inmotion

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A MAGAZINE FOR THE PARKINSON'S COMMUNITY

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IN THIS TOGETHER
parkinson's
VICTORIA

CEO UPDATE

It's impossible to acknowledge the start of 2020 without mentioning the destructive bushfires that swept through East Gippsland, Alpine regions and other parts of Australia. The devastating impact continues long after the flames have gone.

This summer's fire season has been devastating and came on top of continuing drought, which also brought dust storms to the north-west. Even those living in Melbourne were touched by smoke haze and dirty rain.

People with Parkinson's often notice their symptoms are worse when they are under stress, so there is little doubt these impacts have added to the emotional, physical and environmental stresses of our community.

We know that people do need our help, even if it's just a quick question to put someone's mind at ease. That's because we've experienced a record amount of calls throughout January to our health information phone line - double the number compared to last year.

Many members of our Parkinson's community are living and working in drought and fire-affected areas. We will be there for them as part of their support network to help them get back on track, a process that will take many months, if not longer.

Members of our health team will be visiting a number of Parkinson's peer support groups in regional Victoria over coming months, including Corryong in North East Victoria, which was surrounded and cut off by fire.

We have been, and will be, visiting a number of regional areas across Victoria, including Wangaratta, Beechworth, Portland, Colac, Leongatha, Moe and many more in between.

Supporting, informing and empowering our members, and the wider Parkinson's community, remains at our core. This is underpinned by our multi-disciplinary and evidence-based practice and model of care.

This year, we are seeking to expand our information supports and services with the development of new programs and resources, including implementation of online education. We are also updating the Peer Support Group leader training manual, to be released later this year.

We are particularly proud to announce our sponsorship of Insight 2020, the largest online global conference for people living with Parkinson's.

Running from 1-3 April and delivered entirely online, it will feature some 60 renowned international and national speakers presenting on a range of topics and live panels. Importantly, our sponsorship of this event has helped to ensure it is free and accessible to all.

In addition, we have secured a special discount for members of our community who wish to pay to upgrade their event registration. You can read more about this on Page 4.

Recognition of the difficulty some people face attending our events, including InSearch and the highly successful Smart Health in November, was behind our decision to sponsor INSIGHT 2020, making its highly regarded presenters accessible to all, no matter where you live.

Living well with Parkinson's is best achieved through building your understanding of Parkinsons, so we see INSIGHT 2020 as complementary to our own InSearch research lecture series, which will be held in March. Prof. Mal Horne, Dr Scott Ayton and Dr San San Xu will provide valuable insights into current studies and the latest findings from groundbreaking Parkinson's research, including causation, emerging technologies and preliminary results from the Treat to Target research.


Parkinson's Victoria CEO Emma Collin

In December, the Parkinson's Victoria Board approved a new research agenda, following an extensive review by the Board's research committee. Our approach is to seek to initiate research that supports our mission.

We will continue to partner and invest in research that improves quality of life for people living with Parkinson's today.

ParkinDance and ParkinSong are excellent examples of translational research, providing a unique opportunity to ensure safe, accessible research-based programs are delivering improved life outcomes for people with Parkinson's now.

At the same time, our support of pure science will also continue as we seek grants for dedicated research in pursuit of furthering our understanding of Parkinson's, to ultimately find cure.

Meanwhile, our dedicated team continues to deliver core supports and services, including our valued phone information line. Our Recently Diagnosed Seminar series is underway and community seminars already planned for The Grampians and Swan Hill.

I would also like to acknowledge the very worthy Parkinson's Victoria Recognition Awards recipients, those special people who go above and beyond for their peers. This year they included the Sir Zelman Cowen Award recipient Heather Jobling, who features on our front page.

Recognition, appreciation and service awards were presented at our AGM in November, where it was also lovely to see Judy Phelan – the face of our 2019 Festive Season Appeal – who was awarded honorary life membership.

I would like to end by thanking you for your ongoing support as a Parkinson's Victoria member.

Donations fluctuate and can be impacted when times are tough, as we have seen through our Festive Season appeal. But as we have already seen just weeks into the new year, the need for our services and support continues to grow.

It's through your support that we are able to be there when any Victorian impacted by Parkinson's needs us.

For that I am truly grateful and I encourage you to take advantage of the benefits your membership provides, including free attendance at an InSearch lecture for yourself as a member and one guest. I look forward to seeing you there.

Emma L Collin

Emma Collin
CEO
Parkinson's Victoria

Cover: 2019 Sir Zelman Cowen Award recipient, Heather Jobling.

NEWS & HIGHLIGHTS

Victoria's premier research presentation series designed especially for people living with Parkinson's will be held a month earlier than last year, with the launch event in Echuca on Friday 20 March.

InSearch lectures will also be held in Melbourne and Horsham.

This year's line-up of leading researchers and clinicians will provide valuable insights into current studies and the latest findings from groundbreaking Parkinson's research, including causation, emerging technologies and preliminary results from the Treat to Target research using the PKG watch.

All Parkinson's Victoria members are eligible to receive two complimentary tickets to attend these lectures, featuring **Prof. Mal Horne** (Melbourne), **Dr Scott Ayton** (Melbourne, Echuca and Horsham) and **Dr San San Xu** (Echuca and Horsham).

The Parkinson's Victoria InSearch research series provides a unique opportunity for Victorians to learn more about research being carried out which has the potential to greatly enhance the lives of people living with Parkinson's.

Anyone interested in learning more about some of the science behind Parkinson's, presented in a factual and easy-to-understand format, should attend one of these informative lectures.

SECURE YOUR SEAT NOW!

Free to Parkinson's Victoria members and one guest, or $20 per person for non-members

Echuca Research Lecture

Mercure Port of Echuca
Friday 20 March 2020
Registration from 2pm

Melbourne Research Lecture

The Florey Institute – The Kenneth Myer Building
Thursday 26 March 2020
Session 1 – Registration from 2pm
Session 2 – Registration from 6pm

Horsham Research Lecture

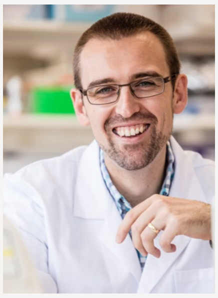
Glen Logan
Tuesday 31 March 2020
Registration from 2pm

Register: www.parkinsonsvic.org.au/events
or call Parkinson's Victoria on (03) 8809 0400

Prof. Malcolm Horne
St Vincent's Hospital Melbourne

Prof. Malcolm Horne is the lead researcher on the national Treat to Target study into managing Parkinson's using a wrist-worn device (the Parkinson's Kinetigraph or PKG) that records symptoms and movements and provides patients with medication reminders.

