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Welcome

Welcome to the first edition of Signpost for 2013!

With World Parkinson's Day (W.P.D.) just around the corner on Thursday, 11 April*, Parkinson's Victoria and our state counterparts are busy preparing to mark the day with special events, news stories and important information about key issues affecting our community.

Our theme for this year's W.P.D. is Young Onset Parkinson's, and it is a theme we have adopted for this edition of **Signpost**.

Inside, you'll find a number of articles that specifically address Young Onset concerns, such as raising a family, resources and support options. Of course, there is also the usual information about upcoming events, personal stories, research updates and advocacy news.

The year ahead is an unwritten page, but one thing is for certain: Parkinson's Victoria is committed to delivering timely, relevant and reliable information, events and resources to assist you, your family and your community.

To enhance and improve support services we are also making working in partnership a priority, as well as developing our programs to include innovative resources and to address areas of need not currently or sufficiently supported, such as advanced care needs and peer support.

We are excited about our growing network of supporters – people who are 'moving to make a difference' in the fight against Parkinson's, by sharing personal stories, fundraising, spreading the word and hosting events.

These people are integral to our own efforts to raise awareness and funds.

World Parkinson's Day and, later in the year, **National Parkinson's Awareness Week**, as well as **Walk in the Park** in August, provide significant opportunities to raise awareness.

Whether you choose to support these or other events throughout the year, or you prefer to "get moving" yourself**, we each have an important role to play if we are serious about making positive and lasting change to improve the lives of people living with Parkinson's and finding (and funding) a cure.

In 2013, Parkinson's Victoria is committed to creating and making the most of every opportunity – will you join with us? Get involved, share your story, start a conversation, invite others to join with you. Together, we will make a difference.

***World Parkinson's Day is celebrated on the birthday of Dr James Parkinson (1755-1824). Dr Parkinson was an English apothecary surgeon, geologist, paleontologist, and political activist. He is most famous for his 1817 work, An Essay on the Shaking Palsy in which he was the first to describe "paralysis agitans", a condition that would later be renamed Parkinson's (disease) by Jean-Martin Charcot.**

****If you have an idea to raise awareness or funds, have an opportunity to share or would like to speak to us about "moving to make a difference" we'd love to hear from you. Please contact Judith: judith@parkinsons-vic.org.au or (03) 9581 8700.**



The PV team (from left): Lesley Speirs, Database Manager, Jo Berthelemy, Health Team Administration Officer, Breanna Wotherspoon, Health Promotion Officer, Joelle Metcalf, Database Officer, Alisha Chand, Client Services Officer, Judith Mooney, Development Manager, Victor McConvey, Parkinson's Nurse Consultant. Not shown: Dianne Rayner, Client Services Officer, Melissa King, Office Manager and Ian Hosking, Finance Officer.

News & Highlights



From the desk of the President

"And, I'd like to thank all the people who work so hard behind the scenes to make this event possible..."

How often during the holiday season do we hear such thanks extended to the people working so hard "behind the scenes"? At the tennis, the golf, the cricket. "I'd like to thank the ball boys and girls, the umpires and referees, the drivers, the car park attendants, the massage therapists, the crowd controllers, my coaching team ... and, of course, the sponsors. And oh yes ... I nearly forgot to thank my family."

Yes, we must never forget *the people behind the scenes*.

Last year, on 2 December, Parkinson's Victoria, hosted its annual **Thanks a Bunch** event where we had the opportunity to publicly acknowledge the people behind the scenes, especially Ambassadors, Support Group leaders and those who assist with administration and events. Every role undertaken is absolutely critical to our everyday work.

Later this year, perhaps YOU will be invited to our annual **Thanks a Bunch** celebration, in appreciation of your contribution. Please contact Parkinson's Victoria if you'd like to volunteer your time or talent to help us.

In the last edition of **Signpost**, I mentioned that I hoped to introduce some new Board members who have volunteered their time and skills to work behind the scenes.

I am pleased now to confirm the appointments of Damien Farrell and Adam Conrad to the Board.

Throughout a distinguished career in the higher education sector, Damien has built a reputation as an innovator and builder of highly regarded adult education institutions.

Outside of his business interests, Damien enjoys a rural lifestyle in Woodend with his young family. A familial connection to Parkinson's triggered Damien's passion to actively support the critical work of Parkinson's Victoria.

With CPA qualifications, Adam Conrad is another highly-credentialed person with a young family who was inspired to stand for the Board by his father who has lived with Parkinson's for over 30 years.

Adam is currently a Senior Manager with the ANZ bank and he has agreed to the role of Treasurer

We welcome both Damien and Adam to the Board, where I am sure their work behind the scenes will be invaluable.

On a personal note to you, our valued members and supporters, I wish you and your families the very best for a happy and healthy 2013. If you would like to share your positive experiences of the year or if we can assist you through any challenges, please remember, we are here for you. We can provide vital support and information, but importantly, there are also many opportunities to share and celebrate. Cards and letters letting us simply know how you feel are always appreciated and a wonderful way to connect. We look forward to hearing from you – and seeing you – through 2013.

Peter Raymond, President

Changes at Parkinson's Victoria

We've recently undergone some staff changes. These have been implemented in order to improve office efficiencies, provide greater support across our team, and prepare for planned growth across our business.

Josephine Berthelemy has moved from *Volunteer Coordinator/Event Assistant to Health Team Administrative Assistant*.



Lesley Speirs (left) and Josephine (Jo) Berthelemy at Walk in the Park.

Jo has done an amazing job in her role working with Volunteers and assisting with our community fundraising events (movie nights, Bunnings BBQs, our Back to the Future event and Theatre nights).

She has grown our volunteer support network by nurturing these valued supporters, implementing processes for managing enquiries, developing volunteering opportunities and working with a number of companies wishing to place staff in volunteering positions.

Jo will be a great asset to the Health Services team, applying her natural skills and experience in administration and her exceptional attention to detail.

Joelle Metcalf has joined our Development team as a part-time *Data Entry Officer*.

Joelle will provide administration and data support to Lesley Speirs, our new Database Manager. With several year's experience working in similar roles for other charities, and with extensive experience with our particular database software program, Joelle will not only be able to 'hit the ground running' but will be the ideal pair of hands to assist Lesley, improving our processes and assisting with donor enquiries.

Lesley Speirs has been with our Development team for 4 years and has recently been promoted to *Database Manager*.

Until now, Lesley had handled all data entry, donations, receipts and memberships single-handedly. The role, which began as a 4-hours/3-day role, quickly expanded to a full time job. In recent months, the number of donations and the general responsibilities of the donor management team have increased sufficiently to necessitate additional resources.

CEO pursues a dream opportunity!

We know you will join with us in wishing Ann Burgess all the best in light of her recent decision to resign from her position as Parkinson's Victoria CEO. Ann has chosen to pursue a long-held ambition to form her own consulting business. Her resignation was effective on Thursday 14 February.

During the two years Ann was with us, she steered us through a major office relocation, two Annual General Meetings, and contributed to some significant 'wins', including partnerships, industry awards, and grants.

Ann headed up our involvement with the National Disability Insurance Scheme (NDIS) and initiated meetings with Medicare Locals. She helped us to meet our government obligations, apply successfully for funding, and promoted our cause through the media.

At a 'bon voyage' morning tea and presentation, President Peter Raymond wished Ann every success in her challenging endeavour, both personally and professionally. He thanked Ann for her contribution to our team and its work on behalf of people living with Parkinson's, their carers, families and friends.

"We will begin immediately the process of recruiting a new CEO. In the meantime, the Staff, together with the Board, remain committed to providing their usual outstanding service and support."



From the desk of the CEO

Recently, the AGE newspaper published an article about a patient advocacy service that charged a fee to advocate on behalf of patients. For more information about any Parkinson's treatments or advice on becoming a better self-advocate, please contact our Health Team.

Over the last few years, many positive moves have been made towards making health care more consumer-focused. But as health care gets more complex, more specialised knowledge is required.

Unfortunately, this lack of knowledge about the system and treatment options can make it difficult for consumers to be in control of their health care decisions.

Sometimes, consumers are not well advised of their options; sometimes they are rushed by busy doctors, nurses and hospital staff to sign paperwork without fully understanding what they are signing or agreeing to.

