

SIGNPOST

• Winter 2012 • Volume 11 Issue 2 A Magazine for people living with Parkinson's

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Two massive events are coming to Melbourne this August

Three little letters: M.J.F

Yes. Michael J Fox, the man who made his fame going **'Back to the Future'**, and who has become the most well-known Ambassador in the fight against Parkinson's, after being diagnosed himself in 1990, is coming to Melbourne.

Michael J Fox - A Funny Thing Happened on the Way to the Future

will see Michael take centre stage at the Melbourne Convention and Entertainment Centre on 14 August in a 'one-man' show to share insights from his professional and personal life.

The show is presented by the team behind the **Visionary Series** and Parkinson's Victoria is proud to be the charity partner for this event.

We are particularly excited to welcome Michael J Fox because his story is such an inspiration to thousands of Australians living with Parkinson's. His presence will be a major boost for increasing awareness and understanding of Parkinson's in Australia.

Tickets are available for this once in a lifetime event from Ticketmaster.

www.visionaryseries.com.au

STOP PRESS

Parkinson's Victoria will be conducting a TIN RATTLE COLLECTION during this event on the evening of 14 August. If you can volunteer your time to help out, please contact Jo Berthelemy in the office.

Please note: the tin rattle will take place **outside** the main auditorium so if you would like to attend the event, you will still need to purchase your own ticket.

www.ticketmaster.com.au

Will you take a Walk with us?

The largest event of its kind for the Australian Parkinson's and wider community is back for its fourth year.

Walk in the Park, hosted by Parkinson's Victoria, is taking place at Federation Square on Sunday 26 August and we want you to join us, and thousands of others who have been 'touched by Parkinson's', for this special community event.

Parkinson's challenges independence, physical health, financial stability and the ability to enjoy the simple and important things of life. Parkinson's can stop people **from** moving in so many ways. It can limit hopes and dreams. But it doesn't have to.

With the right support and information people with Parkinson's can continue to enjoy long and productive lives.

Since 1981 Parkinson's Victoria has helped thousands of Australian's in their journey with Parkinson's, not only in the early stages after diagnosis, but throughout the condition's progression.

Walk in the Park brings the community together and puts Parkinson's centre stage to help raise awareness. Most importantly, it raises vital funds to ensure we can continue to provide **Help for Today and Hope for Tomorrow**. Our goal this year is \$150,000 which will assist us to provide information kits, conduct education workshops, keep our free Help line open and assist you and your family to face Parkinson's with professional support, the right information, and confidence.

Please walk with us on Sunday 26 August. Invite your family, friends, workmates and community to join you and together we can make every step count in the fight against Parkinson's.

For more information about the event and to register visit:

www.parkinsonswalk.com.au

News & Highlights

Deep Brain Stimulation surgery - survey

Parkinson's Victoria is once again working with two second-year medical students on placement from Monash University.

As part of their placement, these students are learning about people living with Parkinson's in the community, as well as interacting with support groups and medical professionals in an effort to better understand the condition. In addition, their placement (which emphasises personal contact with people with Parkinson's) will assist in developing their professional medical conduct and 'bed side manner' for when they have their own patients.

Whilst on this placement, the students will be carrying out a project that would benefit greatly from your participation.

The area of focus is **Deep Brain Stimulation (DBS) surgery** as a treatment option for some of the symptoms associated with Parkinson's.

The students have designed a survey, and feedback and responses will assist us in developing better information resources regarding issues related to DBS.

If you are a person living with Parkinson's who has had or is considering DBS, your input would be invaluable.

The link to this survey can be found on the Parkinson's Victoria homepage
www.parkinsonsvic.org.au

A time for change

Parkinson's Victoria recently farewelled Catherine Watson from its Health Team.

Catherine has been the Community Development Worker at Parkinson's Victoria for the last five and a half years. During this time, Catherine delivered more than 150 presentations to Parkinson's Support Groups, as well as more than 200 presentations to Health Professionals.

Catherine also coordinated our annual Recently Diagnosed Seminar, and made a significant contribution in the coordination and delivery of the inaugural **National Young Onset Parkinson's Conference** in 2010. She contributed to the development of the Parkinson's Victoria website and social media pages, chaired a special interest group for Social Workers in Progressive Neurology and participated in our 2009 Charity Challenge bike ride through Vietnam, fundraising over \$6000 along the way.

We wish her well in her new job and all the best for the future.

World Parkinson's Day update

On **World Parkinson's Day**, Wednesday 11 April, Parkinson's Victoria made sure Parkinson's was in the spotlight.

We secured a number of media stories including the high rating TV program **The Project** as well as a number of radio programs and newspapers.

We hosted an information session on Parkinson's in the South Eastern suburbs.

In addition, we secured the support of AAMI Park Stadium to help raise awareness of the fight against Parkinson's and to highlight the important message that we need to help people living with Parkinson's to *keep moving*.

To symbolise this message and highlight the 80,000+ Australians living with Parkinson's, we lit up the night with AAMI Park Stadium's distinctive roof light show and turned on 1544 GREEN LED light bulbs, each one representing approximately 52 Australians living with Parkinson's.

Special thanks to AAMI Park Stadium for their generous support.

Important news: Changes to Sinemet CR

MSD, the manufacturer of the Parkinson's medication **Sinemet**, have advised of changes to the appearance of the tablet **Sinemet CR**.

The most significant alteration is that this tablet will no longer be scored and cannot be safely broken in half.

People who use ½ Sinemet CR as part of their medication regimen should seek advice from their Neurologist or GP. Other changes are that the medication will now be coloured purple and will no longer carry the letters **MSD** or be labelled **Sinemet CR**.

The company have made these changes to secure a supply of the medication ingredients to prevent future shortages.

Consumers can provide feedback directly to MSD via their consumer phone line: 1800 818 553.

If you are having difficulties with respect to your Sinemet medication or would like more information please contact Parkinson's Victoria.

Launch of Hindi resources

On Saturday 2 May, Parkinson's Victoria launched its new Hindi language information resources at the monthly meeting of the **Indian Senior Citizens Association of Victoria**, Mount Waverley.

President's Message

Dr Sanjay Raghav presented "What is Parkinson's Disease" (a summary of key information from the Hindi help sheets) and Peter Raymond shared some of his personal story. Victor McConvey from our Health Team officially launched the materials, and the formalities were concluded with a fun Bollywood dancing workshop and a delicious lunch of traditional Indian foods, generously provided by members of the Association.

We were fortunate to have in attendance The Hon. Nicholas Kotsiras MP, **Victorian Minister for Multicultural Affairs and Citizenship**, who gave a brief speech, congratulating Parkinson's Victoria on delivering these resources to the community. Mr Kotsiras also shared that his mother had recently been diagnosed, making the cause one especially pertinent to him.

The launch of the materials generated a lot of media interest and the following print, radio and TV outlets ran stories, with members of our team providing interviews:

3AW/MAGIC; 3zzz (Ethnic Community Broadcasting Association of Victoria Ltd); **Southern FM** (Indian Segment); **SBS Radio** (Hindi program)

SBS Radio (Punjabi program); **TVS Chandana** (Melbourne, Sydney and Adelaide); **Monash Weekly**; **Greater Dandenong Weekly**; **Waverley Leader**; **3SER Casey FM** (Viewpoints); and **3SER Casey FM** (Women of Today)

We would like to acknowledge Project Worker Jackie Jenkins for working with the community and professionals to develop these resources, and to thank the ISCA and its members for so enthusiastically supporting and hosting the launch, also MC Dr Kauhali Srivastava, ISCA Secretary and Dr Prem Phakey, President, ISCA, as well as Dr Sanjay Raghav and President Peter Raymond, and Jo Berthelemy for coordinating the day's proceedings.

Parkinson's Victoria Board President PETER RAYMOND provides an update on Parkinson's news and views from a personal, state and national perspective.



It seems like only yesterday that the Board assembled after the November AGM with three new members (Professor Meg Morris, Andrew Suggett and Joanna Hill) keenly anticipating the year ahead. Regrettably, we are very sorry to have recently lost the services of Brendan Lourey, but we know that he will remain an active and enthusiastic member and continue to contribute to our work as his health improves.

The casual vacancy created by the resignation, through ill-health, of Brendan Lourey, will be filled by Damien Farrell, whose late mother was a member of the Essendon Support Group.

Married, with three young children, Damien has overseen board and executive responsibilities for several entities including the **Workplace Training Advisory of Australia**, **Women & Leadership Australia**, the **Australian School of Applied Management**, the **National Leadership Institute** and the **WTAA Registered Training Organisation**. His experience has covered all aspects of organisational governance. Damien will be eligible to nominate for the Board at the next AGM (currently scheduled to take place in November).

In the six months that have elapsed since the AGM, the Board has focused its attention on several major initiatives.