He will share preliminary results from the research, which involved a number of Victorian participants, and was jointly funded by Parkinson's Victoria.



Dr Scott Ayton
The Florey Institute

Dr Scott Ayton is the head of the Translational Neurodegeneration Laboratory, and Deputy Director of the Melbourne Dementia Research Centre, at the Florey Institute of Neuroscience and Mental Health.

He will discuss current international research looking at prevalence and causes of Parkinson's, as well as insights into new and emerging treatments.

Dr San San Xu
Austin Hospital, Melbourne

Dr Xu is a movement disorder neurologist at Austin Health. She was part of a team of researchers working on developing the next generation of deep brain stimulation (DBS) with highly regarded neurologists and neurosurgeons.

She will talk about emerging technologies in the diagnosis of Parkinson's, including recent advances in DBS and focused ultrasound.

In a first for 2020, we are complementing InSearch by sponsoring the 2020 INSIGHT into Parkinson's online conference, helping to provide free access to 60 leading national and international presenters (see more overpage).

MAKING THE LATEST DEVELOPMENTS ACCESSIBLE TO ALL

Access to quality information and experts in Parkinson's from Australia and around the world is the reason behind our decision to partner with PD Warrior as Platinum Sponsor of INSIGHT 2020.

INSIGHT into Parkinson's is the largest online global conference for people living with Parkinson's. From just a handful of webinars three years ago, INSIGHT 2020 is expecting 60 speakers. The theme is Future Frontiers.

The event is the brainchild of specialist neurological physiotherapist, Melissa McConaghy, owner and founder of PD Warrior, a rehab program designed for people with Parkinson's.

Online software brings the conference to life, with online presentations, panel discussions and exhibition halls.

"Access to quality information is key to increasing understanding of Parkinson's and building an individual's capacity to manage condition and access effective treatments, so they can lead full and active lives," said Parkinson's Victoria CEO Emma Collin.

"We also know many more people are seeking information online – but we want to help ensure what they view is robust. This is a perfect opportunity to support quality, online information, making it available and accessible to everyone, no matter where they live."

RENOWNED PRESENTERS

Those who missed seeing **Prof. Bas Bloem** speak at Parkinson's Smart Health in Melbourne in November, will be pleased to hear he will be one of the INSIGHT 2020 speakers. Other international speakers include:

Prof. Fabrizio Benedetti MD, Professor of Neurophysiology and Human Physiology at the University of Turin Medical School, Turin, Italy, and Director of Medicine and Physiology of Hypoxia at Plateau Rosà, Switzerland.

Dr. Maria De Leon MD (USA), a movement disorder specialist. Diagnosed with Young Onset Parkinson's, she has championed women's issues, helping to re-write understanding of gender differences in Parkinson's.

Matt Eagles (UK), a passionate patient engagement advocate and keynote speaker, he heads up the Parkylife project, helping people with Parkinson's and their families live brighter, happy lives.

Prof. Matt Cooper, National Health and Medical Research Council (NHMRC) Principal Research Fellow. He is an expert in label-free technologies and their application to drug discovery and development with two books in this field.

Dr Victor Fung, Clinical Associate Professor at Sydney Medical School, The University of Sydney and Director of the Movement Disorders Unit, Department of Neurology, Westmead Hospital. He has a clinical and research interest in Parkinson's disease and movement disorders.

Prof. Meg Morris, a registered practicing physiotherapist with a special interest in Parkinson's. She is the Professor of Clinical & Rehabilitation Practice, La Trobe University and Healthscope and research lead of current Parkinson's Victoria-led research into the therapeutic health benefits of dance.

Our own **Victor McConvey** will present his popular, Between the Sheets presentation, which he presented at Smart Health. Learn more from Victor about sleep, sex and Parkinson's on Page 12.

PROUD PLATINUM SPONSOR
2020 INSIGHT INTO PARKINSON'S
Future Frontiers
www.insightintopd.com

"We are proud to come on board as platinum sponsor to help make the event free of charge for the first time." Parkinson's Victoria CEO Emma Collin.

HOW DOES IT WORK?

This virtual summit is delivered like a normal conference, except it's completely online. There are three days of speaking events programmed across eight separate streams. Each session is 90 minutes long, with three presentations of 30 minutes each per session.

There will also be two virtual Exhibition Halls. Here you can interact online with the exhibition booth holders, download their content, watch additional videos and get up to speed with what each booth holder is offering.

What does free registration offer?

Parkinson's Victoria's sponsorship of INSIGHT 2020 will help enable everyone to stream this 3-day online conference **free of charge**. The FREE registration ticket gives you up to three days of programmed content from 1 - 3 April. You can watch this as it is delivered in the program, or in your own time on demand. You will have these three days, 24/7, to watch and replay the broadcast content.

What is an upgraded package and what does it include?

If you want more, you can pay to stream-on-demand for an additional 30 days. This allows you to watch all presentations at a time that suits you.

As part of our member community, a **30% discount** on the upgrade package is available too. Just enter our discount code - InsightPV20. Please select Parkinson's Victoria as your charity of choice when you register.

How do I register?

Go to **www.insightintopd.com**
and click on the register tab.

Five reasons to join INSIGHT 2020!

1. First three days are FREE! If you want more, you can upgrade to stream-on-demand for another 30 days' access.
2. You get world-class speakers direct to your living room.
3. All of the ticket profits go to registered charity partners (including Parkinson's Victoria) to support Parkinson's research and support services globally.
4. INSIGHT is the largest online annual event in Parkinson's.
5. You can connect with more than 5000 researchers, academics, clinicians and other people living with Parkinson's from around the world.

PARKINSON'S VICTORIA: HELPING TO MAKE INSIGHT ACCESSIBLE.

