

SIGNPOST

Autumn 2014 • Volume 13 Issue 1 A Magazine for people living with Parkinson's

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News & Highlights

PRESIDENT'S MESSAGE



Welcome to the first Signpost issue for 2014 – my first as President of the Parkinson's Victoria board. I am excited and proud to take on this position – one that has been so well executed by outgoing President, Peter Raymond; I

would like to take this opportunity to thank him for his service. Peter started his work with Parkinson's Victoria in 2005, and his commitment and leadership has made an impact that won't soon be forgotten. I am sure I speak on behalf of Parkinson's Victoria's many stakeholders in thanking Peter for his tremendous dedication and wisdom.

As President of Parkinson's Victoria I look forward to working closely with my fellow board members and our CEO, Emma Collin, to ensure our strategic goals are ambitious and innovative, but sustainable in the long-term. My time on the board has shown me that there is so much passion and expertise in the organisation and the Parkinson's community; with our vision clearer than ever and our mission laid before us, we can achieve big things in 2014 and beyond.

I am happy to be joined by two new board members, Geoff Pearson and Sue Harper. Geoff was diagnosed with Parkinson's at 42 years of age; since his diagnosis, Geoff has openly shared his experience of young onset Parkinson's with the media and community, and is a member of the Monash University Parkinson's Research Steering Committee. Sue brings 20 years of management and leadership experience to her role on the board; she has a strong interest in the health sector, and a dedication to furthering the wellbeing of people with Parkinson's and their families. I warmly welcome Geoff and Sue to the board.

Damien Farrell, President,
Parkinson's Victoria Board

CEO'S MESSAGE



This issue's theme of *here, there and everywhere* resonated with me because it speaks so strongly to the developing goals of Parkinson's Victoria. Over the past year, significant work has been undertaken to review and plan our

direction, vision, and values for the coming years – and our sights are set high.

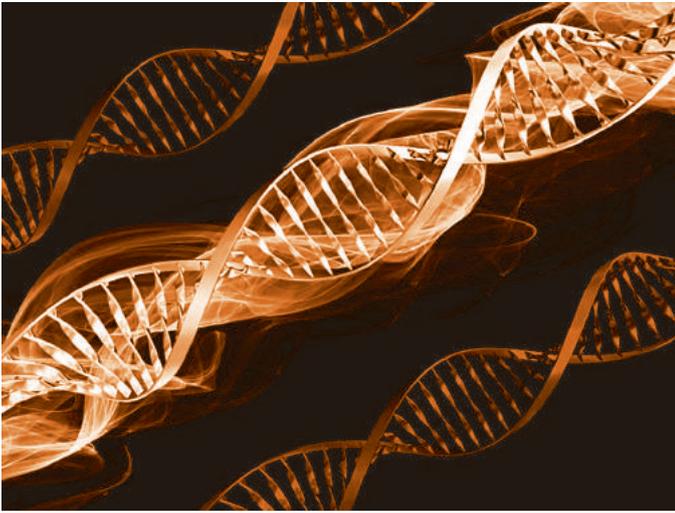
Our vision is of Parkinson's Victoria as a supporter of a **global Parkinson's community**; our mission now supports services that will be flexible and relevant, and commits us to a strong research path; and our values prioritise **innovation, quality and continuous improvement**.

To deliver on our mission, we will need to be dynamic and agile, using technology to support our work and connect us with the Parkinson's community locally, nationally and internationally. We will look to partnerships and government to increase the services and products available to people affected by Parkinson's, including family carers and health professionals. We will listen to, and be a voice for, the community.

In 2014, we will work smarter, more efficiently, and with greater confidence than ever as we strive to create effective and positive change both internally, and for the Parkinson's community. We are thankful to our members and supporters, and look forward to going on this exciting journey of growth and change with you.

Emma Collin, CEO,
Parkinson's Victoria

A STEP FORWARD FOR GENE THERAPY



The results of an early-phase clinical trial into a new surgical intervention applying gene therapy to people with advanced Parkinson's were published in the January 10 issue of medical journal, *The Lancet*.

Why gene therapy?

At present, medications such as levodopa and dopamine agonists are the most commonly used treatments for Parkinson's. While these medications are effective, they are not a cure and do not slow the progression of Parkinson's. As Parkinson's progresses, the body doesn't respond to the medications as well and people may experience dyskinesia and wearing off.

The therapy in this trial (ProSavin) involves injecting corrective genes into the brain in the hope that this will stimulate the cells there to continually produce dopamine, and ultimately be able to slow or stop the progression of Parkinson's.

How is it done?

The genes for three enzymes that play an important role in manufacturing dopamine are packaged into a virus that has been modified so it doesn't carry infection. This modified virus is then injected into the basal ganglia region of the brain.

This trial

This trial involved 15 patients and took place over four years in France and the UK. The patients were aged between 48 and 65, had lived with Parkinson's for more than five years, and responded well to Parkinson's medications.

Results

- At six months and 12 months after treatment with the gene therapy, motor symptoms had improved in all patients.
- The treatment did not address non-motor symptoms of Parkinson's.
- The improvements lasted up to four years, but after that the improvements fell back as Parkinson's progressed.
- Some patients experienced side effects such as dyskinesia, but there were no serious adverse events as a result of the treatment.

What now?

The primary goal of this study was to determine whether this therapy is safe, and can be tolerated by the body; that was demonstrated to be the case.

However, much more research needs to be done to find the best dose and method of delivery for this therapy, and then trials need to be conducted on a much larger scale.

Gene therapy is not yet available as a treatment option for people with Parkinson's and is still in the early stages of clinical research. These results are very encouraging, but more research is needed before we can say if and when this will be available as a treatment.

JUST THREE MINUTES



Taking time out from your caring role can sometimes seem impossible. But we know - both instinctively and through extensive research - that making time for self-care is crucial to maintaining personal health and being able to continue caring. The key word there is *making*: some carers will receive respite through service providers or family and friends, but such breaks may be few and far between, and hanging on until being granted that rest can be excruciating. Setting aside just three minutes each day to nurture, pamper, relax and acknowledge your own needs can make all the difference. Schedule this at a regular time which suits you; it might be after dinner, or first thing in the morning.

Here are some examples of how you can take some well-earned time for yourself.