- Conducted by the Disegno Group, we have commissioned a **professional market survey** to ensure that we are meeting the needs of our members and delivering our services in the best way possible. The feedback from this survey will help us provide support and service of the highest order. Based on your feedback, we will also seek to improve our website, so it is easier to navigate and find the information, support and advice you are looking for.
- The **Research Sub-Committee**, chaired by Fred Van Ross, has been particularly busy assessing applications and ensuring that bequests specified for Research are honoured and monies spent prudently.
- As always budget deliberations occupy much of our time.

Indeed, we are often asked why we need to focus so much on fundraising and financial control. The reason is simple. If we were to rely on government grants, we would not be able to offer the outreach services we supply to Support Groups, the newly-diagnosed and the medical and nursing professions. There would be nobody to advocate as we do, so strongly, for the families and friends of people living with Parkinson's.

Whilst bequests and in memoriam donations are generous, we can't rely on them, year in, year out, to sustain the work we do and to fund the new ventures we need to undertake on behalf of the Parkinson's community. It is important that we generate regular sources of income through events like **Walk in the Park**, quarterly giving campaigns, tin rattles, BBQs, theatre and movie nights, and third-party events like the Tulip Ball, Open Gardens, Art Shows and Golf Tournaments, etc.

That's why we need to see you, your friends and family at this year's **Walk in the Park** on Sunday 26 August at Federation Square. You can register today at: www.parkinsonswalk.com.au

And, of course, if you have your own ideas about fundraising, support or volunteering your time or skills, our Marketing Coordinator would love to hear from you: Judith@parkinsons-vic.org.au

Peter Raymond, President

Parkinson's - My Journey

Getting to know you

Personal Dopa-meanings: written expressions or anecdotes of life's challenges and experiences relating to people living with Parkinson's.

Peter Nassau has recently joined our editorial team in a voluntary capacity to source and present personal contributions from the wider community.

"We should all have a voice and be heard by those that are working to help us and the wider community.

We can learn from others who are dealing with similar challenges and they can learn from our experiences too. This should reassure us that we are not alone in the fight against Parkinson's.

In my poem on the right, I set out to highlight how difficult it was to be correctly diagnosed. But you don't have to resort to poetry to relate your story, and you may just focus on a certain stage of your life with Parkinson's.

You may be diagnosed or a partner, carer or family member.

I am looking forward to the challenge of assisting with this aspect of the newsletter, and feel charged with a great responsibility – **to share your story.**

You are welcome to submit your articles, poems or stories in writing or electronically. If you prefer to relate your story verbally, I would be happy to listen and put 'pen to paper' on your behalf.

I look forward to hearing from you soon.

Peter Nassau

Peter's aim is to ensure the 'voice' of the Parkinson's community is heard and celebrated. Personal Dopa-meanings provides the opportunity to share and benefit from the range of stories that reflect and explore the many facets of living with Parkinson's.

Peter Nassau can be contacted C/- Parkinson's Victoria. Please address your correspondence to: (email) Subject line PETER NASSAU SIGNPOST or (post) Parkinson's Victoria, PETER NASSAU SIGNPOST, PO Box 2606 Cheltenham, VIC 3192.

When I was told I had Parkinson's Disease
For a moment I felt my body freeze
I'd been struggling for some years before
My balance on downhill slopes was poor
The medical profession was unable
To give my complaint its correct label
So I had many visits to endure
Before the diagnosis was really sure
Doctors were perplexed how to deal with this guy
'Let's tell him he should have an MRI'
This only proved that I had a brain
And left me back at square one again
A top physician in the medical profession
Told me that I had endogenous depression
This didn't help me to improve my state
And of course the symptoms did not abate
My GP was the one who ultimately said
I have some news that you will dread
Your symptoms could be those of Parkinson's Disease
This news caused weakness in my knees
I went to Boston and had tests for a week
Devised by an 'expert' who wanted to peek
At what was happening behind my eyes
That didn't help - surprise, surprise
I then saw a naturopath who advised what to do
'Homeopathy, vitamins and Bowen Therapy should help you
And I also advise that you avoid dairy and wheat
And to help recovery, generally watch what you eat'
But nothing stopped the gradual decline
Of what was happening to this body of mine
So I started taking dopamine pills
And paying expensive neurologist bills
I searched for a neurologist who would listen to me
And use his knowledge to keep me free
By prescribing precisely what I needed
And to this end I believe I have succeeded
Sifrol was added to my medication
However it came with a serious stipulation
If I noticed an increase in impulsive acts,
hyper sexuality or gambling, then report these facts
I've had more than 10 years of reasonable life
Supported by my wonderful wife
However it's getting much harder each year
As I move into top medication gear
Involuntary movements are part of the deal
When I'm sitting with my wife and having a meal
I'll do what I can but I'm not always able
To stop kicking her accidentally under the table
At present there is some measured elation
About the success of deep brain stimulation
I think I'd still like something instead
Of having a hole drilled in my head
However I think the future looks grim
As my movement facilities become more dim
But I have a family when push comes to shove
That will always shower me with absolute love.
My symptoms these days are worst upon waking
I take my tablets to stop shuffling and shaking
I then need to dose up 4 times a day
In order to keep those symptoms at bay
I am lucky that together with my wife
I can still lead a pretty normal life
There are very few things I can no longer do
So I can generally say that I don't feel blue
One always hopes for that special news
That researchers have unearthed the clues
So that all us parkies can be sure
That we will be saved by a miracle cure

Peter Nassau

Healthy Minds

BREANNA WOTHERSPOON from our health team shares some handy tips for keeping your brain 'healthy'.

Keeping yourself healthy will assist you in living well with Parkinson's, while giving your body the best chance to cope with symptoms. There is plenty of information available on how to keep your **body** healthy, but what about keeping your **mind** healthy? Scientific evidence suggests that certain activities, such as exercise, nutrition, and relaxation, may not only be therapeutic for managing Parkinson's symptoms, but may also help to improve the brain.

Exercise

We already know that exercise can help improve and maintain mobility for people with Parkinson's, but now we know it can also help the brain.

Exercise may help increase the connections between neurons and improve blood flow. Exercise helps to combat depression by releasing serotonin and other mood-elevating chemicals in the brain.

Tips

- Try incorporating some incidental exercise into your everyday activities: park your car further from the shops than usual, march your feet during the commercial break when watching TV, or stretch while you wait for the kettle to boil.
- Find someone to exercise with, even if it's simply going to an exercise class with a friend or walking around the block with your dog.
- Exercise at a time you are feeling your best when you have the most energy and your medication is at its most effective.
- Consider seeing a Physiotherapist to have a program designed especially for you.

Nutrition

As a general rule, good nutrition for the body means good nutrition for the brain.

Tips

- Research suggests that Omega 3 oils (found in walnuts and flaxseed as well as oily fish) can improve brain function and concentration and reduce depression.
- Avoid excessively unhealthy foods.
- Enjoy caffeine and alcohol in moderation.

Social interaction

Experts recommend thinking of social interaction as another important form of 'mental exercise'.

Tips

- Look for opportunities to interact with others in settings where you feel comfortable and supported; attend your local Parkinson's Support Group or an art therapy class.

Mental Health

Up to 50 percent of all people living with Parkinson's will experience depression and/or anxiety at some stage during their illness.

These conditions can occur as a natural reaction to your diagnosis, but are also related to underlying chemical changes that occur in the brain as a result of Parkinson's.

It is important to identify and seek treatment for depression or anxiety as early as possible.

Relaxation

There is evidence that long-term stress, depression and anxiety can damage the brain, so learning relaxation techniques can be invaluable in helping to maintain brain health and ability.

Tips

- Try meditation. It can lower blood pressure and help with concentration, even when you are not actively meditating.
- Take time for yourself and concentrate on things you enjoy.
- Actively relax by tensing then relaxing individual muscle groups.

Mental stimulation

Research indicates that ongoing mental stimulation is good for a healthy brain and mind.

A combination of physical and cognitive (brain) exercises may help brain cells to develop richer, more extensive connections with each other, helping to promote protective chemicals in the brain, and allowing brain cells to receive important nutrients and oxygen.

Tips

- Get creative: experiment with your inner artist in the form of drawing, painting, music or writing.
- Learn something new: study a new language or learn to play a musical instrument.
- Read: Reading, especially reading aloud, can assist with mental development. The benefits of reading are increased if you also take the opportunity to discuss what you've read.
- Have fun and challenge yourself: Games and memory exercises can improve loss of memory and recollection speed. Challenge your mind with card games, Sudoku, crosswords or quizzes. (You can try it now with the medium level Sudoku puzzle featured below. Answers: page 9)

					7			
	5					8	4	
	9		5	3	6	1		
6		1		7		3		9
		8	3	9	4	6		
5		9		6		2		4
		2	9	4	3		1	
	1	3					9	
			7					

Just Breathe

In recent times there has been great interest in whether or not yoga could be helpful to people living with Parkinson's. DR SANJAY RAGHAV explains the benefits.

The Sanskrit word "yog" shares its roots with "yoke," as in the alignment of mind, body and spirit. The ultimate goal of yoga is liberation from all worldly suffering and thus attaining *moksha* or **enlightenment**.