2020
INSIGHT
INTO PARKINSON'S
Future Frontiers

Proudly Hosted By

PDWARRIOR

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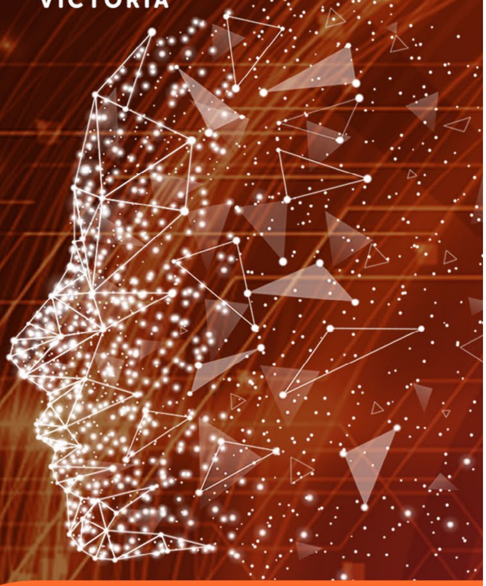
VICTORIA



GLOBAL ONLINE PARKINSON'S CONFERENCE

APRIL 1ST TO 3RD, 2020

ONLINE ...
ANYWHERE!
ANYTIME!

60 INTERNATIONAL PARKINSON'S SPEAKERS

Dr. Randy Schekman
Scientific director
Aligning Science
Across Parkinson's
(ASAP)
initiative and
Nobel Laureate

Prof. Bastiaan Bloem
Neurologist &
Director of the
Radboud
University
Medical Center

Emma Lawton
Author, TEDX Speaker,
Vlogger & Advisory
Board Member
Bansen Labs

Dr Maria De Leon
Neurologist and
Author of Parkinson's
Diva

Dr David Perlmutter
Neurologist and
New York Times
Best Seller

REGISTER NOW FOR FREE

www.insightintopd.com

Retired Geelong Parkinson's PSG Leader, Harold Waldron.

NEW CARERS' AWARD ANNOUNCED

The long-standing contribution of Harold Waldron, the retired leader of the Geelong Parkinson's Peer Support Group has been recognised with the creation of a new award in his name – the Harold Waldron Carers' Award.

"Harold has been supporting the Parkinson's community for more than 38 years, 31 of them as Geelong PSG leader, and has received every honour we are able to award," Emma Collin said.

This included the Sir Zelman Cowen Award in 2008, Parkinson's Victoria's highest honour to acknowledge an individual for their outstanding service to people living with Parkinson's.

The **Harold Waldron Carer Award** will recognise a family member or friend who has been touched by Parkinson's and made a significant difference to the Parkinson's Community, through their voluntary leadership or support of a PSG leader.

"Harold's dedication and care for others is an example and inspiration to us all – and we know Harold's legacy will remain with us through this award," Emma said.

Harold, who is 91, said he was initially overwhelmed by the honour, but then conceded that he had been connected with Parkinson's for a long time.

Harold was a local builder who became a carer for his wife Margaret after she was diagnosed with Parkinson's. Both were present at the very first Geelong PSG meeting in 1981 and Harold became leader in 1987.

But what is so extraordinary about his involvement is that it continued long after Margaret passed away in 1999.

"I am very, very thankful that I have been able to help so many people," Harold said, adding he also got a lot out of helping people living with Parkinson's and their carer's.

The inaugural recipient of the Harold Waldron Carer's Award will be announced at the 2020 Parkinson's Victoria AGM.

COMMUNITY RECOGNITION AWARDS

Judy Russell: Leader of the Camberwell PSG, Judy enthusiastically and passionately fulfils this role, often beyond the call of duty.

Richard Grimmett: Community fundraiser and passionate Parkinson's advocate.

Mike Atkinson: Former leader of the Geelong Young Onset PSG and current working group member of Geelong PSG. Mike is involved in Surf Coast Painting with Parkinson's, Torquay Dancing with Parkinson's, has organised community seminars in the Geelong area and was 2019 World Parkinson Congress Ambassador.

Christine Anderson: Facilitator of the Kyabram PSG, passionate fundraiser for A Walk in the Park and the face of the Parkinson's Victoria 2019 winter appeal.

Christine Anderson receives her award from Board Chair, Philip Thomas.

HONORARY LIFE MEMBER

Trevor & Pearl White: Foundation members of the South Gippsland Support Group (since 2004) and regular participants in Parkinson's Victoria events, particularly a number of years attending A Walk in the Park. They have also actively fundraised for Parkinson's Victoria.

Judy Phelan: A major fundraiser for Parkinson's Victoria and a passionate participant and regular top fundraiser for A Walk in the Park since 2010. Judy has been a Parkinson's Victoria Ambassador and featured in the 2019 Festive Season appeal.

10 YEAR SERVICE AWARD

Louise and Paul Zajac (Geelong Young@Park)

5 YEAR SERVICE AWARD

Darryl Keeble (Mildura), **Cynthia Parker** (Mildura), **Christine Anderson** (Kyabram), **Joy Shortis** (Kyabram), **Kathy Kukuljan** (Kyabram)

CERTIFICATE OF APPRECIATION

Kirsten George: The Geelong Walk in the Park was an outstanding event, thanks to Kirsten's leadership and tireless work supporting this regional community event, with 625 participants raising more than $10K.

Peter Walsh: Peter has supported the Warrnambool PSG for over 10 years by providing a venue for the monthly group meetings and catering free of charge. Peter has regularly sponsored Parkinson's events in the Warrnambool area.

Dr John Locke: John has served on the Parkinson's Victoria Research Committee since 2016 and retired in 2019.

Fred Van Ross: Fred is a former board member and Essendon PSG leader who also served on the Research Committee after retiring as a Director.

Shane Murphy: Shane is a retired Parkinson's Victoria Board Director.

Judy Phelan (with her husband Ian), received her Parkinson's Victoria honorary life membership from Board Chair, Philip Thomas

BOARD MEMBER ELECTIONS

Current board members Philip Thomas and Sue Harper were re-elected for another three-year term. The election of three new board members was also approved at the AGM. They are:

Steve Watts: Steve has a background spanning 34 years in Emergency Services and was diagnosed with Parkinson's in 2017. His experience has been gained by fulfilling committee roles across a variety of management and leadership positions. As a fire officer he has established an operational and functional leadership/management style with an emphasis on personal communication, wellbeing and accountability.

Faye Spiteri: An accomplished strategist, Faye has an excellent record of moving strategic ideas through to successful implementation, underpinned by practical, sound governance. She has led organisations – through clear vision and strong purpose – to meet rigorous governance standards in social and financial performance, accountability and transparency to create value and build social capital for social impact.