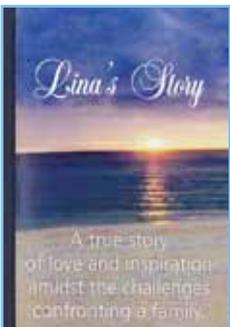
Before genuinely informed consent can be given, consumers should be able to understand their options, have time and mental space to make a decision and not feel under pressure.

Make sure you take the time to understand the proposed treatment or ask a few more questions to get extra information. Remember, **it's your life, your body and your money.**

Older consumers are sometimes worried that asking questions will turn doctors and nurses against them for "being difficult", so they avoid asking for information to which they are entitled.

Unless it is an emergency situation, take the time you need and obtain the information you want. Often people sign forms agreeing to treatment because they feel that it is the only option.

Ann Burgess, Chief Executive Officer



A story of life, love and learning...

My name is Lina Ricci and I am "living with Parkinson's".

Since the passing of my husband, I felt compelled to tell my story.

"Lina's Story" describes my journey in life as an only child of New Australian parents, growing up in the sixties, and being challenged by a strict Italian upbringing.

Most of all, my book is a story of love defying all of

life's challenges that were handed to us.

I have dedicated my book to my late husband, Mario Ricci. His dignity and integrity when confronted with several life-threatening encounters are to be admired.

My story is a story of inspiration and determination.

Lina has generously donated 50 copies of her book to Parkinson's Victoria. 100% of proceeds will help fund our support services, and on Lina's request, will help fund vital research into finding a cure. To obtain a copy (\$10, includes postage), please contact our office.

Thank you Lina, for sharing your story and your generous support!

Children & Parkinson's



Coming to terms with a diagnosis of Parkinson's can be hard enough for adults, let alone children. If you have been diagnosed with Parkinson's and have young children or teenagers (or are considering having children) there will be additional issues to consider that will affect the whole family. These might include how to explain Parkinson's to your child and how to manage family life around your illness. BREANNA WOTHERSPOON, from our Health Team, offers some insight.

Explaining Parkinson's to young children and teenagers

It can be many months (or even years) between first noticing symptoms and being accurately diagnosed. Often children will have picked up on the fact that something is wrong - even if they're not quite sure what - so it is important to be open and honest.

- ◆ Remember that talking to children is an ongoing conversation, not a one-off. Try not to overload them by attempting to explain everything at once. Encourage them to ask questions and share their concerns at any stage, now or later.
- ◆ Be specific and clear in describing the condition, and clarify some of the common terms, such as tremor, posture and fatigue, in ways they can understand.
- ◆ Don't assume anything – you may know that Parkinson's isn't contagious, but do they?
- ◆ Explain the symptoms you experience, particularly those aspects of your Parkinson's that are likely to affect them. For example, facial masking may make you look uninterested in

what they're saying, but actually you do like to hear how their day was.

It is important for children to understand that these things are a result of Parkinson's, and not something that they have done.

- ◆ Reassure your children that you are the same person you have always been – you are still their parent, and you are still there for them. But also be specific about what you need. For example: "Parkinson's makes it difficult for me to concentrate on more than one thing at a time, so I need you to take it in turns speaking and not talk over each other".

Children may have a range of responses when they learn a parent (or grandparent) has Parkinson's. These may include grief, fear, rejection, anxiety and embarrassment. Let them know it's OK to experience these emotions, and work with them to help them manage their feelings.

Remember too that children will often take their cues from you – so the more open and accepting you are of your condition, the more open and accepting they will be. If you are struggling with depression and anxiety, which can often be associated with Parkinson's, make sure you address these challenging issues, for your own benefit and for the benefit of your children.

The positive side

While it is understandable to be worried about the negative impact that Parkinson's may have on your children, keep in mind that there can be some positive effects as well.

Through these sorts of life experiences children can become more responsible, independent, resilient, patient, mature and less self-centred.

Parkinson's and parenting: A juggling act

Being a parent is daunting at the best of times, but especially if you are dealing with the additional load of living with Parkinson's. However, coping with the exhausting schedule and everlasting energy of children while also managing Parkinson's can be done!

- ◆ *Don't try to do it on your own*

Don't be afraid to ask for help. You'll probably find that many of your friends and family would love to lend a hand, but aren't sure what would be of most benefit. Friends might be happy to collect your kids from school when they pick up their own. Your parents may love the

idea of babysitting while you attend specialist appointments – after all it means they get to spend more time with their grandkids! Even for two healthy parents, building a support network of friends, relatives, neighbours, babysitters and so on, is extremely helpful.

- ◆ *Prioritise: Devote your energy to what matters most*

It is important to stay involved in family activities and tasks as much as possible, but don't overdo it. Prioritise tasks and activities and give your attention to "must-do" items, while less critical matters can be ignored, delayed, or delegated to others.

You may have volunteered for canteen duty at your child's school in the past, but now find it leaves you too tired to spend quality time with your children after school. You may ask another parent to take your child to and from football training, so that you have enough energy to attend their football match on the weekend.

Decide what events, activities and experiences are most valuable to you, and make them the focus of your time and energy.

- ◆ *Be realistic about your abilities*

Have a pragmatic look at all the things you do around the house and within the family, and work out if they need to be done by you. For instance, could your children make their own beds? As well as freeing you up, this will encourage your children to become responsible. Can your partner make school lunches the night before? This will relieve you from having to multi-task (which can be difficult for people with Parkinson's) in the mornings, which could make it easier for you to handle the school run. Can you access assistance with housework (either through your local council or privately)? You may be able to do the ironing, but is that an ideal use of your time?

Restructure your day around your 'on/off times'. For example, volunteering for afternoon pickups from school, rather than early morning carpools (if the effects of your medications are more predictable later in the day), can allow you to be an active and participating parent within your own abilities.

- ◆ *Don't be too hard on yourself*

This is a trap that any parent risks falling into. In our quest to be 'good parents' and do the best

for our children we can forget that we are not perfect, nor do we have to be. It's ok to have a bad day, and it's ok if everything doesn't get done. You are doing your best, and that is all any parent can do.

Having children after diagnosis

Parkinson's itself does not affect a woman's ability to fall pregnant, or the ability to carry a baby to full term. It does not increase the likelihood of physical or cognitive birth defects. However, for a woman diagnosed with Parkinson's who wishes to become pregnant there are additional considerations.

So far there has not been a lot of research into the potential effects that Parkinson's medications may have on an unborn child. For this reason, many doctors recommend reducing the dosage of medications during pregnancy. Of course, this will make Parkinson's symptoms more challenging. Additional, hormonal changes and general stress related to pregnancy may further exacerbate symptoms.

In these circumstances, general principles of living well – looking after yourself, eating and exercising appropriately, and applying stress management techniques - can help you to maintain control and comfort.

If you are contemplating having children after being diagnosed, it is important to discuss the matter thoroughly with your specialist and with your loved ones.

Recently Diagnosed Seminar

The **Parkinson's Victoria Recently Diagnosed Seminar** is ideal for those diagnosed in the past 5 years, as well as family members and friends. This half-day event is an excellent opportunity to learn more about living with the condition and strategies on living well with Parkinson's. Experts in a range of fields will provide information and advice, and attendees will learn about support services and have the chance to meet others.

This event will take place in November, however, the location and date are not yet confirmed. For more information on this event, register your interest by contacting our Health Team.

Personal Dopa-meanings

We are pleased to share an insight into the personal journey of some of our readers and members. Personal Dopa-meanings is compiled by PETER NASSAU, a volunteer of Parkinson's Victoria.

My Story - Gay Giovanetti



Gay Giovanetti with husband Bruce.

It began as a slight tremble in my right hand, which for a nurse was troubling. Whenever I picked something up, the tremble would stop. But when my hand was at rest, it would start shaking again.

Seven years later, I am living with Parkinson's and working as a women's health nurse at Goulburn Valley Health.

I do not have to do any task that demands fine motor skills. Parkinson's doesn't affect my work at the moment. I go on with my working life, stay positive and exercise regularly. But my diagnosis five years ago has meant a change in my outlook on life. For a start, travel plans with my husband, Bruce have been brought forward. And, things we had planned for retirement, we'll do now rather than wait. The future is unknown.

It took two long years to find out why my hand trembled. I went to my GP and then it was a slow process of doctor's visits and tests. Multiple sclerosis and a brain tumour were both ruled out. The only diagnosis left was Parkinson's. I was devastated, in shock. It was the 'shaky old man's disease' I thought. I spent a week crying. But then I rallied and accepted my life as it was.