Saint Patanjali, in the 2nd century BC, compiled all the steps necessary to achieve **moksha**. However, one can also find treatise on yoga in other ancient Indian texts.

In the contemporary western world the meaning of yoga is mainly limited to a set of postures (Asanas) and controlled breathing (Pranayama) to attain good physical and mental health. There have also been numerous studies which prove, without doubt, that yogic exercises assist in achieving good health.

Further, studies have been conducted in the last decade on Parkinson's patients which prove that yoga can be beneficial in relation to managing some of the symptoms of Parkinson's and improve their experience of the condition.

In 2002, a study performed at the **John F. Kennedy Institute** in Denmark recorded a 65 percent short-term increase in dopamine levels during restorative yoga and meditation in the test group. *[Dopamine is produced by certain nerve cells (neurons) in the brain and acts as a chemical messenger to enable a person to control muscles and move their body smoothly, easily and with coordination. People with Parkinson's have fewer dopamine producing cells, resulting in less coordinated movement, rigidity, and reduced mobility and muscle control].*

In a study on yoga and Parkinson's at **Kansas University Medical Center**, Yvonne Searles, Physiotherapist, PhD, said, "I think I was most amazed by the visible reduction in tremor... and improvement in the steadiness of gait immediately following the yoga sessions."

A recent research study was carried out by **Parkinson Disease Society (India)** in collaboration with the **Light on Yoga Research Trust, Mumbai**. The objective of the study was to determine the efficacy (effectiveness) of yoga in altering the quality of life of patients with Parkinson's. The result of the study showed a significant improvement in those individuals participating in the yoga group in their mobility, flexibility, emotional state and quality of life, as compared to the control group.

Claire Henchcliffe, assistant professor in the **Department of Neurology and Neuroscience at Weill Cornell, USA** has conducted a pilot study (2005) indicating that gentle yoga may alleviate some of the symptoms of Parkinson's, especially cognitive dysfunctions such as depression, anxiety and fatigue. In interviews, participants reported increased energy, reduced stress, improved sleep, reduced stiffness and ongoing social support from others in the class - an incidental but beneficial by-product! The study tentatively concludes that yoga is a safe exercise regimen in a carefully chosen, screened subset of patients with Parkinson's.

There are three components to any good yoga program:

- 1) Controlled breathing (Pranayam)
- 2) Postures (Asanas)
- 3) Meditation.

Yoga practice, whether at home or in a class, starts with the breath. One area we can still control in our dopamine-challenged lives is our breathing. According to the **Parkinson's Research Foundation (PRF), USA**, "Controlling your breath (Pranayama) helps in moments of panic such as feet sticking to the floor when walking."

We can choose to take a deep breath. We can use the breath as a tool to lead us 'inside' and notice what might be going on in there.

In this form of yoga, the mind is always watchful. When we notice stress from the vantage point of an inner witness, our response can shift from the fear or anxiety of stumbling to choosing to take a deep breath and relax.

Yoga stresses the importance of proper breathing techniques into its movements to enhance emotional wellbeing and control tremor.

Alternate nostril breathing (*Anulom Vilom Pranayam*) is quiet helpful to control shaking (tremor) and abnormal body movements (dyskinesia). Other breathing exercises (*Kapalbhati*) help individuals to be more alert during the day (day time drowsiness can be a significant problem for those with Parkinson's).

Yoga Asanas involve stretching the body, which may help people with Parkinson's to improve their mobility and range of motion.

Some yoga classes that are designed for students with special needs, such as those with Parkinson's, incorporate balance training and gentle yoga poses, including back strengthening postures and shoulder movements.

The Asanas can be done in such a manner that



even patients with very limited flexibility or mobility could be trained to perform them. In other words, they can be modified for students with Parkinson's (for example a wall or chair can provide support rather than sitting on a mat, and bolsters or pillows can also be used).

Certain exercises that target the torso and trunk can help prevent rigidity and maintain normal walking and a sense of balance. Stiffness in the body's core is one of the most debilitating symptoms of Parkinson's because it hampers a person's ability to walk across a room or simply stand upright. Restorative twists and poses that strengthen the trunk are thought to reduce stiffness and improve mobility.

Meditation is the third and most essential part of any yoga program.

Since meditation is known to increase the release of the vital brain protein **striatal dopamine**, it could help people with Parkinson's.

Meditation helps more with emotional and spiritual wellbeing. The instructions a yoga teacher gives in class build awareness by getting you to concentrate on the details of the yoga poses (positions). But they also focus the mind and therefore bring you to the present.

For someone with Parkinson's, this is particularly helpful as due to decreased body perception, it is common to become less and less aware of the motor control you're losing. But the mind-body awareness that yoga encourages helps you to self-correct and compensate for these new impairments.

Yoga is one of today's leading alternative therapies.

It doesn't require any special equipment, clothing or weather. The yoga mat is a handy accessory, but it's not necessary. Yoga pants? Yoga studio? Yoga music? All are add-ons. When it comes down to it, yoga requires only one thing - **breath**. If you can take breath, you can also do yoga!

I have seen firsthand what happens when people with Parkinson's embrace yoga: It helps in relaxation, which helps control tremors, activates affected muscle groups, and can be a steady reminder of where your body should be and how it should move.

An effective exercise program can make a huge improvement in the quality of life for someone with Parkinson's. Yoga especially has much to offer because it enhances range of motion, strength, awareness of the body, balance, mental focus, and peace of mind — all of which are compromised by Parkinson's.

Yoga Workshop

Parkinson's Victoria is seeking expressions of interest from people interested in attending a yoga workshop in the coming months, hosted by Dr Sanjay Raghav.

Details are being finalised (depending on level of interest) but the proposal is 4 sessions over 4 weeks (9-10.30am on Sunday), at a venue in the South Eastern Suburbs. Please contact our Health Team today to register your interest.

Research Update

Would you like to be part of the answer to curing Parkinson's, improving our understanding of the condition, and the search to find more effective treatment options?

Research is taking place around the world – and right here in Australia. Getting involved is easy and a tangible way to help make a difference. (Research projects promoted and/or funded by Parkinson's Victoria have appropriate ethics approval.)

Mind over matter

Parkinson's Victoria is pleased to announce that a unique research project into 'mindfulness and Parkinson's', being funded by the organisation, is now seeking participants.

The full name of the project is: **Essence Project: The impact of a mindfulness-based lifestyle program for Parkinson's disease.**

The Essence program is a 6-week mindfulness and lifestyle course developed by Dr Craig Hassed from Monash University. Dr Hassed gave the keynote address at our 2011 AGM.

'Essence' stands for: Education, Stress management, Spirituality (meaning), Exercise, Nutrition, Connectedness (social support) and Environment.

The course will explore the potential role each of these elements has in managing Parkinson's and improving quality of life.

The researchers aim to find out if this program has any impact on Parkinson's-related function, health behaviours, mental health and people's ideas of self-empowerment.

The program will introduce participants to simple strategies that can help them to live well with Parkinson's and they will be encouraged, but not pressured, to apply aspects of the Essence model that are most relevant to their own lives.

The program is looking for 60 volunteers who are living with Parkinson's to participate in the program. This will involve attending a series of weekly, 90 minute group sessions beginning in July. Sessions will be run on Tuesday evenings, between 6pm and 8pm.

You may be eligible to participate if:

- You are fluent in English
- You are under the age of 70
- You are able to attend a minimum of 4 out of the 6 sessions
- You experience tremor, stiffness, or difficulty of movement on both sides of your body
- Most of the time you are able to walk straight and stand up without assistance

To register your interest in participating in this research study or for more information, contact Breanna in our Health Team: (03) 9581 8700 or email your contact details to info@parkinsons-vic.org.au

Research update

Neuropathy, B12 deficiency & Parkinson's

A small scale UK-based study of people with Parkinson's has identified a third of participants experienced a deficiency in vitamin B12, thought to be related to long term levodopa exposure, which resulted in them developing Neuropathy.

Neuropathy is pain that originates in the nervous system. It may feel like pins and needles or burning or tingling sensations and can be hard to treat.

A similar study carried out in Canada found that 10 percent of people on long term levodopa experienced vitamin B12 deficiency and Neuropathy, which appeared to be cumulative; the longer the levodopa therapy, the more likely it was for the patient to develop B12 deficiency and Neuropathy.

Ensuring you have a well balanced diet and maintaining a healthy weight will help reduce the risk of developing a vitamin B12 deficiency. Your doctor is also able to measure your B12 levels and can prescribe a supplement if needed.

Passive smoking reduces risk of Parkinson's

One of the mysteries of Parkinson's has been its reduced incidence in people who regularly smoke tobacco. Further, a recent study published in the **Movement Disorder Society Journal**, which looked at the effect of passive smoking, has identified similar results.

Studies found that exposure to passive smoking appears to reduce the risk of developing Parkinson's in direct correlation to the level of passive smoking the individual is exposed to.