Orlando Viola: Orlando has more than 30 years' experience in the Commonwealth Public Service. During this period he undertook a range of roles and responsibilities covering the technical, operational and administrative realms. With parents impacted by Alzheimer's and Dementia, Orlando has experienced first-hand the issues faced by those caring for and living with neurodegenerative disease.

AWARD A HIGH NOTE FOR HEATHER

From sky-diving to singing, Heather Jobling has not been one to stick to the norm when it comes to supporting the Parkinson's community.

Diagnosed with Parkinson's in 2006, Heather has been a long-time supporter of her local Parkinson's community in Williamstown and was instrumental in introducing the ParkinSong therapeutic singing program into Victoria.

She was named the 2019 recipient of the Sir Zelman Cowen Award at the Parkinson's Victoria AGM in November.

"I feel deeply honoured and accept this award on behalf of all the people who have contributed in so many different ways and shared the journey to make the dream a reality," Heather said.

The Sir Zelman Cowen Award is Parkinson's Victoria's highest honour, first presented in 2006 to acknowledge an individual for their outstanding service to people living with Parkinson's.

Heather's first fundraising and awareness activity was Jump for Parkinson's in April 2011 to coincide with World Parkinson's Day and her 70th birthday. In 2012, she was asked to lead a local support group in Williamstown.

"I initially declined – I wanted to do something different. After I listened to an address by a speech pathologist, and later talked to her, my idea started to take shape. If people were to exercise their voices through singing, this could perhaps assist with speech and swallowing."

After discussions with Parkinson's Victoria staff, a small steering committee was established, with funds from the Hobson's Bay Council mayoral fund helping get the new singing group started.

"On Thursday 21 March, 2013, my dream was born.

"We had no name and no accompaniment, but what we did have was the irresistible good humour of Doug Hayward OAM, and we did have fun. Everyone present wanted to repeat the experience."

Doug Cameron, who to this day leads ParkinSong Williamstown with his wife Alex Cameron on keyboard, recalls being struck by Heather's energy and passion from the day she approached him after a performance of The Messiah in Williamstown.

"What I saw in Heather was a woman with the warmest of hearts and an incredibly strong belief that it (Parkinson's) wasn't going to get the better of her. Her positivity to what she has and how she copes with it - and how she helps other people cope with it - is just amazing."

Doug described her as 'visionary' in what she wanted to see achieved through ParkinSong.

"She's inspirational - a warm-hearted lady with an infectious smile. And she's a great example of how not to let this sort of thing get the better of you, either physically or mentally – she's still in charge."

Heather's next dream came to life in 2018 with the ParkinSong Concert at the Williamstown Town Hall.

"We had hoped for an audience of 200 but over 430 turned up to enjoy listening, participating and watching and over 100 ParkinSong singers have fun," Heather said.

Parkinson's Victoria CEO Emma Collin thanked Heather and her husband Mike, who is always by her side, for their tireless support of the Parkinson's community.

"Heather's contributions are an inspiration to others and we thank her for making a significant difference by bringing happiness and social connection to so many in the Parkinson's community," Emma said.

Smart Health attendees.

THE LOWDOWN ON SMART HEALTH

When knowledge combines with passion and empathy, the result can be mesmerising. So it was for the 400 people who came to hear Dutch neurologist, Professor Bas Bloem in Melbourne in November.

Prof. Bloem was keynote speaker at Parkinson's Victoria's inaugural Smart Health event.

An engaging and inspiring presenter, his excitement when he recounts stories of patient successes is tangible. Successes that he learned of – or helped spur on – simply by speaking to patients as people.

"We don't talk about patients, we talk with patients – this is modern medicine," Prof. Bloem said.

He spoke of the man who had freezing of gait – but who said he'd recently ridden 50 miles on his bike. A bike was found at the clinic and the man rode around the carpark.

He also illustrated the transformation of a former Netherlands Philharmonic Orchestra concert-master who was able to confidently play violin again with the use of a wrist splint. The man's symptoms were initially masked as he was taking extra medication prior to his medical visits.

Both cases have been documented in published articles and demonstrate the need to listen to patients: Find out their goals and what is important to them so they can be helped to lead a meaningful life while living with Parkinson's.

For the concert-master, it was playing the violin. For Russell, the patient case-managed by Prof. Bloem and a multi-disciplinary team at the Smart Health event, it was being able to, "walk without thinking about it".

Advocating a multi-disciplinary approach to Parkinson's healthcare – a position supported by Parkinson's Victoria – was the reason Prof. Bloem spoke in Melbourne at two events – one for people impacted by Parkinson's, another for healthcare professionals. And he left many people wanting more.

"To my mind, Parkinson's is the most complex and fastest growing neurological condition on the planet. It is incredibly complex, but fascinating. Drugs are helpful, but it's not the whole story," Prof. Bloem said.

"Parkinson's is personal so each person deserves tailor-made, personal treatment. Evidence is growing that multi-disciplinary care is good for you – both medical and allied healthcare to fully understand and optimally treat people with Parkinson's."

Prof. Bloem also espoused the importance of staying active.

"We live in an era of hope. There are drugs on the horizon that will hopefully slow down progression. But the one intervention that is closest is exercise!"

He recommended 30 minutes of exercise that leaves you panting, but not unable to take part in conversation, was the ideal and to do it every day – so you will never be able to say, "I will do it tomorrow."

Prof. Bas Bloem and Parkinson's Social Worker, Amanda Spillare.

Patient Russell (left) with Prof. Bloem and Social Worker, Amanda Spillare

THE MULTI-DISCIPLINARY APPROACH IN ACTION

Russell, who was diagnosed with Parkinson's nine years ago, bravely volunteered to be a patient on stage at Smart Health, as he talked about his symptoms, frustrations and hopes to a multi-disciplinary team, made up of:

- Prof. Bloem - Neurologist
- Dr. David Blumberg - GP
- Assoc. Prof. Jennifer McGinley - Physiotherapist
- Caterina Marigliani - Speech Pathologist
- Natalie Delac - Occupational Therapist
- Dr. Luke Smith - Neuropsychologist
- Victor McConvey - Nurse and patient educator
- Amanda Spillare - Social Worker
- Amanda Longo - Dietician

When asked what he most wanted, Russell replied without hesitation:

"I want to be able to walk without thinking about it. It's what I miss most. The other things I can deal with."

