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Australia's Unity Walk: Be a part of history

With your participation, **Australia's Unity Walk for Parkinson's** will be the largest gathering of people living with Parkinson's, families and friends in Victoria's history.

We're aiming to bring together at least 1,000 people at Federation Square on Sunday, 30 August to launch National Parkinson's Awareness Week with **Australia's Unity Walk for Parkinson's**. (Parkinson's NSW will be doing the same at Olympic Park).

Details of the event have been mailed to you in June, and further information is available at www.unitywalk.com.au

We urge you to be a part of this unique event as we work to raise community awareness about Parkinson's and funds for research and services.

Corporate Australia has already shown its support in a number of ways:

- **Telstra** is our major event sponsor and **Novartis** is our supporting event sponsor.
- The prize for the highest individual fundraiser - a trip for two, plus accommodation in Hawaii was generously donated by **Hawaiian Airlines, Hawaii Tourism** and the **Outrigger Enterprises Group**.
- The prize for the corporate team that raises the most money - a corporate box on day two of the Boxing Day Test - has been kindly donated by the **Melbourne Cricket Ground**.
- Federation Square has waived their booking fee for the use of their facilities on the day.
- **The Voice of the AFL', Craig Willis** has donated his services to record radio advertisements, which are currently being broadcast on **3AW693** and **Magic 1278**.



Parkinson's supporters unite during the 2008 NSW Unity Walk.



Illawarra North Parkinson's Support Group prepares to start the 2008 NSW Unity Walk at Sydney Olympic Park.



- **Langham Hotels** has donated a magnificent prize of two night's accommodation at their luxurious hotel in Southbank, to be drawn from **all registrants** on the day.
- **AFL legend Sam Kekovich** donated his services to appear in our community service announcements (CSA) promoting Unity Walk, which are currently appearing free-of-charge on commercial television stations.

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.

Parkinson's services go west

One of the strategic aims of Parkinson's Victoria is to increase the services available to **all** people living with Parkinson's. One of our main strategies to achieve this is to establish a Parkinson's dedicated health care professional in each of the eight Victorian health care regions (five in regional areas and three in metro Melbourne).

We are pleased to advise that as a result of lobbying the State Government and Department of Human Services, we are one step closer to achieving this.

In collaboration with Western Health, funding has been awarded for a 2-year pilot project that has seen the appointment of Ms Joanne Bolton to the role of Parkinson's disease Clinician within the Western Health Care Network.

The Western Health Care Network delivers health care in the most rapidly growing areas of Melbourne and is both economically and ethnically diverse.

The region was identified as an ideal location for this project, as there are currently no Parkinson's or specialist Movement Disorder services in this region.

Ms Bolton is an experienced health care professional who will be able to see people living with Parkinson's who are located within the five council areas of Brimbank, Maribyrong, Melton, Hobson's Bay and Wyndham.

The Parkinson's disease Clinician can offer support to individuals newly diagnosed; support with understanding medication and side effects; education about Parkinson's; and referral to and co-ordination of available resources. The Clinician also acts as a point of contact for people who are unsure from whom they should seek assistance.

Referrals can be made by local GP's, neurologists, community health care teams and organisations such as Parkinson's Victoria by faxing a referral form to Ms Bolton: (03) 8345 1339. Alternatively, individuals with Parkinson's can self-refer by calling (03) 8345 1283.

This is a positive and exciting development for patients living with Parkinson's in the west.

If you would like further information about this initiative, please contact Victor McConvey at Parkinson's Victoria.

Parkinson's Victoria looks forward to bringing you more information and updates on the pilot project and what it means for all Victorians living with Parkinson's in future editions of Signpost.

A time of change at Parkinson's Victoria

Amanda Spillare, Client Services Coordinator, recently announced her decision to resign from her role at the organisation.

"It is with much sadness that I say goodbye to Parkinson's Victoria.

I have loved working with people with Parkinson's over the last 5 years and being able to help families through their journey with Parkinson's.

The friendships and positive feedback I have had along the way has been a truly enriching experience.

I would also like to thank our members, volunteers, staff and board for their support in allowing me to follow my ideas and initiatives over the years, and I hope to work with the organisation again in the future.

From here, I will be taking up a position with the Cancer Council, facilitating support groups. My long term goal is to set up private practice and continue to work one-on-one with people living with Parkinson's."



Amanda and Board Member Fred Van Ross during Amanda Churchill Fellowship presentation.

Amanda has been an invaluable asset to our organization and to those in the community and health profession we support. She will be greatly missed and we wish her well and best of luck for all her future endeavors.

We are pleased to share the news that Donna Willis, the cheery voice that greeted many of you on the end of the phone - and in person - during her 3 years as receptionist and volunteer coordinator with Parkinson's Victoria - and who recently left us to go on maternity leave - gave birth in June to a healthy baby boy, Gibson John. Congratulations to Donna and husband Matt on the birth of their first child.

We also welcome to the team Lesley and Dianne who have joined our administration department.

New information kit for people with PSP

People living with Progressive Supranuclear Palsy (PSP) now have a new information resource to help in managing this challenging condition.

The Australian-produced **PSP Information Kit** contains a series of 16 Help Sheets on topics including:

- Managing the symptoms of PSP
- Where to go for help
- Planning for the future
- Staying independent
- Caring for carers, and much more.

The Help Sheets are also available to download from: www.psp-australia.org.au.

The kit has been developed by PSP Australia, in collaboration with health professionals. The information is presented clearly and simply, and is relevant to people from all Australian states and territories.

To order a copy of the kit, contact Parkinson's Victoria.

A brush with fame

In May, Anne Atkin, Parkinson's Victoria volunteer librarian, Painting with Parkinson's Leader and Ambassador had the opportunity to meet one-on-one with **Federal Minister for Ageing Justine Elliot**. The meeting was part of the Government's **Community Cabinet initiative** where Cabinet Ministers visit various community groups, giving members of the public the opportunity to engage directly with government leaders.

Anne and the Minister discussed Parkinson's and the need for improved funding.

Anne was also delighted to meet personally with Prime Minister Kevin Rudd. Anne shared some of her personal story of living with Parkinson's and her volunteer work for the organisation and Parkinson's community. Prime Minister Rudd's mother was diagnosed with Parkinson's, and she passed away in 2004.



Anne Atkin met with Prime Minister Kevin Rudd (right) and Anthony Byrne MP, Federal Member for Holt (left), during the City of Casey Community Cabinet in May.



Access, Advocacy & Assistance

Disability travel pass

From September this year, people who have a severe and permanent disability and can travel independently on public transport will have access to a new travel pass. This includes people who are in a wheelchair and have limited fine hand movement, which stops them from being able to reach a ticket machine or barrier, as well as some people who have an intellectual disability.

The pass will be used in same way that people currently use the Vision Impaired Travel Pass. Pass holders will need to carry it whenever they use public transport and it will entitle them to free travel.

The application process for the Access Travel Pass will include a number of steps:

- A registered health professional will need to certify that the applicant can travel independently but cannot use tickets; and
- All applications will be reviewed by an independent panel.

Application forms for the Access Travel Pass will be administered by the Metlink Central Pass Office and will be available from the office or www.metlinkmelbourne.com.au from September. Contact Parkinson's Victoria for more information.

Three brains better than one

The Howard Florey Institute, the Brain Research Institute and the National Stroke Research Institute, which all specialise in conditions affecting the brain, have amalgamated to form the **Florey Neuroscience Institutes (FNI)**.

The new group brings together 700 scientists and support staff to become the largest brain research group in Australia and the fourth largest in the world.

The Melbourne Neuroscience Project, as it is known, is a collaborative approach to research, where basic and clinical scientists will combine their expertise to work towards common goals, namely improved patient outcomes.

Two new facilities will be constructed, one in Parkville on the grounds of the University of Melbourne, and the second in Heidelberg at the Austin Hospital.

Building should be complete by mid-2011.

A watchful approach to Parkinson's

Victorian researchers have developed a wristwatch that continuously monitors the health status of people with Parkinson's.