The reason for this effect in both instances is at yet unknown, but remains an interesting field of research for the scientific community, so much so that researchers are also planning to explore the effect of nicotine (a constituent of tobacco) on people living with Parkinson's.

Health Team note: Of course, while reducing one's risk of developing Parkinson's may seem an appealing reason to stand next to a smoker and inhale, the harmful effects of passive smoking have been well-documented and would outweigh any perceived benefits.

Fundraising Events

A night at the theatre

On Thursday, 26 April an intimate group gathered at Peridot Theatre in Mt Waverley for a thought-provoking and emotive performance of "The Peppercorn Tree". Thanks to Peridot Theatre Company for partnering with Parkinson's Victoria and helping raise a tidy profit of \$445.

And...we will be hosting another charity event at Peridot Theatre on Thursday, 8 November, this time of the company's production of "Me & Jezebel".

Synopsis: Elizabeth Fuller's true life account of the summer of 1985 when screen legend Bette Davis came to her home in Connecticut to stay for one night and ended up staying a month.

Tickets will be available online in the coming months. To register your interest today, please contact Jo Berthelemy: (03) 9581 8700 or jo@parkinsons-vic.org.au

Swinging into action - charity golf day

This annual event will be taking place on Friday, 6 July at Spring Valley Golf Club in Heatherton.

Funds raised are donated to Parkinson's Victoria and the Kingston Charitable Trust. This will be the fifth time the club has used the event to raise funds to support our work and in that time, has raised and donated in excess of \$31,000.

Why not get a team together and register for the 4BBB Stableford competition? Or contact the office and they can match you with a team (mixed and single sex). Entry is \$75 for the competition which includes straightest drive and nearest the pin prizes, 2-course sit-down lunch, 2 complimentary bottles of wine per table and the chance to win great prizes with a raffle, spin the wheel and auctions!

www.springvalleygolf.com.au / (03) 9562 3811.

Having a ball

We are very pleased to announce that the Tulip Ball is back for 2012.

TULIP BALL®, sponsored by South Yarra Volkswagen, is the gala fundraising ball supporting people living with Parkinson's by helping fund the work of Parkinson's and, importantly, raising awareness.

As always, all money raised is donated to Parkinson's Victoria. Jo is now a valued Parkinson's Victoria Board Member.

www.tulipball.org.au

Event details:

What: The Tulip Ball

When: Saturday 10 November

Where: The Plaza Ballroom, Regent Theatre, Collins Street Melbourne

Tickets: Available through Ticketmaster®

Purchase tickets, get a table of friends together and/or contact Julie and Jo to discuss becoming a corporate sponsor via donations of prizes

<http://www.tulipball.org/how-can-you-help.html>

For more information contact Jo: 0417 503 803

/ johill@tulipball.org or Julie 0417 384 954 /

juliesewell@tulipball.org

Pat a Pacca fundraiser

Everyone is welcome to drop into Freshfield Alpaca Farm for a "cuppa" during the annual Pat a Pacca Day to help raise awareness of PSP and to support PSP Australia.

A sausage sizzle will be part of the fundraising, and there will be spinning demonstrations and photo opportunities with the Alpacas. A raffle will be drawn at 3.00pm on the day.

www.freshfieldalpacas.com.au

PSP is a devastating brain disease that progressively robs the victims of their ability to walk, talk, see, swallow, eat and drink. In the later stages of the disease patients are confined to a wheelchair or are bed-bound, unable to communicate with the world around them, yet remain mentally alert.

Currently, there is no effective treatment and no cure for PSP.

On average patients die within some seven years of onset of the disease. The cause of PSP is unknown and it can strike anyone regardless of gender, race or social class, although it tends to appear in the over forties. Events such as Pat a Pacca, generously supported by the Freshfield Alpaca Farm, help raise vital funds to enable PSP Australia to provide support, information and friendship.

Event details

What: Pat a Pacca for PSP

When: Sunday, 21 October, 2012

Time: 10.00am - 3.00pm

Where: Frankston-Flinders Road, Somerville (Melways Ref: 107 C8)

For more information about this event or PSP Australia, please contact: Jill Sole: (03) 9782 4166; Anne Mooney: (03) 9568 7748 / damooney@bigpond.com; Mary Ann Drysdale: (03) 5977 9334 / johndry@bigpond.com

Volunteers

Volunteer Coordinator & Events Assistant JOSEPHINE BERTHELEMY talks about the value and rewards of a 'different kind of giving'.

You've got e-mail

If you are a registered Parkinson's Victoria volunteer, you will have received our new e-newsletters, updating you on goings-on and events here in the Volunteer division of Parkinson's Victoria.

The newsletter is an initiative to enhance my communication with you, our valuable volunteers!

I hope the e-newsletter will help volunteers to stay up to date with volunteering news and opportunities. And, most importantly, it's a great way to share with you the wonderful results from various activities you've supported with your time and skills (like the results of our BBQ's and tin rattles).

If you would like to register to Volunteer, please email me: jo@parkinsons-vic.org.au. Aside from being part of a wonderful community of people who share your desire to 'give something back', you'll receive a one-page e-newsletter every two months.

Run Melbourne supports Parkinson's

Parkinson's Victoria is recruiting volunteers to assist at this iconic event, which is being held on **Sunday 15 July**, around the Royal Botanic Gardens and Federation Square.

For every volunteer who nominates Parkinson's Victoria as their preferred charity, **Run Melbourne** will donate \$25!

If 30 volunteers sign up, they'll provide us with a free marquee on the day to hand out brochures and raise awareness.

Keen? It's easy...

- Visit www.runmelbourne.com.au and click on the "Volunteer" tab
- Complete your details, scroll down to the "preferred charity" field, nominate Parkinson's Victoria
- Click "Submit" and you're done! (You'll be contacted directly by the Run Melbourne organisers)

Please note, this is not a Parkinson's Victoria event, but by registering yourself this way, you'll be supporting us nevertheless! And, we'd love to see you at the Parkinson's Victoria community information tent on the day; so pop in and say hello!

Keep an eye out for members of Team Parkinson's who will be participating in the Run and will be wearing Team Parkinson's gear! So far we have 40 people signed up and they've already raised \$7910!

Read who they are on page 19 "Our Supporters" and you can donate at http://runmelbourne.everydayhero.com.au/run_melbourne_team_parkinsons

Cooking up a storm!

So far this year, with the help of our terrific volunteers, we've hosted two successful sausage sizzles at local Bunnings stores.

- On **Friday 24 February** we endured the 35 degree heat at Bunnings Mentone and
- On **Sunday 15 April** we enjoyed a pleasant sunny day at Bunnings Moorabbin

These events raised a combined total fundraising amount of \$2014.05! Wow! We thank those volunteers who participated so enthusiastically on these days.

Special thanks to Bunnings Mentone and Bunnings Moorabbin, and Coles Supermarkets Southland and Sandringham for their continued support.

Our next barbeque will be at Bunnings Moorabbin on Saturday 11 August, which will coincide with the fast-approaching Parkinson's Awareness Week. If you'd like to help out with a three hour shift, please let me know and of course you're welcome to pop in to buy a snag and say G'day!

Helping out? It's a WALK IN THE PARK

The biggest event hosted by Parkinson's Victoria and the largest event of its kind for the Parkinson's community in Australia needs volunteers! **Walk in the Park** is coming on Sunday 26 August.

With more than 2,000 people taking over Federation Square for a day, executing this event is no mean feat! Volunteers play an integral role in making sure the day goes off without a hitch.

We have lots of fun planned and will need a dedicated team of volunteers to make it happen. Volunteering at this event is an immensely fun and rewarding experience; so come along and be part of this fantastic day: **Sunday 26 August**, 7.00am-2.00pm.

www.parkinsonswalk.com.au

Volunteering!

Volunteering! What better way to spend a day?

If you would like to volunteer for any of these events, or have other ideas for how you could volunteer your time or skills, I would love to hear from you. Please contact me, Jo Berthelemy, Volunteer Coordinator: (03) 9581 8700 or jo@parkinsons-vic.org.au

Mum's the word

On a beautiful sunny day in February, golf lovers and others gathered at The Sands Golf Club, Torquay for Tessie's Day – a fundraising event organised by Tessie's son Tim Diamond.

The day included a fierce competition on the green, lunch, a raffle and live entertainment, and it was terrific to see so many people get behind the event to support the cause.



Tim & his mum Tess



(Above: Rian and Travis accept the inaugural Tessie's Day Winners Cup from Tess Diamond (left) and Parkinson's Victoria CEO, Ann Burgess).

Congratulations to competition winners Rian McKee and Travis Faulkhead.

The day was an overwhelming success and thoroughly enjoyed by all. We were absolutely thrilled to receive a cheque for \$9585 from Tim, which included a number of donations as well. What an outstanding effort!

Parkinson's Victoria would like to thank Tim and the Diamond family who worked so hard pulling the event together, as well as their corporate supporters and sponsors. We also thank Anne Atkin, one of our Ambassadors, who shared her personal story.