It wasn't a death sentence. At least I know what I have. Many people don't. The fact that I have Parkinson's has made me more aware of my own health. I walk and do yoga. It makes my body stronger. If I sit for too long, I get stiff. Bruce is realistic about my future with an incurable disease. He knows that it is not going to get any better.

We are thankful that so far the progress of my Parkinson's has been slow. Friends with Parkinson's have progressed more quickly. Everyone is different. Everyone has a different story to tell.

In 2012, for the first time, Bruce and I joined **Walk in the Park** to help raise much needed funds for research into Parkinson's. We joined hundreds of other families affected by the debilitating disease.

My story - Norman Williams

I am 74, and was diagnosed with Parkinson's 8 years ago after I noted that my hands were shaking.

I had already been in retirement for about 2 years, having enjoyed careers firstly as a fitter and turner, then as a Marine Engineer and underwater diver. All these skills came together on ships, which are simply floating cities.

The training and skill level took many years to attain. My theoretical training took place at RMIT, and then I went away to sea to undertake the practical training. During this period I also spent time working at the naval dockyard in Williamstown.

Cyclones at sea are the scariest things imaginable. I have experienced five and each one was awfully frightening.

I now live in a retirement village in Kilsyth and consequently, I have social contact with the others in the village. I play tennis and attend exercise sessions on a regular basis.

Sadly, I am the subject of derision and emotional pain as relatives refuse to acknowledge that I have Parkinson's. This obviously is the cause of much sadness as I battle the disease without family support. My symptoms include shaking, sleep problems and constipation.

I am a member of the Ringwood Parkinson's Support Group and feel comforted by sharing my thoughts and feelings with the other members as I know that they understand my situation. The Support Group also provides me with useful information about living with Parkinson's and related topics.

I look after myself (am pretty self-sufficient) and hope that my condition does not deteriorate too quickly over the coming years.

If you'd like to share your story, email Judith@parkinsons-vic.org.au or phone our office. Submit your story (word limit 500; personal photo to accompany your piece welcome) or Peter can work with you to help you write your piece. The topic is up to you! Please note submissions may be edited for style and clarity.

Parkinson's Victoria has recently updated and reorganised our resource library members and the general public are welcome to visit!

The library contains books and DVDs on a range of topics – from personal biographies to advice on caring for a loved one or dealing with depression. There is also information on financial issues for people living with a chronic illness, contacts for the purchase of adaptive clothing, Parkinson's Fact Sheets in 11 community languages, and much, much more.

Members can borrow books and DVDs for free, though the general public are welcome to pop in and check things out. All brochures, fact sheets and other information resources are free.

To request a loan from our resource library, contact our Health Team and we can post the item out to you. Alternatively, give us a call for a chat or make a time to come in and have a look at what is available.

Young Onset resources

ALISHA CHAND from our Health Team looked into some great resources for those diagnosed with Young Onset, and their family and friends.

There are many books and online resources available which address the unique challenges faced by the Young Onset community. Below is a list of some of these resources:

Online resources:

Between personal and health professional blogs, discussion boards and chat rooms, the Internet provides an excellent forum for people all over the world to connect. Many of these are mediated by people with Young Onset Parkinson's. There are blogs describing the day-to-day challenges and triumphs faced by those diagnosed; discussion boards where people can come together to ask each other about the particular symptoms and issues they are faced with; and chat rooms providing advice and an emotional support network.

Some suggested sites

♦ **Young @ Park:**

Young @ Park, or "Y@P", is a Victorian-based social group especially for people living with Young Onset Parkinson's and their partners. The group also has a website with a message board and a video chat room where people from all backgrounds can come together, ask questions, provide support to each other and meet individuals they may not otherwise. <http://yap.org.au>

♦ **Uniquely Young Onset: A Different Perspective For a Different Population**

Run through the *American Parkinson's Disease Association National Young Onset Centre*, this blog is written by Dr Paul Short, a psychologist specialising in neuropsychology.

Dr Short writes about many different topics and issues which those living with Young Onset Parkinson's may face day-to-day, including raising a family, relationships, parenting, independence,

employment, disclosure, dating and many other topics. <http://www.youngparkinsons.org/blog>

♦ **Karyn's Journey with DBS:**

Karyn Spielberg, who established and until recently coordinated the Young @ Park group, underwent deep brain stimulation surgery in August 2011. In the days leading up to the surgery and since, Karyn provides an honest, and often humorous insight into her journey through it all.

<http://karynsjourneywithdbs.blogspot.com.au>

Books:

Lucky Man: A Memoir, Michael J. Fox, 2003

In this memoir, Fox writes about his early life, his rise to fame as a television and movie actor, his Parkinson's diagnosis and the first 10 years of living with Parkinson's.

Fox has since become one of the world's most active campaigners in the search for a cure.

Always Looking Up: The Adventures of an Incurable Optimist, Michael J. Fox, 2009

Fifteen years on from his diagnosis, Fox writes about the personal philosophies which have carried him through his "new life" with Parkinson's.

When Parkinson's Strikes Early: Voices, Choices, Resources and Treatment, Barbara Blake-Krebs & Linda Herman, 2001

This book addresses the personal and social impact of a diagnosis of Young (Early) Onset Parkinson's in the midst of an active life and career.

The collection of personal stories, quotes and poems covers symptoms, side effects of medication, support networks, and surgery options. It also explores the emotional and social struggles, and highlights the need for people to seek help.

Living With the Invisible Monster: A Young Onset Parkinson's Disease Patient's Perspective on Living a New Life, Kathleen E. Webster, 2004

An autobiography of a young woman diagnosed with Parkinson's at the age of 33 and having to face the challenges of everyday life while living with the 'invisible monster' of Parkinson's.

This is a story of self-empowerment and rising to meet the challenges of relationships, working, marriage and raising a family - all while living with Parkinson's.

Defying Despair: How One Man is Winning His Battle with Young Onset Parkinson's Disease, Anthony Scelta Jr., 2003

Despite a diagnosis before he was 25, Anthony Scelta, a strength and conditioning specialist, chose to continue his career in the fitness industry.

By the age of 33 he had hit rock bottom, struggling to even do a push up. Instead of giving up, Anthony created a mind-body strategy to conquer some of the challenges of living with Parkinson's. He has gone on to share his strategy with others, helping and inspiring those facing similar situations.

Our community

With your help, we can continue to reduce the impact of Parkinson's through our service and support programs, our information Help Line and community events and information. We can also continue to create ways for you and your family to connect with others. Our social events and fundraising activities are a great way to come together, to show your support for a loved one, make a contribution, catch up with friends and help in the fight against Parkinson's.

Save the dates!

Grab a pen and pop these important dates in your diary right now!

- ◆ World Parkinson's Day – Thursday 11 April. National theme: Young Onset Parkinson's. Keep an eye on our website for more information and how you can get involved.
- ◆ Walk in the Park – Federation Square, Sunday 25 August (registrations open soon!)
- ◆ Parkinson's Awareness Week – 2 - 6 September. Our theme will be 'communication'. Stay tuned for more details!

Art exhibition

"Magnificent," "beautiful," "inspirational" and "O.M.G. cool!" are just some of the remarks already recorded in the visitors' book on display during *Painting with Parkinson's* exhibitions. And, an upcoming national exhibition of art works by people living with Parkinson's is sure to inspire many more comments like these.

Art is increasingly recognised as a means of making the most of life with Parkinson's.

Participants of *Painting with Parkinson's* groups across Australia attest to the groups' value in reducing the severity of symptoms, improving self esteem and overcoming loneliness and isolation.

Victorian *Painting with Parkinson's* founder, Anne Aitkin, swears that Parkinson's can bring out one's inner creativity: "It's the colours! People with Parkinson's develop an amazing sense of colour. It's as if the movement part of the brain slows down and the creative part takes off".

You can experience the amazing creativity of people with Parkinson's across Australia by visiting "**A Walk through Our Art**" at Kingston Arts Centre, 979 Nepean Hwy Moorabbin, during March and April.

The exhibition will be hosted by Parkinson's Victoria and supported by the Australian Government Department of Families, Housing Community Services and Indigenous Affairs. Most of the art works will be for sale and proceeds will go to the individual artists.

