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Unity Walk: making things possible

What does Unity Walk mean to you? Is it a chance to come together with family and friends? To remember someone special? To show you care? To raise money to help fund important research and services? Is it a chance to make some noise about Parkinson's? To increase awareness? To feel like you are making a difference? To feel a part of something 'bigger'? To remind others they are not alone? To remind yourself?

We believe Parkinson's Unity Walk means all these things, and...that it makes things possible. And the most important thing is change.

Parkinson's Unity Walk has the power to create change; for the individual, and from the general public right up to the big decision makers of our community; corporate Australia and Government.

Change rarely happens like a tidal wave. It usually starts with a trickle. It's like adding pebbles to a scale to make it tip – you keep adding pebbles, one at a time, until it reaches a tipping point – and suddenly, it happens. Change. The balance tips and everything has a whole new perspective.

Every action we take, every noise we make, every media story, every member, every letter to Government, every pair of feet walking on Sunday, 28 August, is another pebble tipping the scale to increase awareness, funding, support services, and "a better deal" for people living with Parkinson's. As long as it is constant, momentum builds. As long as it is consistent, the message will get through. As long as numbers grow, influence is inevitable.

Parkinson's Unity Walk brings together an incredible, dynamic, powerful, passionate and resolute community.

And **together**, we make a difference.

How does yesterday differ from today? How will today differ from tomorrow?

Every day, Parkinson's Victoria is working hard to create, facilitate and instigate positive change for all those living with and affected by the impact of Parkinson's.

Parkinson's Unity Walk is a powerful opportunity to drive change at the grassroots level – but we can only do it with **your** support.

Parkinson's Unity Walk is YOUR event, and whether or not you are able to participate personally on the day, it is so important that you get behind this unique event that firmly positions Parkinson's under the public spotlight and shouts, loud and proud: "We're here. We matter. We deserve to be seen and heard".

Parkinson's Unity Walk makes the *invisible*, **visible**. Won't you join us on this journey? You could be the pebble that tips the scale. What would that mean to you?

Parkinson's Victoria is grateful to the following sponsors, without whose support Unity Walk would not be possible:

Associate Sponsors

- MECU
- Outlook Financial Solutions
- Martin & Pleasance
- St Jude's Medical Australia

Sponsors

- Australian Unity Retirement Living
- City of Melbourne
- Boehringer Ingelheim
- BUNZL Australasia

We look forward to continuing our partnership with these valuable and influential companies and organisations, as we work towards creating positive and lasting change for all people living with Parkinson's.

News & Highlights

New support for Tasmanians living with Parkinson's

The valuable role of Parkinson's nurses in improving the care of people with Parkinson's was raised during the 2010 Tasmanian state election and funding the role received bi-partisan support.

As a result, three nurses have been appointed to provide state-wide specialist support to those living with Parkinson's and other neuro-degenerative illnesses such as Multiple Sclerosis (MS), Motor Neurone Disease (MND) and Huntingdon's disease.

Parkinson's Victoria, in collaboration with Parkinson's Tasmania and clinicians from the Royal Hobart Hospital, worked closely with the new team to provide training and assistance to ensure the nurses are able to respond to key client needs with a best practice approach.

Funding for more specialist nurses in Victoria and around the country continues to be a top advocacy priority for all state Parkinson's organisations.

Parkinson's message loud & clear

Some recent media interviews that can be accessed online (podcast, transcript and video):

7.30 Report (July 26) Parkinson's drug accused of inciting compulsive behaviours:

<http://www.abc.net.au/7.30/content/2011/s3278637.htm>

The Pulse (Geelong community radio) (July 20)
Interview with Parkinson's Victoria and Young @ Park Members:

<http://947thepulse.com/programs/roads-to-recovery.html>

Everyone can help make a difference

If you are a member of a club or organisation you may be inspired by the ideas and actions of some of this edition's **TULIP TRIBUTE** recipients (read more on page 20) and we'd be happy to discuss how you too can support our work. You may like to invite an Ambassador to share their personal story, host a special event fundraiser, or simply ask for a gold coin donation to Parkinson's Victoria at your next meeting. Perhaps there is an event you already host regularly that you could enhance by making it a **'fundraiser' for Parkinson's Victoria?** You may like to suggest to your club or company that they purchase this year's Christmas cards to support us!

Please contact Judith Mooney, Marketing and Fundraising Coordinator: (03) 9581 8700 or email judith@parkinsons-vic.org.au

Special events

If you're keen to try something different, why not support one of these terrific fundraising events, knowing you're also supporting Parkinson's Victoria!

☛ **Dartmouth Women's Fishing Club annual Fishing Classic;** a weekend-long "catch and release" competition with auctions, raffle and a dinner, plus \$15000 in prizes (11 and 12 November, Dartmouth). For more information contact the Club: Robyn 02 6072 4233 or Ebony 02 6072 4213 or register online: www.dartmouth.net.au

☛ **The Handweavers and Spinners Guild of Victoria has organised a** "Footy Woolies" exhibition (during the month of September), PLUS a "Bad Taste Fun Day" (Friday 23 September, 10.30am-2.30pm, \$5 entry) with special guest speaker, Dr Juliet Taylor, Medical Researcher (with a focus on Parkinson's) at Melbourne University, plus games, shared lunch, raffle prizes for the worst dressed outfits and special prize for the best Crimplene ensemble. Guild Rooms: 655 Nicholson Street, Carlton North); enquiries (03) 9387 9222 or www.vicnet.net.au/~handspun/

Get it on Time survey

Parkinson's Victoria is conducting an online survey to collect data from people with Parkinson's regarding their experience "getting medications on time during a hospital stay". We are encouraging participation from members and the wider Parkinson's community to ensure the survey sample is extensive and representative of all regions.

The survey is part of a major review of our **Get it on Time Project** (launched in 2006), which aims to improve education around Parkinson's medication in the care environment, whether hospital, respite or nursing care. This phase of the project is being undertaken by two second-year Monash Medicine students who are currently on placement at Parkinson's Victoria.

Please visit our website to participate in this important research project and to share your valuable experiences: www.parkinsonsvic.org.au

Click the link on the homepage to complete the brief survey, which should take approximately 5-10minutes. Your answers will be treated with the utmost confidentiality and the survey is completely anonymous.

For people who do not have access to the Internet, please contact the Parkinson's Victoria Health Team, who can send you a hard copy.

New home, same committed service

Parkinson's Victoria relocates and opens headquarters to the public.

On Monday, 1 August, we hosted an Open Day to officially welcome the community to our new office, located in the hub of Cheltenham's shopping precinct.

The recent office move has seen relocation from the grounds of the Kingston Centre health facility to a ground floor office with excellent disability access, not to mention improved visibility for the organisation.

"Our focus is providing comprehensive, reliable and useful information and support services to all people living with Parkinson's, as well as health professionals who work with Parkinson's clients and patients," said CEO Ann Burgess.

"And while our office is based in Cheltenham, our team services all of Victoria. We auspice 47 regional and metro Support Groups, and our health team is often on the road visiting local communities and health care facilities. Our free telephone help line and website provide information and support to people not just around the state, but nationally, and even internationally".

The new facilities include an extensive resource library, meeting rooms for visitors to meet confidentially with the health team, and an on-site "media" room where the team can create information videos about Parkinson's which can then be uploaded to the website www.parkinsonsvic.org.au

The Open Day provided the public with the opportunity to meet the Health Team, as well as Ambassadors and Support Group leaders and members. Visitors also took a guided tour of the office and learnt about the comprehensive range of support services and programs. Highlights from the 2011 Annual Movement Disorder Society Congress (held in Toronto, Canada) were presented by Victor McConvey from our Health Team (*read more about the Congress on page 16*).

"We are excited at the prospect of being able to better serve the Parkinson's and wider community from our new offices and look forward to becoming an integral part of the local community. We hope local residents and retailers will also assist in raising awareness of Parkinson's by letting people know we're here to help," said Ann.

We look forward to hosting more 'open days' in the future.

Please note our new details are:

- 📍 **Street address: 8b Park Road, Cheltenham, 3192 (near the intersection of Charman and Park Road, opposite the Caltex service station. Free street parking)**
- 📍 **Postal address: PO Box 2606, Cheltenham, 3192**
- 📞 **Phone: (03) 9581 8700**
- 📞 **Fax: (03) 9583 9952**
- ✉️ **Email: info@parkinsons-vic.org.au**
- 🌐 **Website: www.parkinsonsvic.org.au**

Advertisement

We offer specialist massage & acupuncture for Parkinson's disease

As part of our commitment to offer people living with Parkinson's disease (PD) the highest level of care at Neurology Network Melbourne we have developed a program that takes advantage of the proven health benefits of massage and acupuncture: non-drug treatments for PD. Massage has been shown to reduce muscle pain and stiffness. Specifically in PD, massage appears to mildly reduce symptoms for at least one week following treatment.¹ Acupuncture is established as a non-drug treatment for many of the muscle and orthopedic injuries that are common in PD (e.g. frozen shoulder, joint and muscle pain). It appears to improve the 'quality of life' in people living with PD.²

Our Parkinson specialist massage therapist and acupuncture doctors welcome all enquiries, as no GP referral is needed

Medicare and Health Fund rebates apply to most treatments

Massage	Jennifer Drummond
Acupuncture	Dr Michael Ben-Meir MBBS FACEM Dr Allen Yuen MBBS FACEM
Neurologists	A/Prof David Williams PhD FRACP Dr Kelly Bertram MBBS FRACP Dr Saman Punchichewa MBBS FRACP

neurology
network melbourne
Call (03) 9500 8366
www.neurologynetwork.com.au

References: 1 Movement Disorders (2006), 2 Journal of Complimentary and Alternative Medicine (2006)

Events & Fundraising

Throughout the year, we host a number of special events and fundraising activities to raise vital funds to support our information and service programs and initiatives. They also help connect our community and help raise awareness of Parkinson's in the wider community.