- Moisturise your hands or feet: buy a special hand or body cream, or add a couple of drops of lavender or peppermint oil to Sorbolene cream and massage in well. Look carefully, lovingly at your hardworking body and offer yourself kind words of support for the care and love you give to others.
- Take a few extra minutes in the shower or bath to massage your face and neck gently with your fingertips. Press steeped and cooled tea bags onto your eyes; or mix half a cup of plain instant oats (or rolled oats whizzed up for 10 seconds in a blender) with enough warm water to form a thick paste, spread on your face and throat and rinse off after 3 minutes.
- Start a gratitude journal: list three things you are grateful for, including things like spending time with a family member, enjoyable weather, a phone call from a friend, or a tasty meal. Scientific research shows that people who keep a regular gratitude journal report better sleep and fewer illness symptoms, experience increased empathy, less anxiety and depression, and feel better about the future and their lives as a whole.
- Sit or lie in a quiet place, outdoors in sunshine or shade, close your eyes and take ten slow, deep breaths.
- Consider your own health needs: mentally scan your body from top to bottom and take action on one thing. This might include booking your overdue doctor or dentist's appointment, or stretching your arms up over your head or out in front of you and rotating your hands at the wrist 10 times in each direction.
- Use headphones to listen to or sing along with just one song.
- Visit your local library or swap a book or a magazine with a friend and read a couple of pages each day: consider choosing something that can be briefly dipped into, such as poetry or short stories, recipes, gardening, craft or self-help.
- Simple gardening: sow herb seeds in a small pot (parsley and coriander are quick and easy to grow). Plant a second lot 7-10 days later to ensure constant supply.
- Write a small card or email to a loved one just to say hello and let them know you are thinking of them; this will prompt them to think of you, too.

Life is made up of a series of moments. Giving ourselves a few minutes of 'me time' each day, without compromise, can help us get through tough times or long stretches without respite so that we bend rather than break.

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www.carersvictoria.org.au

Research is increasingly reinforcing the importance of exercise for the bodies and minds of people living with Parkinson's. Physical exercise is vital in maintaining balance, mobility and day-to-day activities - it can also help enhance cognitive function. The following are some exercises adapted from an exercise DVD, called Keep Moving, which you can try out at home. Shoulder retraction exercises can help to strengthen your upper back and improve your posture, which can be compromised in Parkinson's.

The Shoulder Retraction

Stand with your feet shoulder-width apart. With your elbows bent, pull your shoulders back so that you're squeezing your shoulder blades together; make sure that your elbows are moving back and down as you squeeze your shoulder blades together. Hold this position for three seconds then relax. Try to do three lots of 10 repetitions, making sure you have a short rest between sets.



For those who want a higher level of exercise, try doing the shoulder retractions holding a weight in your hands. This can be a gym weight you already own, or something as basic as a bottle of water or tin of vegetables. Make sure the weight is not so heavy that you can't complete the exercise or that it makes you too sore or tired.



The Keep Moving DVD has a range of interactive exercises targeting posture, flexibility, and strength – all of which may be compromised in Parkinson's.

Contact Parkinson's Victoria on 1800 644 189 or via info@parkinsons-vic.org.au for more information or to purchase a copy of the Keep Moving DVD.

Contributing Factors

POTENTIAL ENVIRONMENTAL RISK FACTORS IN PARKINSON'S

In December 2013 there was a story in the media about a flight attendant looking to take legal action against the Commonwealth Government; he claims to have developed Parkinson's as a result of being exposed to chemicals while spraying plane cabins as part of Australian quarantine regulations. While there is evidence supporting increased risk of developing Parkinson's for those exposed to certain chemicals, many factors are in play, including: the type of chemical; the amount of exposure; and other environmental elements unrelated to chemicals, which may make someone pre-disposed to Parkinson's.

Here, our Health Team looks at a recent piece of research on the evidence behind environmental risk factors, such as pesticides.

Genetics

A number of genes have been identified that appear to contribute to Parkinson's, or that confer a risk of developing Parkinson's. However, these genes are only present in a small percentage of people with Parkinson's (5 - 10%), and the evidence is still conflicting; some of those who carry the mutation do not develop Parkinson's, and those who do not carry the mutation may go on to develop the illness. Most of those with a diagnosis have what is referred to as 'idiopathic Parkinson's' – that is, Parkinson's with no known cause.

Causal Factors

Currently the only environmental factor to be considered 'causal' in Parkinson's (that is, it leads to an increased risk of Parkinson's) is age. Since the condition was first described by James Parkinson back in 1817, age has been recognised as a risk factor for Parkinson's. Recent epidemiological evidence confirms that as age increases, so does the risk of developing Parkinson's.

Association

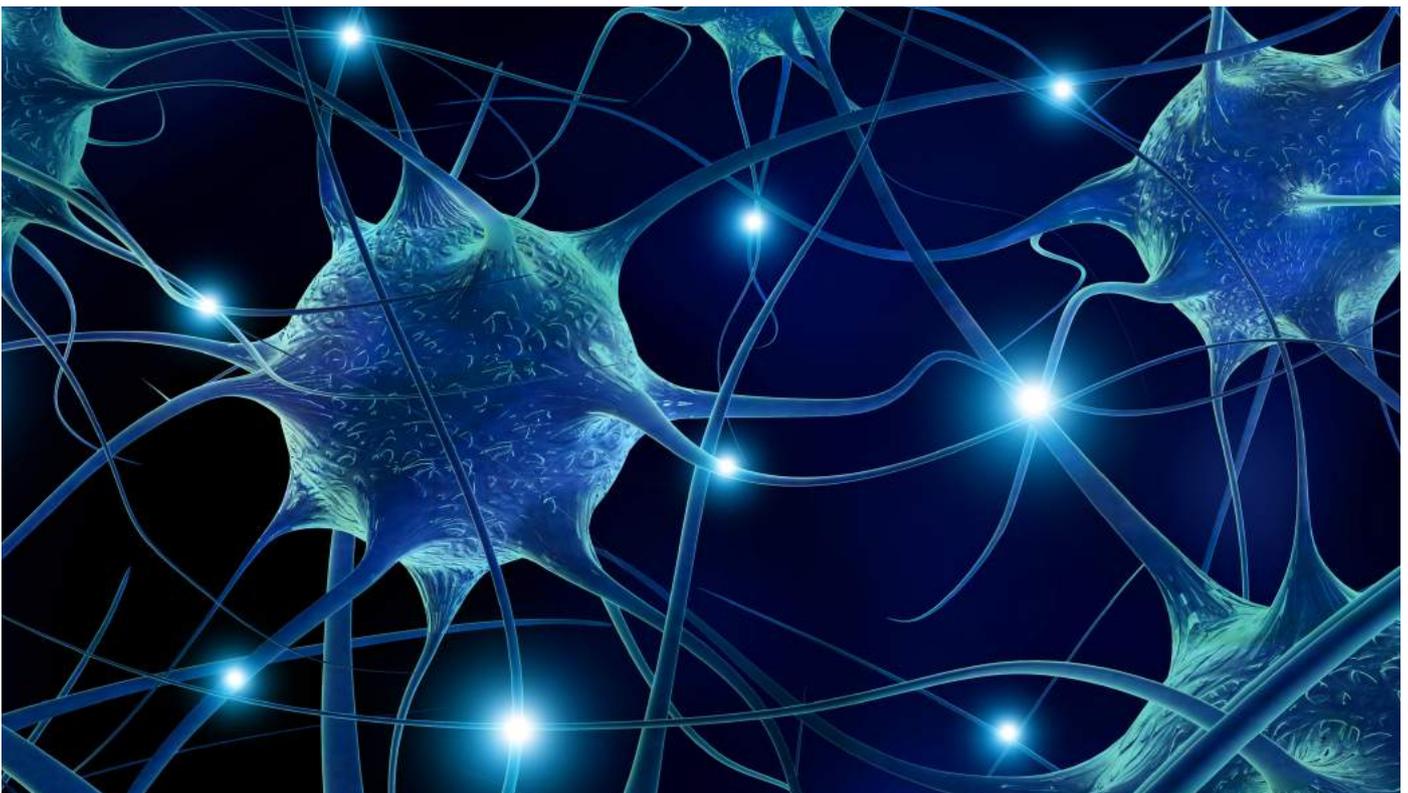
There are some other environmental factors that have been found to have an

association rather than be considered 'causal', as their exact relationship to Parkinson's is unknown.