And some event updates:

- ◆ Our second "**Back to the Future**" movie trilogy at St Kilda's Astor Theatre in December was attended by almost 500 people and raised just under \$10,000.
- ◆ Peridot Theatre's production "**Me & Jezebel**" in November was a terrific night out, with 21 guests attending our charity preview. A total of \$413 was raised from ticket sales.
- ◆ Our charity screening of the latest Bond movie "**Skyfall**" at the Dendy cinema, also in November and with 42 guests, raised \$610. Special thanks to our generous supporters who donated raffle prizes: *Ce Soir Lingerie*, *Wrapt*, and *Thesaurus Books*.
- ◆ Our January screening of the spectacular "**Les Miserables**", also at the Dendy, was attended by 20 people. While this event only raised \$143 it was our first ever 'day time movie event' and it was great to see some new faces!

So come along to show your support for *Painting with Parkinson's*, and don't forget to sign the visitors' book!

The exhibition will open on Thursday 28 March and run until Tuesday 16 April, with a special event on Thursday 11 April, to celebrate World Parkinson's Day.

Opening hours for the centre are Monday – Friday 9am to 5pm, and Saturday 12.30 to 5.30, excluding public holidays.

For more information, including further details of the opening event and World Parkinson's Day event, visit the Parkinson's Victoria website.

Coming up...

We are currently planning our 2013 calendar of fun and social events. Why not register to receive our new monthly e-newsletter and stay up to date with all the news – education events, new initiatives, social events and fundraising! Simply email info@parkinsons-vic.org.au and write **e-news** in the subject line. You can also keep an eye on our website, www.parkinsonsvic.org.au

Looking for volunteers

We have secured a spot for a sausage sizzle at Bunnings Mentone on Saturday 10 August 2013 and at Moorabbin on Sunday 23 June. If you'd like to help out by volunteering, please email info@parkinsons-vic.org.au (write **BBQ** in the subject line).

Support Services

National Disability Insurance Scheme - update 33

This update from Jenny Macklin, Bill Shorten and Jan McLucas, was provided to the general public via email on 12 February, 2013.

"Dear Friends

The Prime Minister and Minister for Workplace Relations announced this week that the Australian Government will amend the Fair Work Act to provide greater flexibility for a number of workers, including workers with disability and their careers.

The changes will give people with disability and their carers the right to request flexible working arrangements.

Currently, the right to request flexible work hours is restricted to parents with responsibility for the care of a child under school age or a child with disability aged under 18.

The change will extend the right to request flexible work arrangements to include:

- employees with disability;
- employees who are parents, or have responsibility for care of a child of school age;
- workers with other caring responsibilities;
- mature age employees; and
- workers experiencing family violence and workers providing personal care, support and assistance to a member of their immediate family or member of their household because they are experiencing family violence.

These changes are in line with a range of submissions to the recent review of the Fair Work Act, including from the Australian Human Rights Commission.

We are making the changes because we know that some people with disability only need a little bit of consideration, like more flexible working hours, to make a real and sustained contribution in the workplace.

As a Government, we are committed to helping all Australians reach their full potential, and participate in work, education and community life.

That's why a Labor Government first introduced the right to request flexible work arrangements and it is why this Labor Government is extending them now.

That's also why we are working hard to design the National Disability Insurance Scheme (NDIS), which will help change the lives of thousands of Australians with disability, their families and carers.

This historic reform will give people with disability more choice and control – and more flexibility – over the care and support they receive.

So they can make their own decisions about how to live their life and reach their goals.

Share your views on the NDIS at www.ndis.gov.au/ (**follow the link to the "Your Say Forum"**)

If you want to know more about the NDIS, you can read the factsheets on the NDIS website, which cover important information about the scheme.

Continuity of care for Bentleigh East patients

For the past two years, Professor Robert Iansek, OAM, has been operating his private practice within the larger **Neurology Network Melbourne** in Bentleigh and St Kilda Road.

Professor Iansek recently decided to retire from private practice and has entrusted the care of his patients to other Parkinson's specialist doctors at the same practice, who have experience with deep brain stimulation surgery, Duodopa, Apomine and in-patient rehabilitation.

As part of this evolution, all patients of Professor Iansek's have been referred on to Dr Will Lee, Dr Kelly Bertram or Dr David Williams for ongoing care. The process should be seamless, as all existing medical notes are shared within the practice, and Professor Iansek has specially referred each of his existing patients.

The Bentleigh East practice will close at the end of February, and future appointments will be available at Knox Private, St Kilda Road or Ballarat. Sue Varley, the Network's Clinical Nurse Consultant, will be available for discussion if required.

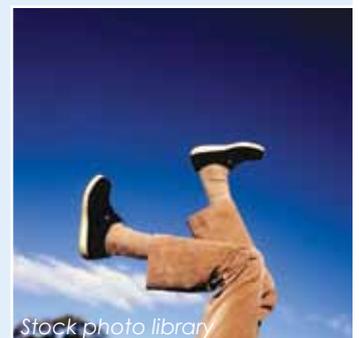
The team at Neurology Network Melbourne, including Dr King, will be pleased to help facilitate this important transfer of care, and make it as easy as possible for patients and their families. Please call the Network team if you have questions or concerns: (03) 9500 8366.

WORLD PARKINSON'S DAY

Thursday 11 April

Join us for Tai Chi at Federation Square as we launch an exciting new resource! Free and all welcome.

Keep an eye on our website for more information, coming soon!



WALK IN THE PARK

Sunday 25 August

Who will you walk for?

**Registrations open soon:
www.parkinsonswalk.com.au**

Medication update

Disappointing results from PSP drug trial

Allon Therapeutics, Inc. recently announced the results of the study on davunetide - a potential treatment for Progressive Supranuclear Palsy (PSP).

Analysis of the study results has shown that the drug is ineffective in treating PSP.

The trial was conducted at leading medical institutions in the United States, Canada, the United Kingdom, France, Germany and Australia. (Details found at clinicaltrials.gov)

Allon President and CEO Gordon McCauley said, "This is a very sad day for patients, family members, and caregivers living with PSP because so many of them held out great hope that these results would define a drug that has an impact on their disease. Sadly these results have not fulfilled these hopes but we are deeply grateful to them for their unrelenting support of this study. While this outcome is not at all what we anticipated, we do believe that we designed the correct study and executed that study well."

For more information visit: <http://www.allontherapeutics.com/2012/12/allon-announces-ppsp-clinical-trial-results/>

(Note: Australia was proud to be one of the top recruiting sites (worldwide) for this study, which included screening and randomization numbers. The team comprised Associate Professor David Williams, Dr Kelly Bertram, Dr Will Lee and nurse Sue Varley from the Neuroscience Department at the Alfred Hospital in Melbourne. Logistically and practically the study was an enormous challenge for a relatively small team, with each visit lasting anywhere between 2 and 5 hours and a total of eight visits over about 13 months. The participation and involvement of this small team has to be commended and congratulated.)

Azilect®, anti-depressants and...cheese!

A recent concern coming through our health information line and discussed in online Parkinson's forums has been regarding Azilect® and a rare interaction with some food groups and also with a common anti-depressant medication.

Azilect®, a brand name for rasagline tablets, is the latest medication to become available in Australia to assist in managing the symptoms of Parkinson's.

Azilect® is a Monoamine oxidase inhibitor (MAOI-B) which acts to alter the way dopamine (the brain's chemical messenger) is metabolised or broken down. This makes it a useful drug for those living with Parkinson's, where dopamine production reduces significantly.

While it is considered to be a safe drug with minimal side effects, there have been some interactions documented between the MAOI-B class of drug which Azilect® is from and some foods and commonly used anti-depressants (the latter from the class of selective serotonin re-uptake inhibitors referred to as SSRI/SNRI).

Food-interaction: When tyramine-rich foods* are ingested in conjunction with MAOI-B medications (such as Azilect®), the interaction may cause unstable blood pressure, or severe hypertension.

(*In foods, tyramine is often produced during fermentation or decay, so tyramine-rich foods include cheese, pickled products, sour cream, and even teriyaki sauce and miso soup, among others).

Anti-depressant interaction: The interaction between MAOI-B and anti-depressants in the SNRI/SSRI category is known as *Serotonin Syndrome*. It can include increased tremor, hypertension, sudden onset of confusion and diarrhoea. The reaction is rare and hard to diagnose, and can vary from being mild to fatal.

While this might sound very dramatic, Lundbeck Pharmaceuticals, the company marketing Azilect® in Australia, have not identified any adverse reactions in their studies. They do however note that the potential exists for adverse reactions and this information is included in the *Consumer Medical Information* accompanying the medication.