The innovation, still at prototype stage, was introduced onto the world market by the Victorian Minister for Innovation Gavin Jennings at **BIO2009** in Atlanta, USA.

Developed by a team led by Professor Mal Horne and Dr Rob Griffiths at the **Florey Neuroscience Institutes**, the wristwatch device is designed to help physicians better manage people with Parkinson's.

"The right dosage and correct timing of medication has enormous impact on the wellbeing of a Parkinson's patient," said Mr Jennings.

"What this device does is provide the physician with an objective measurement of how a patient's symptoms have changed over time. For the first time, it will provide physicians with information about the effectiveness of medications and will guide them in adjusting the timing of medications."

The next stage in the development of the device – refining the prototype and completing clinical trials – is being funded by **Melbourne's Medical Research Commercialisation Fund**.

Parkinson's is a progressive disorder of the brain that affects body movements, with the main symptoms being tremors, muscle stiffness and slow movement. The device records and reports the patient's key symptoms and movement patterns, providing clinicians with a better understanding of the patient's disease status and enabling them to adjust dosing and the timing of dosing to optimise symptom control.

Currently, neurologists use a subjective scoring system to check dosage and timing by observing the patient during a consultation. Without an objective measuring system, neurologists find it difficult to know whether the medications are effective. Currently, neurologists only have a brief snapshot of the patient during their visit to the consulting rooms (typically every 6-8 weeks), but the patient's symptoms vary continuously through the day, every day.

Having an accurate measurement of the effect of treatment will also reduce the cost and time of bringing a new drug to market.

A step forward for stem cells

In May it was announced that the **Florey Neuroscience Institutes**, a Parkinson's Victoria research partner, in association with **Monash University's Australian Stem Cell Institute** has been successful in obtaining an Early Translational research grant from the **Victoria-California Stem Cell Alliance**.

The purpose of this award is to advance basic research into stem cells toward eventual patient benefit. This hotly contested grant comes from the recently formed international alliance between the **State of Victoria** and the **California Institute of Regenerative Medicine**.

The successful project entitled, **Developmental Candidates for Cell-Based Therapies for Parkinson's disease**, aims to identify the best candidates for stem cell therapies in Parkinson's using animal models. The long term aim is to ascertain which person living with Parkinson's will get the most benefit from stem cell therapies.

This is a collaborative project with principal researchers, Dr Clare Parish (**Florey Neuroscience Institutes**), Professor Colin Pouton (**Monash University**) and Professor Evan Snyder (**Burnham Institute of Medical Research, California**) leading the research.

Dr Parish advises us that the Californian collaborators have discovered that human neural stem cells have the potential to improve Parkinson's in some animal models. Some of these cells are observed to change and become dopamine producing cells, but a possible, more beneficial, action has also been observed. This has become known as the **"Chaperone effect"**.

The Chaperone Effect is when transplanted stem cells that do not become dopamine producing cells appear to contribute to the reversal of Parkinson's symptoms in other ways. This represents a more encouraging impact of stem cell therapies.

Q: My grandmother and uncle both had Parkinson's. I'm concerned that I'll be diagnosed too. Does Parkinson's run in families?

A: This is a very common question asked of the staff at Parkinson's Victoria, and unfortunately it has a very complex and inconclusive answer.

Parkinson's is largely thought to be an **Idiopathic illness**. This means it occurs spontaneously with no distinct family history.

However, in some rare instances it does appear to run in families. It is thought that between 2 - 5 percent of people diagnosed with Parkinson's may have a genetic link to developing the illness.

There has been much research across the globe exploring familial links in relation to Parkinson's, and researchers have found several different forms of genetic mutation that may relate to the disease.

Some of these mutations appear to be seen in certain ethnic groups and often have a very distinct presentation.

If there is a distinct family history - where Parkinson's is seen in several people across several generations in your family - your neurologist may talk to you about undergoing a genetic screening for Parkinson's [see below]. If your Neurologist is at all concerned about a familial link to Parkinson's they will refer you to a specialist Neuro-genetics clinic for further consultation and to receive genetic counselling. (Counselling will help individuals in the decision making process, explain the procedure, the potential outcomes and provide general support).

It is important to remember however, that familial Parkinson's is extremely rare. It is also treatable in the same way that we treat Idiopathic Parkinson's, in other words with medication that treats the symptoms only.

So, can you be tested for familial Parkinson's?

In Australia, there are currently no conclusive genetic screening tests available to diagnose familial Parkinson's. If your neurologist suggests a gene test, the blood sample will be sent overseas for analysis.

In endeavoring to learn more about the genetic make up of people with Parkinson's, the Parkinson's Victoria Research Register is taking some genetic material (in the saliva cells) from research participants. This research project may

in time assist in developing a conclusive test for Parkinson's.

Q: I have Parkinson's and recently noticed difficulty with my eating and swallowing. Food 'sticks' in my throat and frequently I cough and choke when drinking water. Can anything be done to help me?

A: A referral to a speech pathologist (also called a speech therapist) is the first step towards obtaining help. These people are experts in swallowing problems, as well as speech and communication.

The speech pathologist will take a full history of your swallowing problem, and then examine your mouth and throat. They will watch while you try to swallow different consistencies of food and/or liquids, to pinpoint the precise nature of your swallowing problem. They may also undertake an x-ray examination of your swallowing, called a *videofluoroscopy swallowing study*. From this videotaped exam, you can be shown the exact problem you have.

Coughing and choking each time you swallow can be frightening and embarrassing for you, and for your family and friends. If the choking continues over many months, it can lead to serious health problems, such as pneumonia, so it is important to have this assessment.

Speech therapy can help you to address your swallowing problems. Once the exact nature of your problem has been analysed, a speech pathologist can show you exercises or manoeuvres to improve your swallowing safety. For example, swallowing with your head down to your chest may stop food or fluid from going down the wrong way.

This question has been answered by Professor Alison Perry, School of Human Communication Sciences, La Trobe University, Bundoora. Professor Perry is involved in the "swallowing research study" (featured on page 10 under Participate for Parkinson's).

How do I find a speech pathologist?

Call Speech Pathology Australia: (03) 03 9642 4899, or email them at office@speechpathologyaustralia.org.au to find a local speech pathologist.

Make sure you state that you want a speech pathologist that is skilled in treating adults with swallowing disorders. Your neurologist or local GP may also know of speech pathologists that have experience in helping people with Parkinson's.

Highlights from the Movement D

Postcards from Paris

In June, VICTOR MCCONVEY, our Parkinson's Specialist Nurse Consultant, travelled to Paris to attend the Movement Disorder Society's annual congress on Parkinson's disease and movement disorders.

The information presented was extensive and extremely comprehensive and we are pleased to present highlights from the congress in *Signpost*. Here, Victor provides an overview of the following topics discussed at the congress: Managing Early Parkinson's, Impulse Control Disorder and surgical interventions. (*Signpost* (summer) will feature the concluding instalment).

This congress is considered by many in the field of Neurology to be one of the most important opportunities to hear expert opinion and the latest developments in treatment for movement disorders, including Parkinson's.

The major themes of this year's conference included: Early Management, Deep Brain Stimulation (DBS), managing later-stage Parkinson's, Non-Motor Symptoms, and the challenge of Movement Disorders in the developing world. Other areas included management of Dystonia, the nurse's role in managing Parkinson's, and recent developments in understanding and managing Multiple System Atrophy.

Managing Early Parkinson's

The scene was set by defining the treatment paradigm for Parkinson's: Parkinson's is caused by a degeneration of cells that produce a brain chemical called **Dopamine** and the simplest and best way to treat this degeneration is by providing additional or replacement dopamine through medication.

It was acknowledged however that, in early illness, it isn't, unfortunately, that simple, and much debate continues over when and what specific agent to use to get the best results for the Parkinson's patient. However, the treatment aim of improving *quality of life* while decreasing motor and non motor symptoms remains essential.

The decision of when to treat and the options of *watch and wait* or *treat on diagnosis* were also hotly debated, and while there still does not appear to be a *right* or *wrong* way to manage early illness, many of the research papers presented suggested that early treatment may have long term benefits.