Fashionable Fundraising

Earlier this year, Sally Pittard hosted a fundraising **Postie Party** (a party-plan fashion label) and raised \$572.00!

A BIG Tulip Tribute to Sally for organising such an enjoyable event for guests and helping to raise awareness of Parkinson's while raising vital funds!

Fashionable Fundraising

In March, Jo and Chris Boland opened up their stunning garden in Yarra Glen to members of the public as part of the Open Garden Australia Scheme. An amazing \$500 was raised, including generous donations from the Scheme and Jo and Chris.

You already have a beautiful garden Jo and Chris, but we'd like to send you a Tulip Tribute! Thank you!

Ladies who lunch

A group of Lancefield residents recently came together to raise funds for Parkinson's support programs.

Inspired by the strength of her mum's 10-year battle with the incurable condition, Lancefield's Lucy Brown organised the event which brought more than 100 people together – including friends and family from across Victoria - for a garden-style fundraising party.

The event, entitled 'A lazy Saturday' was held on January 28 and saw guests buy raffle tickets, play games and enjoy a Lorraine Lea demonstration. The result was an impressive \$5000.



Lucy Brown with a cheque for Parkinson's Victoria following her fundraising event.)

Lucy said she had watched her mum fight the condition for more than a decade now and decided it was time she did something to help.

"I knew living in a small town was special but this day showed just how special it was, the generosity and kindness of everyone was overwhelming," Lucy said.

"The day would not have been possible without all the support of local businesses, guests who attended and Lorraine Lee Linen, which donated 10 per cent of sales on the day."

On the day Lucy urged others wanting to contribute to cause to take part in this year's Parkinson Walk in the Park, to be held on Sunday, August 26.

"The walk involves a 4km leisurely stroll along the Yarra River and there is a shorter 2km option also," Lucy said.

"I'm hoping to get a big enough team together this year to run a bus from the Lancefield/Romsey/Kilmore area down to the walk and back again."

If local residents from Lucy's area are interested in joining her, please contact our office and we will put you in touch with her.

On behalf of Lucy, Parkinson's Victoria gratefully acknowledges the generous support of the various businesses that made this day possible, especially the local wineries!

We would like to congratulate Lucy on organising such an incredibly successful event. A colourful BIG Tulip Tribute Lucy – thank you!



Health & Symptom Management

A Tough Act to Swallow

LINDA MARINIELLO has worked in Speech Pathology for over 7 years, both in hospital and community settings, with the majority of her clients being people with Parkinson's. Linda is well qualified to discuss some of the communication problems people with Parkinson's experience and how a speech therapist can help.

Speech Pathologists are specialists who assess and treat people of all ages who have difficulty communicating or swallowing. They work in a variety of settings.

Why might someone with Parkinson's see a Speech Pathologist?

Approximately 75 percent of people with Parkinson's will experience communication and/or swallowing difficulties at some stage of their diagnosis.

Changes to communication

Communication is a vital part of our everyday life; it allows us to express our needs, thoughts and feelings. People with Parkinson's often have difficulty being heard in conversation and on the telephone. They may also experience negative or reduced responses from listeners, reduced confidence, decreased enjoyment in conversation, and social isolation.

In someone who has Parkinson's, speech may sound slurred, be too fast or slow, and have more pauses and hesitations. Volume is often reduced and speech sounds quieter than normal. The voice can also sound rough, breathy or monotonous. Accompanying this can be reduced facial expression and eye contact. Individuals may have difficulty finding the right word, and reduced motivation to start or maintain conversations.

Changes to swallowing

The medical term for swallowing difficulties is **dysphagia**.

Some of the signs of dysphagia are: coughing when eating or drinking; gurgly sounding voice; difficulty swallowing certain foods, fluids or medications; meals taking longer to finish than usual; and unexplained weight loss.

A person with dysphagia is at risk of inadequate fluid or food intake, which can lead to weight loss, dehydration and malnutrition.

Dysphagia may also result in "aspiration" - choking or obstruction of the airway -, or food and drink "going down the wrong way", which can result in chest infections, known as "aspiration pneumonia".

Dysphagia can also impact on the quality of life of the person with Parkinson's. They may not enjoy eating, feel embarrassed, and become anxious about eating.

How can a Speech Pathologist help?

A Speech Pathologist will talk to you about any communication or swallowing difficulties you are experiencing and ways to manage them.

Your first appointment is likely to involve an assessment of your swallowing and/or communication. This helps the Speech Pathologist decide what treatment you may benefit from.

The type of therapy you receive, the number of sessions and the frequency of sessions all depend on your individual needs. Therapy is personalised and can occur individually or in a group. It can also include family and friends. The Speech Pathologist will also educate you and your family about communication and swallowing changes associated with Parkinson's. They will teach you strategies and may give you exercises to practice that will help with dysphagia and communication difficulties.

Tips for managing swallowing difficulties

- See a Speech Pathologist that has an interest in Parkinsons
- Sit up straight when eating, drinking and taking your medications
- Take small mouthfuls and sips
- Have one sip of drink at a time
- Reduce distractions and avoid talking whilst chewing and swallowing.

Tips for managing communication difficulties

- See a Speech Pathologist
- Reduce background noise and distractions
- Face the person you are speaking to
- Capitalise on times when your speech is best
- Do one task at a time. For example, don't try to walk and talk on the phone at the same time
- Be well rested before a social event and prepare; think about whom you will be meeting and what you might talk to them about
- Get your family and friends to help. Explain the difficulties you are having and ask them to give you time to communicate and help you to join in conversations.

You can access Speech Pathology services in a number of ways. Some public services may have specific eligibility criteria.

- Ask your GP to arrange a **Chronic Disease Management Plan**. Through this you can arrange an appointment to see a Speech Pathologist and access Medicare rebates on services. <http://www.humanservices.gov.au/customer/services/Medicare/chronic-disease-management-plan>
- Contact your nearest Movement Disorders Clinic and request a referral to a Speech Pathologist.
- Contact your local community health centre and request a referral to a Speech Pathologist.
- Contact Speech Pathology Australia. Phone: (03) 9642 4899 or visit: <http://www.speechpathologyaustralia.org.au/> to find a Speech Pathologist in your area.

Linda Mariniello currently works as a Speech Pathologist in a specialised in-patient Movement Disorders Program, run at the Kingston Centre, a part of Southern Health.

linda.mariniello@southernhealth.org.au

Access, Advocacy & Assistance

Money Matters

KATHRYN HUMPHREYS explains: how a financial adviser can help you gain peace of mind now, and plan for the future.

When I tell people that I'm a financial adviser, they often respond with "So, what's a good investment?" or "I don't have a lot of money so there's no point in me seeing someone".

For people who question me about investments I respond with a few questions of my own such as:

What are your lifestyle goals? What are your plans for this money? Do you know how much you need to cover your everyday expenses and have some available if an unforeseen event occurred? What experience have you had with investing? Are you concerned with the effect of inflation on your capital?

In fact, investments form just one part of the advice process. I provide tailored advice to help people identify and set financial goals and then develop a strategy to ensure that they can achieve them. Depending on the answers, the investment strategy could vary significantly. For instance a good investment for someone planning to buy a car in 6 months time would be very different compared to someone who was investing for their retirement in 20 years time.

Another question that I've heard recently from investors is whether to continue to contribute to superannuation. Given that for many people superannuation has gone backwards in recent years, this is a valid concern. While we have undoubtedly experienced some turbulent sharemarkets, the fact is that superannuation still remains one of the best tax effective structures for the average Australian to invest in to secure their retirement lifestyle.

Financial advice is first and foremost about having a detailed understanding of your personal and financial goals and of the trade-offs to achieve your goals. Only by following a framework will you have confidence, clarity and control over your financial position.

I do this by ensuring I have a thorough understanding of my client's personal circumstances, exploring their goals and aspirations and addressing any issues and concerns that they may have. Once I understand my client I can develop a plan that will help to maximize cashflow, minimize tax, grow assets including superannuation and explore eligibility for government support. A

sound financial plan extends to protecting income and assets through insurance as well as putting into place an effective estate plan.

With a diagnosis of an illness such as Parkinson's, you and your family may find that you need to address some of these financial aspects earlier than you expected. It can be a time of uncertainty. While dealing with important medical decisions, establishing a sound financial plan can also help to give some peace of mind.

In these circumstances, my advice would cover the areas outlined above, but with a greater focus on issues such as cash flow and financial support. This involves considering your ability to continue earning the same level of income, the cost of ongoing medical treatment, and your eligibility for insurance payouts and access to government support.

I hope that I've provided insight and understanding into how a financial adviser can build and protect your lifestyle so that you can concentrate on what's most important to you.