Currently there is little information regarding these interactions and both Lundbeck and Parkinson's Victoria recommend you discuss any concerns with your prescribing neurologist or physician.

Pain medication now on PBS

While many people would not immediately associate pain with Parkinson's, it is certainly an issue that can have significant impact.

While rare, some people living with Parkinson's experience nerve pain, which can be a burning or sharp tingling sensation often felt in a distinct area of the body (e.g. *Burning Mouth Syndrome*).

In Parkinson's this sensation may fluctuate in relation to the ingestion of medications.

Lyrica®, a medication known to be effective in managing nerve pain, is safe to take with Parkinson's medication. From March it will be available through the *Pharmaceutical Benefits Scheme* (PBS) at a subsidised rate, making it more accessible and affordable for people experiencing this condition.

Neurological Alliance Australia chairperson Carol Birks said, "Many people living with neurological diseases experience the debilitating effects of chronic nerve pain. The subsidy means these people will be able to afford a clinically-proven treatment".

"Accessible treatments are crucial in providing people with chronic neurological conditions like MS and Parkinson's disease the opportunity to remain employed for longer and to stay active in their communities," said Ms Birks.

Neurological Alliance Australia encourages people with neurological conditions to see their treating neurologist for specialist medical advice on the best treatment available for them.

For more information about pain and Parkinson's contact our Health Team. If you have specific concerns, please speak with your treating doctor.

Symptom Management

Benefits of exercise

Another research study has shown the benefits of exercise in helping to manage some of the symptoms of Parkinson's.

To examine the effects of various forms of exercise on gait speed, strength, and fitness in patients with Parkinson's, researchers in the US performed a prospective, single-blind trial.

They randomized 67 patients to one of three exercise treatment arms, performed three times a week for 3 months:

- ♦ lower-intensity treadmill training,
- ♦ higher-intensity treadmill training,
- ♦ or stretching plus resistance exercises.

Higher-intensity training sessions lasted 30 minutes, and patients had to achieve 70 to 80 per cent of their heart-rate reserve. Lower-intensity training sessions lasted 50 minutes, but patients only had to reach 40 to 50 per cent of their heart-rate reserve.

The stretching and resistance exercises were low intensity and included use of three resistance machines in a gym setting. The primary outcome was improvement in gait speed (on the 6-minute walk); secondary outcomes were cardiovascular fitness (peak oxygen consumption per unit time) and muscle strength (1-repetition maximum strength).

All three interventions significantly improved gait speed. Interestingly however, lower-intensity training improved gait speed to the greatest degree (by 12 per cent, vs. 9 per cent with stretching/resistance training and 6 per cent with higher-intensity exercise). Both treadmill groups had improved cardiovascular fitness variables, whereas the stretching and resistance training group had improved muscle strength and improved scores on the *Unified Parkinson's Disease Rating Scale (UPDRS)* motor subscale.

Comment: These findings add to an expanding literature revealing the benefits of exercise for patients with Parkinson's. Experiments in animals previously revealed that exercise up-regulates chemicals that may be important to the Parkinson's brain, although the mechanisms underpinning these positive effects remain unknown.

These results may need to be reproduced in a larger clinical trial. The benefits in the stretching and resistance arm might have been greater with a more intensive intervention. Also, it is unclear how much gait speed and fitness measures will translate into quality-of-life improvements. The UPDRS motor scores did not improve for treadmill training, as they

did in other studies, calling into question whether the benefits of exercise occur more in non-motor domains, or whether this lack of improvement was specific to that intervention.

All patients improved in this study, but the results revealed important differences between the therapies that may be helpful in tailoring regimens in clinical practice.

Aerobic exercise, stretching, and resistance training may all be used and may all be potentially useful in a single patient. How to administer exercise, in what dose, and what types of exercise to use remain to be clarified by future studies.

Source: *More Evidence That Exercise Is Beneficial in Parkinson Disease*, Michael S. Okun, MD (This article appeared in *Journal Watch Neurology*, November 20, 2012. www.jwatch.org)

Keep Moving!



A new Parkinson's Victoria resource, ***Keep Moving!*** An exercise guide for people living with Parkinson's will be available soon.

This DVD, which can be watched in the comfort and privacy of your own home, provides practical exercises and tips to address some of the mobility and physical challenges of living with Parkinson's. The exercises, which include a brief Tai Chi program, are underpinned by expert advice from a Movement Disorder physiotherapist.

For a copy of the DVD (\$10, includes postage and handling) please contact our Health Team.

Parkinson's Victoria advises that prior to commencing any exercise regime, you should consult your doctor.

Access, Advocacy & Assistance

An update from Canberra

The following is an update from Daryl Smeaton, CEO Parkinson's Australia.

The holiday season started later than usual this year for myself and my state CEO counterparts, as we were kept busy developing applications to the Australian Government for scarce funds to enable us to better support our members.

About 10 per cent of people with Parkinson's are currently in residential aged care and their needs are often complex. Parkinson's Australia – and our state counterparts – want to develop and deliver training for staff working in aged care to help them provide a better service for people with Parkinson's in their care.

Also, following our 2013 AGM, the Parkinson's Australia 2011/2012 Annual Report is now available online at www.parkinsons.org.au

The New Year has started briskly and I hope you survived the very hot weather. I also hope that no one was badly affected by the bushfires or recent floods.

This year the first stages of the National Disability Insurance Scheme (NDIS) commence and, in the longer term, this national initiative, which has bi-partisan political support, will provide greater certainty of support for all Australians with a disability.

Finally, a reminder that the 3rd World Parkinson Congress is taking place in Montreal, Canada from 1 to 4 October 2013. It would be wonderful for Australia to have a large presence at this important opportunity to raise the awareness of Parkinson's worldwide. www.worldpdcongress.org

Daryl Smeaton

This section aims to inform and empower you to play an active part in managing your Parkinson's – or assisting a loved one – by providing information about your rights, assistance schemes and subsidies, as well as aids and support, and new initiatives.

Mobility Centre closes

The Mobility Centre, which was located in Federation Square's car park, has recently closed. Members of the public and city travellers seeking mobility equipment and access advice should contact Travellers Aid, located at Flinders Street and Southern Cross stations: 03 9610 2030. To book online <http://www.travellersaid.org.au/services/request-equipment>

Helping hands

We know that if you live in regional Victoria it can be especially taxing having to travel to Melbourne for neurology or other Parkinson's appointments. The *Medical Companion Service* can make your time in Melbourne just that little bit easier.

Approximately 50,000 regional Victorians travel to Melbourne each year for medical treatment. Many rely on others to drive or accompany them, and when assistance is not available, they risk their health by delaying their appointments or not going at all.

The trained volunteers from the **Medical Companion Service** meet medical travellers and accompany them by public transport to and from their appointment in central Melbourne. They assist people who are able to travel independently but who are unfamiliar with Melbourne or who feel anxious using public transport alone.

The service is:

- ♦ Free
- ♦ Available to regional and metropolitan travellers

- ♦ Can be booked by calling 1300 700 399 (Must be booked in advance and a minimum of 48-hours' notice is required)

Travellers must purchase their own public transport tickets, and the volunteer 'companion' costs are covered by the service.

Source: www.travellersaid.org.au

Going digital to improve health outcomes

The Government's new '**eHealth**' initiative is based on the premise that technology already permeates every part of our daily lives with significant benefits. Applying this technology to our healthcare system is designed to improve the way health information is collected and shared, resulting in significant benefits to the consumer and improving the effectiveness and efficiency of the healthcare system and the consumer experience.

eHealth aims to introduce electronic services to improve upon some paper-based systems.

eHealth will give you and your healthcare providers (from your GP to your hospital and specialists) access to your health summary information electronically. Consolidating your health information in this way has enormous scope for improving the quality of your personal healthcare.

Source:

<http://www.ehealthinfo.gov.au/what-is-ehealth>
and an e-update from Dr Mukesh C Haikerwal AO, General Practitioner, Chair of the Council of the World Medical Association and Head of Clinical Leadership, Stakeholder Management & Clinical Safety, National E-Health Transition Authority (NEHTA)

Access, Advocacy & Assistance

Want to know more about eHealth?

There are also lots of websites providing information about eHealth. If you are unable to access the following websites, call our Health Team who can assist with information and advice, not to mention reassurance and peace of mind.