Here is a snapshot of past events and upcoming activities, there's something for everyone!

Off to the movies

Over winter, Parkinson's Victoria held two charity movie screenings, enjoyed by all who attended.

On Sunday 3 July, a throng of Lightning McQueen fans swamped the Dendy Cinema in Brighton to be the first to see Disney Pixar's animated smash hit sequel, **Cars 2** (right).



On Thursday, 21 July, we were fortunate to be able to screen a preview (two weeks before its official release) of the thought provoking movie: **The Beaver** starring Jodie Foster and Mel Gibson. A glass of wine and delicious cupcakes were enjoyed by all.

We are grateful to Palace Cinemas for their continued support, and the following companies for donating generous raffle prizes: Luna Park, Puffing Billy, Collingwood Children's Farm and the Cotton on Foundation. Congratulations to all the winners of those great prizes!

A special Christmas message

Show your support for people living with Parkinson's and help spread a message of awareness and understanding this festive season by purchasing our Christmas cards. Our new range includes 2 cards exclusively designed for Parkinson's Victoria by artists Jean Smith and Anne Atkin – **thank you Jean and Anne for your beautiful designs.**

The sale of all cards helps fund the information, education and support services of Parkinson's Victoria, and will raise awareness about Parkinson's.

GREAT SCOTT! Don't miss this one...!

In November, we invite you to take a ride with us, Back to the Future!

We'll be hitting 88 miles per hour and breaking through the time barrier on **Saturday, 5 November at the Astor Theatre** in St Kilda when we host an exclusive screening of the one and only **Back to the Future** trilogy! This is the first time the films have been screened at Victorian cinemas since they were originally released in 1985, 1989, and 1990 respectively.

This iconic movie, which celebrated its 25th anniversary last year, stars Michael J Fox, who has been living with Parkinson's for many years. And for the real cinephiles, you'll be excited to learn that we have secured a brand new digitally re-mastered print that will come to life on the Astor's state of the art Barco 4K 32B projector. This state of the art equipment boasts four times the resolution of the industry-accepted standard of 2K (which is what you'll get in every other digital screen in Australia).

Get into the spirit of the event and come dressed as your favourite character or period from one of the films (1950s, 80s, cowboy or future!) and have a chance to win a fantastic prize. There'll be other fun competitions on the day, the chance to write a special message to Michael J Fox, share your favourite Back to the Future moment and one of the highlights is sure to be... having your photo taken with one of THE stars of the film, the ORIGINAL time machine; Doc's **DeLorean**

See one film or see the trilogy, either way, it's going to be a colossal charity screening event. All films are rated PG.

Register your details today at info@parkinsons-vic.org.au (write **Back to the Future in the subject line) to be one of the first to find out when registrations will open. All tickets available for sale ONLINE only.**



*Judith Mooney, Marketing and Fundraising Coordinator, has been a BIG MJF fan since the days when mullets were considered trendy! Here she proudly shows off a TV Week poster of her first true love. Fast forward 27 YEARS and... well you'll just have to get along to our **Back to the Future** event to find out what her hair style looks like now!*

Events & Fundraising

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



Cards can be purchased securely online at www.parkinsonsvic.org.au or contact our office for an order form. Alternatively, you can purchase our cards from the following outlets:

- St Paul's Combined Charities Christmas Card Shop, Myers Street, **Bendigo**
- Mornington Community Information and Support Centre, 320 Main Street Mornington
- Camcare Combined Charities Card & Gift Shop, 19 Fairholm Grove, **Camberwell**
- Ballarat** Combined Charities Card Shop, 27 Magpie Street
- Banyule** Support & Information, 101 Burgundy Street, Heidelberg

A vine romance

Just a few more days left to take up the fantastic offer from Gisborne Peak Winery, a stunning vineyard located just out of Melbourne (20 minutes from Tullamarine Airport).

Throughout the month of August, as part of their **Action Day For Parkinson's initiative**, they are offering a special on their **Adopt-a-Vine™** program: Fifty dollars from every vine "adopted" during this month (RRP\$75) will be donated back to Parkinson's Victoria when you mention our name! What a great gift idea – perfect for Father's Day (Sunday, 4 September).

Adopt-a-Vine™ is fun, yet educational too. Adopt a red or white grape variety (adoption rights are for three years) and receive an Adoption Kit with information and pictures. You'll also receive:

- Personalised Hang-tag (on the vine) and Adoption Certificate
- Adopt-a-Vine® Newsletters

- Chance to order personalised wine labels
- Hands-On Days** in the Vineyard (including the chance to prune your vine in winter, with a lesson from the vineyard manager - of course! And pick the grapes from your vine at vintage)
- A 25 percent discount on wines purchased (for the three year period)
- First notification of wine specials and events
- Option to receive a bottle of wine from the grapes where your Adopt-a-Vine® is located.

One Step at a time

If you haven't already received our latest **Steps** donor update newsletter in the mail, keep an eye out: It's filled with news about what our team has been up to, including a 'day in the life' of our health team, the value of becoming a member, and how important your continued support is.

We believe it's important for you – our valued supporters and members of the Parkinson's community, to know what we've been up to and how your past support has been put to use, helping us to provide essential support and information to those living with Parkinson's. **Steps** is our way of sharing news and updates with you, and reassuring you that your contribution is making a real difference.

If you would like to read Steps and do not receive your copy in the coming weeks, please contact our office to request a copy is sent to you today.

Award for partnership

People living with Parkinson's now have access to specialised financial guidance, thanks to a partnership between Parkinson's Victoria and Outlook Financial Solutions.

The significance of this partnership and its positive impact for the community was recently acknowledged with a 2011 Rotary Southbank Community Service Award for **Aged Care & Community Support**.



Scott Brower, Senior Financial Adviser, Outlook Financial Solutions, with Kate Brown, Parkinson's Victoria Vice President, during the award ceremony.

Health & Wellbeing

Improving your Quality of Life

Health-related quality of life (HRQOL) is how a person perceives their health and well-being to be in specific areas of daily life that are important to them.

Parkinson's symptoms can compromise HRQOL by making it difficult to participate in valued activities and roles in the home and community life. Yet, individuals who feel mastery over life activities and maintain participation in them experience less depression and improved 'well-being'.

It stands to reason therefore, that effective management of Parkinson's must involve promoting a sense of control in valued life domains that realistically are within the person's capacity to influence.

A study published in the **Movement Disorders Journal** (vol 25, No2, 2010 P194-204) looked at a multi-disciplinary team of physiotherapists, occupational therapists and speech therapists who put into practice methods designed to improve **HRQOL** in community-dwelling adults in early-to-middle stages of Parkinson's by promoting their ability to manage daily life in valued areas.

Participants were taught how to observe their own behaviour, identify strengths and problems in mobility, communications and activities of daily living, set realistic goals to manage these problems and implement action plans.

They practised evidence-based exercises and activity-modification strategies that could be incorporated into their daily routines.

The goal of the study was to see if such rehabilitation could promote **HRQOL** beyond best medical treatment alone.

Participants were divided into three groups:

- ☞ One group had no therapy.
- ☞ One group had 2 x 1 and a half hour sessions in a clinic, each week for 6 weeks.
- ☞ One group had 2 x 1 and a half hour sessions in a clinic each week, plus a third, 1 and a half hour session in their homes to consolidate what was learned in the clinic.

Each clinic session involved physical exercises, speech exercises, functional training and a discussion about self management strategies.

Participants were taught to problem solve by asking themselves a key question "Can I change something about **myself**, about the **task** or about the **environment** to improve my ability?"

*For example: They could elect to increase their speech volume (change **self**) by doing speech exercises, or to change their method of rising from a chair (change **task**) to improve their function, or they could choose to wear a coat lined with satin instead of lined with felt (change their **environment**) to help them put on a coat.*

Results of the study showed that only 18 percent of those patients who had no therapy (and only continued their current medical treatment) showed improvement, whilst 53 percent of participants in

rehabilitation showed improvement. The difference of these two rates is 36 percent, the absolute benefit increase due to rehabilitation. Domains that improved the most from self-management rehabilitation were communication, mobility and activities of daily living.