A presentation during the 2009 Movement Disorder Society's World Congress.

These suggestions highlight the importance of early diagnosis, and the use of medications that have **neuro-protective** actions.

Neuro-protection involves taking a drug or dietary supplement that appears to slow the progression of the illness in its early stages.

The potential for neuro-protection was showcased with the release of the ADAGIO and TEMPO studies that specifically looked at the effectiveness of **Rasagaline** (Azilect™).

Currently, this medication, which is a **MAO-B inhibitor*** is not available in Australia, however a similar drug called **Selegiline** (Eldepryl™ and Selgene™) is. These studies indicated that use of Rasagaline in early illness appears to decrease motor complications and increase functional status. These benefits were also reflected in an 8-year follow up study.

The action causing this response remains unknown, and there is no conclusive evidence, as yet, to support the idea that the medication is neuro-protective. Factors such as the early adaptive or compensatory mechanisms in relation to Parkinson's (in other words the body's ability to adapt to changes) also remain unknown.

There is ongoing research into the potential role of MAO-B inhibitors in neuro-protection, and the value in using Selegiline over Rasagaline is yet to be ascertained.

The discussion around neuro-protective agents was not limited to medication and identifying alternative agents was raised.

For example, there is ongoing research - with promising outcomes - into the use of Co-Enzyme Q10 and Creatine.

Disorder Society's World Congress

Both of these agents are currently dietary supplements and the results of research into their potential as neuro-protective agents are eagerly awaited.

The value of exercise, both physical and mental, and its potential to be neuro-protective was also discussed. This has been supported in studies using rat models. While still theoretical in relation to the impact for humans, exercise was acknowledged as being very important in **living well** with Parkinson's.

Many research papers presented at the Movement Disorder Congress supported the idea that keeping 'active', both physically and mentally, was important in maintaining physical and intellectual function.

Causes of Parkinson's

In the early part of the congress there was naturally debate over the cause of Parkinson's, and suggestions were raised about the role of environmental factors, particularly "endogenous oxidative stress" or external agents that lead to cell oxidation and death.

Unfortunately, no commonly used agents have yet been identified as causes of Parkinson's.

Genetic causes of Parkinson's were also discussed, and the role of external agents, in combination with genetic factors in developing Parkinson's, was thought to be an important factor to consider.

The fact that leading experts and researchers around the world are still debating the cause of Parkinson's clearly indicates the complex nature of this condition.

Dispelling "Levo-dopa-phobia"

Dr Stanley Fahn, a pioneering Parkinson's neurologist, acknowledged that this was a very important aspect for patients to overcome in early illness.

Levo-dopa or Dopamine replacement therapy is essential in treating Parkinson's and continues to remain effective throughout the condition's progression (although changes in dosage are typically required over time).

Unfortunately, Levo-dopa is also the medication implicated in developing motor fluctuations, "wearing off" and dyskinesias* in particular.

Emphasis was given in this segment of the conference to treating medication-related symptoms early and reassuring people living with



From left: Dr Kate Kotchet, Victor McConvey, Dr Andrew Hughes and Marion Hoffman (Parkinson's Nurse, Austin Hospital) together at the World Congress.

Parkinson's that dopamine-replacement therapy is safe and effective and the side effects are manageable.

Managing Dopamine Agonist (DA) Therapies & Impulse Control Disorder

Dopamine Agonists (which include drugs such as Sifrol and Cabaser) were acknowledged as being an alternative medication to Levo-dopa in managing early illness, and having a significant role in preventing and managing motor fluctuations, such as "wearing off" and dyskinesia.

Much of the discussion surrounded the incidence of Impulse Control Disorder (ICD).

This behaviour, which commonly presents as developing a desire to gamble, compulsively eat or shop, or becoming hypersexual, is commonly associated with these medications.

Recent research seems to indicate that the incidence varies between individuals, and may be related to the dose or the product. For example, reducing the dose of a Dopamine Agonist or switching to another DA may stop the side effect of ICD, although this research is unreliable.

Studies into ICD noted that people affected often became secretive and reluctant to divulge the occurrence of these behaviours. Interestingly, people who had previously experienced some compulsive behaviour were more at risk of developing ICD after taking these medications.

There have also been reports of occurrences of ICD in people on high doses of anticholinergics such as *Bromocriptine* (Parlodel™), Dopamine Replacement Therapy and following Deep Brain Stimulation (DBS) surgery (although these tended to occur at a much later stage of the illness and were much rarer).

Continued on Page 18

Support Groups

Going from strength to strength

Parkinson's Victoria has more than 45 affiliated Support Groups serving local communities throughout the state.

Members can be anyone who is "living with" Parkinson's; whether they have been diagnosed with the condition, or are a partner, family member or carer of someone with Parkinson's.

Support Groups offer members a chance to meet and talk with others who share similar experiences, situations and problems. Most groups invite guest speakers to various meetings and many organise excursions and day-trips. Monthly meetings are informal and friendly, and new members are always welcome.

Over the years, we have seen our Support Groups grow, evolve and change, from member numbers and leadership to meeting locations and personality!

The common thread has been that our Support Groups continue to provide much needed support to hundreds of people living with Parkinson's, their partners and family members. They also continue to play an invaluable role in promoting Parkinson's awareness within the local community.

In recent months it has been exciting to see new groups forming, including some 'specialty' groups:

The latest additions have been the Wodonga Parkinson's Support Group; a new branch of the **Young Parkinson's (YAP) Group**, which has been established in Geelong; and **Painting for Parkinson's** groups, which are now established in Essendon and Leongatha.

All groups are keen to grow their membership and to offer support to all members of their local community affected by Parkinson's.

Please contact Parkinson's Victoria to find out more about becoming a part of a general support group in your area, or a specialty support group, such as those mentioned above.

Health Team note: A Support Group Leader Training Day and Thank You get together was hosted by Parkinson's Victoria on 31 July.

Support network for DBS patients

Expressions of interest sought...

Have you had Deep Brain Stimulation (DBS) surgery for Parkinson's symptoms? Would you like to meet and talk with others who have had this operation?

Parkinson's Victoria is seeking expressions of interest from people who would like to connect with others to share their post-operative experience of DBS.

The purpose of the get-togethers is to meet others who are keen to share their personal experience of DBS surgery, including the impact surgery has had on their lives, and to share information.

Health Team note: Please note, this group does not aim, nor is it equipped to be, a therapy group.

If you are interested in participating in this new Victorian-based initiative, please contact Catherine at Parkinson's Victoria: (03) 9551 1122 or email catherine@parkinsons-vic.org.au

On the road with our health team

In July, Amanda Spillare, Client Services Coordinator, visited the areas of Swan Hill and Mildura to provide information, support and education to people living with Parkinson's (during their monthly Support Group meetings), as well as the region's medical community.

Amanda, who was there at the formation of these two regional groups back in 2006, is pleased to report that both groups have gone from strength to strength, with the Mildura Parkinson's Support Group now boasting more than 60 members.

While in the area, Amanda made time to meet with local Member of Parliament, Peter Crisp, to highlight the need for improved services and increased funding to support people living with Parkinson's in the rural community. Mr Crisp learned of the funding inequities between Parkinson's and other chronic conditions, and the fact that numbers of people diagnosed with the condition is set to increase by 15 percent over the next 5 years.

We hope that Mr Crisp will be committed to supporting our efforts to raise awareness of Parkinson's in the community and to increasing government support.

Research opportunity

Parkinson's Victoria, Swinburne University Alumni Association and Swinburne Psychology are currently conducting a study exploring the experiences of both people living with Parkinson's and the caregivers of people living with Parkinson's.

Researchers Zahra Tasha Wahid, Nicole Aimers, Dr Simon Knowles & Professor Sue Moore of Swinburne University of Technology, Melbourne are conducting a study titled, **Comparing Differences between Caregivers and Parkinson's Disease Patients: Illness Beliefs, Coping Strategies and their Implications for Well-being.**

The study will investigate issues such as symptoms, illness representations, coping strategies and health outcomes. The study is questionnaire based and takes about 30 minutes to complete.