- ◆ www.ncbi.nlm.nih.gov/books
- you can download a free health e-book
- ◆ www.ehealth.gov.au
- access information about the eHealth card
- ◆ www.patientopinion.org.au
- where patients share their stories

- ◆ www.healthissuescentre.org.au
- general information
- ◆ www.chf.org.au
- a Consumers Health Forum
- ◆ www.hconc.org.au
- Health Consumers Council
- ◆ www.healthbeatblog.com
- A blog from America with practical advice
- ◆ www.healthtalkonline.org
- general patient information

You can also speak with our team about the new National Disability Insurance Scheme (NDIS) and how it might affect you.

Carers Corner – Role reversal

As Parkinson's progresses and the impact of symptoms on day-to-day life increases, it is likely that the roles and duties of individual family members will be adapted. BREANNA WOTHERSPOON from our Health Team offers some advice on caring for children who take on a caring role.

In general, children are keen to help. Being able to assist a parent with Parkinson's can give children a strong sense of value and allow them to feel more in control. These positive experiences may help them to process what you are going through and how they feel. However, it is important to be aware of how much you might be depending on them, and try not to overburden them with responsibilities.

Talk to them – again and again

Discussing Parkinson's with your children is not a one-off event, but an ongoing dialogue between you and your child. As symptoms develop and progress, you will need to talk to children about what is happening.

It may be a good idea to have regular get-togethers as a family, to check how everyone is feeling and managing. Reassure them that you are still there for them in many ways, even if you need their help with some things. As your child gets older, learning more and becoming more aware of what's happening, it is likely that you will need to revisit particular topics. For example, biology class may raise issues around whether Parkinson's is hereditary.

Keep children active outside the home

Living with a chronic illness can become a major focus for the person diagnosed, as well as for those they are closest to. It is important to make sure that a child's life is not 'all about Parkinson's', and that they are active outside the home.

Encourage children to participate in social and sporting activities so that they get a break from thinking about Parkinson's and can make the most of 'being a kid'.

Make the most of available resources

Reinforce to your children that they can discuss with you any questions or concerns they may have, but also make them aware of other sources of information and support that are available.

Providing them with age-appropriate, reliable resources can give them the tools to learn more about Parkinson's on their own.

The US website **Kids Health** explains many health problems, including 'Health Problems of Grown-Ups' in ways that are easy for adolescents to understand (For an explanation of Parkinson's, go to <http://kidshealth.org/kid/grownup/conditions/parkinson.html>; older teenagers may like to have a look at the Parkinson's Victoria website).

There are also a few books in the Parkinson's Victoria library which explain Parkinson's in ways that young children can understand, including **'I'll hold your hand so you won't fall'** by Rasheda Ali (daughter of Muhammad Ali). Copies are also available for sale (\$10 plus postage).

Children may find it difficult to identify how they are feeling, or know how to respond to their emotions. Sometimes they might need someone neutral to talk to, as they don't want to upset the people they are close to. Individual or family therapy might be an option if a child seems to be struggling, or if Parkinson's is affecting the relationships of family members. This may be a therapist, a friend of the family, or a children's service. **Kids Helpline** is a free Australian telephone and online counselling service specifically for young people aged between 5 and 25 (1800 551 800 or www.kidshelp.com.au).

Latest research updates

A futuristic approach to health

In a recent test of 76,000 urine screens conducted by Quest Diagnostics, 63 per cent of the patients tested did not take their medications as directed. But innovative technology to assist is now underway in the US with the Food and Drug Administration (FDA) recently approving tiny digestible microchips that can be added to pills, allowing providers to monitor whether they take their medicine.

The microchips previously had been allowed only in placebos to determine whether they worked and posed no danger. California-based Proteus Digital Health plans to market the chips to drug manufacturers.

The chips, about the size of a grain of sand, are made of copper, magnesium and silicon. They react with stomach juices, then send a signal to a skin patch, which then relays it to a smartphone, then on to the doctor's office. Afterward, the chip dissolves and passes through the digestive system normally.

The chips are aimed more toward people taking medications for chronic conditions than those on a short round of antibiotics. They don't however provide any information on how well pills are absorbed or whether they help.

Continuous monitoring holds promise to alert physicians immediately if there is a problem, though plenty of people, no doubt, will find it just too Big Brother.

"The point is not for doctors to castigate people, but to understand how people are responding to their treatments," George Savage, Proteus co-founder and chief medical officer, told Nature.com. "This way doctors can prescribe a different dose or a different medicine if they learn that it's not being taken appropriately."

Source: <http://www.fiercehealthit.com>

This article appeared online on 02/08/2012. Author: Susan D. Hall

Raise your voice

The **Parkinson's Voice Initiative** aims to record 10,000 voices across the world in order to build a system to screen for and monitor the symptoms of Parkinson's.

Current objective symptom tests for Parkinson's are expensive, time-consuming, and logistically difficult, so mostly they are not done outside trials. Those behind the voice recognition initiative believe that subtle changes to the voice, including tremor, breathiness and weakness (detected by specialised computer algorithms) can be used to diagnose Parkinson's: "voice is affected as much by Parkinson's as limb movements. This initiative aims to

provide technology to test for symptoms using voice recordings alone".

"This could enable some radical breakthroughs, because voice-based tests are as accurate as clinical tests, but additionally, they can be administered remotely, and patients can do the tests themselves. Also, they are high speed (take less than 30 seconds), and are ultra-low cost (they don't involve expert staff time). So, they are massively scalable."

The initiative is based on adults (those diagnosed with Parkinson's and 'healthy' individuals) providing 'voice information' via an anonymous, three-minute phone call.

It is important to stress that the initiative is for scientific research only and participating will not result in a diagnosis or clinical information, although participants can register for feedback on their voice recordings.

Source: <http://www.parkinsonsvoice.org>

NB: The initiative does not currently allow for Australian participation but those interested are able to lodge an expression of interest through the online 'feedback' page.

Stem cell advance

Pig cells will be transplanted into the brains of New Zealanders with Parkinson's as part of an experimental treatment of the neurological disorder. Kiwi scientists will undertake the clinical trial after Living Cell Technologies gained government approval to test the treatment in humans in 2013.

"Receiving regulatory approval to conduct clinical trials is a critical step in developing a treatment for this debilitating condition," said the company's chief executive Andrea Grant said in a statement.

She says pre-clinical trials suggest the treatment, known as NTCELL, can protect brain tissue which would otherwise die, potentially delaying or preventing the effects of Parkinson's.

Only those who have been diagnosed for at least four years will be part of the study, which will last for up to 60 weeks.

The trial will involve patients getting either the pig cells or the current gold standard of treatment - deep brain stimulation.

The leader of Auckland District Health Board's movement disorder clinic, Barry Snow, will oversee the trial.

Pre-clinical studies had shown improvement in movement and neurological defects and a rise in dopamine-producing neurons within two weeks of treatment.

Source: <http://www.couriermail.com.au/news/breaking-news/pig-cell-treatment-for-parkinsons-okayed/story-e6freoo6-1226488892665>

Update on the Essence Project

The **ESSENCE Mindfulness Research Project**, led by Monash University's Dr Craig Hassed has recently completed its first stage.

The project, funded by Parkinson's Victoria, has seen the delivery of ESSENCE (Education, Stress management, Spirituality, Exercise, Nutrition, Connectedness and Environment) programs to 73 participants at venues in Camberwell and Essendon.

Over the course of six weekly sessions, participants learnt tips for practising a healthy lifestyle and how to be more "mindful".

Mindfulness - in its simplest sense - is a mental discipline that involves training attention. Techniques include meditation and being aware of thoughts and feelings without being so reactive to them.

The project is the first of its kind to look at how incorporating healthy lifestyle strategies and mindfulness techniques may be useful in supporting people to live better with Parkinson's.

Brooke Vandenberg from the **Southern Academic Primary Care Research Unit (SAPCRU)**, the team leading the evaluation of the project, expressed her gratitude to all those involved, "I would like to extend my appreciation to Parkinson's Victoria for funding this innovative research into ESSENCE mindfulness and Parkinson's, and to all the participants and their carers who attended the program."

Feedback received from program participants and their accompanying carers indicates that the program has been a rewarding experience for all involved, with many highlighting the supportive group environment as a forum where they could openly discuss their achievements of implementing the ESSENCE strategies and the reality of living with Parkinson's.

Findings of this innovative research will be made available via Parkinson's Victoria and the Southern Academic Primary Care Research Unit (SAPCRU) later this year.