Unfortunately, the study also showed that improvements declined each time at the 2 month and 6 month reviews, which implies that individuals would continue to decline over time without any booster sessions. This is a well known phenomenon, and shows how important it is to participate in ongoing maintenance sessions of therapy.

Reading the results from this study compels us to think about what we can do to improve our own **HRQOL**.

The first way would be to get in touch with a movement disorder clinic or community health centre that has experience treating people with Parkinson's, and start getting therapy, as outlined above. This may be your first time employing such techniques, or if you used them a long time ago, it might be a good idea to have some booster sessions if you think your function is starting to slide.

Another thing you can do is ask yourself exactly what was asked in the study: "**Can I change something about myself, about the task or about the environment to improve my ability?**"

This question is so powerful because it can be applied to an entire spectrum of activities that we do each day, from writing a cheque to how we brush our teeth. Sometimes the answer may come quickly, other times it may require thinking outside of the box. Asking that question to someone else can help generate ideas that you may not have thought of on your own.

Either way, this study teaches us that rehabilitation which involves both problem-solving, as well as physical exercises will help improve a person's function well beyond medical treatment alone.

For information about Movement Disorder Clinics or suitable community health centres, contact our Health Team: (03) 9581 8700 or email info@parkinsons-vic.org.au

Tai Chi and Parkinson's

The **Tai Chi for People with Parkinson's** classes will continue to run at Oakleigh Rehabilitation Programs, 68-72 Atherton Road, Oakleigh, with input from Parkinson's Victoria.

This program is based on Dr Paul Lam's **Tai Chi for Health**, which was developed together with a team of tai chi experts and medical specialists. It is a safe and effective program which has many diverse health and lifestyle benefits including:

- ☞ Improving mental and physical wellbeing
- ☞ Improving balance and mobility
- ☞ Improving coordination
- ☞ Promoting relaxation and alleviating stress

If you would like more information contact Anastasia at the Oakleigh Rehabilitation Programs: (03) 9568 0466

This is our quarterly column dedicated to Volunteering for Parkinson's Victoria; keeping you up to date on volunteering opportunities and highlighting the invaluable contribution of our ever growing team of selfless volunteers. Compiled by JOSEPHINE BERTHELEMY, Volunteer Coordinator and Fundraising Events Assistant.

Thank you

Firstly, a word of thanks to all the wonderful volunteers who assist at our fundraising events throughout the year.

The success of these activities rides on the invaluable contribution made by our volunteers. What we achieve is not only raising funds to support those living with Parkinson's, but building awareness of Parkinson's in the wider community. The more donations we collect when shaking tins, or the more sausages we sell at a Bunnings barbeque – enhance and strengthen awareness of the Parkinson's cause and Parkinson's Victoria, reminding people of the organisation that is here to help.

Many volunteers come back from an event with stories of the personal connection they have made with someone who has been touched by Parkinson's. Hearing someone say "My grandfather [or other loved one] has [or had] Parkinson's" as they drop a gold coin into our collection tin or they buy a sausage is becoming more and more common. The volunteers always enjoy the gratifying and rewarding experience of having given a few hours to help make a difference.

All our volunteers are dedicated, sensitive and receptive as they represent us in the community – and they are to be commended for their efforts!

On **Saturday 6 August**, we conducted our first ever **Tin Rattle** on the famous hallowed turf of the MCG. Much anticipation surrounded the round 20 game between Carlton and Melbourne (*who that week were in the midst of administrative crisis!*) Volunteers endured the wintry conditions and helped collect a grand total of **\$2,328.75** – an extremely rewarding result.... Also on that busy weekend we hosted a **Charity Sausage Sizzle** at Bunnings Moorabbin on **Sunday 7 August**. That too was a frenzied day of fundraising, making a worthwhile profit of **\$1,503**.



Volunteers during our recent Charity Sausage Sizzle at Bunnings Moorabbin.

Parkinson's Awareness Week Tin Rattle

This takes place on **Thursday, 25 August** at various CBD and metropolitan train stations, and we hope to better April's total of \$6,527.65.

We will give you an update on results in our next Signpost.

Unity Walk

The big one on **Sunday 28 August!** We need 120 volunteers to assist with registration, course marshalling, distribution of T-shirts and show bags, on the day. Shifts are between 7.30am and 2.30pm at Federation Square in the city.

Spring time twilight Charity Sausage Sizzles

It's spring; the birds are singing, the trees are blossoming and the hungry tradies are visiting Bunnings stocking up on supplies!

Bunnings Mentone has generously offered us the opportunity to host two barbeques between 10.00am and 5.00pm on **Friday 16 September** and **Friday 14 October**.

Please let me know if you can help cook sausages and serve customers for a few hours on either date. You might like to follow the great example of **Zacks Gourmet Meats** in Research, **Morris Meats Supplies** in Mentone, and **Crisp'n'Fresh** in Parkdale who donated goods for our August BBQ! Please let us know if you can help out with a donation of suitable goods (onions, sausages, bread, condiments, napkins etc). Either way, we'd love to see you on the day. Feel free to stop by, say 'g-day' and thanks to our volunteers, and of course, buy a snag!

If you would like to volunteer contact Jo Berthelemy, Volunteer Coordinator: (03) 9581 8700 or jo@parkinsons-vic.org.au

We express our sincere thanks to the following organisations, which have generously supported our recent fundraising efforts:

- ✦ **Citywide** created a magnificent adaptation of the Parkinson's Victoria logo on the St Kilda Road flower bed during the autumn months.
- ✦ The **AFL** and **MCC** for helping make our MCG tin rattle such an easy and smooth running event to coordinate.
- ✦ **Puffing Billy Railway; Luna Park** and **Collingwood Children's Farm** for kindly donating family vouchers for the 'Cars 2' movie event held on 3 July.
- ✦ **Café Florentine** and **Ella & Friends** for their generous vouchers, used as prizes for 'The Beaver' movie night held on 21 July, and **Martin & Pleasance** for their generous supply of showbags.
- ✦ The unwavering support of **Bunnings Moorabbin** and **Bunnings Mentone** and all the suppliers who donated goods for the sausage sizzles: **Zacks Gourmet Meats, Bakers Delight at The Glen, Crisp'n'Fresh Parkdale Plaza, Morris Meat Supplies** and the following **Coles** supermarkets: **Brighton, Mentone, Bentleigh, Sandringham, Hampton** and **Southland**.

Participate for Parkinson's

Parkinson's Victoria, through its dedicated **Research Fund** continues to actively and financially support a wide range of promising research that will ultimately improve the lives of those living with Parkinson's and, we hope, will find a cure. We also believe it is important to support research by promoting studies that are taking place and encouraging the Parkinson's community to participate. Here is a brief snapshot of some exciting research currently underway here in Australia.

Update on the living database initiative

The **Victorian Parkinson's Research Register** is a joint initiative of Parkinson's Victoria and the Florey Neuroscience Institutes. In partnering on this research project, 'to create a living database' of people with Parkinson's who are able to participate in and contribute to relevant research, Parkinson's Victoria is able to enhance the work of a major research institute, connecting it with viable participants, and to contribute to promising research taking place here in Australia. Because researchers around the world have also accessed the database, it means Parkinson's Victoria is also contributing to international efforts to find a cure and improve treatments.

In 2008, Parkinson's Victoria provided the financial support to establish a research registry for Parkinson's disease. People who joined the registry included nearly 200 people with Parkinson's and about 80 people of similar age, but without Parkinson's.

In joining the registry, people were volunteering to be approached to participate in future research studies. Participants with Parkinson's underwent a detailed examination to measure their symptoms and signs, and everyone participating in the registry had blood taken for biochemistry and examination of DNA.

So far eight research studies are using the registry. These include:

- ☞ Dr Simon Knowles, Swinburne University: **Comparing Differences between Caregivers and Parkinson's Disease Patients: Illness Beliefs, Coping Strategies and their Implications for Well-being.**
- ☞ Dr Andrew Evans, Royal Melbourne Hospital: **The genetics of Pain in Parkinson's Disease**
- ☞ Dr Danuta Loesch, LaTrobe University: **Fragile X permutations as a risk factor for PD.**
- ☞ Prof Malcolm Horne, Florey Neurosciences Institutes: **α -synuclein as a biomarker for Parkinson's Disease**
- ☞ Prof Malcolm Horne, Florey Neurosciences Institutes: **Genetics of Parkinson's Disease**
- ☞ A/Prof Gary Rance, University of Melbourne: **Auditory Processing in Parkinson's Disease.**

- ☞ Ms Wendy Lang, Florey Neurosciences Institute: **Working Memory in Parkinson's Disease subjects receiving Deep Brain Stimulators.**
- ☞ Prof Malcolm Horne, Florey Neurosciences Institute: **The development of the Parkinson Kinesograph (the PKG) for measuring bradykinesia and dyskinesia in Parkinson's Disease.**

The **Victorian Parkinson's Research Register** has been an important part of the success of these projects, and all of the scientists are grateful to those who have been willing to participate.

Several of the projects have already led to publications and the PKG may soon become available for routine clinical use around the world.

If you wish to participate in the Registry, contact Parkinson's Victoria for further information.