Gender

While the exact ratio varies according to different studies, men have a higher incidence of Parkinson's than women, averaging approximately 1.5 males to every female.

The science behind this is not understood – do the hormones testosterone or oestrogen affect your chances of developing Parkinson's? Or is there something about the male lifestyle that increases the risk?



Contributing Factors

Tobacco

Multiple studies have found that exposure to tobacco reduces the risk of PD. However we **do not** recommend taking up smoking in an effort to prevent or improve Parkinson's. Keep in mind that we do not understand the relationship between tobacco and Parkinson's. Is it that nicotine exposure can promote the survival of the relevant neurons in the brain? Or is it that tobacco-related causes of death mean smokers do not have the same age-related risk of developing Parkinson's?

Caffeine

Not only does caffeine appear to have a positive association with lower risk of Parkinson's, but the amount of coffee does, too - people who drink more coffee seem to have lower risk of Parkinson's. It is unknown whether this actually protects against the degeneration that occurs in the brain, or simply acts to mask Parkinson's signs and symptoms.

Limited evidence of association

The following factors have been investigated, but have limited

evidence of an association with Parkinson's.

Pesticides

Exposure to some pesticides may increase the risk of Parkinson's, but at this stage the evidence is inconclusive. Different studies have given varying weight to the role of pesticides, depending on: the age of exposure, as there is possibly a higher risk for younger exposure; the specific pesticide - paraquat and permethrin seem to lead to greater risk than some others; and the presence of a family history, as pesticides may not increase the risk at all in those with a family history of Parkinson's.

Occupation

Farmers and those with agricultural occupations appear to be at greater risk of developing Parkinson's. However, it isn't clear whether this is because their occupation exposes them to pesticides, or other environmental factors.

A link between Parkinson's and welding as an occupation has also been explored, but there is not a consistent relationship.

Traumatic Brain Injury

The research suggests that only those who had experienced head injury/injuries associated with more than five minutes of unconsciousness and a long repeat in the polymorphic region in the gene for alpha-synuclein had a notable increase in the risk of developing Parkinson's - not those with a head injury alone.

Exercise

With light to vigorous physical activity, individuals appear to have decreased risk of PD. Women seem to benefit more from moderate to vigorous physical activity, but it is not understood why this is the case.

Conclusions

The above research looks at environmental risk factors, but it is important to remember that risk factors do not act in isolation. The current evidence suggests that these environmental factors are only part of the picture, and that perhaps it is these in combination with genetic predispositions that lead to the development of Parkinson's.



Personal DopaMeanings

A TEARDROP IN MY LATTE by Gloria Nassau

My husband was diagnosed with Parkinson's ten years ago, but there were related symptoms that doctors were unable to explain that manifested earlier.

The diagnosis evoked in my husband feelings of uncertainty, self-doubt, and guilt.

In me, it triggered a desire to reaffirm my commitment to him. I knew instantly that I would have to stay strong. That my husband's life, and the way he would navigate his illness, would very much be influenced by the way I responded to the changes Parkinson's would inflict upon him.

I could feel our life beginning to shift. It felt unreliable and unsettling. But then I told myself that every day in life is unpredictable - that at least we knew our enemy. That all we had to do was to alter our life's dreams a little and live one day at a time.

I didn't understand then about the day-to-day fluctuations of the illness and how the side effects of certain medications could threaten to bring about unrecognisable changes in the man I had grown to know so well.

There are days when I feel things intensely. Feelings of resentment clash with a fierce desire to protect. Sadness, intermingled with fear of the future, competes with feelings of gratitude that my

husband still walks beside me.

We stay vigilantly in tune with the latest research and therapies, yet still I often wake at night, mind racing, wondering if there is something out there that we are not aware of.

On good days it is easy to keep the condition in perspective. I embrace the contentment that flows from spending time with our children, grandchildren and close friends.

I watch over my man with pride as he strives to find ways of continuing to make a difference in the community and searching out new interests. I know why I love him.

Visits to the neurologist re-ignite in me a longing to hear the reassuring words that everything will be alright. Surgery is discussed, medications are re-balanced. We walk out of the consulting suite hand-in-hand. We are one.

A tear drops into my latte... my longing remains a longing, but hope remains forever enfolded in my heart.

Get your medicines on track in 2014 with the help of TabTimer Reminders™

Medicine Reminders | Timers | Electronic Pill Box Reminders | Vibrating Watches | Talking & Vibrating Clocks

The advertisement features a collection of TabTimer products. On the left, a hand holds a circular pill box with a digital display. Next to it are several electronic pill boxes, some with digital displays showing times like 10:10 and 23:29. In the center, there are several vibrating watches in various colors (black, silver, blue, pink, yellow). To the right, there are talking and vibrating clocks, some with large digital displays showing times like 12:30 and 15:28. The TabTimer logo is prominently displayed in the center, with the tagline 'helps keep medications on time'. Below the logo are social media icons for Facebook, LinkedIn, and Twitter. At the bottom left of the product display, it says 'VIBRATING BOX NOW AVAILABLE'.

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PARKINSON HOME EXERCISES APP

Wherever you look it seems that smartphones and tablets are *here, there and everywhere*. It's not surprising that innovators around the world are embracing this ubiquitous technology to make change and contribute to better health outcomes. One of our latest discoveries is an app released by the European Foundation for Health and Exercise, for people affected by Parkinson's and related disorders. The app provides advice and instructions for completing a range of daily movements and exercises.

The app is available for iPhone and iPad users. To find the app, visit the Apple App Store and search 'Parkinson Home Exercises.'



Content

The app divides daily movements and exercises into 9 categories: **walking; posture; standing up; balance; bed mobility; flexibility; physical condition; and relaxation**. Each category has an introduction explaining possible problems that may arise during that activity for people with Parkinson's. Selecting a category directs you to a series of sub-categories where the app delivers its recommendations through a short video with instructions. For instance, if you identify that you are having difficulty with bed mobility, the app uses short videos to demonstrate strategies for getting into and out of your bed, and moving about while in bed.

In addition to video instructions, the app has a metronome function that can be used to improve rhythm whilst walking, and reduce episodes of freezing.