If you would like to take part in this research, please visit the Parkinson's Victoria website and follow the online link to the study questionnaire.

If you would like the questionnaire mailed to you, please contact Dr Simon Knowles on 03 9214 8206 or email sknowles@swin.edu.au

Pioneering support for Young Parkinson's

Being diagnosed with Parkinson's presents many and varied challenges. While the age of onset is typically 60 years and over, more and more people are being diagnosed "younger", and we know of several people diagnosed as early as their 20s.

Naturally, people diagnosed at a younger age will face different challenges to those of their older counterparts. Parkinson's Victoria understands that subsequently, younger people have different information and support needs. The organisation has been active in recent years developing appropriate responses to these needs, with specialist information, support and lobbying.

Over the past 6 months, Parkinson's Victoria has engaged the services of researcher Dr Chris Fyffe to conduct a study into the unique issues faced by people diagnosed with young onset Parkinson's and their families.

The study has been engaged in response to Amanda Spillare's 2007/08 Churchill Fellowship recommendations.

Findings from the project, including the survey, will assist Parkinson's Victoria and other service providers to better understand this group's information, service and support needs and preferences, with the aim of responding appropriately.

If you have been diagnosed with **Young Onset Parkinson's** (*see definition below) or have a family member who has been diagnosed, we encourage you take time to complete the survey, and **have your voice heard**.

***Diagnosed younger with Parkinson's disease' for this project means anyone diagnosed with Parkinson's disease younger than 65 years, particularly people diagnosed in their younger and middle adult years. This includes people now over 65 years who have lived with Parkinson's disease for many years.**

People diagnosed younger live a larger part of their lives with Parkinson's than people diagnosed in older age. People diagnosed in younger and middle adult years, (given they are typically at a different stage of life than those diagnosed older), may experience challenges and changes in relation to relationships, work, family, finances and asset acquisition, independence, family and child rearing.

This project is also an opportunity to inform policy makers and service providers about the practical issues facing people diagnosed with Parkinson's younger than 65 years and is the first of its kind in an Australian-context. The project also aims to dispel

the myth that Parkinson's is an issue only affecting the elderly, a misconception that has hindered research, services and assistance for the younger demographic of people living with Parkinson's.

We encourage you to talk about the survey with your various networks and, where possible, to distribute the survey as widely as possible. Surveys and an overview of the survey project can be obtained from the office of Parkinson's Victoria or downloaded from our website.

Following analysis of the survey results later this year, Parkinson's Victoria anticipates hosting several focus groups, facilitated by Dr Fyffe, with people with young onset Parkinson's. The aim will be to discuss the implications of the survey, and develop strategies to put young onset Parkinson's, on the political agenda.

If you have questions or would like further information, please contact Parkinson's Victoria.

Participate for Parkinson's

Volunteers are required for a research study investigating Parkinson's and swallowing difficulties, performed by speech pathology researchers at La Trobe University.

This study is examining swallowing in people with Parkinson's, before and after a new therapy technique called *electrical stimulation*.

The speech pathology researchers use a safe, portable device called VitalStim. Participants will be required to use VitalStim daily, in their own home, for 4 weeks.

Eligible volunteer participants will need to attend two x 1 hour sessions at Peter MacCallum Cancer Centre (PMCC), to perform a swallowing assessment and complete 3 short questionnaires. This will take place before and after using VitalStim. Transport to and from PMCC will be organised and paid for. Altogether, volunteers will be required to participate in the study for approximately one month.

The researchers are seeking people diagnosed with Parkinson's, who are over 50 years of age and have difficulties swallowing.

If you would like further information please contact Kim Matthews at La Trobe University: (03) 9479 1820 or 0417 580 347.

Reflections

A time to grieve

How does one respond to a life with Parkinson's? NERISSA MAPES, diagnosed at 28 and now 32, responded by establishing her own foundation POP (Perspectives on Parkinson's) to find a cure in her lifetime.

Her story is all the more powerful because she has never shied from sharing the details of her personal journey, including her emotional rollercoaster ride. Here, Nerissa reflects on how grief remains a constant companion, but it too is part of the journey.



Nerissa Mapes with comedian Russell Gilbert at a POP fundraiser.

I am grieving.

I have been for almost four years. And I am quite certain I will be for the rest of my life. I haven't lost a loved one – a family member, a friend or beloved pet.

I have lost me.

From the moment I was diagnosed with Parkinson's disease at age 28, my future became a question mark. Things like falling in love, having and raising children, enjoying a long and prosperous career, all became slightly more difficult to see in my future. Parkinson's descended like a fog, lying thick and heavy on things once crystal clear.

Naively I thought I would go through the cycle of grief:

- Denial and isolation
- Anger
- Bargaining
- Depression
- Acceptance

I say "naively" because living with my loss each day, experiencing incremental changes in my ability to do everyday tasks opens fresh wounds.

Eventually, the things that are already difficult for me will become almost impossible.

You wouldn't think it from reading this story so far, but I am actually a glass-half-full kind of girl.

Yes, I admit I am grieving. It knocks me sideways every now and again. I can't always be coming at life head-on, arms swinging.

But when I say "grief", I have moments of grief. I let myself feel them and then move on. I feel sadness, loss and frustration in equal measures. If I don't recognise them, letting them have their time in the sun, they bite. And they bite hard.

About a year ago, I hit a rough patch. I had had little if no sleep for two weeks and it began to show in my work. My boss called me into her office.

"Tidy up your desk," she said. "You're going on holidays, as of now."

It was exactly what I needed: For someone to give me permission to take time for me.

I went to a friend's house on the Mornington Peninsular and read a book in front of a fire for four days. Bliss.

During another stressful period, I went into the same boss's office, closed the door and burst into tears. Again, I needed permission for time out.

What followed was the most sensitive, understanding thing anyone has ever said to me about my diagnosis:

"Wherever you are must be the loneliest place...I can never understand what you are going through."

I was moved by her awareness. Most of the time, I don't even know what I am going through. To have someone recognise how lonely and isolating living with a chronic illness can be actually made me feel as though someone understood. She is one hell of a boss.

Sometimes it is the people closest to you that understand the least. It may be because they are more comfortable when you are brave or it may be that they get as worn down by the day-to-day battle as you do.

At first my ex-boyfriend wanted to solve me. If I mentioned a symptom, he had a solution. Typing is hard today? Let's swap laptops. Having trouble with your jacket? I'll help put it on.

It exhausted him and in turn caused him to become immune to my symptoms, which sometimes made him come across as uncaring.

Then there were the moods – or emotional unraveling occasionally brought on by the medication. I became a little clingy – a complete first for me! Understandably, the combination made him run for the hills. But not before he kindly diagnosed me with "mental health issues" and "delusions". Not very helpful, very hurtful and totally untrue.

Grief and I have come to an understanding. I give it regular, small amounts of attention and it stays under control. It is a healthy relationship and one which we will have to sustain for a long, long time.

Nerissa Mapes, www.pop.org.au

Cure the Masquerade

Several months ago, we were contacted by a young woman keen to create a fundraising event that would not only raise funds for Parkinson's, but would also increase awareness amongst her friends and age group.

Vesna Bosancic was inspired to create **Cure the Masquerade** (a fundraising masquerade cocktail party) by her mother Duja, who was diagnosed with Parkinson's about 6 years ago.

Vesna, understanding that our organisation receives little government support to run our information and support programs and services, was also very keen to support us.

"I wanted to ensure people were going to be part of a fun event and for each person to know they were contributing towards a worthy organisation and cause.

The Masquerade theme is very symbolic. I wanted there to be meaning, rather than it just being a party. The 'masked face' symptom of someone with Parkinson's is the link to the masquerade. This is why, during my speech on the night, I asked guests how they felt trying to interact with each other while wearing masks. I wanted to emphasise the difficulty of expressing yourself when you have little to no facial expression to help support what you are saying or feeling. This is something that a person with Parkinson's experiences on a daily basis."