Virtual Reality and Parkinson's

Dr Simon Lewis, Director of the **Parkinson's Disease (PD) Research Clinic at the University of Sydney's, Brain & Mind Research Institute (BMRI)**, has spent many years researching motor and non-motor symptoms of Parkinson's. One of his current projects explores the exciting possibilities that virtual reality – typically associated with Hollywood films and video games – can have for people with Parkinson's who experience difficulties with walking and balance.

When Dr Lewis was working in the UK, he utilised a new type of Magnetic Resonance Imaging (MRI) called functional MRI (fMRI) to study memory problems in Parkinson's.

Whilst lying in the scanner, patients had to solve problems that they saw presented on a small screen and recorded their answers by pressing buttons.

The images recorded by the fMRI were then used to see which areas of the brain were working hardest in performing the task, and where they might be failing in patients who had problems with their memory. A failing memory is one of those features that many people living with Parkinson's recognise and find most troublesome.

In response, Dr Lewis' research team are now trialling a free 7-week **Memory Training and Education** course for patients at the **Brain & Mind Research Institute (BMRI)**.

One of the other major areas that Dr Lewis has become interested in is the phenomenon of **Freezing of Gait (FOG)**, where patients suddenly feel like their feet have been glued to floor as they try to walk.

Although, the underlying cause of FOG is not well understood, Dr Lewis' team believe they may have found a way to unravel the mystery and even improve symptoms.

CONTINUED PAGE 12

Ambassadors of Hope

Since December 1, 2010, nine Ambassadors, sometimes with interpreters to assist, have presented the Parkinson's story to approximately 1200 people at the following organisations:

- Australian Unity Victoria Grange Vermont South
- Australian Unity Walmsley Village Kilsyth
- Australian Unity Wahroonga Nursing Home Glen Waverley
- Berwick Lionesses Cardinia Hotel Beaconsfield
- Berwick Rotary Club
- Brighton Greek Senior Citizens
- Camperdown Probus
- City of Casey Disabilities & Inclusiveness Dept
- Clayton Greek Senior Citizens
- Community Outreach Group Airport West
- Donvale Probus Lower Templestowe
- Frankston/Peninsula Greek Citizens Club
- Freemasons Pakenham
- Geelong Private Hospital Rehabilitation Staff
- Gippsland Lakes Community Health
- Greek Cypriot Senior Citizens of Glen Eira
- Greek Senior Citizens Association Rye
- Heartbeat Pascoe Vale
- Hellenic Stegi Friendly Elderly Citizens, Preston
- Kiwanis Warragul
- Koroit Probus Club
- La Trobe University Physiotherapy First Year students
- Langford Aged Care Facility Cranbourne
- Lions Club Warragul
- Mercy Place, Warrnambool
- Migrant Information Centre (Chinese) Box Hill
- National Seniors Dandenong
- National Seniors Rosebud
- Port Fairy Probus
- Rotary Club Prahran

- Salvation Army Companion Club Doncaster
- San Remo Community Health Care
- Terang & District Probus Club
- U3A Deepdene
- Warragul Ranges Probus Club
- Warrnambool Independent Retirees
- Warrnambool Ladies Probus Club
- Warrnambool Support Group
- Westpac Bank Area Managers
- Y@P (Young Onset Parkinson's Support Group)

Heartfelt thanks to:

Anne Atkin, Kieran Donlan, Mel Dougherty, Jill Goss, Angela Page, Judy Phelan, Peter Raymond, Andrew Suggett and Fred Van Ross

A note from Parkinson's Victoria: Special thanks to Josephine Berthelemy Volunteer Coordinator, for her assistance behind the scenes helping to coordinate the program.

Extra special thanks to Peter Raymond Ambassador Coordinator, whose dedication has seen this initiative grow from a simple idea into a vital, 'living' part of our organization. Peter has helped build a professional and passionate team who contribute significantly to our work and who selflessly donate their time and energy, while sharing their very personal story.

For more information about booking an Ambassador, please contact: Josephine Berthelemy, Volunteer Coordinator: (03) 9581 8700 or jo@parkinsons-vic.org.au or Peter Raymond, Ambassador Coordinator: 0438 400 259 pdr@netspace.net.au

If you would like to know more about the Ambassador Program, go to youtube.com/parkinsonsvic to view a short video by Peter Raymond.

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Health & Wellbeing

Reclaim your health

Parkinson's is a degenerative disorder of the central nervous system. It is progressive, meaning symptoms will gradually worsen over time and there is currently no treatment or cure for the condition itself. However medications can assist in treating symptoms and alleviating their impact on day-to-day living, and a range of complimentary and other therapies can also help.
Written by SUSAN GIANEVSKY.

Early in the course of the disease, the most obvious symptoms are movement-related, including shaking, rigidity, slowness of movement and difficulty with walking and gait. Many people living with Parkinson's also experience sensory, sleep and emotional imbalances.

Many are concerned their condition will deteriorate - which is reasonable given the condition is progressive - and fear steps in. It can be very difficult to confidently manage Parkinson's and to remain positive in all that you do.

Everyone wants to live a lifestyle that enables freedom to undertake daily tasks independently, to feel a sense of achievement and to enjoy life. People living with Parkinson's are no different, but symptoms of the condition can significantly impact on their ability to achieve these aims. If the **symptoms** of Parkinson's are left untreated (as there is no treatment for the actual condition), quality of life, independence and overall health and wellbeing are compromised. This can include decline in cellular health and stiffness of joints, which can deplete the individual emotionally. Symptoms of Parkinson's should be treated from a holistic perspective, which includes those non-motor symptoms such as sleep problems, constipation, fatigue and mood disturbances, which not only deplete the person physically but also emotionally.

Complimentary therapies are often used to improve a person's overall wellbeing, in conjunction with treatments prescribed by your treating specialist.

Natural products have long been considered helpful in improving associated symptoms of conditions such as Parkinson's, including fatigue, muscle cramping, insomnia, mood and relaxation, however there is currently limited evidence (research) to support the notion that natural products can actually reduce the impact of the disease itself.

One form of complimentary therapy is the use of **Tissue Salts**.

What are Tissue Salts?

Tissue Salts are a homoeopathically prepared micro-dose of the body's 12 essential minerals and are

considered the "building blocks" of the body.

Tissue Salts assist with cell metabolism and improve the absorption of nutrients from your diet, because even with a well balanced diet, rich in vitamins, minerals and trace elements, the body sometimes fails to assimilate these substances.

Tissue Salts are taken into the blood more easily as they are absorbed through the mouth mucous membrane and don't need to be broken down in the digestive tract. They are therefore more readily available to the body to adjust disturbances of the equilibrium between the internal environment of the cells and the cell gaps.

The cells in our body are like an orchestra; we need to fine tune the orchestra so it plays the music that is soothing to ourselves and can ensure the harmony that is required on every level. Our cells depend on how easily they can receive nutrients via our bloodstream. Tissue Salts provide a key solution to activating body processes where more energy, uplifted mood, improved digestion, better sleep and improved immunity can be experienced to ensure wellbeing is experienced daily.

Specifically, *Tissue Salts* are micro minerals that "bridge the gap" and help restore the molecular imbalance that may be impeding the nutritional process.

The 12 Tissue Salts are:

1. Calcium Fluoride (Calc Fluor)
2. Calcium Phosphate (Calc Phos)
3. Calcium Sulphate (Calc Sulph)
4. Ferrum Phosphate (Ferr Phos)
5. Potassium Phosphate (Kali Mur)
6. Potassium Chloride (kali Phos)
7. Potassium Sulphate (Kali Sulph)
8. Magnesium Phosphate (Mag Phos)
9. Sodium Chloride (Nat Mur)
10. Sodium Phosphate (Nat Phos)
11. Sodium Sulphate (Nat Sulph)
12. Silicon Dioxide (Silica)

These are available in singular form or various combinations. The addition of Tissue Salts to your diet (taken in chewable tablet form, oral sprays or topical ointments) can assist the body in obtaining all the nutrients it needs from the foods eaten, and there is no need for these minerals to be broken down as they are immediately assimilated into the body.

Mag Phos and **Kali Phos** are two Tissue Salts that may help in relieving pain caused by cramps and

Support Groups

Do you know your local Support Group?

Parkinson's Victoria auspices more than 45 Parkinson's Support Groups around the state.

Our Support Group leaders are an invaluable asset as they work 'at the frontline' to provide regular support, companionship and a friendly smile to people living with Parkinson's in their local area.

We believe in the value of 'self-help' style peer support and as such, work closely with Support Group leaders to enable them to run successful meetings on their own, while knowing that we are there to support, resource and assist where necessary.

Our health team also visit support groups throughout the year to provide updates and information to members, and we also provide leaders with resources and the opportunity to develop and build leadership skills to assist them in their important role.

Our Health Team recently sought feedback from Support Group leaders to assess what they felt was working well for their group and leadership needs, and to determine the best way to continue providing valuable support and assistance.

Survey responses indicated that, overall, leaders are happy with the current support provided by Parkinson's Victoria, with 95 percent of respondents saying they felt that Parkinson's Victoria supported them 'well' or 'very well' in their role.