Kathryn Humphreys is a financial adviser with Shadforth Financial Group, a sister group to Outlook Financial Solutions. She has over 11 years experience in the financial services industry and is a CFP® practitioner, which is the highest qualification in the financial planning industry. To arrange a discussion with Kathryn please contact Shadforth's Melbourne office: 1300 657 872 or email: contactus@outlookfs.com.au

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Education

Experts deliver education workshops

In April, Melbourne hosted the seventh World Congress for NeuroRehabilitation. As part of this international gathering of 2000 people, Parkinson's Victoria was proud to present two special workshops.

Thanks to funds provided through the **Colin & Sheila Marshall Trust** Parkinson's Victoria was able to host a major pre-congress workshop titled **Parkinson's Disease: Promoting exercise, physical activity and well-being** for 60 health professionals, and a post-congress workshop called **Meet the Experts**, for 40 individuals living with Parkinson's and their carers/partners*.

The highlight for attendees was being able to hear from a number of experts in the field, in particular, international speakers Dr Samyra Keus and Dr Marten Munekke from **Raboud University** in The Netherlands who are world experts in physical activity for people with Parkinson's. In addition, speakers included Associate Professor Sandra Brauer from **University of Queensland**, Professor Robert Iansek from **Monash University**, Ass. Professor Colleen Canning from the University of Sydney, Professor Meg Morris from the **University of Melbourne** and Dr Jennifer McGinley from the **University of Melbourne**.

At the conclusion of the health professionals workshop, attendees were privileged to hear personal perspectives from three people living with Parkinson's and to gain from their valuable advice and sensible reflections.

The post-congress workshop, "**Meet the Experts: Practical Advice from National and International Rehabilitation Experts on Physical Activity, Exercise and Lifestyle For Living Well with Parkinson's**", was also made possible thanks to the Colin & Sheila Marshall Trust, which was established from a significant bequest.

Held in Moorabbin, the one-day workshop provided a friendly atmosphere where people could raise questions and learn from information provided by Dr Samyra Keus and Dr Marten Munekke, as well as co-presenters and local experts Professor Meg Morris and Ms Mary Danoudis. Slides from the PowerPoint presentations are now available online: www.parkinsonsvic.org.au

Also during the WCNR conference, Parkinson's Victoria supported a large symposium on recently completed large trials on physiotherapy in Parkinson's. This event provided detailed findings of recent clinical trials, as the basis for determining effective methods of evidence-based practice.

There was also an additional comprehensive

afternoon session on "Movement Disorders" where Associate Professor David Williams, Dr Barry Rawicki and Professor Morris spoke at length about movement disorders and Parkinson's.

Of this week bursting with science, research and education, Professor Meg Morris reflected that the great success of this series of major events was in large part due to the leadership afforded by Fred Van Ross and the Research Committee of Parkinson's Victoria, as well as the visionary leadership of the President, Peter Raymond and CEO Ann Burgess. "Without their support and enthusiasm, these events that reached more than 2,500 people simply would not have been possible" said Prof Morris.

***Both workshops were 'sell outs', with a number of people on waiting lists to attend. Given the level of interest from the health professional sector and general public, Parkinson's Victoria plans to host similar events in the future.**

Education

Surviving carer stress

Surviving Carer Stress – understanding how stress affects you is a workshop, proudly presented by Parkinson's Victoria in association with Carers Victoria.

It is designed especially for the partners and family members of those diagnosed with Parkinson's and will provide practical ideas on managing carer stress.

What: Surviving Carer Stress

When: Wednesday, 11 July, 4 – 6:00pm

Where: Multipurpose Room, Eltham Library, Panther Place, Eltham (Mel Ref: Map 21 J5).

Cost: Attendance is \$5 per person. Places are limited and RSVP is essential. Contact Parkinson's Victoria

Treatment Options – a free lecture

Professor Malcolm Horne will present **Parkinson's disease – Exploring Treatment Options** on Thursday 5 July at 6.30pm at the **Melbourne Brain Centre** auditorium.

This free public lecture will discuss the available treatments for the early and middle stages of Parkinson's.

The lecture will explain how current treatments work and which symptoms they aim to treat, including conventional pharmaceutical treatments for early stage symptoms and more complex interventions relevant to the latter stages of the condition (such as brain surgery, pumps and infusion).

Professor Malcolm Horne is a senior member of the Neurodegeneration laboratory at the **Florey Neuroscience Institutes**. He also spends time as consultant neurologist at St Vincent's Hospital,

Fitzroy, and is Conjoint Professor, **Centre for Neurosciences at the University of Melbourne**.

What: Parkinson's disease – Exploring Treatment Options

When: Thursday 5 July, 6.00pm for a 6.30pm start

Where: Melbourne Brain Centre auditorium, corner of Royal Parade and Genetics Lane on the grounds of the University of Melbourne (opposite Royal Melbourne Hospital), Parkville. NB: Look out for the Parkinson's Victoria Banner! If entering off Royal

Parade, head up the stairs and in through the glass doors (there is a cafe located to the right inside called Mr Dax).

Parking: Street parking is available outside the building in Royal Parade. There is also a carpark alongside the Melbourne Brain Centre.

To register: This is a free event, however registrations are essential. You can register online at: www.florey.edu.au/news-events/events-seminar

A lasting legacy to make a difference

In welcoming delegates to both the WNRC pre and post congress workshops, President Peter Raymond acknowledged the generous bequest of Colin and Sheila Marshall. He also mentioned the work of Board member, Professor Meg Morris, who was instrumental in Parkinson's becoming a key conference agenda item and was responsible for the exceptional calibre of presenters from Australia and overseas.

"Parkinson's Victoria, through the generous support of the Colin and Sheila Marshall Trust, is delighted to welcome delegates to Melbourne, to this the **Seventh World Congress of the World Federation for NeuroRehabilitation**.

Parkinson's Victoria was established in 1981 and has grown to a staff of 9 including a Health Services team of professionals.

Without energetic fundraising, Parkinson's Victoria cannot sustain its work, and we remain reliant on the community for donations and bequests.

It is such a bequest from Colin Arthur Marshall and his wife Sheila Logan Marshall (nee Price) that has funded these two workshops.

Colin Arthur Marshall was born in New Zealand on 13 March, 1913. Sadly, his father died when he was four and the family moved to Melbourne where they enjoyed the support and security of other relatives.

Colin served in WWII and marched on Anzac Day every year until 2006, when he stopped driving.

Colin was an active member of the Victorian RSL and gave 32 years of exemplary service to Legacy. He was a founding member of Berwick Rotary, serving as President, and an active Bowls and Tennis player. Colin had a son from his first marriage.

An accountant and book-keeper, in 1950 Colin purchased a bus and took over the running of the Upper Beaconsfield Bus service. It was on his bus route that he met relief teacher Sheila Price who was assisting at Upper Beaconsfield Primary School.

Sheila Logan Price was born in Maffra, on 29 February, 1924.

After working in the CBA Bank in Melbourne, she qualified initially as a Kindergarten Teacher and later as a School Teacher. Sheila was an accomplished artist, well-known for her watercolours and drawings which hang in Local Shire chambers, schools and hospitals (and also the office of Parkinson's Victoria).

Sheila was also the organist for the local church and an active church-goer with Colin for many years. Sheila was diagnosed with Parkinson's a few years before the establishment of Parkinson's Victoria in 1981.

Together in Upper Beaconsfield, Colin and Sheila were famous for their contribution to the community, especially their provision of artistic and creative support to others less fortunate. They continued living in Upper Beaconsfield from 1959, when they married, until 2005 when they moved to a Retirement Village in Pakenham.

Colin passed away aged 93 on April 14th 2008 and Sheila not long after, on 1 December, 2009, aged 85.

Colin and Sheila left their estate, for the benefit of an organisation "... whose objective is to assist in the development of a cure for Parkinson's and related diseases."

In consideration of Sheila's love of art, funds have already been made available to support the **"Painting with Parkinson's Program"**, an excellent initiative undertaken by Anne Atkin, who was diagnosed with Parkinson's in 2005. In an interesting addition to the story, Anne also taught at the Upper Beaconsfield Primary School and her pupils included the children of Mr Simon Conn, Executor of the Estate. Anne also knew Sheila and was well aware of her artistic achievements.

Parkinson's Victoria will continue to apply funds from Colin and Sheila's generous bequest to various worthy research projects in the expectation that we will help discover a cure and also improve the quality of life for people with Parkinson's."

Understanding loss & grief

DIANNE RAYNER from our Health Team provides some reassuring information about what to expect when we experience grief and loss and some tips on how to cope.

What do you think of when you hear the words "grief and loss"? Do you only associate it with someone dying? If you answered yes, you are not alone. But grief and loss can be caused by a number of other types of loss.

While death is one such loss, and probably the most obvious, illness can also bring with it a sense of 'loss', not just for the individual, but also their carer, family and friends.

Loss in this sense might be for the person they were before they became ill, or losing the ability to do certain things (especially if it was something they especially loved or were good at). It may be losing some aspect of themselves which they felt "defined" them and who they are. It may be loss of independence, loss of a position of responsibility (at work or home) or even a physical loss such as the ability to communicate or look after themselves.