Vesna's determination to create an event that was not only fun to attend but also highlighted the cause resulted in a polished event with incredible attention to detail, including acrobatics, great music, delicious food, and themed decorations.

Vesna spent months coordinating the logistics of the night, speaking with sponsors and arranging support and prizes. Often she had to "start from scratch", explaining to potential supporters what Parkinson's was, how it impacts on individuals and families, and why there is such a great need for support.

"Talking to people about Parkinson's is an easy thing for me, although getting up and telling your story in front of a crowd certainly got me emotional. I also realised from my many discussions with people that there was definitely a lack of understanding about Parkinson's. Naturally, I was disappointed by this.

Most people who had some understanding were friends and family – people who had some sort of personal connection to the condition."

Vesna's drive and passion meant she didn't stop until she achieved what she set out to achieve, no matter what setbacks or challenges she encountered.

"The process of organising such an event was interesting. I knew it was going to be a difficult and challenging task, and it definitely tested my patience (and even temper at times). But whenever

I experienced a "knockback" or someone declined to support the event, it simply kept me pushing further. I also realised that all the help and support I **was** offered, whichever way, shape or form it came in, contributed towards the night and helped make the event such as huge success".

And success it was. **Cure the Masquerade** raised almost \$8000! An incredible effort for one young woman and her team of helpers!

Vesna and her fundraising event were also featured in local newspapers, which spread the message even further.

One of the most touching aspects of the night was that Vesna's mum, Duja. The reluctant "guest of honour" hours before the event had stated she was not going to attend. Fortunately she changed her mind and ended up socialising the entire night, chatting with and meeting guests, many for the first time.

Vesna hopes the message of understanding and the need for support continues to live on with her guests, and that they too help spread the word.

"I just hope people were able to take away the importance of supporting an organisation such as Parkinson's Victoria and to understand that they contributed and helped make a difference in a way that was **real**. Most of all I hope people remember the good times they had in support of Parkinson's."

Needless to say, Vesna is already thinking about her next Cure the Masquerade event.

We congratulate Vesna on the success of her event – not only raising funds but also raising awareness. Thank you Vesna for your hard work, initiative, commitment and passion. You have made a valuable and significant contribution to our work serving and supporting the Parkinson's community.

If you would like to hold a fundraising event for Parkinson's Victoria, contact Judith at our office.



*Vesna and her mother (third and second from right) with the Parkinson's Victoria team, following the presentation of a cheque for \$7836.10, the proceeds from **Cure the Masquerade**.*

Reflections

What makes a life? JEAN BOWLES believes it is made up of *A Million Moments*, an apt title for her recent autobiography. Sharing her story has been a labour of love for Jean, who decided to donate the proceeds from the sale of the book to Parkinson's Victoria.

A lifetime of capturing the world around her – on film and in writing – inspired Jean Bowles to collate her reflections and experiences into her autobiography, *A Million Moments*, which was published with the help of Memoirs Foundation last year.

Over the years, Jean's artistic expressions have been her way of exploring life and dealing with the various challenges it presented, including living in Papua New Guinea, travelling to the Himalayas, the passing of her husband and one of her two sons, and being diagnosed with Parkinson's.

"I've always been in the habit of reflecting on things that interested me. For many years I've also kept a journal of special times and experiences, and on occasion my family and friends would read particular pieces. They really seemed to enjoy them, so I looked into the idea of publishing my essays, and including various photographs I've taken over the years".

Jean had already made her mark on the national and international stages through her photography, but her latest venture has a more local flavour, with most of the 200 plus copies of the book being bought by residents from her local town of Newborough. Many of these however, have been passed on to friends, near and far.

"I've always been open and honest about my life and experiences. I've also done lots of public speaking about my many adventures, so sharing my story with the wider public was something I was very comfortable with."

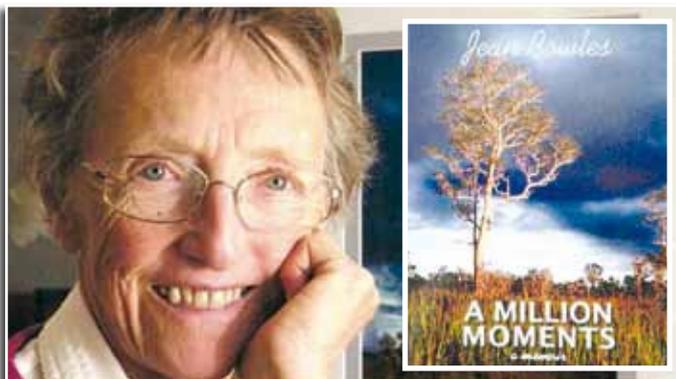
Jean now has more friends than she could imagine – thanks to the publicity of her book, as well as being featured twice in the ***Moe and Narracan News***, and strangers often greet her in the street by name.

"I have been overwhelmed by the support and interest from the local community, including the Morwell and Newborough newsagencies, which have kindly been selling the book on my behalf – and not taking any money for it!

"I worked closely with **Memoirs Foundation** to pull together and publish what became ***A Million Moments***. They were a fantastic support and resource, always there to answer questions and help with advice".

The finished product is not only a great read but a professional looking publication, with all the attention to detail of any book you would see on the shelves of your local bookstore.

No doubt, Jean has many more special moments



Newborough resident Jean Bowles (above) has many fond memories to share with others. Images from the Moe and Narracan News article.

to come and to capture the next million, she has already started work on a sequel.

Jean recently presented Parkinson's Victoria with a cheque for \$3810, proceeds from the sale of *A Million Moments*. Jean is a member of the Moe Movers and Shakers Support Group, which she helped establish.

The stories that bind us

When Memoirs Foundation was established three years ago by education publishers Synergy Publishing, it was in response to an emerging demand for the production of small print runs of personal histories and memoirs. (The "big" publishers seem to be interested only in the stories of celebrities and their large print runs.)

Says CEO of Memoirs Foundation, Arnold Bonnet, "Our aim from the start was to provide the ordinary Australian with the opportunity and the means to publish their story in book form, in an economical way, as a permanent legacy for their families and friends. The event of digital printing made small print runs available and affordable to the general public."

"But", says Deborah Longden, the Foundation's Project Coordinator, "writing one's memoir takes time and may be daunting to some. Not all our clients feel they have the skill to write their story. Many prefer to narrate it during an interview conducted by one of our experienced Personal Historians. The interview is then edited into a flowing narrative. Other clients may have drafted their story themselves and come to us to edit it. We put the stories together into a final book-form of best-seller quality."

"Books, so produced by Memoirs Foundation are just the thing to nurture interest in the tapestry of Australia's unique history and its rich mix of cultures," says Arnold Bonnet.

At Memoirs Foundation, you won't find books on celebrity affairs, but there's a lot of history, achievements and drama to be found in the life stories of the average family.

Life stories tie us to other human beings as a vital connection with those who came before us and with those who will follow us. Memoirs Foundation is about saving those stories, by understanding how connected we really are, and before they are lost and forgotten.

To find out more Memoirs Foundation, call: (03) 98889588, or visit memoirsfoundation.org.au

Tulip Tributes highlight the generosity of those in the Parkinson's community and beyond, from simple gestures to grand overtures. A Tulip Tribute is the ideal way to say "thank you" in appreciation of extra special support or efforts. If you would like to acknowledge someone with a tribute, please send details to judith@parkinsons-vic.org.au. Photos welcome.

Students support the Challenge

We were delighted and touched by a recent letter and donation of \$232.35 from students at the Heatherhill Primary School. The students had conducted a fundraiser to support 2009 Team Parkinson's Challenger (and ex-teacher) Karyn Spilberg.

Fran Hermann, from the school's library wrote on their behalf, explaining that the students had been inspired by our Challenge bike ride to Vietnam earlier this year. They installed a stationery bike in the library and students paid \$1.00 to "cycle" for five minutes. They also spent time learning about Vietnam. **"There was a bit of competition...and it was lots of fun"**.

Thank you to the students of Heatherhill Primary!