While coordinating Support Groups is not always an easy task with meetings, newsletters, awareness and guest speakers to organise, leaders found it very rewarding to be part of such an inspiring and welcoming community.

There were some suggestions for improvement and these included: creating a more personal connection to the Parkinson's Victoria team via videolink; increased visitation of our team to regional areas; and networking opportunities between different Support Groups, where they have a chance to meet other members and leaders, share ideas and generally connect with the wider Parkinson's and Parkinson's Victoria community.

We will endeavour to move forward on many of the suggestions presented in the Support Group leader survey and to incorporate them into the annual Support Group Leader Training Day on Saturday, 27 August, the day before **Parkinson's Unity Walk**. We have combined these two events into one weekend to make it even easier for our Support Group leaders, especially those from regional Victoria to attend and reduce travel time and expense.

For more information about our Parkinson's Support Groups, contact Breanna from our Health Team: (03) 9581 8700 or 1800 644 189 or breanna@parkinsons-vic.org.au

muscle spasms, which can occur as a symptom of Parkinson's.

Both Magnesium and Potassium are constituents of brain and nerve cells and it is important to maintain balanced levels of these crucial minerals. When a deficiency of magnesium phosphate occurs, the white nerve fibres contract, causing spasms and cramps. *Mag Phos* is quick to relieve pain, especially cramping, shooting, darting or spasmodic pain. Magnesium Phosphate (*Mag Phos*) is connected with the nervous system where it supplements the action of Potassium Phosphate (*Kali Phos*) in the body. Homeopaths and Naturopaths would recommend chewing 1 tablet 4 times a day (or spraying 4 sprays into your mouth daily a few times)

as a way to naturally reduce some of the physically debilitating symptoms of Parkinson's.

As a homeopath with over 20 years in the health industry and as Ambassador in Women's Health at Martin & Pleasance, I have had much success in recommending Tissue Salts to clients to be used alongside prescriptive medications as there are no side effects and they do not interfere with ongoing medication. There is also no issue with 'overdosing' on Tissue Salts.

I've found that many people have experienced greater energy and improved sleep when they feel more comfortable within their own body, knowing that they are better absorbing the nutrients from their diet.

To date there is no known cure for Parkinson's, however an holistic approach to overall health and wellbeing, one that incorporates complimentary therapies such as peer support, exercise and a healthy diet will enhance overall wellbeing and optimal health.

Tissue Salts can assist in maintaining ongoing cellular health so you can sit more comfortably within your own body and get through each day.

Susan Gianevsky holds degrees in both education and homeopathy and is the *Ambassador in Women's Health* for Martin & Pleasance which has been producing natural health products for over 150 years.

Proudly Australian made and owned, Martin & Pleasance have been manufacturing Schuessler Tissue Salts for over 130 years and still carefully follow the original process of hand-grinding the minerals.

Schuessler Tissue Salts = rapid absorption, easy to take, cost effective, natural, support the effectiveness of supplements and have no side effects.

Participate for Parkinson's

CONTINUED FROM PAGE 9

Although freezing most commonly affects walking, symptoms can occur during a number of other physical tasks like writing and brushing teeth. This suggested to Dr Lewis that FOG may represent part of a generalised process occurring in the brain and he began to wonder whether he could trick the brain using **virtual reality** (VR).

In real life, FOG is commonly triggered by having to walk through doorways or when multi-tasking. Using the technology commonly found in video games, the BMRI team devised a realistic VR environment with a series of corridors and doorways, which patients navigate using foot pedals whilst they sit watching their progress on a computer screen. Preliminary results show that patients with FOG have a delay in their stepping pattern when passing through narrow doorways in the VR. Researchers did not see this in patients without FOG or in healthy control subjects.

In addition, the team have also been able to correlate the amount of freezing experienced by those with FOG in the VR environment with that observed during their physical assessment in the clinic.

Supported by a grant from the *Michael J Fox Foundation*, Dr Lewis' team have been able to use fMRI technology to see what is actually going on in the brain during freezing episodes. It appears that when patients with FOG are walking efficiently through the VR, they activate the region of the brain controlling their foot movements. However, at the point at which they freeze this region goes 'cold' with little activation. Other areas around the brain become strongly activated, presumably in a desperate effort to 'kick-start' the system.

What is truly exciting about these findings is their potential application to therapy. Currently, FOG does not respond well to available treatments. However, it is possible that 'exercising' in VR may offer a potential way of improving symptoms without the need for medications or surgery. Indeed, that is going to be the next study for Dr Lewis and his team who are now looking to recruit patients for just such a trial. Using this approach, patients would be able to practice walking through doorways and making tight turns in the safety of their armchair at home.

Initially, patients would need to attend the free research clinic in Sydney, but it is hoped that with positive results this technology might become available to patients via the internet in the future.

If you would like more information about the BMRI's PD Research Clinic, please call (02) 9351 0702 or email pdclinic@med.usyd.edu.au

Dr Simon Lewis began his research career at the University of Cambridge and moved to Sydney in 2007. He now works as a Consultant Neurologist

at the Royal Prince Alfred Hospital and is Director of the **Parkinson's Disease (PD) Research Clinic** at the University of Sydney's, **Brain & Mind Research Institute (BMRI)**. In 2011, Dr Lewis was awarded an **NHMRC Practitioner Fellowship** to support him with his program of research, which covers a wide range of motor and non-motor problems in PD.

Dr Lewis led the nationwide '*DASH to the InfoLine*' campaign, producing a free information booklet for people living with PD that is available to download online (www.Parkinson'svic.org.au/about-ps/documents/DASH_Booklet.pdf). He is currently heading the first study to investigate the impact and feasibility of community-based Parkinson's nurses, which has received Federal Government funding.

Community walking and Parkinson's

Do you have trouble walking in your community? Maybe you have even stopped doing things that you used to enjoy, such as having coffee with friends, because you might have to park a long way away; or walking the dog, because you have trouble keeping up?

Physiotherapists often see people with Parkinson's because they are having trouble walking or they are having falls at home. When asked, these people often say that without noticing it, over the last few months and often years, they have restricted the activities they do away from their homes. Often, these people have stopped doing things they enjoyed because they can no longer cross the street in the time the pedestrian lights give them, or they worry that they can't step on or off the travelator at the shopping centre without falling.

In addition to reducing independence and community participation, this creates a vicious cycle where movement and exercise become difficult, so people reduce or restrict their activity, which in turn reduces strength, fitness and endurance, making movement and exercise even more difficult.

There is now a lot of research to show that people with Parkinson's walk slower, with shorter steps than people without the condition, and that this walking pattern deteriorates further when people perform another activity at the same time. This is termed **dual task performance** and is a skill we use every day to manage walking in our community, for example walking and socialising with friends, or walking and searching the shelves for the groceries we want to buy.

Physiotherapists use a series of clinical walking tests to assess how quickly the person can walk, and the size and number of steps they take.

Some physios may even test your dual task performance while walking (e.g. thinking of words or carrying a cup full of water). While these tests are very useful, and provide a lot of information about people's ability to walk, **independent community walking** is affected by other factors such as the required walking distance, external time constraints,

In memory

lighting, weather, terrain, physical demands such as carrying objects, and 'attentional' demands (such as looking out for obstacles, traffic and other pedestrians).

In a current series of studies, researchers at the **School of Health and Rehabilitation Sciences at the University of Queensland** are aiming to improve our understanding of what factors can influence community walking of people with Parkinson's.

To do this they are conducting a survey to give people with Parkinson's the opportunity to identify what they feel restricts, or indeed assists them to walk and move in their community.

Survey responses will enable physiotherapists to better assess and evaluate their treatments of people with Parkinson's, and it is hoped will help make everyday walking easier, safer and more enjoyable.

"Being able to walk in the community is essential to ongoing participation in the community. Understanding the barriers people with Parkinson's face to continuing to walk in the community is essential to improving our ability to manage this complex functional activity," said Professor Meg Morris, Head of School, Melbourne School of Health Sciences (Nursing and Allied Health), who is one of the supervisors for this research project.

You can complete the survey online at: <https://www.surveymonkey.com/s/parkinsonsdiseasewalking>

You can also meet and speak with Robyn at the Parkinson's Victoria Health Team tent at Unity Walk.

If you are interested in finding out more about this research contact researcher Robyn Lamont: 0418 784 464 or email: r.lamont@uq.edu.au

In June, we were saddened to hear of the sudden passing of Dr Ronald Leslie Eisner from cancer. The Board and staff of Parkinson's Victoria take this opportunity to acknowledge his valuable contribution to the Parkinson's community and to Parkinson's Victoria. The following is an excerpt from his eulogy, with additions from Fred Van Ross and Kate Brown, both serving Board members.

Dr Ron Eisner passed away just a few weeks after his 67th birthday. Ron went to Elwood High and dreamed of becoming a surgeon. His hard work paid off and Ron was accepted for medicine at Melbourne University and was awarded a scholarship.

