting with Parkinson's Support Group** and art program here in Victoria.

Anne was recently approached by a research study group keen to investigate the benefits of her program on people with Parkinson's and symptoms. She is now assisting researchers at Swinburne University on a joint Parkinson's Victoria/Swinburne University study. Here, Anne shares the background on how the study came about and what it hopes to achieve:

"Three years ago, I thought how good it would be to use art as a way of helping people with Parkinson's to find an activity that would hopefully make life a little more bearable. I wanted other "Parkies" to feel the way I did when I was sketching, drawing and puddling with paint.

It wasn't until I found out about Nancy Tingey [an art teacher providing art classes to people with Parkinson's in Western Australia] that I learned how art and creativity gave people with Parkinson's so much more.



A member of the Essendon Parkinson's Support Group during a Painting with Parkinson's workshop

I believe passionately that creativity changes the way in which you use your brain. It helps you with relaxation, depression...the list goes on.

Getting **Painting with Parkinson's** up and running in Victoria was a dream. Now I have a second art group. Last year, I knew that if **Painting with Parkinson's** was to continue and develop it had to be shown that its benefits are real - not imaginary - and the only way to do that is through research.

Dr Simon Knowles, Head of the Psychology Department at Swinburne University has agreed to supervise a research project about **Painting with Parkinson's**, entitled **An exploration of the impact of art as therapy on individual well-being**.

You have no idea how excited I am! As Dr Knowles pointed out, this project is breaking new ground as it will show - one way or another - that **Painting with Parkinson's** is therapeutic for people with Parkinson's.

This is your opportunity to help prove this point - and to enjoy the benefits of the art program at the same time!

As a research project, participation couldn't be more simple - or fun! It involves no undressing, no injections and no cost to you! And, your involvement will give you the chance to give your grandchildren loads of paintings to put on their fridge door!

It's important that the research project is conducted correctly and thoroughly, in accordance with all the usual ethical and other requirements, so it is unlikely to begin before May, 2010. In addition, due to limited resources, it will be impossible to make **Painting with Parkinson's** accessible to all areas of the Victoria. Currently, the plan is for art group sessions to be held in Berwick (the original group), Shepparton and Portland."

What it's all about:

Having Parkinson's Disease (PD) can be both physically and psychologically challenging. The aim of this project is to explore the experience of individuals with PD and their engagement in "Art as Therapy: **Painting with Parkinson's**" workshops conducted by Anne Atkin.

Participate for Parkinson's

Specifically, this project investigates the perceptions of individuals with PD in relation to symptom severity (e.g., what are the active symptoms of PD), illness representations (e.g., how much impact does PD have on my life) and coping strategies (how you try to deal with having or caring for someone with PD) on health outcomes (psychological distress, quality of life) while participating in the art workshop. Participants are asked to complete a survey before starting the class and eight weeks after commencing the art classes.

Previous research has found a link between social-

based interventions (such as art therapy) and changes in perceptions of illness, coping strategies and the subsequent health outcomes in patients with chronic illnesses. Identifying these aspects can help to improve the lives of those diagnosed with PD.

This is a joint project between Parkinson's Victoria, Swinburne University Alumni Association and Swinburne Psychology. If you are interested in participating in the *Painting with Parkinson's* art group research project or simply keen to learn more, contact Parkinson's Victoria or Anne Atkin: 0409 188 317.

We're all in this together!

Parkinson's Unity Walk (Victoria) - Sunday 29 August

This special event is a wonderful opportunity for people with Parkinson's to come together in a public display of solidarity.

We also know, from feedback following last year's event, that Unity Walk is a tangible and valuable way for family members and friends to show their support for loved ones, and to walk in memory of those who have passed away.

The event also raises significant awareness of Parkinson's in the wider community, not only on the day, but through publicity and media stories in the lead up to the day.

Finally, through the fundraising efforts of participants, the event raises vital income to support research and our work providing support and information to those living with Parkinson's, including friends and family.

The success of the Walk is very much dependant on securing major sponsorships.

Do you know someone who might be interested in supporting this event with a major financial contribution? In return, we can offer a number of benefits and added value.

Are you able to help sponsor Parkinson's Unity Walk? Perhaps you have a family member, friend or current or past employer who might see sponsoring the Walk as an ideal way to promote their goods and services, while supporting a great cause and showing their community spirit!

What sort of companies might be keen to sponsor Unity Walk?

- Financial/insurance based firms
- Travel companies
- Companies involved in any aspect of the health industry (clothing, gyms, weight loss etc)
- Food manufacturers or distributors
- Car dealerships
- Pharmacy chains
- Business to Business
- Companies with products and services relevant to retirees or young parents
- Pet companies (we had lots of dogs join the walk in 2009!)

And many more!