Some of the observations made by the team based on their conversation with Russell:

- A neurologist could carry out diagnostic testing to look at increasing medication as Russell indicated his medication was not resulting in any improvements.
- An occupational therapist and physiotherapist could do a home visit to reduce hazards and risks in the home and go for a walk with Russell to see how his walking is affected.
- A dietician could work with Russell in relation to diet and food and water intake and the interaction with medication.
- A neuropsychologist can help with cognitive rehabilitation to help with day-to-day functioning.
- A speech pathologist could assist with swallowing difficulties.
- A social worker could help unpack loss and grief and find meaning in a changed life.
- A Parkinson's nurse could act as a case manager and work closely with the GP, who could help related medical issues such as blood pressure and also develop a chronic illness plan.

> "We need to transform healthcare to get rid of the idea that the neurologist is the star of the team. That's not to say they are unimportant, they are important in diagnostics and medical treatment, but most of the time, they are one of the guys in the team." - Bas Bloem

WHO SHOULD BE IN YOUR TEAM:

GENERAL PRACTITIONER (GP)

Your GP is usually the first medical professional you see for a health issue. GPs are not necessarily experts in Parkinson's; however they will be able to assess any symptoms you are experiencing and provide a treatment option or refer you to a specialist. If they suspect you have Parkinson's, they will refer you to a neurologist. Your GP can also work with you to create a Chronic Disease Management plan which enables people living with a chronic condition (including Parkinson's) to receive five rebated sessions with allied healthcare providers per calendar year and up to 10 sessions with a Mental Health Professional.

NEUROLOGIST

A Neurologist is a specialist physician who diagnoses and treats neurological conditions (conditions of the brain, spinal cord and nerves). There are neurologists who specialise in movement disorders such as Parkinson's. A Specialist Neurologist will be familiar with the many different presentations of Parkinson's and be able to identify the best treatment options.

PARKINSON'S NURSE

A Parkinson's nurse has specialist experience, knowledge and skills. They provide advice and support and can recommend symptom management strategies. As Parkinson's progresses, they can offer guidance on managing medication and refer you to other healthcare professionals for more specialist advice. There are very few Parkinson's nurses available currently, however nurses working in chronic disease management programs such as Hospital Admission Risk Programs (HARP) may be able to assist with referral to other member of the multi-disciplinary team.

PHYSIOTHERAPIST

Physiotherapists use exercise and other forms of physical therapy to help keep people mobile. They undertake an assessment to see how Parkinson's affects physical movement, from which they may recommend exercises to improve muscle strength and flexibility, improve balance and prevent falls and help with pain management. Physiotherapists are important healthcare professionals who can assist in keeping you mobile and reducing falls. Physiotherapists are the best healthcare professionals to recommend and prescribe the most suitable walking or mobility aid, if required.

Parkinson's Nurse Victor McConvey, Occupational Therapist Natalie Delac, Neuropsychologist Dr Luke Smith and GP Dr David Blumberg.

OCCUPATIONAL THERAPIST

Occupational Therapists can help people with Parkinson's stay independent for longer and carry on doing the work and leisure activities important in their lives. They can undertake home and workplace visits and can suggest easier ways to do tasks that have become difficult, suggest changes to make your home safer and recommend mobility and aids to help keep you independent.

SPEECH PATHOLOGIST

Speech Pathologists can help make communication easier for people with Parkinson's. They can also help with swallowing and saliva difficulties. They specialise in all areas of communication including facial expressions, body language, speech and fluency. The Speech Pathologist may suggest exercises and techniques to strengthen your voice, help you control your facial expression and suggest communication aids if talking has become very difficult for you.

NEUROPSYCHOLOGIST

A Neuropsychologist is a psychologist who specialises in understanding how the brain's structures and systems relate to behaviour and thinking. They evaluate and treat people with various types of nervous system disorders, including Parkinson's, which can affect how people feel, think and behave. A Neuropsychologist's exam can also provide a baseline to help them determine disease progression and cognitive (thinking) and memory function.

SOCIAL WORKER

Social Workers are trained to help people with the social, emotional and financial challenges of life. Sometimes these challenges can become much greater when you are diagnosed with Parkinson's. In many cases, Social Workers can be an excellent source of counselling. They can also provide practical assistance with regards to matters involving housing, employment, money, relationships and care.

DIETICIAN

Constipation and weight loss can result from Parkinson's. Food can also interfere with medications absorption. A Dietician may suggest eating choices to ensure a balanced and healthy diet, help you coordinate medications with meals and help people maintain a healthy weight.

FAMILY

The most important team members. Family may be a partner, spouse, children, relations or friends. Parkinson's is a complex condition which lasts for a long time and often everyone is touched by it in some way and will also help in some way. The ideal model of care is person-centred and family–focused. The multi-disciplinary team of healthcare professionals are there to support both the person living with Parkinsons and their significant others.

SOME TIPS OFFERED BY PROF. BLOEM:

When you visit your neurologist:

- bring a list with the top three things you want to discuss
- make a home video of symptoms (which may not be evident on your visit)
- bring your medication.

WANT TO SEE MORE OF PROF. BLOEM?

See Prof. Bloem's TedTalk, From God to Guide: youtube.com/watch?v=LnDWt10Maf8

Hear Prof. Bloem's inspiring presentation and case study on medicine and culture at the 2018 Edinburgh International Culture Summit: vimeo.com/305054423

Need advice on putting your own multi-disciplinary team together? Speak to one of our Parkinson's healthcare professionals by calling 1800 644 189 or email, info@parkinsons-vic.org.au

FUNDRAISING

A MARATHON EFFORT

The Melbourne Marathon is Australia's largest marathon, last year attracting more than 37,000 participants. Among them was Andrew Lindsay, who was running to raise awareness of Young Onset Parkinson's.

In the process, he raised $5283 for Parkinson's Victoria (while the marathon has partner and associated charities, participants are able to nominate their own charity to support).

This was Andrew's second marathon supporting Parkinson's. Together with his wife Mandy, they were part of the Young at Parkinson's Runners and Walkers team, raising $11,459 in 2018.

Andrew and Mandy did the half marathon at the 2019 event in October, combining their running training with, "normal weekly activities of going to the gym, Pilates and spin classes."