During his time at the Austin Hospital, he met and married Sandra, a medical technician. They built a new home in Doncaster, and Ron became one of the first surgeons at the Lilydale Hospital; between long hours he still managed to play hockey regularly, which he very much enjoyed.

Sandra had two young boys when she met Ron, and together they had another two children. Sadly, it was also in 1979, the year daughter Samara was born, that Sandra was diagnosed with Parkinson's.

While the diagnosis was a great shock to all, it is likely what prompted Ron to make the most of every opportunity to spend quality time together as a family. As a result this was a period of wonderful holidays.

Since Sandra's diagnosis, Ron continued to be an enormous support for her, caring for her in every way he could, even whilst working, and ensuring the best medical attention for her.

Ron became heavily involved supporting the work of Parkinson's Victoria and the greater cause to improve the quality of life for people living with Parkinson's by increasing awareness and funding. Ron was a committed supporter of Parkinson's Victoria's functions, participating in many awareness-based activities to promote understanding in the community. In addition, both he and Sandra were Parkinson's Ambassadors, giving presentations to various groups in their area. During 2004, Ron was asked to chair the Asian Pacific International Symposium for Parkinson's held in Melbourne. His personal involvement helped to ensure the success of the conference.

When he was 61, Ron decided to take early retirement in order to be with Sandra full-time; his dedication, devotion, care and compassion, not to mention his sense of humour, always helping them both along this difficult path.

Not long after he retired, Ron was diagnosed with cancer. It was typical of Ron that concern for his family continued to be a priority during his battle.

Ron was an unassuming, extremely gentle, quiet and calm man.

Our deepest sympathies to Sandra (Ron's wife of 36 years), and family at this time.

Notice of Annual General Meeting

The **2010/11 Annual General Meeting of Parkinson's Victoria** will take place on **Friday 11 November, 2011**. Official notification will be posted to all members in the weeks prior to the event.

Venue: **Centera Room** of the **Hemisphere Conference Centre**, 488 South Road, Moorabbin (NB. This is the same venue as our 2009/10 AGM)

IMPORTANT NOTICE: As the AGM will be taking place on Remembrance Day, we ask that all guests arrive and are seated in the main room by 10.50am at the latest.

At 11.00am, prior to commencing the AGM and other formalities, we will mark Remembrance Day with a minute's silence. Your assistance would be greatly appreciated.

Access, Advocacy & Assistance

Making a complaint

One important aspect of advocacy and assistance is empowering individuals to play an active role in decision making about their care and well being. Knowing what rights and responsibilities you have as a patient or carer, what avenues are available to you when you believe these rights have been disregarded, and how to take action are incredibly important aspects of patient empowerment. BREANNA WOTHERSPOON from our Health Team offers some tips and advice on how to respond when problems occur during a hospital or care facility stay.

Now and then, our health team hears from people with Parkinson's who have had a negative experience with a health professional, hospital or aged care facility. There are a number of ways in which you can respond if this happens to you or someone you care for.

Prevention is better than cure

Sometimes problems arise due to a miscommunication between the parties or because the health or care facility or staff member does not understand the specific needs of people living with Parkinson's, and/or the individual Parkinson's patient.

- ☞ If there are particular issues you are concerned about, raise them with staff and management at the facility.
- ☞ Contact Parkinson's Victoria for advice and to find out what resources may be useful, such as our **Parkinson's Hospital/Respite Kits, Drugs to be used with caution** sheets or **GP manuals**. The Manual is a concise reference on the most common features and clinically relevant aspects of Parkinson's, with an emphasis on the GP's role in diagnosis and management. This publication is endorsed by The Royal College of Australian General Practitioners.

Why should I take action?

If problems do occur during a stay in hospital or care facility, it can certainly help to do something constructive with a bad situation.

Following up on the matter may improve the situation for yourself, or for others who may use the service in future. In some instances, making a complaint can alert service providers to an issue that they may not have realised was a problem, allowing them to take appropriate action.

How do I make a suggestion or complaint?

It is important to know your rights and responsibilities. If in doubt, ask the organisation about their complaints procedure and get copies of any relevant documents. All hospitals and care facilities should have these readily available on request to clients, patients and family members.

Start with the person at the source of the problem – the doctor, nurse, manager, etc. Resolution at the "provider" level (in other words those directly responsible for providing the care) can deliver a

faster and more effective outcome.

The problem may have been the result of a simple miscommunication or inadvertent error that can be easily rectified.

Choose your time and place

- ☞ Where possible organise a mutually convenient time to speak to staff or management. This way you ensure that you have their full attention and they do not have to rush off to attend to another patient or commitment.

Be prepared and be able to give specifics

- ☞ Write down a list of your issues and concerns so that you do not forget to mention anything. Provide details of particular problems and conversations.

For example, if you did not receive your medications on time, specify "I received my medication 40 minutes late on Tuesday morning and one hour late on Thursday and Friday afternoon".

Decide on the purpose of your complaint, and let the service provider know what action you would like taken

- ☞ Are you purely informing the service of a concern, or providing a suggestion? Do you want action taken and feedback provided?
- ☞ Where possible make suggestions on what steps could be taken.
- ☞ If you are still using the service or are likely to need it again, you might ask them to put a note in your file requesting that attention be paid to a particular issue.
- ☞ You may not need the service in future, but would like them to change their policy to ensure that others do not experience the same problems.

Listen

- ☞ Consider the situation from the other side. Things may be done a certain way for reasons that you had not thought of. Or perhaps the staff member in question was adhering to a policy that they do not have the power to change, and you need to discuss the issue with someone else.

Avoid making personal attacks or getting confrontational

- ☞ Sometimes when a person is upset or angry they can lose sight of their objectives and direct their feelings at people rather than issues. This can be unfair on the other party, as well as being unproductive for your aims.
- ☞ If a personal attack is launched, people are more likely to get defensive and the problem is less likely to be fixed. On the other hand, both parties working together to find a better solution is more likely to lead to positive outcomes.

Formalising a complaint

Write a letter

If talking to the responsible staff member does

Access, Advocacy & Assistance

not resolve the issue or provide some satisfactory response to your concern, consider putting your complaint in writing. While all complaints should be responded to, a written complaint is a more formal method and will often receive more serious attention.

- Your letter should include: An explanation of the problem; what action you want taken to resolve the complaint; a precise but reasonable timeframe for action to be taken (e.g. 28 days); and details of when and how you may be contacted for follow up.
- A typed letter is better than a handwritten one.
- Ensure you keep a copy for yourself, and note the date on which you sent it.

Give them an opportunity to respond

- Though it may be frustrating to wait, remember that change takes time, especially in larger organisations.
- Many external advocacy bodies that deal with disputes or problems will not consider them until the service provider has been given an opportunity to respond (and has failed to resolve the issue appropriately).

Escalating a complaint

If you are unhappy with the response of the person you complain to, or do not believe that they are able to provide an adequate solution to the problem, you may wish to take your complaint to the next level – such as a supervisor, complaints officer, or regulatory body.

Who else can help?

Problems with your Doctor

- **Office of the Health Services Commissioner**

For complaints about a health service or concerns about your health privacy
Phone: (03) 8601 5200 or 1800 136 066 (free call)
Website: <http://www.health.vic.gov.au/hsc/>

Problems with your Hospital

- The Patient Liaison service within the hospital
- **The Health Services Commissioner (see above)**

Problems with your Residential Aged Care service, Community Care Provider or Case Manager

- The manager of the facility
- **Office of Aged Care Quality and Compliance**

For concerns about aged care services (residential or community care) subsidised by the Australian government

Phone: 1800 550 552

Website: <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-complaints-index.htm>

- **Elder Rights Advocacy**

Provide support and assistance to anyone who may be uncomfortable or unsure about making an internal or external complaint
Phone: (03) 9602 3066 or 1800 700 600 (free call)
Website: <http://www.era.asn.au>

Other useful organisations

Disability Services Commissioner

For disability services or service providers in Victoria
Phone: 1800 677 342 (free call) or 1300 728 187 (local call)
Website: www.odsc.vic.gov.au

Australian Health Practitioner Regulation Agency (AHPRA)

For concerns about a medical professional
Phone: 1300 419 495
Website: <http://www.ahpra.gov.au/>

Office of the Public Advocate

For concerns about the rights of people with disabilities
Phone: 1300 309 337
Website: <http://www.publicadvocate.vic.gov.au/>

Ombudsman of Victoria

For complaints about state government departments, most statutory authorities and local government
Phone: (03) 9613 6222 or 1800 806 314 (regional only, toll free)
Website: <http://www.ombudsman.vic.gov.au/>

Commonwealth Ombudsman

For concerns relating to Australian Government Agencies (including Centrelink)
Phone: 1300 362 072
Website: <http://www.ombudsman.gov.au/>

Consequences

Legally, a service cannot hold it against you if you make a complaint. However, it is understandable that someone making a complaint may fear ramifications. Take this into account when deciding whether to make a complaint and the manner in which you complain.

If the reaction to your complaint makes things worse, consider taking further action, such as changing your service provider and/or informing a higher authority.