Ease of use

The appearance and structure of the app is uncomplicated, and your screen is not filled with excessive information. Upon opening the app, the navigation menu appears on the side of your screen and remains present regardless of which page you navigate to. This means that it is always easy to navigate to the next desired page or return to your previous location.

Video demonstrations are combined with step-by-step instructions to advise users how to correctly perform the specific movements and exercises. The language used during verbal instructions can be easily understood and does not include medical jargon. The English version of the app features a narrator with an Australian accent, which is a bonus.

Daily movements and/or exercises can be flagged as favourites, which means that items you'd like to practice regularly are easily accessible.

Upon trialling the app, all pages opened quickly and smoothly – no issues were detected.

Limitations

It is important to note that the app has its limitations. No two people with Parkinson's present with the same symptoms. Depending on your level of function, the app's recommendations may or may not be appropriate for you. There is also the possibility that certain exercises may compromise your safety by putting you at risk of falling. It is always best to consult a qualified health professional, such as a physiotherapist, who can advise on the suitability and safety of any exercises.

At this stage the app is only available for iPhone and iPad users. There is no indication that an Android app is on the cards.

Overall impressions

Parkinson's Victoria is always excited to see innovative technologies used well, and the use of tablet and smartphone apps in Parkinson's is certainly an exciting growth area. It will be interesting to see how our members embrace apps like this; this app certainly has potential to be a valuable day-to-day tool for people living with Parkinson's. However, it should not be used to replace assessment and treatment from qualified health professionals.

Health Tourism



Health tourism', or travelling for treatment, is increasingly being discussed in the media, as it is an expanding area both overseas and within Australia. Some of our well-known Australian hospitals are getting involved, developing areas designed to offer our expertise to international visitors, as a potential source of revenue. Some health funds in the United States are even sending residents to other countries for elective surgery – it works out cheaper to send someone to a private clinic in India for coronary bypass surgery than to have the surgery in some states of the US!

In some instances people living with Parkinson's travel for treatment – this ranges from investigations into new treatment and opportunities to participate in research that aren't available in Australia, through to treatments which may not have a firm evidence base.

Australia does offer the full range of evidence-based treatments that are available for Parkinson's – whether it be oral or continuous medications, surgery, or the allied health approach available through Movement Disorder Clinics; however some people do choose to travel for treatment.

Getting an International Opinion

There are occasions, particularly when symptoms are unusual, that someone may contemplate travelling to get an additional opinion from a notable physician or to access diagnostic technology that is in the development stage overseas.

Mary's story

Mary had Parkinson's symptoms that were unusual and she experienced some difficulties with her blood pressure. In order to get a firmer diagnosis she participated in a trial of a new SPECT scanner which, at the time, was only available in London. This reassured her that she was being treated for the correct condition.

While there is no harm in seeking a second opinion, keep in mind that Australian doctors and scientists are considered some of the best in the world. Don't feel as if you are 'missing out' or receiving inadequate care by not travelling overseas for a second opinion.

- Pros
 - **Peace** of mind.
 - **Contributing to the body of evidence** on Parkinson's, if accessing developing technologies or participating in research.
- Cons
 - **It can be an expensive way to get a second opinion;** you may want to consider getting a second opinion locally first.

Mind and Body

Sometimes people wish to delay beginning medical interventions and seek to manage Parkinson's with a more holistic approach, while others may consider holistic therapies as a way to complement their current medical treatments and address some of the Parkinson's symptoms their medication or surgery does not fix.

Sachin's story

Sachin was worried about his Parkinson's and heard of a yoga retreat that he thought could help. He visited India and participated in this yoga retreat for 7 days. He had to fast (though he was allowed to continue taking his Parkinson's medications) and spend time meditating, which was challenging. While he found parts of the retreat process difficult, Sachin felt his anxiety and mood were improved as a result of the stay.

Exploring complementary or integrated therapy in Australia or internationally is a real consideration for many people, however caution needs to be exercised when alternative treatments are being offered. Some of these treatments may be supported with positive case studies or claims that symptoms will be reversed or cured. People offering these treatments may genuinely believe in them, or they may be seeking to make a profit – you will need to do your research and exercise good judgement to work out what is best for you.

Robyn's Story

When Robyn was diagnosed with Parkinson's she was devastated. She was only 45 and to make it worse, the tablets made her feel really unwell. She did some research and found a clinic in the United States which offered a program of detox and antioxidant therapy to help her Parkinson's, at a cost of over \$30,000. Robyn travelled to the clinic and underwent the treatment, which involved stopping all of her Parkinson's medications, a strict vegetarian diet, colonic irrigation and a course of antioxidant therapy. While Robyn initially felt there were benefits, they did not last for long. The clinic suggested she return for another program; however after consideration she decided that a return to conventional therapy was better for her body and her bank balance.

- Pros
 - **Complementary therapies may improve your general wellbeing**, which can have flow-on effects that help with Parkinson's. For example, tremor can be worsened when you are stressed or anxious, so strategies that reduce your overall stress and anxiety levels may be beneficial.
- Cons
 - **Uncertainty**. Treatments may not work, and results vary for each person. There is not strong evidence behind the role of complementary therapies in Parkinson's, so it can be difficult to know what will work and what won't.
 - **Emotional and financial costs** can be high. Carefully consider the financial cost of the treatment and how likely it is to address your symptoms, as well as your emotional investment; be careful of your expectations of certain treatments – some might claim to have a cure for Parkinson's, and it can be very disappointing after investing time, energy, money and hope in a treatment that does not produce the desired result.

Research

Research into the cause, management and cure of Parkinson's is being conducted all around the world, and it is extremely varied – from dance programs to psychotherapy, genetics to new surgery methods, telephone diagnostics to aids and equipment, right

through to stem cells. Some people might consider travelling in order to take part in research that is not currently being done in Australia.

It is great to contribute to the body of evidence surrounding Parkinson's, and hopefully your contribution will assist in moving towards a world without Parkinson's, but there are a few things to consider before embarking:

- **Can I definitely take part in the trial?** Sometimes the nature of the trial, or the ethics approval received, limits who can participate. Confirm this before you make plans to travel.
- **Will I receive a benefit?** This may not be a consideration for everyone, but when considering the personal cost, consider the personal gain – will you be receiving a potentially beneficial treatment?
- **What are the potential costs and consequences?** Do you have adequate funds or insurance to cover you if you suffer side effects, such as feeling unwell, that hamper other travel plans or your return trip?



Participate in Research – Stem Cell Tourism Research Project

Have you travelled outside Australia for stem cell treatment – as a patient or a carer?

Researchers at Monash University are looking for volunteers to take part in their study *High hopes, high risk? A sociological study of stem cell tourism*.

The project involves in-depth phone interviews with patients or carers who have travelled overseas for stem-cell treatment, as well as with people who have considered travelling and decided not to. Insights from this study will help in producing information for patients and their families who are contemplating stem cell treatments.