At some point in time, we all experience a great loss in our lives. And, whether that loss is of someone we love, a pet or something very important to us (such as our independence), grief is the natural response that follows.

Grief is best described as a multi-layered personal response to losing something or someone with which we had a bond. It can involve a range of emotions, from numbness and disbelief to anger, guilt, loneliness, bitterness, and at times, overwhelming sorrow.

Response to grief is unique to each individual, filtered through our different personalities, life experience and background. Our individuality will also influence the way we view and cope with these circumstances.

Yet, while grief is an individual process, most of the time we grieve with others who share our circumstances (family members, friends, work colleagues or others within our social surroundings).

There is no single way to grieve and no clear set of "steps" in a grieving process. Some experiences of loss and grief include disbelief, denial, shock, helplessness, crying, sobbing, resentment, panic, fear of losing control, disturbed sleep, confusion and anger. These responses can be significant enough to interfere with a person's ability to function and manage the demands of everyday life.

Regardless of how we grieve, the emotional pain we feel when we lose something or someone we value is a natural and normal reaction. Understanding that it is normal for people to respond emotionally and sometimes physically to loss, and that this reaction will be different for everyone will assist those experiencing grief and those supporting them.

The stages of illness and those of grief and loss are similar: typically people will experience denial, anger, fear, and acceptance. However, not everyone will experience these stages in the same order and it is common to move back and forth

between stages. It is important to remember that, no matter what stage you are in, it is where you should be 'at this point in time'. Allow yourself to simply 'go with it', feeling the various emotions as they occur in order to move onto the next stage. Don't rush this process, just let it happen - naturally.

Denial

Any change or loss in your life is likely to bring denial. Learning you have a serious or chronic illness can be no different and just as hard to accept. Of course, some people accept a new situation quickly and are able to focus attention on their wellbeing and a holistic approach to their health.

Anger

What often exacerbates denial is anger. Some people respond with the "why me?" question. Others may direct their anger inwards, blaming themselves for something they did or didn't do. The best way to minimize anger is to find healthy outlets for it. Writing in a journal, attending a support group or meeting with a therapist/counsellor are constructive ways to express anger. Anger is normal, but it can take a long time to work through.

Fear

Often underlying anger is the fear that comes with having a health condition that can't be cured.

Fear may present itself as beginning to look at life differently; perhaps you start to have *small thinking* and make more conservative decisions because you are afraid of the unknown and fear not being in control. You may stop planning ahead or making life changes because of this.

Knowledge is power: Gaining an understanding of the illness you or a loved one has is often helpful in dissipating fear. Typically, the more a person learns about the illness the more they feel in control of it.

Acceptance

Though managing a long-term illness can bring emotional turmoil, it can also foster a sense of victory in overcoming fear and gaining strength that comes with overcoming obstacles.

Living with an illness or experiencing deep loss of any kind is not easy. Coping with change and learning how to 'live well' in spite of it is a process that takes time and requires learning to let go of the past and valuing the future.

Allow yourself – or a loved one – to feel and to express those feelings so you can understand your reaction to situations happening around you. Involving yourself with peer support groups, talking to friends and keeping communication open with partners, friends and family members – so that feelings and resentments don't build up – are also important resources to make the most of.

If you are interested in learning more about grief and loss stages, Google Elizabeth Kubler-Ross or you can find information at your local library. You can also contact the National Association for Loss & Grief (Vic) Inc: www.nalagvic.org.au or the Health Team at Parkinson's Victoria.

Parkinson's Nurses

One of the strategic aims of Parkinson's Australia and Parkinson's state organisations is the provision of funded Parkinson's Nurses or a Parkinson's clinician who would be located within the community at key geographic locations and integrated medical centres.

Parkinson's can be a confusing illness, and available treatment options complex. Prescribed medications are tailored to the individual and change often.

One of the greatest challenges facing people living with Parkinson's is access to health specialists who can, on both a regular and needs basis, assist individuals to better manage their condition and navigate the complex health care system - resulting in improved quality of life.

Having ready access to someone with appropriate knowledge is obviously appealing and in many parts of the world, people living with Parkinson's have access to a dedicated Parkinson's Nurse.

Currently in Australia there are approximately 33 nurses who spend the majority of their professional time working with people with Parkinson's. Given the estimated prevalence of people living with Parkinson's (approximately 100,000) that is a ratio of 1:3030.

Some of these nurses work in private practice, while others support specific drug or treatment regimens for Parkinson's. Others work in the area of research or clinical trials and a few work for public hospitals in Movement Disorder Clinics.

In comparison, other countries with government-funded health care have a different perspective on the value of specialist Parkinson's Nurses. Holland, has an extensive network of Movement Disorder Services (as do Israel, Sweden and many other European countries) in which nurses are considered an integral component. Considered around the world to be the ideal model, the UK National Health Service employs over 360 Parkinson's nurses, many of whom are independent practitioners.

One of the advantages of involving a nurse in Parkinson's care is their accessibility. Generally if you have a concern the Nurse can be contacted quickly and can be relied upon to call you back. In the UK many Parkinson's Nurses run "Telephone Clinics" where the nurse is available on the phone at an allocated time in the day or week. Having a nurse on your case can also be useful when dealing with medications, timing and troubleshooting. Nurses will work with your family, explaining the symptoms and medication side effects.

Typically, a Parkinson's Nurse will have more time to listen to concerns, allay fears and provide answers. They tend to be more approachable and are often important in supporting carers and families.

Navigating the complexities of the Health Care system can be difficult and a Parkinson's Nurse can assist in ensuring that you are able to access the best care. A Parkinson's Nurse will work with other team members to ensure understanding of Parkinson's and how it affects you.

The Parkinson's nursing situation is changing slowly in Victoria. As a result of the work Parkinson's Victoria has done in collaboration with Western Health, there is now on-going funding for a Parkinson's clinician in the Western Metropolitan area of Melbourne. There are also some structural changes occurring in health care. Medicare Locals, which are federally funded and increasingly visible, are starting to identify some health care gaps that need to be filled. While the detail isn't clear, Medicare Locals will fund services relative to the community in which they are located, and may present an opportunity where funds can be identified for a Parkinson's Nurse.

There has been some recent media attention surrounding the Shoalhaven Project, where funding from different sources including the Federal Government made the employment of a Neurology Nurse Educator possible for the area just south of Sydney.

Early outcomes have shown a significant health-care cost saving to Government, by reducing unplanned or unnecessary medical and healthcare appointments and hospital attendances. Further, the pilot project has indicated that active involvement of a specialist nurse in individualised case management has directly resulted in improved quality of life for people living with Parkinson's and subsequently their carers.

Both the Shoalhaven Project and the Nurses recently appointed in Tasmania will address other movement disorders as well as Parkinson's - an ideal model accounting for diversity and equity. Parkinson's, because of its prevalence, will remain the major focus.

Unfortunately, Parkinson's Nurses don't grow on trees, and there is no formal training in Australia. Given that there are very few jobs this is not surprising. However this issue is being addressed and the formation of the **Movement Disorder and Parkinson's Nurse Faculty (MDPNF)**, within the Royal College of Nursing, highlights a Nursing speciality needing both recognition and funding.

The MDPNF is also engaged with the University sector to ensure Parkinson's and other Movement Disorders are part of the curriculum for both undergraduate and post-graduate nursing education.

Keeping the issue of Parkinson's nurses on the agenda is a priority for Parkinson's Victoria and the MDPNF. As an individual or a support group you can also help.

Consider writing to your local MP (State and Federal Government) or your Medicare Local representatives from each Support Group meeting so they can see and hear first hand the particular challenges posed by Parkinson's and how having access to specialist nurses would greatly improve your situation.

Let us know if an MP or Medicare Local is attending a meeting and Parkinson's Victoria will endeavour to have a representative also attend to support the cause.

Parkinson's Victoria supports the value of Parkinson's Nurses and is frustrated by the slow progress in funding and appointing more of these specialists.

An open letter to the Parkinson's community

Parkinson's Victoria Walk in the Park: Taking positive steps towards a better future for people living with Parkinson's

Dear Signpost Reader and member of the community,

I am writing to you with an exciting opportunity to contribute to our work and I am hoping you may be interested, or know someone who is.



Since 1981, Parkinson's Victoria has been dedicated to reducing the impact of Parkinson's by delivering high quality support services to the community.

While this remains our core mission – to provide tangible support to individuals and families **today** – we also remain committed to funding vital research, so that in the future, fewer people will hear the words “you have Parkinson's”.

Parkinson's Victoria, thanks to supporters, donors and community-minded organisations and business owners, has been able to provide more than \$1 million from our dedicated Research Fund to Australian researchers who are making improved treatments and a cure for Parkinson's their priority – and, we hope one day soon, a reality.

I am writing to you now because I believe we can count on you to take a positive step to help fund Parkinson's support services and research.

Will you come walking with us? Every step counts:

Parkinson's Victoria Walk in the Park is the biggest event of its kind for the Victorian community.