Supporters help make an impact

Parkinson's Victoria gratefully acknowledges the generous support – and creative brain power - of the team at DDB Group (communications group and creative agency).

The team has volunteered their time and expertise to create powerful and innovative messaging concepts to help raise awareness and understanding of Parkinson's among the wider community, as well as to promote our Unity Walk.

Make sure you visit Flinders street train station for an eye-catching and truly interactive experience during National Parkinson's Awareness Week!

Thank you DDB (incorporating RAPP and Mango)!

Christmas greetings

We would like to present botanical artist Jean Smith with a special "tulip tribute" for her wonderful, personal addition to our 2009 range of Christmas Cards.

Jean's **"Holly and the Gum"** is an original watercolour, designed exclusively for Parkinson's Victoria.

We are confident that this stunning and delicate rendering of the traditional Christmas foliage and "Australiana" will be our most popular card this year.

Thank you Jean for generously allowing us to use this design as part of our Christmas card campaign. We are so pleased to be able to share your talents with the community.

You can view Jean's design - and our complete range of cards - in the enclosed Christmas card order form or at: www.parkinsonsvic.org.au

A hole in one for Parkinson's

We'd like to give a HUGE tulip tribute to Spring Valley Golf Club and its Charity Day committee for the success of its recent Charity Golf Day (29 May).

This year's event, which supported Parkinson's Victoria and the Kingston Charitable Trust, saw just over 120 players tee off at 9.00am.

The event raised \$18,200 which will be evenly distributed between the two organizations.

We'd especially like to thank our generous corporate supporters who kindly donated prizes for the day: Dymocks (Southland), Alias wines, Bunnings (Moorabbin), iSubscribe, Memoirs Foundation, Tafts the Pen People (Southland), Village Roadshow, Treloar Roses, Cambur Industries, and Westfield (Southland).

We'd also thank all the players who attended and made the day such a great success by participating in the raffles and auctions. Thank you! And special thanks to special guest speaker – Brendan Lourey, Parkinson's Victoria Ambassador.

Running Melbourne, running for Parkinson's

On Sunday, 28 June, several passionate and committed Parkinson's supporters braved the cold and pounded the pavement, running 10 or 21.1kms (a half marathon) to raise funds and awareness for Parkinson's Victoria.

Together they raised a total of almost \$3500.

We'd especially like to acknowledge the fundraising efforts of **Gary S (\$1000), Erez G (\$890) and Andrew B (\$490)**.

Thank you also to **Nicholas T, Team T (also known as Tim and Tania), Michael D, the Running Bears, the Magpies Army for Parkinson's, Jason C and Kellie E**.

Mazal Tov (congratulations)!

We were moved by a young lady, Ella Goldberg, who decided to ask her guests for donations to Parkinson's in lieu of gifts for her recent bat mitzvah celebration. [In the Jewish faith a bat or bar mitzvah is a teenage girl or boy's "coming of age"]. Ella and her guests' generosity raised more than \$4000 for Parkinson's Victoria.

With gestures such as this one - supporting other members of her community and foregoing gifts - we think Ella is well on her way to becoming a thoughtful, responsible and generous adult and valued member of our community. Congratulations Ella and thank you!

Education events

Metro seminar – Dandenong

This seminar is 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.

Dandenong community seminar

Date/Time: Monday, 19 October, 1.30pm

(registration) - 4.00pm

Location: The Mulgrave Country Club Corner of Wellington & Jells Roads Wheelers Hill,

NB: This will be followed by a dedicated evening session for local GPs.

RSVP: This is a free event, however registrations are essential. Please book your seat today.

Regional seminar - Ballarat

Our annual regional education sessions will take place in Ballarat this year, on Thursday, 27 August.

Attendees at the community session will have the chance to hear from keynote speaker Associate Professor David Williams and Victor McConvey from our health team.

Ballarat community seminar

Date/Time: Thursday, 27 August, 11.30am

(registration) – 2.30pm

Location: Lederman Hall, Queen Elizabeth Centre, 102 Ascot Street, Ballarat.

(Separate sessions will also be held on the same day for Ballarat University bio-medical and nursing students and local GPs.)

To book your seat at this special free event, please contact Parkinson's Victoria today.

Our Dandenong and Ballarat seminars and GP dinners are made possible with the generous support of event sponsor Novartis.

Upcoming surgical interventions seminar & AGM

Parkinson's Victoria is currently planning a dedicated **Surgical Interventions** community seminar with two keynote speakers who will provide information from the surgical and neurology management perspectives of the procedure.

This event is scheduled to take place later this year as part of our Annual General Meeting.

All details are to be confirmed, however if you would like to register your interest to attend or find out more, please email judith@parkinsons-vic.org.au or contact the health team: (03) 9551 1122. You will be contacted with further information once details are finalized.

Notice of the Annual General Meeting and associated documents will be posted to Parkinson's Victoria Members in the coming weeks.

Beginning the journey

The Parkinson's Victoria Recently Diagnosed Community Seminar has become one of the most well attended events on our calendar, and a highlight of National Parkinson's Awareness Week (this year taking place from Monday 31 August – 6 September and kick starting with **Australia's Unity Walk for Parkinson's** on Sunday, 30 August).

The annual Recently Diagnosed Seminar delivers relevant and credible information from a range of professionals with expertise in the area of managing and living with Parkinson's. The unique program of information - designed to specifically address the concerns, interests and needs of those *recently diagnosed* (defined as a diagnosis in the past 5 years) - makes this event a one-of-a-kind community seminar.

Event: The Parkinson's Victoria Recently Diagnosed Community Seminar

Date/Time: Saturday, 5 September, 2009. 9.00am (registration) – 3.00pm

Venue: Monash University, Caulfield Campus, Conference Room H116.

Costs: \$35 members. \$55 non-members.

Attendees receive comprehensive take home materials, morning/afternoon tea and lunch.

RSVPs are essential. Please register for your place today by contacting our office (please advise dietary requirements): (03) 9551 1122 or email: info@parkinsons-vic.org.au. Download an event flyer with details about parking at: www.parkinsonsvic.org.au.

Parkville seminar

On Monday, 30 June, Parkinson's Victoria hosted the first of its major public education forums for 2009, titled **Unraveling the Mysteries of Parkinson's**, with keynote speaker Associate Professor David Williams.

More than 170 people attended to hear the latest insights, including the benefits of drinking coffee and eating dark chocolate in relation to Parkinson's.

Parkinson's Victoria gratefully acknowledges our event sponsors Medtronic and keynote speaker Associate Professor Williams who has generously volunteered his time and expertise to present at our 2009 major metro and regional education sessions.

Local perspectives

The **Movement Disorder Program at Wantirna Health** is holding a morning forum on Friday, 6 November to promote community awareness of Parkinson's and to showcase the services provided by its program.

For details, contact Pam: (03) 9955 1229. Wantirna Health is located at 251 Mountain Highway, Wantirna South.

Medication News

Update on Parkinson's patch

Neupro (Rotigotine) is a Dopamine Agonist that is administered in the form of a patch to the skin's surface, with the medication being absorbed through the dermal layer into the bloodstream.

This method of delivery is a revolution in managing Parkinson's symptoms, where typically medications are in tablet form.

Neupro has been available in the USA and Europe for many years and is currently pending approval by the Pharmaceutical Benefits Scheme in Australia.

UCB Australia, the pharmaceutical company that supports Neupro in Australia, has announced that the patch is now available to new patients as a **private prescription** only (at this stage).

Health team note: A medication that is available as a private prescription is not eligible for any government subsidy support and the consumer must pay the full cost.

While this medication will not be suitable for everyone with Parkinson's, and has similar potential side effects to other Dopamine Agonists (such as nausea and impulse control disorder) it does increase the number of choices of medications (including an alternative to tablet form) and is capable of delivering a constant, sustained release of the medication over a 24-hour period.

If you have questions about this or any Parkinson's or other medications, please contact the health team at Parkinson's Victoria.