\$5,000, \$10,000 and \$20,000 sponsorships are available. For more information about sponsoring Parkinson's Unity Walk (Victoria) or for a sponsorship proposal, please contact our Marketing & Fundraising Coordinator, Judith Mooney: (03) 9551 1122 or email judith@parkinsons-vic.org.au



Join your family and friends for this year's Parkinson's Unity Walk

Medication News

Publication details

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ABN: 68 038 728 034

Print Post Approved PP33962/00002

Designed and printed by:

Doran Printing: (03) 9587 4333

www.doranprinting.com.au

Frequency:

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

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Disclaimer:

Information and articles contained in **Signpost** are intended to provide the reader with useful and accurate information of a general nature. While every effort is made to ensure information is accurate and up-to-date at the time of publication, Parkinson's Victoria Inc. does not guarantee correctness or completeness of information. Information is not intended to substitute for legal or medical advice, nor is Parkinson's Victoria Inc. recommending legal or medical advice. Readers are advised to seek their own medical or legal advice as appropriate.

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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.

In this section we highlight important news around medication, helpful information and advice for achieving optimal results, as well as details for accessing relevant support and assistance schemes.

Medication Shortage - Sinemet CR

Parkinson's Victoria has been advised that there is an anticipated shortage of Sinemet CR, likely to continue throughout 2010.

Sinemet CR is the controlled release form of Sinemet, and the shortage is confined to **only** this type of Sinemet. All other forms of Sinemet will continue to be available as normal. The supply difficulty is **not** related to a manufacturing issue and the drug itself is safe.

Neurologists and treating specialists have been advised of the shortage and will be able to offer alternative medication regimes to compensate for the shortage, and to ensure supplies are available to those in most need of this specific medication. It is expected that production of Sinemet CR will return to normal levels in early 2011.

If you are currently taking Sinemet CR to assist with Parkinson's-related symptoms, you should discuss this with your GP or Neurologist during your next consultation.

For further information and updates on this or any other medication-related issue, please contact the Health Team at Parkinson's Victoria.

Managing medicines at home

The Home Medicines Review (HMR) was introduced into the Medical Benefits Scheme in October 2001 to increase the appropriate use of medications and reduce the incidence of 'Medication Misadventures', thereby assisting in improving patient health outcomes.

If medicines aren't used properly, or if the wrong ones are used together (including vitamins and complementary medicines), the results can be serious. Consumers who take more than five medicines a day, are confused or worried about their medicines, sometimes forget to take their medicines, see more than one

GP or specialist, or have recently been in hospital, could benefit from a Home Medicines Review.

How does the HMR work?

The GP generates a referral to the local pharmacy. A pharmacist conducts an interview, preferably in the consumer's own home, and then writes a report back to the GP, who then discusses any recommendations with the consumer and may make appropriate changes to their medication regime.

Often the pharmacist picks up on things in the home that the GP is not aware of, but should know about. The GP and pharmacist work together to help the patient to get the most positive health outcomes possible.

If you, or someone you care for, are interested in a Home Medicines Review, speak to your GP to arrange a referral to your local pharmacy. Visit the Help Finder Section of our website for more information.

World Parkinson's Day 11 April 2010

This day celebrates the birthday of Dr James Parkinson - the first to clinically describe Parkinson's as a unique condition.

It also aims to focus attention on the more than 6 million people worldwide who are living with Parkinson's, including approximately 80,000 here in Australia.

If you would like a free 'Awareness Kit' to promote Parkinson's in your community or workplace, contact Marketing & Fundraising Coordinator judith@parkinsons-vic.org.au

Our Supporters

We gratefully acknowledge the generous donations that have been made in recent months to support our work in the community. Unfortunately, due to the large number of donations we receive, we are unable to list all donors individually. Listed below are the names of those who kindly donated \$200 or more between 16 October 2009 and 24 January 2010 and individuals in whose name in memoriam donations were received. We extend our sympathies to the families who have lost loved ones, and our thanks go to the friends and family members who have donated to Parkinson's Victoria in their memory.

We also thank those who have donated but wish to remain anonymous, and those who have supported our Ambassadors of Hope speakers program.

Donations \$200 and over (individual)

Bruce Barker
Mario Bortolotto
Evelyn Collins
B Elliott
Peter & Rosie Gates
Maureen Hayes
Mike & Heather Jobling
Leong Keong & Family
Paul & Fiona Limoli
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Donations \$500 and over

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Brian and Margaret Weeks
Keith Williams

Donations \$1000 and over

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In memory of...