According to Andrew, Mandy has provided him a great deal of motivation and support throughout this journey.

"This was Mandy's 11th marathon. She's a disciplined runner who does a lot of warm-ups, warm downs and post-run recovery.

"She's on the extreme level of doing things like ice baths – we live at the base of Mount Macedon near Melbourne, so last year during early winter mornings Mandy would have us standing in our unheated pool after our longer training runs."

Since his diagnosis, Andrew is conscious of doing some form of exercise each day.

"Parkinson's affects each person differently. In my case, motor symptoms like rigidity, stiffness through my back and arm, and my walking gait are affected. I feel the impact of Parkinson's most when I'm not active.

"At the same time, it's had a positive impact as well since it's motivating me to stay fit and healthy and providing an extra reason to get out of bed early every morning."

Andrew also received support from his employer, SAP, which was official Innovation Partner of the event, visualising historical marathon data and real-time race data on the day of the marathon.

Andrew is not only a valued fundraiser for Parkinson's, but is also keen to support others diagnosed with young and early onset Parkinson's. Learn more on Page 17.

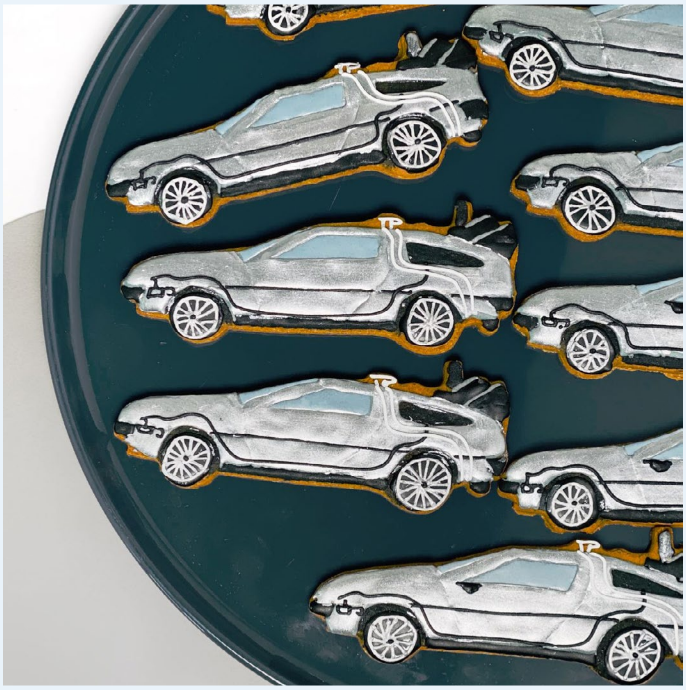
BACK TO THE FUTURE FUNDRAISER

We love seeing the creativity that goes into Parkinson's community fundraisers – and the Back to the Future fundraiser at Boatrocker Brewers and Distillers' Barrel Room in Braeside in November was no exception.

While the event celebrated barrel-aged brews at the micro-brewery and distillery, funds of $1055 was raised for Parkinson's through a raffle to ride in a 'fully pimped' vintage DeLorean and the sale of DeLorean-shaped cookies hand-made by the talented Deb Lieu Bakes (picture below).

Boatrockers founder, Matt Houghton, said they decided to support Parkinson's as a tribute to the man who inspired him to start a brewery, UK author and journalist, Michael Jackson, who died in 2007 after living with Parkinson's.

"He wrote numerous books about beer and whiskey and was considered an authority in the area; and in particular, my bible 'the Pocket Guide to Beer'. It's our little way to say thank you."



A BIT OF TRIVIA

Thanks to the Ross Creek-Smythes Creek Community Group for choosing to support Parkinson's Victoria with the proceeds of their trivia night fundraiser. Despite the bad weather, more than 100 turned up for a fun night, raising $3015 along the way. Pictured receiving the cheque from Dianne Scobie and Cathy Bushell, is Parkinson's Victoria's Health Team Manager, Victor McConvey.

SLEEP, SEX AND ALL THINGS BETWEEN THE SHEETS

When it comes to Parkinson's, some symptoms are easier to talk about than others.

Parkinson's Victoria Health Team Manager and Parkinson's nurse, Victor McConvey has talked about changes that take place between the sheets at seminars and conferences in Australia and internationally.

In this edition of *InMotion*, we share some of his tips with you.

Parkinson's can affect many areas of your life. Some are visible, such as movement changes, some less visible, like sleep changes, and some that can be harder to speak about, like changes impacting sex life.

Problems with sleep and sex can be disruptive and significantly impact quality of life. They may also not be apparent to your healthcare professionals. However, managing these symptoms is possible.

> The first step is open communication – with your partner and treating healthcare professionals. Let them know what you are experiencing and together you can work towards better sleep and sex.

MOVEMENT DURING SLEEP

Rapid eye movement behaviour disorder (RBD) often occurs many years before a person is diagnosed with Parkinson's. It occurs when your brain does not achieve a state of sleep atonia (where body movement is effectively turned off) during deep sleep when you dream; this means you act out your dreams physically.

This sleep disturbance can be worsened by Parkinson's medications.

If RBD is causing a problem for you or your partner, let your neurologist know as treatment is available which may reduce RBD.

Not having enough movement can also be a problem. This is usually at its worst if you wake in the middle of the night when medication levels are low. You may have difficulty moving in bed or experience discomfort or cramping which prevents you from getting back to sleep.

Sometimes the solution can be simple, e.g. a satin sheet or a piece of satin covering the area of the bed where the trunk of your body rests which gives you more glide to slip into a comfortable position. Longer acting medication can also be prescribed by your Neurologist.

DEPRESSION

Depression and anxiety are common in Parkinson's. Mood may fluctuate with medication levels or be low in response to living with Parkinson's. This can be very disruptive to sleep, often worsened at night when you take less medication.

Common signs can include ruminating, worrying, feeling anxious, being irritable and withdrawing from previously enjoyed activities. If you, or your family notice some of these symptoms, getting help from a councillor or psychologist can be very helpful.

Speak to your treating doctor, particularly if you notice your mood fluctuates with medication, as altering your medications can help.

Sometimes an anti-depressant may be considered as they can be a very effective way of assisting mood. However, some anti-depressants can worsen Parkinson's symptoms and sleep so you need to discuss this with your doctor.