Balance & breathing

In Parkinson's, coordinated movements, balance and cognitive function can all be impacted, but exercise and physical activity have been proven to have significant benefits. Specifically, in recent years, numerous studies have been conducted into the health benefits of yoga in managing Parkinson's symptoms. Yoga, which emphasises breathing and relaxation, as well as balance, stability and controlling movement, can help to alleviate some of the symptoms associated with Parkinson's.

Yoga focuses on the body and the mind and consists of a range of stretches and breathing techniques enabling participants to gain more control over their movements and balance. It also aids in improving flexibility and mobility, as well as reducing fatigue and it can assist with constipation.

In addition, research has suggested that yoga can have a significant positive impact on one's emotional state.

Anxiety and depression are common symptoms associated with Parkinson's, and stress is known to exacerbate some of the physical symptoms. Meditation is thought to temporarily increase dopamine levels in the brain, lifting one's mood, and breathing control helps to relax individuals and improve mental focus in times of anxiety or panic attacks.

In November last year, four yoga workshops were held in Melbourne as a pilot for a proposed regular yoga group for people living with Parkinson's. The workshops were run by Dr Sanjay Raghav, a neurologist with special interest in Parkinson's, and Sri Rajendra, a yoga instructor.

Collectively, over the four sessions seven people with Parkinson's attended the group and the feedback after the sessions was extremely positive: Participants noticed a reduction in stiffness and an improvement in flexibility and suppleness. They also found the meditation and relaxation techniques particularly useful.

Due to the success of these sessions, Parkinson's Victoria is now looking to establish a regular group.

If you are interested in joining a regular yoga group or would like further information, please contact our Health Team.

Delusional jealousy:

a new non motor symptom associated with dopamine agonists.

In a recent article by Polietti, Perugi and Logi, published in the **Movement Disorder Journal, November, 2013**, the incidence of people on dopamine agonists developing delusional jealousy has been documented. Delusional jealousy is defined as: *an irrational fixed belief that your partner is being sexually unfaithful, which can be associated with unacceptable or extreme behaviours.*

In the small scale trial of 116 individuals taking dopamine agonist medications, six people (5.2 per cent) developed delusional jealousy.

The researchers noted that dopamine agonists are an important medication in the management of Parkinson's and both individuals and treating/prescribing physicians should be aware of the possible side effect and discuss it if there is concern.

Participate for Research

PSP-MSA research study

Researchers at Alfred Hospital are currently seeking volunteers for a trial in the use of **Transcranial Magnetic Stimulation (TMS)** to measure brain responses in Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Parkinson's.

They are keen to hear from people diagnosed with these conditions as well as healthy volunteers interested in participating as "controls".

What's involved?

Participation involves attending the Alfred Hospital Neurosciences department for a 2-3 hour session once every 6 months for a period of two years.

During this session, participants will have an interview and examination with a neurologist and undergo Transcranial Magnetic Stimulation, a non-invasive stimulation technique using a hand held magnet to stimulate a small area of the brain.

Lead researcher: Dr Kelly Bertram, Neurologist, Neurosciences, Alfred Hospital

Research team: A/Prof David Williams; Dr Will Lee; Ms Sue Varley (PD nurse)

Please note there is no expectation that participation in this study will treat your condition.

If you are interested in participating please contact the research team for a discussion of your suitability and a full explanation of the study.

Contact Alfred Switch: (03) 9076 2000 and ask for Dr Kelly Bertram, or leave contact details with Linda in Neurosciences: (03) 9076 2059

k.bertram@alfred.org.au

This study has received funding from the Brain Foundation and has ethics approval through the Alfred Ethics office, approval number 342/11.

Can you, "lend a hand"?

Hand function is important to all of us in our daily lives and may be affected by Parkinson's.

Researchers from University of Melbourne, School of Health Sciences, are investigating effective ways for therapists to measure manual dexterity in people with Parkinson's and they are currently seeking eligible participants. The study is officially investigating: **"Clinimetric properties of upper limb measurement tools for the evaluation of people with Parkinson's disease"**.

Research participants will be tested on two days, one week apart. On each day participants will be tested twice, once approximately one hour after medication, and again 30 minutes before your next medication dose.

The hand function tests will include picking up and placing items of varied sizes, and testing can take place at the Department of Physiotherapy, The University of Melbourne or in your home.

Eligible participants are those currently taking oral medications for Parkinson's and who have no other condition that affects their arm or hand function.

If you have questions about this study or would like to assist by participating, please contact Libby Proud, PhD Candidate (Physiotherapy), University of Melbourne: (03) 8344 4171 or email eproud@student.unimelb.edu.au



A Tree of Tributes

As part of our annual *end of year appeal*, we invited the community, donors and supporters, to return a 'Tribute' with a message or blessing for the Festive Season.

Along with your generous donations, we were overwhelmed at how you responded to this opportunity to say thanks or remember loved ones.

We received almost 200 'tribute baubles', which adorned our Tribute Tree (right) during December and January.

Our team and visitors loved reading your messages of hope, inspiration, and thanks, along with tips, special blessings and "in memory of" messages, and your words will continue to inspire and motivate us through 2013!

Best wishes for a healthy and happy New Year to all our members and supporters!



Support networks

Young @ Park

Did you know there are two Parkinson's Support Groups specifically for people living with Young Onset Parkinson's?

The Melbourne "Young @ Park" group meets every couple of months at roving locations around Melbourne, while the Geelong-based group meets monthly in Newtown. We also have other support groups located around the state.

If you would like to learn more about our Young @ Park Support Groups, or find a group near you, contact our Health Team or email info@parkinsons-vic.org.au or check out www.yap.org.au

Do you have a song in your heart?

A **Parkinson's Singing Group** will be launched in Williamstown, with its first meeting on Thursday 21 March.

Singing can be both physically and emotionally invigorating, especially when experienced with others who share the same motivation and enthusiasm.

For those living with Parkinson's, research has shown that vocal exercises enhance voice volume, and music and rhythm can improve movement. Musical ability is not required to participate in the Parkinson's singing group, and carers are welcome to come along too.

If you are interested in attending the Parkinson's Singing Group (based in Williamstown only at this stage), contact Support Group Coordinator, Breanna Wotherspoon: breanna@parkinsons-vic.org.au or call our office.

What's in a name?

The new **Parkinson's Singing Group** is looking for a name that will represent what the group is all about: music, rhythm and a sense of fun. Do you have any ideas?

The person who comes up with the most creative suggestion (as judged by representatives from Parkinson's Victoria) will receive a terrific prize; a \$100 voucher generously donated by Cicciolina restaurant in St Kilda, and the honour of having their idea used as the name for this inspiring group.

To enter, please send your suggestion, along with your contact details, to Parkinson's Victoria, PO Box 2606, Cheltenham, VIC 3192 or email info@parkinsons-vic.org.au (write "SINGING" in the subject line).

Young Onset Survey

Are you under the age of 60 and living with Parkinson's? Would you like to help us gather data around the issues that matter most to you?

Parkinson's Victoria is conducting a survey investigating current and proposed services and supports for people living with Young Onset Parkinson's. We are seeking your feedback on what support services you currently access, what you would like to see offered and any ideas you have for improving the experience of younger people living with Parkinson's.

This valuable feedback will help us to shape the future of Young Onset services.

The survey is available online or can be printed from our website. Visit www.parkinsonsvic.org.au and follow the link to the 'Young Onset Survey'.

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Tulip Tributes

Congratulations!

We congratulate the following individuals whose outstanding voluntary contributions to our community were acknowledged during recent Australia Day celebrations:



Terry (second from left) with other Glenferrie Rotarians during our 2012 Walk in the Park.

Terry Rolleston, Boroondarah Citizen of the Year

Terry has been an active volunteer for 15 years. His contribution includes coordinating his Rotary Club's support of **Walk in the Park** for the past 3 years, as well as the Club's fundraising efforts, which so far total \$10,000 in donations to support our work.



Trevor and wife Pearl at Walk in the Park.

Trevor White, Leongatha Citizen of the Year

Trevor has been providing invaluable support to his local community for several years, including establishing the Leongatha Parkinson's Support Group in 2004 and which he still leads. His efforts also extend to fundraising and awareness raising and he is a strong advocate for Parkinson's Victoria.

Anne Atkin, Casey Citizen of the Year



Anne is well known for her work establishing **Painting with Parkinson's** groups throughout Victoria. More recently she self-published "Living and Laughing with Parkinson's", sharing her humorous take on life with Parkinson's.