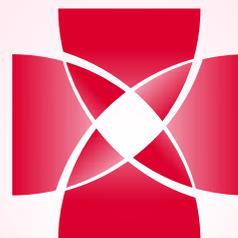
Parkinson's special interest resources

Parkinson's Victoria has developed a number of educational resources, including DVD's and fact sheets, on special interest topics, including:

- Parkinson's and Depression (DVD/fact sheet)
- Parkinson's and Lewy Body Dementia (DVD/fact sheet)
- Lets talk about sex (DVD/Article)
- The Journey: Understanding and Learning to Live with Parkinson's, for those newly diagnosed and their families (DVD/fact sheets)
- Hospital kits (ideal to pass onto hospital staff to assist them in managing your Parkinson's during your hospital stay).
- Constipation in Parkinson's (fact sheet)

To obtain a copy of any of these resources, to ask questions, or to seek advice or referrals in relation to these topics and more, please contact our health team.

We are also currently working on producing an exercise DVD tailored to the needs of people with Parkinson's.



TheAlfred

Do you have
Parkinson's disease
and experience
dyskinesias?

Clinical trial volunteers required

Medical specialists are currently looking for volunteers for a clinical trial who:

- Are aged 30-80
- Have moderate to severe medication-induced dyskinesias/ involuntary movements with Parkinson's disease

If you wish to find out more about this study please contact:

[Movement Disorders Program at the Alfred Hospital, Melbourne](#)

Research Coordinator, Sue Varley:
phone (03) 9076 5187 or (03) 9076 5231.

This study has been approved by the Alfred Health Human Research Ethics Committee.

Fundraising & events

Ready for a Challenge?

We are excited to announce that our second Team Parkinson's Challenge is now up and running!

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!

Earlier this year, 15 excited participants – having reached a combined fundraising goal of more than \$130,000 – headed off to Vietnam for the adventure of a lifetime.

In 2010, Vietnam will again be host to our intrepid Challengers who reach their target fundraising goal.

The Challenge is a truly unique way for supporters and adventurers alike to make a difference while stretching their personal boundaries.

We've partnered with renowned travel agency World Expeditions to create a special experience that combines a fundraising challenge with an overseas adventure.

Your goal will be to raise much needed funds to help in the fight against Parkinson's and increase awareness about this mysterious condition.

Participants will host special fundraising events, talk with community groups and even organize media stories with their local paper! The challenge will then continue with an incredible 13-day adventure, cycling through Vietnam.



Keen to know more about our next Team Parkinson's Challenge? Contact Judith, our Marketing & Fundraising Coordinator: (03) 9551 1122 or email judith@parkinsons-vic.org.au

You can also register to attend our next information session on Wednesday 26 August or log onto www.parkinsonsvic.org.au to read more!
Travel dates: 13 – 25 March 2010.

Calling for Volunteers!

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

Thanks to the generous support of Connex, we

are once again seeking friendly and enthusiastic volunteers who are able to "shake a tin" and collect donations during peak hour on WEDNESDAY 2 SEPTEMBER, 2009, from 7–9.00am.

Last year we raised almost \$4500 in just two hours! The more volunteers we have on the day, the more donations we can accept. We'd love you to be a part of this rewarding experience that makes such a valuable contribution to our annual fundraising efforts.

If you are interested and available to participate please contact our Volunteer Coordinator Dianne: (03) 9551 112 or email info@parkinsons-vic.org.au

2009 Christmas cards

Show your support for people living with Parkinson's and help spread a message of awareness and understanding this festive season by purchasing Parkinson's Victoria Christmas cards. Our new range includes a card exclusively designed for Parkinson's Victoria by artist Jean Smith.

All our cards feature the Parkinson's Victoria logo and a message about how we support the community.

The sale of these cards will help fund our information, education and support services and will raise awareness of the condition in the wider community.

An order form is enclosed with this edition of **Signpost**. You can also purchase cards securely online www.parkinsonsvic.org.au or contact our office. Our cards can also be purchased through the following Community and Charity Card outlets:

- St Paul's Combined Charities Christmas Card Shop (Myers Street, **Bendigo**)
- **Mornington** Community Information and Support Centre (320 Main Street)
- Camcare Combined Charities Card & Gift Shop (19 Fairholm Grove, **Camberwell**)
- **Ballarat** Combined Charities Card Shop (27 Magpie Street).

Thank your clients and show you care

In partnership with **Charity Greeting Cards**, we are pleased to offer our corporate supporters the opportunity to purchase Christmas cards and/or a range of gift hampers for clients, suppliers, family and friends – and to support Parkinson's Victoria at the same time!

Corporate Cards:

Choose your preferred design from the range on offer (also featuring Parkinson's Victoria logo and information), and add your own personal message and/or logo.

Fundraising & events

Log onto: christmascards4charity.com.au/parkins (online orders receive a 5 percent discount) or phone our office to request an order form. Orders are dispatched professionally and quickly and 40 cents from every card sold is donated to Parkinson's Victoria.

Corporate Hampers:

Log onto charityhampers.com.au/parkins and choose from the selection of gourmet hampers on offer, all featuring delicious goodies such as biscuits, condiments and nibbles (no alcohol), and priced from \$50-\$150. You can also contact Parkinson's Victoria to request an order form.

Hampers feature a Parkinson's Victoria logo sticker to show your support and 10 percent of the retail price is donated back to Parkinson's Victoria.

There are no costs to Parkinson's Victoria for either of these initiatives, which helps us to keep administration costs down and makes it a fantastic fundraising idea for the organisation!

Volunteer Recognition Awards

Parkinson's Victoria values the outstanding contribution volunteers make in reducing the impact of Parkinson's. We have several ways to ensure that volunteers are appropriately recognised for their services.

Certificate of Appreciation: Recognising the contribution of an individual or an organization to an event or activity.

Five and Ten Year Services Awards: Recognising the continuous service of volunteers in an administrative, project or service capacity.

Honorary Life Membership: Recognising outstanding service, normally over a period of at least fifteen years.

Further to these awards, we introduced the **Sir Zelman Cowen Award** in 2006. This award, the highest honour available, is presented annually to an individual, recognising their outstanding service to Parkinson's Victoria or services to People living with Parkinson's. Sir Zelman Cowen generously gave his permission for the award to be in his name, which is most appropriate, recognizing his outstanding community service to all Australians, and his personal journey with Parkinson's. Last year, we were delighted to present the Sir Zelman Cowen Award to Harold Waldron for over twenty seven years of wonderful service to the Geelong Support Group.

Nominations for these awards can be forwarded in writing to Glenn Mahoney by 18 September 2009 for consideration by the Board of Parkinson's Victoria.

National Parkinson's Awareness Week

There are a range of activities to get involved in this year for Awareness Week, from special events and fundraising to community education events.

What about conducting your own 'awareness campaign' at your work or in your community? Contact Judith (03) 9551 1122 or judith@parkinsons-vic.org.au to request a free kit of materials to create a display at your local shopping or community centre, school or day-care, workplace, place of worship, library or chemist.

Key dates for the diary:

➤ **Sunday, 30 August: Australia's Unity Walk for Parkinson's, Federation Square, Melbourne.**

Register to walk and fundraise and find out more at: www.unitywalk.com.au

➤ **Tuesday, 1 September: Parkinson's Passion special planting at Morwell Rose Garden.**

Further details to be advised. Contact Judith if you would like to attend this event.

➤ **Wednesday, 2 September: Connex City Loop tin raffle**

Volunteers needed. Please see details above. Please encourage your family, workmates and friends – anyone who is heading into town on this day - to have their gold coins ready and to be as generous as possible.

➤ **Thursday, 3 September: Postcards from Paris**

Highlights from Victor McConvey's trip to the Movement Disorder Society's World Congress presented in person with images! (read more on page 6).

LOCATION: Kingston Arts Centre
979 Nepean Highway, Moorabbin

Registration: 10.00am (registration and morning tea)

Event: 10.30am - 12.30pm

RSVP: (03) 9551 1122

Saturday, 5 September: Recently Diagnosed Seminar

Register to attend today. Find out more on page 14.