Not only has it brought together more than 5000 people in the fight against Parkinson's, and generated more than half a million dollars in media coverage, but importantly it has raised more than \$200,000 to help fund the service and research initiatives of Parkinson's Victoria.

But increasing demand to access our health services means we need to do more. Government support is simply not enough – we need your help.

To ensure the Walk continues to successfully raise both funds and awareness we are looking for **100 Walk Patrons** to play a central role in building this year's event and help win the fight against Parkinson's.

A **Walk Patron** is a person, business or community group which donates \$1000 towards our 2012 Walk fundraising goal of \$150,000.

As with all donations to **Parkinson's Victoria**, your Patron donation is 100% tax deductible and can be made as a one off donation or over 2 donations of \$500*. In return, Walk Patrons will receive an exclusive **Founding Patron Walk in the Park** lapel pin and a **Certificate of Appreciation**.

In addition, for every Patron, a Tulip – the international symbol for Parkinson's awareness – will be “planted” at this year's walk. Each Tulip will feature the name of its Patron. Or, you may choose to celebrate someone special with a Tulip Dedication; simply let us know the name of the person you would like to see celebrated at this year's **Walk in the Park** and we will include their name on your Tulip.

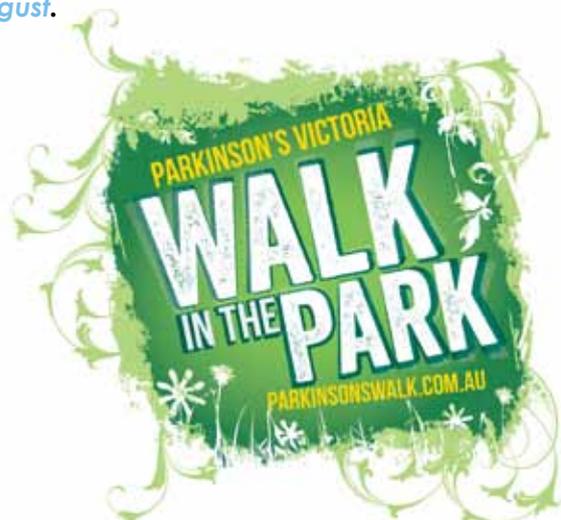
You have been an instrumental part of the journey so far and we know you share our vision for the future: **a world without Parkinson's**. We trust you will want to continue the journey with us. Please consider becoming a Walk Patron or introducing the initiative to your family, workplace or social organisation.

If you would like to become a Walk Patron or to find out more, please contact Judith our Marketing Coordinator (judith@parkinsons-vic.org.au) or phone: (03) 9581 8700. To support the Walk you can also register to walk at www.parkinsonswalk.com.au – your participation is absolutely vital. You can also contact Judith if you have ideas about other ways to support **Walk in the Park** or our everyday work helping people with Parkinson's.

Yours sincerely

Ann Burgess, CEO

***To become a Walk Patron your \$1000 donation must be received by Parkinson's Victoria in full (as one or two payments) prior to Walk in the Park, Sunday 26 August.**



Supporters

Publication details

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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) 9581 8700 or email info@parkinsons-vic.org.au.

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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 20,000 Victorians living with this chronic progressive condition, their family, friends and allied health professionals.

THANK YOU to those who have given so generously to Parkinson's Victoria in recent months. Listed below are those who kindly donated \$200 or more, those in whose name In Memoriam donations were received, and corporate/organisation supporters from 1 February to 31 April 2012.

We extend our sympathies to the families who have lost loved ones, and we thank those who have donated anonymously.

Donations of \$1000+

John & Deirdre Collier
John Alford & Sue Harper

Donations \$500+

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Douglas Ellinger (for his father)

In celebration

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The Colin and Shelia Marshall Bequest

In Remembrance of..

Jean Marie Jennings

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Sally Pittard (Postie Party)
Una Robertson - Daughter
Julie & Granddaughter Laura
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Airlie Birch
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Vince Spano

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3	5	7	1	2	9	8	4	6
8	9	4	5	3	6	1	2	7
6	4	1	2	7	5	3	8	9
2	7	8	3	9	4	6	5	1
5	3	9	8	6	1	2	7	4
7	6	2	9	4	3	5	1	8
4	1	3	6	5	8	7	9	2
9	8	5	7	1	2	4	6	3

Sudoku Answer

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Shaking with Laughter



ROWENA HUTSON shares what she hopes is not a unique approach to living with Parkinson's, or loving someone who has been diagnosed with this challenging condition.

I recently read an article on the Michael J Fox Foundation blog titled **"Why Love May be the Best Medicine"** – to which I would personally add as a codicil - But Laughter is Even Better.

And I mean the kind of tear-inducing, down-in-the-belly laughter that makes your stomach ache and your cheeks feel like they might burst. The kind of hilarity that catches you unawares, but makes you keep breaking into bizarre snorts every time you remember the original moment. The kind of laughter that releases endorphins, and makes you realise that every dark moment has its opposite number (and often they happen so closely together it can be a strange and amazing experience for everyone).

I would claim that I have enough experience in this area to make that addition – even if I lack a PhD.

For one, my mother has Young Onset Parkinson's, and as a family we have lived with "Parky" for almost two decades. Secondly, that natural instinct to laugh at ourselves and our hardships, luckily, has always been a part of our family life. And thirdly, and perhaps most pertinently, I am a comedic actress.

And thus, the old adage 'If you don't laugh, you'll cry' has very real implications in my life. Growing up as a teenager, knowing that Mum had Parkinson's but having no real concept of what that was, was indescribably scary.

Until I had the bright idea of reading *Lucky Man* under the bedcovers, so I could secretly gain knowledge, it seemed as if every nightmare of ill-health I could possibly imagine would be visited on my brilliant, hard-working and fabulous mother. But then Marty McFly (as I like to think of him), opened my eyes enough to imagine the future in realistic terms, but also to grasp that if, by necessity, you have to live with a chronic illness, or indeed any type of hardship, it helps to find the humour in the darkness. That's why it's called *Black Comedy*.

Just this week, Mum and I were reduced to inarticulate gurgles and painful tears of laughter as we recalled for my sister the moment my Dad had a 'soft-shoe shuffle' incident (a term we've employed in our family for when you unsuspectingly 'come across' a pile left by our beautiful, but house-trained-challenged puppy)!

Dad had leapt about six foot in the air, and been left standing on one leg for ages whilst I tried to control my hysterics and scramble for the cleaning equipment.

Ridiculous, silly, slightly gross and relatively banal,

and yet it is a perfect example of the beginnings, the edges of black comedy. At least from my understanding of it.

In acting terms, **comedy** is when a man walks down a street, trips on nothing and falls flat on his face. **Tragedy** is when he doesn't get up again. **Black comedy** is when the person who falls over has a mobility disorder and has their epic fall broken by an enormous pile of shoes and then sits there amongst the smelly sneakers laughing (true story). Black comedy is (ironically) the grey area between comedy and tragedy, the place that real life inhabits. The place where we can laugh with the underdog at the absurdities life has dished up to us all.

Tim Ferguson, of **Doug Anthony All Stars** fame has said of his life with MS, "You can laugh, or you can cry. Laughing takes fewer tissues."

Even Jean-Dominique Bauby, after surviving a massive stroke only to live with the condition called "locked-in syndrome", wrote; "there comes a time when the heaping-up of calamities brings on uncontrollable nervous laughter – when, after a final blow from fate, we decide to treat it all as a joke." And if they can laugh, surely we can too?

Understandably, not everyone shares my need for regular tummy aches from laughing too hard and too long. But the magic flip-side of black comedy other than the marvellous feeling of well-being from all those endorphins is that allowing others to laugh at our troubles and woes means that when they stop laughing, they are suddenly faced with the reality of the situation. They see the darkness, and all the complexity that goes with it, and in that moment they understand that they've made a choice to join us in laughter. They quite literally laugh so that they won't cry.

And so I agree with the Fox Foundation – love is the best medicine. But if you want to encourage empathy, understanding and *joie de vivre* in the face of life's absurdities, than what better than a huge, communal belly-laugh?

Rowena will be performing her solo show *The Unstoppable, Unsung Story of Shaky M* at La Mama Theatre in June/July. She would be honoured if you came along and laughed.

Event details:

What: *The Unstoppable, Unsung Story of Shaky M*
Synopsis: *Shaky M has waited twenty-three years, three months and sixteen days to be rescued. Now she's decided to become her own hero, tell her own story, and make the ultimate mixed tape. Combining elements of physical theatre, clowning and puppetry, Shaky M plunges us into the world of a woman held captive by her own body and her imaginative quest to set herself free. Created and Performed by Rowena Hutson. Directed by Xanthe Beesley.*

When: June 20 – July 1 (Wed, Sun 8.30pm; Thu, Fri, Sat 6:30pm)

Where: La Mama Theatre, 205 Faraday Street, Carlton
Tickets \$25 Full | \$15 Concession

Book at: www.lamama.com.au

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