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Corporate, Community & other donations & support

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Staff of the City Loop Stations
Avenel Card Ladies
Baker's Delight (The Glen)
Beaconhills Christian College Ltd
Bendigo and Adelaide Bank Ltd (workplace giving)
Breville Pty Ltd
Bundoora Extended Care Centre
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The Monash-Aires
Townsville City Council
Uniting Church - Synod of

Victoria & Tasmania
Vermont Secondary College
WAM Personal Training
Wantirna Health Facility
Warren Opportunity Shop Inc.
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Western Aged Care Assessment Service

Parkinson's Support Groups

Ballarat
Beechworth/
Yackandandah
Camberwell
East Gippsland
Essendon
Rosebud
South Gippsland
Wimmera

Bequests

The Estate of Trevor James Scott
The Estate of Stella Margaret Hanson

Trusts and Foundations

Danks Trust
The William Angliss (VIC)
Charitable Fund

We also thank those who generously supported our annual End of Year Appeal. We received donations from individuals and many corporate supporters, a number of which gave generously to Parkinson's Victoria in lieu of gifts or staff gifts, or who chose to remember loved ones at this time with a donation. Our End of Year Appeal for 2009 raised a total of \$17802 to support our work in the community. In addition, our Christmas Card campaign raised \$8253 (with an additional \$1439 donated with card purchases). We also thank all those who have recently renewed their Membership or become Members of Parkinson's Victoria.

Library

Our library is a terrific resource of information to help you not only learn more about Parkinson's, but learn how to 'live well' with Parkinson's.

The books, videos and DVDs cover a wide range of topics, from personal reflections and self-help-style books through to the more clinical-based explanations of the condition (with information about symptoms, medication, treatment strategies), as well as exercise, and diet.

Members of Parkinson's Victoria are able to borrow books, but anyone is welcome to visit the office and spend time browsing the shelves. To become a member please contact our office (\$30, 12-month membership).

We are pleased to advise that the library has recently been re-located to the large meeting room in our office, which provides visitors the chance to sit quietly and read before making their selection.

Of course, members of our Health Team are on hand to assist with your needs and answer specific questions and to make recommendations on particular resources; however we do recommend making an appointment to visit so we can ensure a team member is available.

In addition to the library resources, visitors can access a number of Fact Sheets and newsletters from other Parkinson's organisations around the world, as well as back issues of our own newsletter, **Signpost**. Our volunteer librarian, Anne, who will happily share her personal experience of living with Parkinson's and can assist with recommendations, will ensure an up to date list of current resources is available.

While we are constantly updating our library with the latest titles and thought-provoking subject matter, it is interesting to pick up some of the 'older' books to note how approaches to Parkinson's and symptom management have changed over the years.

We have recently purchased a selection of new titles which focus on personal reflections. To borrow one of these titles please contact our office:

- **Ponderings on Parkinson's: An Inside View of PD**
- **Living with PD (short pieces written by PLWP)**
- **Always looking up (Michael J Fox): The Adventures of an incurable optimist**
- **Living well, running hard**
- **Living with PD: how to make the best of it**
- **I will go on: Living with a movement disorder**
- **A life shaken: My Encounter with Parkinson's Disease**
- **Pills, bills and PD: Coping with the On-Off Syndrome**
- **My Shaky Grandma**
- **Living with a Battery-Operated Brain**

If you have read a book that you feel would be of interest or benefit to others, please let us know.

Tune in: Parkinson's Victoria television

Introducing, Parkinson's Television via your personal computer!

Parkinson's Victoria now boasts its very own dedicated YouTube channel – www.youtube.com/parkinsonsvic



YouTube is a public website that allows users to post and share videos. Resources, footage and information from all around the world on just about every topic imaginable can be found here and watched for free.

Parkinson's Victoria is committed to using technological tools to ensure information is more accessible to a greater number of people. YouTube is a well-known and popular tool that is accessible to anyone with an internet connection. It is used by people of all ages, and in the case of Parkinson's TV, facilitates the sharing of Parkinson's Victoria resources to even more family members, friends, professionals and interested members of the general community.

As Parkinson's Victoria continues to build its educational video resources, keep checking our YouTube channel for interviews, discussions and presentations by a range of professionals who have expertise in Parkinson's.

By watching videos through the Parkinson's Victoria channel, users can be confident that they are viewing reliable and up-to-date information.

We welcome you to take a look today - and on a regular basis - by visiting www.youtube.com/parkinsonsvic

As with any information posted on the internet, youtube features video uploaded by anyone and everyone, so we encourage you to be careful of what you watch and stick to material posted by reputable organisations.

The 2009 seminar **What lies Beneath: an information session on Deep Brain Stimulation (DBS) Surgery**, featuring presentations by Neurosurgeon Dr Richard Bittar and Neurologist, Dr Richard Peppard, hosted by Parkinson's Victoria and proudly sponsored by Medtronic, is now available to view on the new Parkinson's Victoria TV Internet 'channel': www.youtube.com/parkinsonsvic