If you would like to share your story or find out more about this research visit the project website at: <http://artsonline.monash.edu.au/stem-celltourism-research-project/> or contact Claire Tanner directly: claire.tanner@monash.edu.au or 0433 817 048.

Young Onset

YOUNG ONSET PARKINSON'S



Young At Park (Y@P) is a social group especially for people living with Young Onset Parkinson's, and their families. The group strives to provide a welcoming, friendly and relaxed environment for people to meet others, share information, and provide support to each other.

In a world where there is still the misconception that Parkinson's is only an older person's condition, Y@P breaks stereotypes and is a testament that younger people living with Parkinson's are still very active in the community – working, travelling, raising kids and getting on with their preferred lifestyle despite the challenges that Parkinson's presents.

Y@P started in Melbourne in 2005 and has traditionally provided face-to-face get-togethers over a meal at various restaurants and pubs. It has since grown and a group now also meets monthly in Geelong.

The Y@P group also has a website dedicated specifically to young people with Parkinson's: <http://yap.org.au> This website aims to improve the connectedness between members by providing a message board and connections to social media; as well as a blog, the latest information about Y@P events, and other news items which are particularly relevant to younger people living with Parkinson's.

You can also connect with the Y@P group via Facebook (www.facebook.com/youngatpark) and Twitter (<http://twitter.com/youngatpark>), or sign up to the mailing list via the 'Contact Us' page on the website (<http://yap.org.au/contact-page/>)

Y@P Blog

A 'blog' is a kind of online journal or forum with regularly updated content, and visitors are often given the opportunity to provide feedback or leave comments.

The Y@P blog (<http://yap.org.au/blogs/>) was launched at the 2013 Young Onset Parkinson's Conference in Melbourne, and serves to provide information that is specifically relevant to people living with Young Onset Parkinson's in an informal and interactive way.

Visit the blog to see posts on a range of topics, such as "Eat Well, Live Well" by accredited practising Dietician and Nutritionist Amy Peng.

Ever wondered whether there is a specific diet or types of food you should be eating when you have Parkinson's?

Eating the right food is important for any person but particularly for people with Parkinson's disease (PD) it is essential to maintain the right dietary intake to help manage other potential risks down the track. PD is associated with chronic symptoms including weight loss, swallowing difficulties, dry mouth, constipation and other gastro-intestinal difficulties.

The most important dietary advice for a person with PD is to maintain a healthy, balanced diet, with plenty of fibre and fluids.

In 2014 the Melbourne Young At Park group will meet every two months, alternating between an evening dinner and drinks, and a Sunday lunch. The venue will change each time in order to cater to people from all over Melbourne.

Be sure to put these 2014 meeting dates in your diary:

- Thursday 10th April
- Sunday 1st June
- Thursday 14th August
- Sunday 26th October
- Tuesday 2nd December

Please note dates may be subject to change. Latest information will be available through the Y@P website <http://yap.org.au>

The Geelong Young @ Park group meets on the second Thursday of each month over dinner. Sometimes they have a special guest or presenter on a topic of interest to the group, and other times they are content to share in good conversation and a good laugh!

For more information on either of these groups, contact the Health Team at Parkinson's Victoria, 1800 644 189 or info@parkinsons-vic.org.au.

THE 2013 VICTORIAN STATE ELECTION

On Saturday, 29 November 2014, Victorians will go to the polls and have their say on who should be our next state government. That date will be here before we know it, and there is much work to be done before it arrives.

The team at Parkinson's Victoria have been engaging with politicians from both sides of the aisle over the last six months in an effort to put the needs of the Parkinson's community on the agenda for the election, including research, supports and services.

We have met with the Premier of Victoria, Denis Naphine – who has his own family connection to Parkinson's – to discuss the strong need for Parkinson's nurses in Warnambool and across the state to support people with PD to manage their medications and symptoms more effectively, maintain independence for longer, and improve quality of life.

We have met with Assistant Treasurer, Gordon Rich-Phillips, as well as the Shadow Minister for Health, Gavin Jennings, advocating for better services and supports for the 20,000 people who rely on us every year.

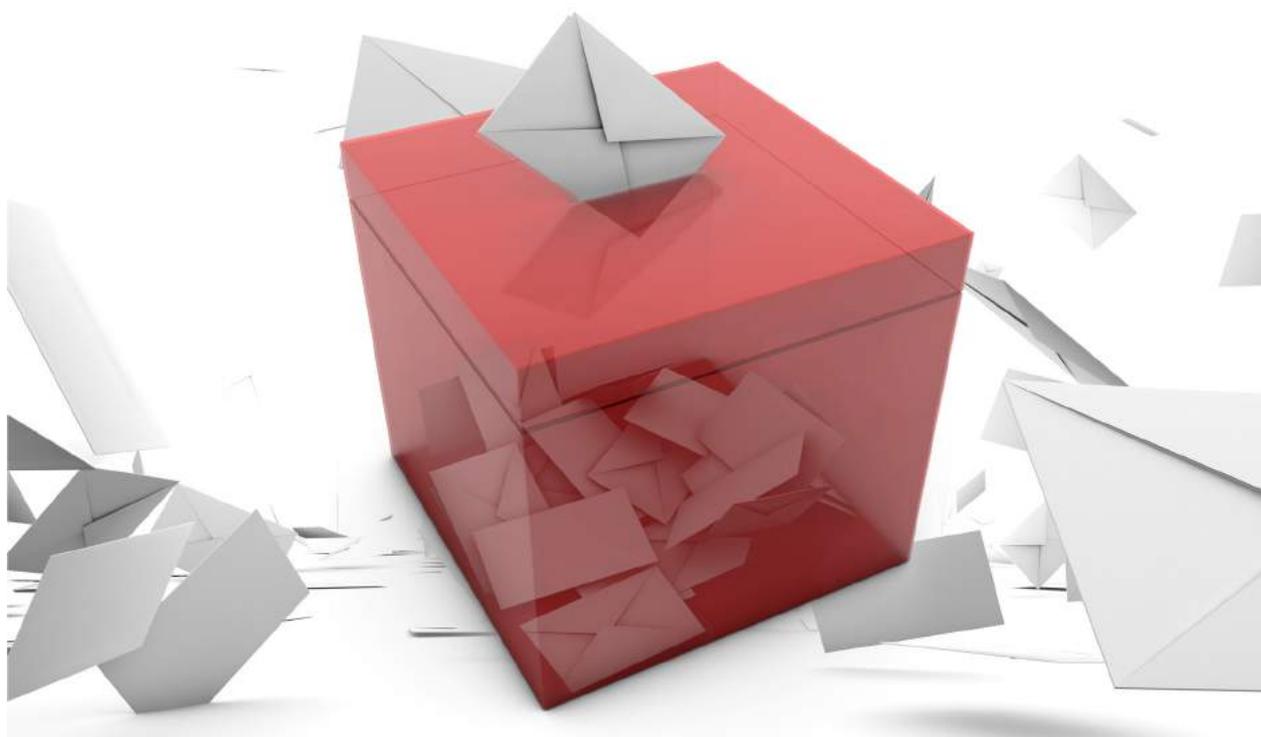
We are thrilled that the Camberwell and Ringwood support groups have arranged to meet with Andrea Coote, Parliamentary Secretary for Families and Community Services.