TOILET TRIPS

Needing to pass urine frequently at bed time can be very disruptive. This is often caused by a disturbance between the bladder and the part of the brain responsible for letting us know we need to urinate, causing urgency. This may be worse when medication levels are low.

Pressure fluctuations, common in Parkinson's, may cause daytime fluid retention, which is passed at night. To help manage this, reduce fluids in the hours before bed. Taking a short afternoon power nap, lying completely flat, can help move some of the fluid which may have collected.

Some people also find elevating the head of the bed will help reduce this symptom as the fluid stays in the lower limbs rather than being passed.

GETTING SEXY

For many of us, going to bed is associated with sex as well as sleep. Unfortunately, Parkinson's will impact sexual performance and desire.

Lowered levels of dopamine will reduce libido and impact motor performance. Males will find it more difficult to get an erection and females will notice reduced vaginal secretions which assist with lubrication.

Movement changes, such as stiffness, can make it difficult to get into the positions you previously enjoyed. Fatigue will also impact desire. However, most sexual difficulties can be overcome, with communication with your partner the first step.

Practical ways to manage these challenges can include the following:

- Changing the timing of your planned sexual activity - 10am may be much better than 10pm as fatigue will be reduced and medication levels higher.
- The use of oestrogen cream applied to the perineal area for females helps to make tissues more pliable. Use of water-based gels or body glides will also assist lubrication.
- Males may find medication such as Cialis or Viagra may assist with erections, however flexibility is required as delayed gastric emptying caused by Parkinson's can also result in a delay in the medication's impact.
- Males pelvic floor exercises can assist with maintaining an erection and further support can be gained from using a rubber ring which sits under the scrotum and around the top of the penis, impeding blood flow from the penis when it is erect.

Thinking differently about intimacy, experimenting and being open to new ideas can all help enhance your sexual activity.

HYPER-SEXUALITY

A side effect of Dopamine Agonists, a common medication used in Parkinson's, can be hyper-sexuality, or an increase in sex drive. It's important to understand that this is a medication side effect and is not the fault of the person experiencing it.

Hyper-sexuality should be reported to your neurologist, who will slowly reduce the medication and the behaviours will stop.

TIPS FOR A BETTER SLEEP:

- Try to go to bed and get up at the same time each day.
- Reduce stimulation, turn off the TV and avoid using electronic devices for at least an hour before bed.
- Read a book rather than a magazine (the coloured images can be stimulating).
- Keep your bedroom cooler.
- Go to bed when you feel sleepy.

Talk to us: Parkinson's Victoria health phone line offers confidential information and advice. If you feel uncomfortable asking intimate questions, you can remain anonymous. Our aim is to enhance quality of life while you live with Parkinson's. Call 1800 644 189.

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TRAVEL

TRAVELLING TIPS FOR A GREAT JOURNEY

Living with Parkinson's doesn't have to stop you from travelling. In research carried out by Monash University, (Warren et al) concerns about Parkinson's affecting ability to travel were highlighted as impacting on quality of life.

While there can be some additional challenges, research and planning can easily overcome them, enabling many people with Parkinson's to continue to enjoy travel.

DO YOUR HOMEWORK!

Investing in a good travel guidebook and checking out Trip Adviser and other peer review websites can provide tips on accessibility, as well as general destination and accommodation tips and highlights.

Do some investigating to find out about safety issues and other hazards. You can also check out if the place you are visiting has a local Parkinson's Association; they may give you an insight into what services and supports are available locally.

Getting help can be useful. While booking everything online can be attractive and has the flexibility of making bookings 24/7, finding a travel agent to do all the running around may be easier and save time.

If using a travel agent, make sure you use one who has some experience and a willingness to do some research, so they can let you know the lovely hotel in London you were thinking of has impossibly small rooms, and recommend somewhere more suitable.

When you or your agent books your airfare or other transport, book any additional assistance you may need. You should always do this as soon as possible and avoid doing it on the day you are travelling.

INSURANCE

Consider getting travel insurance early, at the point where you're starting to pay money, and invest in a policy that includes cancellation. You will need to disclose you have Parkinson's and some companies will request a letter from your Doctor or Neurologist on your fitness to travel.

Having Parkinson's will not prevent you from getting travel insurance. Once you have disclosed your diagnosis it will be listed on your policy, and you may need to pay a little more.

You may need to shop around for the coverage which is right for you and your trip. Sometimes using an insurance broker or having a travel agent can save time and get coverage which meets your needs.

If something happens and you think you may need to make a claim, gather as much information as you can. This might include photographs, receipts and names of witnesses to support the claim you make.

In most cases the insurance will only cover things you aren't able to claim back directly from the provider- e.g., for a cancelled airfare, you make the claim for the money the airline has not refunded.

VACCINATIONS

If you're travelling to a destination where vaccinations are required, be aware you may need to have these several months before you travel. Some countries also need proof of vaccination before they let you enter.

There is little evidence suggesting vaccination or anti-malarial medication will affect Parkinson's or interact with treatment, and most people have no difficulty. When you have your vaccinations, it is common to feel lethargic, generally unwell and sometimes feverish for a few hours following the injection. For some people living with Parkinson's, this may feel a little like your medications are wearing off. This shouldn't persist longer than 3-4 days.

MEDICATIONS

While on holiday, it is not uncommon to experience some nausea, vomiting or diarrhoea. Managing this quickly and correctly will get you back up and enjoying your trip. Be aware that many anti-nausea medications need to be avoided as they can worsen Parkinson's symptoms, so it is worthwhile taking a supply of approved anti-nausea tablets with you.

Travellers' diarrhoea is often caused by a bacteria in food or water and is easily overcome with antibiotics, which are safe to take with Parkinson's. If you are using medication to stop the diarrhoea try to use them sparingly, remembering a common Parkinson's symptom is constipation.

Once you're ready and packing your bags, don't forget your medications!

You should have at least one week's worth of medications in your carry on. Checked luggage rarely goes astray, but it's best to be prepared. It's also a good idea to have your medications in the original containers and bring your prescriptions as well.

Taking an extra week's worth of medication is a good idea in case of delays. Medications may not be available in some countries, or may only be available in different strengths. While there are no medications used in Parkinson's that are prohibited, getting a letter from your doctor with a list of your medications can assist if there are any concerns raised during your journey.