Anne Atkin receives the Parkinson's Victoria 2012 Sir Zelman Cowen Award, presented by Lady Anna Cowen.



Professor Iansek receives an Outstanding Achievement Award from Parkinson's Victoria President, Peter Raymond.

Professor Bob Iansek, Order of Australia Medal (OAM), awarded in recognition of his contribution to the field of Neurology.

In 2012, Professor Iansek received an **Outstanding Achievement Award** from Parkinson's Victoria (awarded at our 2012 AGM).

And, Parkinson's Queensland patron, Professor Peter Silburn, was also appointed a Member of the Order of Australia (OAM).

A little help from our "friends"



We received a generous donation of \$2400 from the team at **Ella and Friends Photography**, following the publication of 'Generations' (above), a stunning coffee table book. Combining beautiful family photos with 'words of wisdom' from parents and grandparents, the book is a celebration of life. Many of those featured in the book are living with Parkinson's.

A copy is on display in the reception area of Parkinson's Victoria.

A Golden Age

Special thanks to Helen and John Staite, who recently celebrated their 50th "Golden" Wedding Anniversary. They kindly asked friends and family to make a donation to Parkinson's Victoria in lieu of gifts and an incredible \$1530 was raised.

Congratulations Helen and John, and thank you so much!

Dressed for success!

Thanks to the team of **The Victorian Student Centre**, a section of the Department of Immigration and Citizenship for a recent donation of \$209. The team holds a weekly "casual clothes for a coin" Friday and for the past few months, Parkinson's Victoria was the nominated charity.

What a great effort!



John and Helen Staite celebrate their Golden Wedding Anniversary.

Education & Learning

Throughout the year, Parkinson's Victoria hosts education and information events for both health professionals and the general public. In addition to general information sessions, we address specific topics and also host industry-specific health professional events. Contact our office if you are interested in any of the events below. If you know a health professional that you think would be interested, why not tell them about it and encourage them to attend one of our events!?

Surviving Carer Stress

Presented by Carers Victoria, 'Surviving Carer Stress – understanding how stress affects you', is a workshop geared towards the partners and family members of the person diagnosed with Parkinson's, rather than the individual themselves.

Carers Victoria has an excellent reputation for facilitating informative, engaging and practical workshops. This one will address how everyday stress associated with the caring role can affect a person both physically and emotionally. Not only will the impact of stress be explored, but practical ideas will be provided on how to manage.

When: Wednesday 8 May, 4-6pm

Where: Eastern Access Community Health, 75 Patterson St, Ringwood East

Cost: \$5 per person

To book: Contact Parkinson's Victoria

Community Seminars

Parkinson's Victoria invites those living in Pakenham or Geelong, and respective surrounding areas, to a community seminar for people with Parkinson's, their carers, family and friends.

Join us for an informative and friendly afternoon where we will provide a general overview of Parkinson's and the latest symptom management strategies and treatments. There will also be information about relevant Parkinson's support and specialist services available in the area.

If there is sufficient interest, an ongoing support group will begin in Pakenham in March.

PAKENHAM Seminar

When: Thursday, 28 February, 1:30pm–3:30pm

Where: Senior Citizens Centre, 38-42 James Street, Pakenham

GEELONG Seminar

When: Wednesday, 13 March, 4pm – 6pm

Where: All Saints' Hall, 113 Noble Street, Newtown

Cost for either event: \$5 per person.

To book: Places are limited and RSVP is essential. Contact our Health Team: (03) 9581 8700 or email info@parkinsons-vic.org.au

Introduction to Parkinson's for Healthcare Professionals

This event is aimed at health professionals in Geelong and surrounding areas, who are working with people living with Parkinson's or who would like to know more about the condition and quality of life strategies.

The seminar is ideal for professionals with a basic understanding and experience of Parkinson's who want to enhance their current knowledge base. Keynote Speaker: Professor Robert Iansek, OAM.

When: Wednesday, 13 March, 1.30pm-3:30pm

Where: All Saints' Hall, 113 Noble Street, Newtown

Cost: \$20 per person

Places are limited and RSVP is essential. Contact our Health Team on (03) 9581 8700 or email info@parkinsons-vic.org.au

PSP and MSA education day

PSP Australia, in partnership with Parkinson's Victoria, is proud to present the **PSP Healthcare Professionals Seminar**.

This one-day professional development seminar is for allied health professionals who work with clients and carers living with PSP, CBS/D and MSA*, and for other interested members of the health profession.

The day will provide an insight into these conditions, as well as practical advice and strategies for assisting patients and their carers.

When: Thursday, 21 March, 9.00am–4.30pm

What: Encore, St Kilda Beach, St Kilda

Cost: Early Bird \$110 per person / Regular \$130 per person (includes GST and morning tea/ lunch)

Book online www.trybooking.com/CINQ

Places are limited and RSVP is essential. Contact our Health Team: (03) 9581 8700 or email info@parkinsons-vic.org.au

***MSA, PSP, CBS/D: Multiple System Atrophy, Progressive Supranuclear Palsy, Cortical Basal Syndrome Degeneration.**

Supporters

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Disclaimer:

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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 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.

**We are pleased to acknowledge the support of a number of businesses and organisations.*

*We also honour those in whose name **In Memoriam, In Remembrance, In Honour and In Celebration** donations were received between the months of November 2012 – January 2013. We extend our sympathies to the families who have lost loved ones, and we thank those who have donated anonymously.*

We also acknowledge other members of the community who have 'Moved to make a difference' by actively fundraising on our behalf.

In Memory of...

Bill Bennett
Robert Henry Brauhn
Roy Bright
Don Brown
Les Burgess
Desolina Caluzzi
Betty Clayton
Lida Dall'Óglio
Adeline Denny
Maria Dimasi
Saverio Fotia
James "Alan" Gaylard
Elizabeth "Beth" Harris
Ernest Hosking
Terrance Hunt
Francesco Iaia
Edward Peter Ingham
Norman Jacobson
David Lewis
Joan McIvor
Margaret Megee
Anthony "Tony" Messina
Mrs Pascal
Dr Charles Proctor
Brian Quigley
Margaret McGregor Rivers
Sidney Douglas Savage
Thomas Shippick
Mr Sum
Maria Thompson
Lorraine Thomson
Guisepe Toro
Joan Mildred Williams
Anne Wood

In celebration

Margaret Livermore (birthday)
Karyn Spilberg (birthday)
John & Helen Staite (50th Wedding Anniversary)

We also gratefully acknowledge the individuals and families who generously chose to make a donation in lieu of Christmas cards or gifts. Thank you!

In Remembrance of...

Hilton Flegg
Angelo Ricci
Mr Smith
John Steele
Team Parkinson's Fundraisers (third party)
Jason Lavery (Garage Sale)
Edward & Susan Coleridge (open garden & art exhibition)
Team Turner (Walk in the Park 2013)

Corporate, Community & other donations & support

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Ella & Friends Photography
Entertainment Publications of Australia P/L
Ernst & Young
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GC Bitsis Nominees Pty Ltd
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Italian Senior Citizen of Ballarat Inc
Kleid Nominees Pty Ltd
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MD Kirby Nominees Pty Ltd
Meeniyan and District RSL
Melbourne Welsh Church
Melco Electrics Pty Ltd
Meriba Service Club
Midwood Roses Pty Ltd T/As
Treloar Roses
Militsa Pty Ltd
Mornington Community Information & Support Centre
No.3 Masonic Master Group
Officeworks Store Development & Procurement

Prahran Seafoods Pty Ltd
Rotary Club of Mount Beauty
St Andrew's Anglican Church Brighton Op-Shop
St Paul's Bendigo
Combined Christmas Card Shop
Sunshine Scenic Tours
Telstra - Staff
The Lutheran Laypeople's League of Australia Inc
Tripix Holdings Pty Ltd
WD Designs & Construction

Matched Payroll Giving

National Australia Bank
Thiess Pty Ltd

***Donations acknowledged were received between 1 November 2012 – 31 January 2013.**

Please note: Due to privacy obligations and the increasing number of supporters, we regret that we will no longer be able to provide a comprehensive list of donors, but all support is most gratefully received.

We gratefully acknowledge the generous support of those who responded to our recent requests for support and are pleased to provide this update:

- **End of Year annual appeal:** 340 people responded to our 2012 End of Year appeal, and together you donated a total of \$31,580. An incredible result - Thank you! A total \$8,000 was donated by just 5 people!