The list of things the government could and should invest in for people affected by PD is long. Right now, the key issues we're addressing with state politicians and policymakers are:

- Support for better medication and symptom management through increased availability of specialist Parkinson's nurses
- More funding for information and support for people with Parkinson's
- Access to counseling and education for people with Parkinson's and their families
- Greater access to allied health services and support

But the best way for us to advocate for the Parkinson's community is to hear from you!

What is top of your list? What are your key issues for this state election? Your stories can make all the difference in our campaign work. Contact us on info@parkinsons-vic.org.au or 1800 644 189 with your suggestions, thoughts and ideas.



TRAVEL: THE PRACTICALITIES

Living with Parkinson's doesn't have to stop you from participating in one of Australia's favourite pastimes... travel! Many people with Parkinson's continue to enjoy travel; with a bit of planning ahead, travel - whether it's local or long haul - can remain a part of your life.

Do your homework!

Research your destination, check out the Department of Foreign Affairs and Travel web site (www.smartraveller.gov.au). Invest in a guide book that includes information on accessibility, look online for reviews written by other travellers, and check out websites of attractions or places you're considering visiting.

Getting help in the planning can be useful; booking everything online can be tempting, but a travel agent can save you time and – believe it or not – money! Agents may also have some experience of your destination, and be able to let you know that the lovely hotel you are considering in London has impossibly small rooms!

Protection

Consider getting travel insurance early, and investing in a policy that includes cancellation. You will need to disclose that you have Parkinson's, and some companies will request a letter from your doctor or neurologist on your fitness to travel. Maurice Blackburn solicitors recommend shopping around, or using an insurance broker who will have good knowledge of the product available.

If you're travelling to a destination where you may need vaccinations, be aware sometimes you need to have these several months before you travel. There is little evidence identifying any vaccine or anti-malarial medication as affecting Parkinson's or its treatments, and most people have no difficulty. When you have your vaccinations, it is common to feel lethargic, unwell and sometimes feverish following the injection; for some people living with Parkinson's this may feel a little like your medications are wearing off. This feeling shouldn't persist for longer than 3-4 days.

Fasten your seatbelts

Many people with Parkinson's may feel they don't need special assistance from the airline, however this can be a valuable service. Common things to

request are: assistance from check-in to gate, or a seat close to toilets. If you'd like assistance, you or your travel agent should alert the airline when you book.

Bags packed? Don't forget your medications! You should have at least a week's worth of medications with you in your carry-on in case your luggage goes astray. It's also a good idea to have your medications in the original containers and bring your prescriptions. Taking an extra week's worth of medications is important in case of delays... or if you decide that an extra few days in Paris is a must!

At the airport, getting through security can be enough to cause anxiety in even the most seasoned traveller. Remember that the security officers may not be familiar with Parkinson's. When you're approaching security give yourself plenty of time, go through the normal procedure as directed. If you have problems with freezing, look ahead and concentrate on maintaining big steps as you walk through the metal detector. If you have had DBS you should not go through the metal detector or have them pass the wand over you, as there have been some reports of these instruments interrupting the stimulation. You will still have to go through security, but may need to be frisked instead. A letter from your doctor explaining you have an indwelling electronic device should be sufficient.

Juggling medications in other time zones can be challenging, and has the potential to throw your medication timing into disarray. While there is no hard and fast rule to follow, planning ahead is a good idea. Plan your sleep or rest times, so you know when to take less medication. When you are arriving or transiting you may need to take an extra tablet to get you through the airport, and to settle into your new time zone. Speak with your neurologist who can give you some tips on medications.

When you pack, don't forget our contact details! We can be emailed if you have any questions or concerns while travelling. Bon voyage! And safe travels as we go **here, there** and **everywhere!**

TRAVEL Q&A WITH KARYN SPILBERG

From diagnosis, Sir Zelman Cowen Award winner Karyn Spilberg has immersed herself in the national and international PD community and agenda. Karyn is a seasoned traveller and has travelled extensively since her diagnosis. Karyn sat with us to chat about her experience of travelling with Parkinson's.

Where have you travelled since your diagnosis?

I've been to America six times. I did a bike ride about 4 years ago in Vietnam for Parkinson's Victoria to raise money and awareness. I've been to Poland, which is where my father's roots are. I've done the whole Europe thing, including driving around the UK. We've also done Petra, in Jordan. I've been to Hong Kong, Canada, and Alaska. As well as going to the Northern Territory, and quite a bit of Australia.

Did you research your destinations, or did you just go and figure it out when you get there?

We plan it more. You've got to think about where you want to go. I'm going to Ireland in a few months; I know where I'm going to be every night, so I can plan ahead. You talk to people, and I get recommendations about the areas more so than the hotels; research is more about where I want to stay, the local area. I like to be near a station, usually.

What type of travel do you prefer? Active/ adventure, culture, relaxation?

I go for culture, not to relax. I go on local holidays to relax, but overseas I'll be on the go all the time. My husband is a bird watcher, so in Ireland we'll go and look at the birds, but I'm more into the castles, and I also want to get into the culture. In Berlin, I want to explore the Communist history. My husband also likes to paint, so we visit art galleries.

Why have you travelled so much over the last 10 years?

My neurologist said to me, 'You've got five good years – if I was you, I'd travel while I could'. I've been diagnosed for 10 years, but I took him to his word.

How have you found getting travel insurance with Parkinson's?

Well, you pay a premium. Last year, I had a trip booked and they just put a small premium on my

insurance cost. I recommend Covermore, though I have heard that other people have had problems with things like lost luggage, been given the runaround. But don't leave without travel insurance! If you apply and they don't give it to you, keep trying. Don't leave without it.

Do you have any tips on managing meds as you cross multiple time zones?

I have one of those pill boxes, the square one with seven days in it. I take one of those, and I just use my common sense. Like, if you take something four times a day, you might take it every four hours – maybe you have to take another one at some stage; when it's morning wherever you are, you take the morning tablets and continue from there. A bit of common sense. If I feel off, I take my tablets.

How is it travelling since undergoing Deep Brain Stimulation (DBS)?

I haven't been overseas in the last two years (since the DBS) so that will be interesting.

When I travel, all I do is say 'pacemaker to the brain' – the security people tell me they see 10-12 pacemaker people every day, so it's common. You get patted down, so you've got to allow for time – you have to be there at least two hours early.

Any other challenges when travelling? Managing fatigue or other symptoms?

Sleep is an issue for a lot of people with Parkinson's, and I don't sleep much. It is a worry, because I can't keep going like I used to... I have to plan a rest during the day. Planning is important. 20 minutes is all I need – just a catnap – but I need it because I really slow down.

Any other advice for Parkinson's travellers?