Commendations

This article has looked at how to approach things if you have had a negative experience. As much as a negative experience can be upsetting, a positive experience can be affirming and leave you impressed with the service.

If you have a particularly good experience, consider using the above avenues to commend someone who has done a good job, or gone above and beyond. Making a complaint can be an effective way to ensure that bad behaviour and procedures change; acknowledging someone's efforts can be a nice way to ensure that good behaviour and procedures continue.

If you would like further details about any of the information covered in this section, or have a question in general about what support services might be available to you, our Health Team is just a call or email away: (03) 9581 8700 or info@parkinsons-vic.org.au (Enquiries may be anonymous if you wish).

Research Update

Movement Disorder Congress, 2011

The Movement Disorder Society Congress 2011 was held in Toronto, Canada in June. At this important annual meeting, the world's neurologists, scientists and nurses gathered to hear and discuss the latest research and developments in Movement Disorders, particularly Parkinson's.

Delegates had the opportunity to learn about current fields of research, as well as exchange opinion on "best practice" treatment strategies. VICTOR MCCONVEY, our Parkinson's Nurse Consultant attended the congress and shares some of the learnings.

The Congress drew an estimated 4000 attendees from all over the world, with many Australian delegates and keynote speakers presenting scientific and clinical research papers.

Getting the house in order

The congress has been held annually for a number of years.

In 2010, the **Movement Disorder Society** (MDS) commenced an initiative to get the house in order; to develop a systematic review and aggregation of evidence to date of support treatments and Parkinson's care models from a world perspective.

The ultimate aim of the initiative is to develop treatment guidelines to support the means by which care is delivered.

While this may appear an 'un-exciting' project, it is of tremendous benefit to patients, ensuring care design and delivery is based on research that meets both ethical and appropriate trial criteria. This benefit extends to supporting patients who may not have access to a movement disorder specialist or neurologist, which is thought to be over 60 percent of the world's population of people living with Parkinson's.

The development of clinical guidelines will assist in highlighting issues such as the need for equitable access to medications and ensuring that physicians are able to prescribe the best possible combination for a patient's particular presentation. However, while there are many benefits in developing **treatment guidelines**, the MDS acknowledges that no guidelines can ever be prescriptive, and care must be tailored to individual's needs.

The model that is developing is one where current research, existing clinical evidence and patient values are all considered when making decisions about care and lifelong management of Parkinson's. This model, and the clinical guidelines that go with it, will continue to evolve and change as more research and evidence is gathered.

Personalised medicine

The conference also discussed the emerging area of **pharmacogenetics** and personalised medicine.

Recent research tells us that the way each person metabolises medication, and the effect that medication has on the individual is often related to genetic factors.

In an ideal world, the application of such research would enable medications to be prescribed based on one's genetic makeup, improving the possibility of determining the most effective medication for each individual. Unfortunately, as it is currently impossible to determine complete genetic make-up for most of us, prescribing methods will remain unchanged. However, personalised medicine may become important for the small percentage of people with **familial** Parkinson's (5-10 percent of the Parkinson's population).

Familial Parkinson's tends to present in those individuals in a similar way, and they will also tend to respond to the same or similar group of treatments.

Getting to know the basal ganglia; understanding how "cueing" works

The basal ganglia, one of the oldest part of the brains (being present in evolutionary vertebrates prior to development of the cerebral cortex), is significantly affected by Parkinson's.

The basal ganglia, which contains both *dopamine producing cells* and *dopamine receptor cells*, works with other cortical and sub cortical structures of the brain to enable the body to undertake spontaneous/habitual **and** thought-driven movements (such as walking and talking at the same time).

While it is usually difficult to differentiate between these two types of movements, the impact of Parkinson's makes this distinction easily apparent, hence a decline in habitual or automatic control and an increased reliance on goal-directed actions, which rely on relevant brain pathways.

In real-life terms, this explains the occurrence of some Parkinson's symptoms, such as difficulty in multi-tasking and the phenomenon of freezing, and why developing goals or 'cues' can overcome these difficulties (for example, focussing on stepping **over** a line on the floor if the person has difficulty with freezing when walking through a doorway).

Biomarkers, genetics and Parkinson's

In most cases, Parkinson's is **idiopathic** - its cause is unknown. It is understood that the underlying pathology of Parkinson's relates to a disruption of the body's metabolism of *Alpha Synuclein* (a protein). As a result, there is a build up of this protein in nerve cells which impacts on conduction of messages, ultimately causing cell death. However, in a small percentage of cases, around 5-10 percent,

Parkinson's is believed to be **familial** – in other words having a genetic cause or a mutation of Alpha Synuclein metabolism occurs.

Emerging research shows that many people carry an Alpha Synuclein mutation, and while this is not necessarily a precursor to developing Parkinson's, it does seem that the more Alpha Synuclein mutation one has, the greater the chance of developing Parkinson's.

The research also supports the consideration of Alpha Synuclein as a bio-marker for Parkinson's. In other words, the level of Alpha Synuclein may tell us how effective treatment is, and may one day be useful as a diagnostic tool. It may also mean that modifying or limiting the spread of Alpha Synuclein can itself assist in treating the symptoms of Parkinson's.

Mitochondrial dysfunction and Parkinson's

An important part of all cells, including those in the nervous system is the mitochondria. This dynamic organelle has many functions including being the "power plant or battery" for the cell. A Congress presentation proposed that mitochondrial dysfunction may be one of the causes of Parkinson's.

Parkinson's can be created in the laboratory in animal models using mitochondrial toxins such as MPTP and the results are Parkinson's-like symptoms in the animal subjects.

In addition to this emerging knowledge is the recent discovery that the rare mutations named *PINK* and *PARKIN* (a cause of familial Parkinson's) occur as a result of mitochondrial dysfunction, causing Alpha Synuclein build up.

Further questions are raised when it is identified that mitochondrial dysfunction can also result from placental insufficiency: *Are you born with Parkinson's or does the genetic predisposition cause placental insufficiency?*

Research continues raising more questions in the process. Importantly answers are being found.

So what does the Movement Disorder Congress mean for you?

In the first instance, reassurance. While research findings can be confusing, we are closing in on discovering the cause/s of Parkinson's. Along the way, we are improving our understanding of the mechanisms behind the condition and what happens to our bodies as the condition progresses. This, in turn, has led to improved treatment options which in the long term, should encourage a positive outlook.

Major events such as the [Movement Disorder Society and the Annual Congress](#) ensure that the dialogue and action around Parkinson's remain focussed on discovering and sharing best practice

treatment options, new learnings about symptom management and disease understanding, as well as research findings.

New member for our Health Team

Parkinson's Victoria is very pleased to welcome Dianne Rayner to our Health Team.

Dianne's previous employment over the last 12 years has been predominantly in the not-for-profit sector, specifically working in mental health. Her background highlights extensive experience in an office support role where she has kept the cogs of the office running smoothly.

Dianne's passion to engage and equip people to regain and maintain emotional wellbeing, combined with a natural talent for helping others, finding new ways of doing things and implementing effective support processes led her to further study and she graduated with a **Diploma in Counseling and Advanced Diploma in Family Counselling** in 2005/06.

In addition, Dianne recently completed **Certificate IV** training in both **Mental Health** and **Youth**.

Dianne comes to us from a role as Program Facilitator within women's and men's groups who experience mental health issues, and also within a group for young women who experience anxiety and depression.

While she has been with us only a few weeks, Dianne has already observed that when "Parkinson's" is mentioned, the majority of people focus on the physical symptoms associated with the condition. But, her experience and expertise tells her that being diagnosed and going on to cope and 'live with' Parkinson's also takes a tremendous toll on one's emotional wellbeing – not just the individual who is facing the diagnosis, but their family and friends too. "This is something I believe people often don't consider, or factor into their journey and support needs", says Dianne.

Dianne has commented that she is excited to be joining our staff as a member of the Health Team, and we know she will bring some wonderful skills and attributes to our organisation. "I have already met some amazing people from the Parkinson's community and look forward to meeting many more of you in the future".

On a personal note, Dianne is married to Richard and has two daughters, Ashleigh 14 and Charlotte 10. She enjoys reading, walking and spending time with family and friends and playing with the family's cheeky but very cute dog Ollie. Travelling is a passion, and in recent years she has travelled to Malaysia, Thailand, Vietnam and America.

Beginning the journey

The Parkinson's Victoria **Recently Diagnosed Community Seminar** has become one of the most well attended events on our calendar.

This event delivers relevant and credible information from a range of professionals with expertise in the area of managing and living with Parkinson's. It is specifically tailored to those recently diagnosed (defined as a diagnosis in the past 5 years), and the program addresses the relevant concerns, interests and needs.

Keynote speaker: Dr. Kate Kotschet, Movement Disorder Neurologist. Additional presentations will give attendees the opportunity to hear personal stories, a session on **Frequently asked Questions** about Parkinson's and well-being advice.

Date: Saturday, 12 November, 9:30am – 2:30pm

Venue: Eastern Golf Club, 473 Doncaster Road, Doncaster.

Cost: \$25 members (and family members, per person), \$40 non-members (and their family members, per person).