➤ **Party for Parkinson's** with friends and family ANY DAY during Awareness Week (or anytime of the year – perhaps as part of your next celebration!). You'll be helping to raise awareness and vital funds to support those affected by Parkinson's. Contact Judith for your FREE Party Pack and register your party today!

Keep an eye on our website: www.parkinsonsvic.org.au for more information about these and other Awareness Week events.

Continued from Page 7

Delegates at the conference acknowledged that thorough medication counselling regarding ICD was essential for patients, and when commencing a Dopamine Agonist it was recommended, as was going "slow and low" when increasing the dose.

Surgery and Parkinson's

The history of neuro-surgery and the latest developments in Deep Brain Stimulation (DBS) were presented at the conference.

The practice of Neuro-surgery appears to be more 7000 years old! However, many of the recent developments in the surgery - in relation to Parkinson's - were related to serendipitous mistakes.

In 1942, Russel-Myers created a lesion in the Basal Ganglia while conducting surgery on a neighbouring area of the brain, and was able to observe the response. This - in combination with the discovery (in 1870) that introducing electrical current to the brain could stimulate movement - led to the first implantation of electrodes to trigger response in 1965. In the 1970s, when DBS first became available as a surgical intervention, it was initially used as a treatment for pain.

In 2009, the medical fraternity's use of DBS has moved significantly forward and is now performing very sophisticated surgery for Parkinson's, which is being continuously refined.

Neurologists and surgeons are now able to select different areas of the brain in which to introduce stimulation in order to treat specific and various symptoms, improving motor function and quality of life.

During the conference, **Subthalamic Nucleus (STN) stimulation** was reported to be effective for stiffness, slowness and tremor, while **Globus Pallidum Stimulation** was good for rigidity and **Thalamic Surgery** was effective in managing tremor.

The most significant achievements of surgery discussed were managing the symptoms of Parkinson's and surgery's potential as a disease-altering intervention with benefits, seen even when the stimulator is turned off. DBS has also been shown to reduce medication side effects, such as dyskinesias, with additional improvements in bladder control, pain, blood pressure regulation, sleep and mood.

Some of the limitations of the surgery were also discussed, and covered in the research presented,



Dr Kotchet and Victor McConvey enjoy some sightseeing during the MDS World Congress.

while improvements in reducing the incidence of stroke, bleed in the brain, infection and equipment failure were noted. Voice and speech problems, particularly volume control, and increased risk of suicide had occurred in some patients.

It was incredibly valuable to attend the congress, to hear expert and respected opinion and debate, and to learn the latest trends, theories and treatments in managing Parkinson's. It was also reassuring to see many colleagues from Victoria and all over Australia hearing the same messages. The most important aspect of the conference was affirmation that people with Parkinson's in Australia are – in the main- receiving effective management for their illness, and that in some areas; our practice is leading the world.

- MAO-B inhibitor: MAO type B inhibitors work by interfering with one of the enzymes that breaks down dopamine. They are used frequently as the first drug in the treatment of Parkinson's and work by promoting and prolonging the action of levodopa.
- Dyskinesia: Abnormal movement of voluntary muscles.

Our Supporters

We gratefully acknowledge the generous donations that have been made by our supporters 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 our donors individually. Listed below are the names of those who kindly donated \$200 or more between 15 April and 10 July 2009, and individuals in whose name in memoriam donations were made. We extend our sympathies to the families who have lost loved ones, and our thanks go to the friends and family members who have donated to Parkinson's Victoria in their memory.

We also thank those who have donated but wish to remain anonymous.

Donations \$200 and over (individual)

Geoff Alexander
Dominic Boffa
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Sir Zelman Cowen
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Mr & Mrs J Robinson (FHB Holdings)

Donations of \$2000 and over

Mary Kentish
Jean Bowles

In memory of...

Bronwyn Andrews
Leonard Breen
Joan Odgers
Allison Patrick

In celebration of...

Ella Goldberg

Corporate, Community & Other donations & support

Alias wines
All Souls Opportunity Shop
Flash ID Australia
Geelong Street Rodders
Heatherhill Primary School
Knitters for Melbourne's Needy Inc
Mayflower Retirement Community
Medtronic Australasia
Novartis
PSP Australia Support Group
Rotary Club of Geelong
Strathmore Rotary Club
Victorian Workcover Authority

Bequests

The estate of Audrey MacDonald

Team Parkinson's

(auxiliary fundraisers)

Vesna Bosancic
(Cure the Masquerade)

Parkinson's Victoria conducts only two annual appeals where we actively seek donations from our members and the wider community. We thank all those who generously supported our recent mid-year appeal. Your support makes a valuable contribution to our work. Thank you.

Unity Walk

Continued from Page 1

- Sam was joined by basketball legend **Andrew Gaze**, Olympic swimming champion **Brooke Hanson**, **Sarah Wall** and **Ama Agbeze** from the **Melbourne Vixens**, and **Graeme Joy**, the first Australian to ski to the North Pole.
- Our thanks to media company **Resolution**, which kindly donated its services in filming/editing the CSA announcements and to Nerissa Mapes from Telstra who coordinated their participation and also appeared in the advertisement.
- We also thank Fi Parrey who donated her services as make up artist for the advertisement.
- **IGA Supermarkets** promoted Unity Walk in their recent catalogue, which went out to 100,000 households.
- **Australian Senior** has donated advertisements which will be seen on their website www.thesenior.com.au, and also supported with editorial in the newspaper.
- **The Victorian Employers Chamber of Commerce (VECCI)** has promoted the walk in their latest newsletter, circulated to major employers state-wide.
- Our thanks to all our event sponsors and supporters, to our Unity Walk "Think Tank" Committee members who have volunteered their time and expertise, and to our wonderful volunteers and staff who continue to work hard to ensure this event is a success.

Now all we need is you.

Join us on Sunday, 30 August and make a day of it. Please register to walk **today**, and invite family and friends to participate. This is your chance to be a part of history.

Glenn Mahoney
Chief Executive Officer

The gift that keeps on giving

Bequests make a real and lasting difference to our work.

Please remember
Parkinson's Victoria in your will:

**For further information,
contact Glenn Mahoney: (03)9551 1122**

ALOHA Unity Walk

Thanks to event sponsors **Hawaiian Airlines**, **Hawaii Tourism** and the **Outrigger Reef on the Beach** hotel, our highest **Unity Walk** individual fundraiser and their guest will be flying off on a 5 days/4 nights holiday to one of the most exotic locations in the world... Hawaii!

For more information about Australia's Unity Walk for Parkinson's, to register to walk and fundraise, visit www.unitywalk.com.au (**Please note: the deadline for receipt of fundraising money is 30 September, 2009.**)

Outrigger Reef on the Beach's \$110 million makeover has created a delightfully unexpected and truly unforgettable new vacation experience in Hawaii.

Ideally situated between famed Waikiki Beach and the entertainment centre of Waikiki, the new Outrigger Reef is a stunning new oceanfront haven of elegance, comfort, gracious hospitality, and unparalleled commitment to Hawaiian culture. For more information on the Outrigger Reef on the Beach hotel, please visit www.outriggerreef.com.

Hawaiian Airlines operates three weekly non-stop flights from Sydney to Honolulu, with onward connections to the islands of Hawaii and 10 US mainland cities including Las Vegas, Los Angeles and San Francisco. Hawaiian Airline's fares from Australia include complimentary meals, snacks, drinks, main screen entertainment and a generous baggage allowance of two 32kg items per passenger – no hidden extras!

For more information on Hawaiian Airlines, contact www.hawaiianairlines.com.au or phone: 1300 669 106.

To learn more about Hawaii and what wonders it has to offer visit www.hawaiiitourism.com.au

Thanks to the generous support of Hawaiian Airlines, Hawaii Tourism and the Outrigger Reef on the Beach hotel, Parkinson's Victoria is able to offer you - our Unity Walk participants - the chance to win this fantastic prize. It is our way of saying thank you for helping to make Australia's Unity Walk for Parkinson's the largest gathering for Parkinson's in Australia's history.



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