Do it while you can. I think people do realise that you have to travel while you can – it shouldn't stop you. I love to see new places, experience new cultures. Think simply, don't take too much junk with you.

Tulip Tribute

In November 2013, Alan Barber of Ocean Grove ran the New York Marathon to raise awareness and funds to support Parkinson's Victoria. Inspired by his friend Richard, who is living with Young Onset Parkinson's, Alan set himself a goal of \$10,000... and raised more than \$17,500. We caught up with Alan to find out more about the marathon, and what's next for him.



Where did the idea to run the New York Marathon come from?

I always thought I wanted to do the New York Marathon. About 6 years ago, I started running; you do a fun-run first, maybe a 5km, then a 10km, then you get up to a half-marathon, and then you say, 'Maybe I should do a marathon'. I sat up and watched the 2009 New York Marathon in the middle of the night on the internet, and thought, 'Right, I'm going to do this'.

How did you get in to the Marathon? Is there an entry process?

The only way for me to get into it was to go into the lottery; otherwise you have to have a ridiculous time qualification. So they have a lottery, which is 'three strikes, then you're in', so you apply three times, and then in the fourth year you're guaranteed an entry. Which is how I got in 2013.

The New York Marathon is famous for its crowds – what was the atmosphere like?

The atmosphere is incredible. You run through all five boroughs... and finish in Central Park; you're not less than three people deep the whole run. And every time you engage with the crowd – you high-five the kids, and the adults go to high-five you, too

– it gives you a lift, and off you go again. It's the closest I've ever come to being a rock star.

It's so international, as well. We were members of a Facebook group, and it had members from Peru, Africa, Afghanistan and all over America. Most of us met up in Central Park the day before the run.

So you were set to run the Marathon in 2013, and the fundraising idea came next?

As soon as I got the entry, I thought I'd like to be able to raise some money for something close to me... Then a good friend of mine was diagnosed with Parkinson's; Richard was diagnosed at just 48, and I thought, 'Okay, there's something I should look at'. When I spoke to Richard about it, I said that I wanted to raise money for Parkinson's and he was completely supportive. I didn't want to load him up with anything, but he grabbed it and carried it himself. It ended up quite a good partnership.

We've been trying to raise awareness, more than fundraising. The fundraising has been good, but for me, the opportunity has been to get people talking about Parkinson's.

What was the community response like?

What became apparent quite early on was that if I'm going around saying to people that I'm fundraising and raising awareness, then I had to make myself much more aware, because every time someone asked me, "Why Parkinson's?" I thought, 'I have to have some information to give them'. I was amazed, because I was able to have a decent discussion with people when they asked about it, and by doing that people come out of the woodwork who have had experiences with a parent, or their uncle, or someone they knew; so many people had a connection with Parkinson's somewhere along the line.

Your fundraising efforts were fantastic – to the tune of around \$17,500 – how did you do manage it?

The shirt was a good boost – we got about \$1000 for the shirt, and then that gave us some momentum. We had the first proper fundraiser night – we had some bands playing, raffles, silent auction, that sort



of stuff; I think we raised around \$2,000. The soccer club did a sausage sizzle at one of their events; the junior football club did a sausage sizzle; the cricket club had a raffle and auctions – they raised about \$2,000; the Rotary Club made a donation of \$1,000 to put their logo on my shorts; another fellow paid \$1000 to have his logo on my beanie; also, the local Athlete's Foot donated my runners for the training.

We also got donations along the way... I was pretty blown away. Every once in while I'd be out doing photos for the local paper; I'd turn up for a choir practice or something, and at the end of it, there'd be an envelope, where they've all put in \$5 or something. How nice is that?

You're doing more than raising funds and awareness – you're also advocating for a specialist nurse for the Geelong/Barwon region. Why did you choose that as your goal?

I've never been one for shaking a tin to raise money for health; I think governments should be paying for it, and that whatever we raise is going to be a drop in the ocean; but the more we raise, the more we can go back to government and say 'Look, this mattered to the local community, and you need to be chipping in yourself'. That (advocating for a nurse) came out of me talking to people around here who are living with Parkinson's; it came across to me as a really good, tangible way that we can take some action to improve the lives and independence of people around here. It's just so logical – at the end of the day, if governments can see the benefit in saving themselves money, let alone improving the lives of local people, it's a no-brainer.

Are you proud of your achievements?

What we're so proud of is that we've been able to engage so many different organisations and age groups – everything from junior footy to the church to Rotary, to Lion's Club, builders, retailers, all sorts

of people have got involved. It's been really, really good.

There is a positive vibe that comes out of the community when people come together and do things for each other. I think when you've got people who are very positive, like Richard, everyone gets a certain amount of inspiration and it can generate something else that you weren't really planning. I've been lucky to be part of the dynamic thing that's happened here; rather than thinking you can do it all by yourself, there's a whole heap of people, and some of them are very talented people with skills you can tap into. I think that's the special thing in all of it - people step forward.

What's next for Alan Barber?

One of the things that has come out of this is an organisation in America that we've connected with, called the Light of Day Foundation, which raises money with music festivals. They're based in New Jersey, and for the last 14 years they've had music concerts at Asbury Park. The fellow that started it up was a music promoter at Asbury Park who was diagnosed with Parkinson's; he had a birthday party, and a whole bunch of musicians that he had worked with turned up and they had a great big party – and he said, 'Oh, we should do this every year!' and that's where it's grown from. They now have them in Canada and a number of places in Europe.

One of the things we're hoping to do is bring one to Australia; it would be Light of Day Australia. If we can get this music thing going, we can get a whole new audience involved. We want to attract some big names to put it on the map, and hopefully the next year people will be lining up to get in. We've got a bit of planning to do. You've just got to have a go – with these things, we've found, once you get the momentum locally... you grow from there.

Peer Support

IDEA X-CHANGE

Some of the best ideas for running a support group come from the support groups themselves!

Be inspired by updates from support groups across the state:

- As their meetings are held on the first Tuesday of each month, the **Portland Parkinson's Support Group's** November meeting fell on Melbourne Cup Day. The group celebrated the day with raffles, sweeps, afternoon tea, and wonderful company!
- In December, the Parkinson's Singing Group **ParkinSong Victoria** sang Christmas carols to residents at a Williamstown aged care facility
- While many of our support groups didn't meet in January due to the holiday season, some groups took the opportunity to have a more casual meeting, such as a summer excursion to their local beach or community pool, or even a traditional BBQ on Australia Day!

FUN-raising

The Shepparton & District Parkinson's Support Group continue to stir the pot – at least as far as cookbooks go! Raising awareness while raising funds, the group have sold hundreds of copies of their *Just Soup* cookbook since its launch in 2013!

In the spotlight

Camberwell Parkinson's Support Group

Meeting monthly at St Mark's Hall, the Camberwell Parkinson's Support Group welcomed many guest speakers throughout 2013, such as movement disorder neurologist Dr Katya Kotschet, and celebrated the end of the year with an outing to Werribee Zoo (with the generous support of the Boroondara council).