Morning tea, lunch and handouts are included in the ticket price. Places are limited and RSVP is essential.

Become a member today and attend the seminar for \$50 (includes 12-month membership and annual subscription to our member newsletter [Signpost](#)).

Register today to reserve your seat. Contact our Health Team: (03) 9581 8700 or

info@parkinsons-vic.org.au

Free Parkinson's Community Seminar – Williamstown

Parkinson's Victoria is hosting a free community seminar in Williamstown for people living with Parkinson's, their carers, family and friends.

Jointly hosted by **The Village Williamstown**, we invite all members and the community to join us for an informative and friendly seminar to hear a general overview of Parkinson's as well as information and advice about the latest treatments. Information about Parkinson's support and specialist services will also be available.

Date: Monday, 12 September, 2.00pm

Venue: The Village Williamstown, 1-49 Paas Place, Williamstown

Registrations are essential.

To register your interest or find out more contact Breanna Wotherspoon from our Health Team: (03) 9581 8700 or 1800 644 189 or

breanna@parkinsons-vic.org.au

A special trust for succession planning

*This article discusses a trust that you can establish for the purpose of succession planning. **Special Disability Trusts** are one way that parents and immediate family members can prepare for the future care and accommodation needs of a family member with a severe disability.*

The main advantage of this kind of trust is that it allows you and other immediate family members of the beneficiary who are over age or service pension age, to concessionally 'gift' money up to a combined amount of \$500,000. The other benefit is that the beneficiary receives a Centrelink Assets Test exemption of up to \$563,250 (annually indexed).

Immediate family members can be natural parents, legal guardians, adoptive parents, step parents, grandparents or siblings.

It's a good idea to speak to a financial or legal adviser about this option, as a **Special Disability Trust** must meet a number of conditions and contributing to one can affect your financial security or social security entitlements.

Conditions include having only one beneficiary who meets the eligibility criteria, being 'protective' in nature, and providing only for the beneficiary's accommodation and care needs. You'll also require a trust deed, an independent trustee and annual financial statements.

To be eligible as a beneficiary, your family member must meet the definition of 'severe disability' as defined by Centrelink, e.g. for someone aged 16 or over, they would qualify for a Disability Support Pension and not be working, or ever likely to earn at or above the minimum wage.

If you'd like to find out more about this option, or any other provisions you can make for your family's future, you may find a discussion with a financial adviser worthwhile. A financial adviser is someone who will understand how to help you or your family, given your unique circumstances.

This information was provided by Outlook Financial Solutions who specialise in finding solutions to help people achieve their goals - regardless of their current financial circumstances, or stage they're at in life. This covers anything from advice on one small issue, through to a complete investment strategy, or a full financial plan.

For more information, call 1300 657 872 or visit www.outlookfs.com.au.

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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.

We gratefully acknowledge the generous donors who have made a financial contribution in recent months to support our work in the community. Unfortunately, due to the large number of donations we receive, we are unable to list all of them. Listed below are the names of individuals who kindly donated \$500 or more between 29 April and 8 July, 2011, and individuals in whose name in memoriam donations were received.

We extend our sympathies to the families who have lost loved ones, and our thanks go to the friends and family members who have donated to Parkinson's Victoria in their memory

*We are also pleased to list those companies, organisations and others who have shown their support, either financially or in-kind. We thank those who have donated but wish to remain anonymous, those who have supported our **Ambassadors of Hope** speakers program and those who are currently fundraising as part of **Parkinson's Unity Walk 2011** and their generous donors.*

Donations \$1500 & over

Mary Kentish
Fiona Lourey
Barry Williams

Donations \$1000 & over

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In Celebration of...

Thelma Payne, 70th Birthday
Trevor White, 80th Birthday

Team Parkinson's Fundraisers (third party)

Rosemary Murphy & Heather Jobling (Jump 4 Parkinson's)
Peter Curtin (Walk for Parkinson's)
Procure Fitness (supporting Peter Curtin)
Gail Pagon (Open Garden Day)

Corporate, Community & other donations & support

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East Gippsland
Essendon
Frankston
South Gippsland

A total of 238 donations were received in response to our **2011 Pre Tax Appeal**, raising **\$24,006** and a total of 134 donations were received in response to our **Steps donor update newsletter**, raising a total of **\$14,978**.

Special thanks to all those who gave generously!

Tulip Tributes

Three's a (welcome) crowd

We are very pleased to formally acknowledge the incredible efforts and contribution of our ever-growing team of 'third party fundraisers': Those passionate members of the community who are **moved to make a difference** by requesting donations in lieu of gifts during special occasions, or who undertake organising a fundraising event of their own, with proceeds going to Parkinson's Victoria.

These include:

- Our **Charity Challengers**, Jo and Nicole Goodridge, Simone Douglas and Nikki Jordan – who are heading off to India in September as part of their Challenge – having each fundraised approximately \$7000 to support our work
- Peter Curtin who is **'Walking for Parkinson's'** on the **Camino de Santiago de Compostela** in Spain in August.



Clients, friends and family of Procure Fitness join Peter Curtin (third from right) for one of his regular training walks along Sorrento back beach. The Walks also raised \$780!

- Gisborne Peak Winery and the Judge Family who together organised an **Action Day for Parkinson's**. And artist Helen Cottle for generously donating an original watercolour for a raffle, and frame donated by Gisborne Peak Winery. "Winter Morning, Gisborne South" will be on display during Unity Walk and tickets on sale.
- Dartmouth Women's Fishing Club**; members have nominated Parkinson's Victoria as the beneficiary of this year's annual Dartmouth Women's Fishing Classic (11 and 12 November).
- The Handweavers and Spinners Guild of Victoria** who have organised "Footy Woolies" (an exhibition) and a "Bad Taste Fun Day" in September, with proceeds to Parkinson's Victoria.

Awesome Ambassadors

A big **Tulip Tribute** to all our wonderful Unity Walk spokespeople! Thank you to all those who have already responded to our request and helped raise awareness of Parkinson's and the Walk by talking with your local newspaper or radio station.

Last year, the generosity of our spokespeople resulted in \$300,000 worth of FREE media support – more than 100 stories, TV and radio interviews! This is publicity we simply could not afford to purchase as "traditional advertising" and makes a major contribution to our publicity efforts.

Running for a cure

On 17 July, 36 people got serious about **Moving to Make a Difference for people living with Parkinson's** when they participated in this year's annual Run Melbourne event, undertaking the 5km, 10km or half marathon (21km).

Together they raised an amazing \$10,898.10! A highlight on the day was seeing our Team Parkinson's sports singlets and caps in the crowd.

Congratulations to the following for not only achieving a personal fitness goal but for garnering such fantastic support from your friends and family.

Chris Fogarty (phenomenal effort raising \$2060), Belinda Nussbaum (\$927), Steve Schutt (\$896), Kevin Pollard (\$695), Justin Charlot (\$647), Sally Nepean (\$615), Niall Munro (\$590), April Kendall (\$555), Lissette Knight (\$520), Debbie Argyropoulos (\$500); and Lisa Pastor, Kristen Robinson, Andrew Bromell, Robert Murray, Fiona Nicholls, Andrew Millington, Jacqueline Higgins, Hayley Page, Anthony Noor, Kay Millington, James Lewis, Neil Berry, Mark Greenham, Alli & Keith Burrell, and Michael Young (who all raised between \$100 and \$490); and Angelo Augello, Jessica Hartsilver, David Inge, Micha Helbig, Simon Wilkins, James Lewis, Darren McPherson, Lisa Nolan, Ji Eun Lee, James Pan Yan and Michael Bayley.

Going the distance

On October 9, we will also have a courageous contingent of **Team Parkinson's** athletes undertaking the gruelling Melbourne Marathon (42kms) while raising funds to support our everyday work.

Thanks to: Kevin Pruden, Gillian Rawson Harris and Heather Etherton.

Stay tuned as our Team is sure to grow. Contact Judith if you'd like to find out more about Team Parkinson's: judith@parkinsons-vic.org.au

Putting for Parkinson's

Once again, the **Spring Valley Golf Club** went all out to put on a fantastic Charity Golf Day in May, which was enjoyed by the full capacity field of 129 players.

Almost \$22,000 was raised, with 50 percent of proceeds going to help fund our information and support programs (the other 50 percent was donated to the Kingston Charitable Trust).

Big thanks to Club management and members, and to the Charity Golf Day committee. Thanks also to the many wonderful organisations who donated goods and prizes, especially [Between the Bays Retreat \(Cape Schanck\)](#), [Endeavour Hills/Mojo Wines](#), [Ella & Friends photography](#), and [Bunnings Moorabbin](#).

Thanks a bunch

Local florist **Ann's Flowers** has been keeping our new office looking and smelling *bee-yoo-ti-ful* with a fresh bouquet every week since we arrived. **Thanks a bunch for your generous donation of weekly flowers Ann - they create such a lovely welcome for staff and visitors alike.**

Ann's Flowers: 255 Charman Road, Cheltenham; 03 9583 7527 or www.annsflowers.com.au