On 6 December 2013, members of the Camberwell group, along with the former President of Parkinson's Victoria, Peter Raymond, and Parkinson's Victoria staff, had morning tea with the Honourable Josh Frydenberg MP – the Federal Member for Kooyong and the Parliamentary Secretary to the Prime Minister. This provided an invaluable opportunity to discuss issues important to people with Parkinson's, such as the lack of

awareness of Parkinson's in the community, the need for more research funding, the financial costs of Parkinson's and the limitations of the NDIS in relation to Parkinson's. The event also featured Mr. Frydenberg's photography, and information on the history of Kooyong!

Acknowledgements

Around 1200 people with Parkinson's and their partners attend the 58 Parkinson's peer support groups that operate around Victoria. Parkinson's Victoria would not be able to support so many without the help of the wonderful people who coordinate, facilitate and provide assistance to these groups.

We would like to thank the following people for the leadership, dedication and compassion they have shown within their groups and their communities:

- Indra Jury: Yoga for Parkinson's Camberwell

In 2013, Indra Jury ran a *Yoga for Parkinson's* group in Camberwell. A physiotherapist, yoga instructor and a person living with Parkinson's, Indra's unique skills and insight saw her run the sessions sensitively, professionally and with great success.

- Ainsleigh Skeels: Lakes Entrance Parkinson's Support Group

Ainsleigh coordinated the Lakes Entrance Parkinson's Support Group for 18 months; in that time, she organised exciting events such as an art therapy group, and an art show and information seminar to coincide with World Parkinson's Day 2013.

- Jackie Bickerton: Kororoit (Melton) Parkinson's Support Group

Jackie coordinated the Kororoit (Melton) Parkinson's Support Group from the time of its inception in 2008. In her time with the group, Jackie organised everything from wonderful guest speakers, to the sale of tulips to raise money for the group and Parkinson's Victoria.

- Geoff Alexander (Leader), Rob Stone (Treasurer) and Rob Squire (Chairman): Shepparton & District Parkinson's Support Group

Geoff Alexander and his committee members, Rob Stone and Rob Squire achieved some wonderful advances for people with Parkinson's in Shepparton and the surrounding district. In the last couple of years the group have fundraised over \$60,000 which, in conjunction with their active lobbying and the support of Parkinson's Victoria and Goulburn Valley Health, has seen the trial commencement of a dedicated Movement Disorder Nurse for the region.

During their time as leaders they have worked tirelessly to raise awareness and increase the support available to those living with Parkinson's in their community.

Advice for running a successful Support Group

Each group has its own copy of the Parkinson's Victoria Support Group Manual. Don't forget to make the most of this comprehensive resource! "Section 3: Running Meetings" is particularly good as you plan the year for the group, with suggestions for meeting activities and guest speakers.

DISCUSSION QUESTIONS...

The following are a few questions that you might like to ask your group members as a way to help them get to know each other and to stimulate discussion.

1. What do you now know that you wish you had known when you were first diagnosed with Parkinson's?
2. Share a story of how someone (friends, family, colleagues) responded positively when you first told them of your Parkinson's diagnosis.
3. If you were a celebrity, what 3 things would you tell the public about Parkinson's?
4. What is your 'had no choice but to laugh about' Parkinson's moment?
5. If you had 3 wishes, what would you wish for (and don't get tricky with a wish for 3 more wishes!)?

The start of the New Year is a good time to take stock of how your group is going. Do you have a balance between information sharing - such as that provided by guest speakers - and socialisation - the opportunity for group members to talk to each other and participate in fun activities together?

You might like to consider getting members to fill out a survey or anonymous ballot at the next meeting to determine what they are after, and if there is anything the group would like to do differently. A survey does not have to be long, but may be something like this:

Would you like our support group meetings to have more:

- Guest speakers on Parkinson's topics
- Guest speakers on other topics
- Activities and outings
- Time for group and individual discussions
- No, I'm happy with our meetings the way they are

Do you have any suggestions for guest speakers? Do you know of anyone who might come and speak to our group?

Would you like our support group to be involved in awareness and fundraising?

- Yes, more fundraising activities
- No, fewer fundraising activities
- I'm happy with what we do at the moment

Additional comments:

Giving members the chance to provide feedback on how your support group runs not only helps ensure everyone has a say in the running of the group, but may also turn up some great ideas for your next meeting!

Events

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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.

SUPPORT FOR THE WHOLE JOURNEY

Events for different stages of Parkinson's

Recently diagnosed (less than 5 years)

Events

Recently Diagnosed Seminar

Saturday 15 November

Further details will be available soon

This annual event in Melbourne is tailored specifically to people who have been diagnosed with Parkinson's in the last five years, as well as their family and friends. It is an excellent opportunity to learn more about living with Parkinson's from experts, have your questions answered, and meet others facing the same day-to-day challenges.

Living with Parkinson's for some time (more than 5 years)

Events

Living Well Seminar

September 2014

(exact date to be confirmed)

Further details will be available soon

This seminar is designed to meet the needs of people who have been living with Parkinson's for more than five years, and want to increase awareness of treatment options and effective symptom management. There will be two components to this seminar, with a portion for health care professionals, and one for people with Parkinson's and their carers. Topics will cover latest treatments, support, and planning for the future.

Parkinson's Community Seminar (and New Support Group) - Lancefield

Wednesday 12 March 2014, 12.30pm
to 3.00pm

Lancefield Neighbourhood House,
78 High Street Lancefield

Cost: Gold coin donation

Join us for an informative and friendly community seminar where members of the Parkinson's Victoria Health Team will talk about

Parkinson's disease, the latest treatments, and relevant support services in Lancefield area. We are also seeking expressions of interest in forming a local Support Group. RSVP is essential. For more information or to reserve your place, contact the Health Team on (03) 9581 8700 or email info@parkinsons-vic.org.au

A special international event

Parkinson's Program Cameroon

In March 2014, Breanna and Victor from the Health team will join the Movement Disorder Society in an exciting international initiative at Laquintinie Hospital in Douala, Cameroon. From Melbourne, Breanna and Victor will deliver a 2-hour webinar education session focussing on cognitive changes in Parkinson's and strategies to help overcome them. Douala is the largest city in Cameroon, and is the major health centre for much of the country.

Other special events

PSP, MSA and CBS Carers Seminar

Friday 28 March

PSP Australia, in partnership with Parkinson's Victoria, will be presenting a seminar in Mordialloc specifically for carers of people living with the atypical conditions of PSP, MSA and CBS. For more information contact Parkinson's Victoria, or visit the PSP Australia website, www.psp-australia.org.au.

Essendon Painting with Parkinson's Exhibition Launch

Friday 11 April 2014

The Essendon Painting with Parkinson's group was recently awarded an exhibition space in the Moonee Valley City Council's art gallery; the exhibition, called 4 Seasons in 3 Scapes will officially launch with a free event on 11 April 2014. Visit www.incineratorgallery.com.au for more details.