If you are using an infused therapy, there are often support services to assist with transport of the medication to your destination. Your treating doctor should be able to let you know what is available or put you in contact with a representative from the pharmaceutical company.

FASTEN YOUR SEATBELTS

Unfortunately having Parkinson's will not get you an upgrade to Business Class! Many people with Parkinson's may feel they don't need any special assistance from the airline; however this is a service available to all passengers.

You should do this when you book, either with the airline directly or your travel agent. Common things to ask for are: Assistance from check-in to the gate (especially in big airports) and a seat near the toilets. Airlines may allow you to carry on additional baggage if this is medical equipment.

Melbourne Airport now has a Hidden Disability Program for its international terminal to help people who require special assistance at the airport. Further information can be found at: **melbourneairport.com.au/Passengers/Passenger-information/Hidden-Disability-Program**

Once your bags are checked and you're ready to go, getting through security is often enough to cause anxiety in even the most seasoned travellers.

Remember the security officers are there for our protection but may not be familiar with Parkinson's and some of the changes it can cause.

When you're approaching security, give yourself plenty of time to take your belt and shoes off and put your phone wallet/purse in your bag. If you have problems with freezing, look ahead and concentrate on maintaining big steps as you walk through the metal detector.

If you've had DBS, you shouldn't 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 will smooth this over.

In most cases, full body scans are safe for people with DBS and pacemakers to use, but again let the security officers know. Always have your DBS charger or reader with you - as it is a medical device it does not count as a piece of carry-on luggage.

CHANGING TIME ZONES

Juggling medications over time zones can seem challenging. As a rule try to maintain normal medication patterns as you would at home so on night sectors, take less medication and treat daytime sectors as day.

Consider your arrival time when working out when its night-time as this can mean you have some extra-long days and may need an extra dose of medication as a top up.

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 or a Parkinson's nurse who can give you some tips on medications.

If you have any questions about travelling with Parkinson's, our Health Team is here to help. Contact them on 1800 644 189 or info@parkinsons-vic.org.au

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CARE FOR YOU

THE IMPORTANCE OF SELF-CARE FOR CARERS

Caring for a loved one with a long-term, chronic condition such as Parkinson's can be physically and emotionally draining, especially as the carer themselves grows older and experiences their own health concerns.

As evidenced by phone calls to our Health Information phone line, we know there are times when it can become overwhelming. That is why self-care for the carer is so vital.

The following tips to help manage stress have been provided by Carers Victoria, the peak body providing a voice for Victorian carers:

Change what you can and accept what you can't change: Focus on what you can do to make a difference and identify and accept the things that you can't change. Stress can sometimes be reduced by changing how you react to it.

Learn skills to help you manage: Learn as much as you can about the condition of the person you are caring for and techniques that can help you to manage your caring role better.

Build resilience: Nurture the traits that are common in people who respond well to change and adversity, such as building self-esteem, focusing on good experiences and learning, and moving on, from unpleasantness.

Implement practical strategies for reducing stress: Keep yourself healthy by eating well and exercising regularly. Get a good night's sleep and take time out yourself to re-charge. Try to do something you enjoy every day. Let off steam and ask for, and accept, help.

CARER CARD PROGRAM

Did you know there is a Victorian Carer Card program in Victoria, offering discounts and benefits to carers?

Victorians who are the primary carer of a person with a disability, severe medical condition or mental illness, or someone who is frail aged or in need of palliative care, is eligible for the card.

Eligibility is confirmed via a Centrelink Customer Reference Number (CRN) or by a medical professional verifying your eligibility.

For information on how to apply: www.carercard.vic.gov.au/

Carer card holders are also eligible for public transport concession fares, free weekend travel vouchers and free travel during Carers Week (October).

COMMON SIGNS THAT MAY INDICATE YOUR STRESS LEVELS ARE TOO HIGH:

- Disturbed sleep or insomnia, tiredness and apathy
- Racing heart or sweating with no obvious cause, digestive problems, headaches and muscle tension
- Overeating or loss of appetite, weight loss or gain
- Feelings of tension, impatience or irritability, anger and resentment
- Lack of self-esteem, depression and helplessness, anxiety or guilt
- Forgetfulness and indecision
- Misuse of alcohol, drugs, tobacco, or gambling
- Feeling negative about things, withdrawing from other people or activities you normally enjoy.

WHERE TO FIND HELP?

If you feel stress is affecting your physical health:

- Talk to your GP.
- Speak to a member of the Parkinson's Victoria health team on 1800 644 189.
- Contact Carers Victoria (carersvictoria.org.au) for counselling services and workshops.
- See the Victorian Government's Better Health Channel website (betterhealth.vic.gov.au) for information and links to services.

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YOUNG & EARLY ONSET GETS NEW SUPPORT

Geoff Constable and Andrew Lindsay are two names that may be familiar to you. Both have previously featured in *InMotion*, with stories of their marathons and treks around Australia and internationally.

Both have thrown themselves into keeping fit to help keep symptoms at bay and have been keen to educate themselves on their condition not only for themselves and their families, but to help and support others.

Their compassion and enthusiasm has now solidified through their new group, the Young & Early Onset Parkinson's Alliance (YEOPA), an independent support group focused on connecting people living with Young and Early Onset and their families.

"We have found on our journeys with Parkinson's that some of the best support and advice has come from more regular connections within the Parkinson's community," Andrew and Geoff said.

"In fact, following our attendance at the 2019 World Parkinson's Congress in Kyoto, Japan we discovered we were not alone. Talking with and hearing from other attendees who also had a YOPD focus we found that our experiences were not just local but felt globally."

The group, which plans to meet monthly, had its first meeting in early February, with a BBQ/picnic in Clifton Hill, where adults and family members of all ages were invited to come along to mingle and play.

YEOPA aims to:

- meet regularly (monthly), at times that suits those working, and in an environment that is appropriate and welcoming to people of all ages, their family and friends
- connect those of a similar age, similar stages in life and shared interests
- unite those in a similar mindset who want to keep active, support others and live well with Parkinson's
- offer a welcoming environment and a place where all family members and friends feel included and comfortable connecting with others living with or who have a loved one living with Young or Early Onset Parkinson's
- come together to support or participate with others in events of interest outside the group.

WHO IS BEHIND THE GROUP?

Geoff Constable: Geoff has been living with Parkinson's for 8 years. His early symptoms included dizziness, balance issues, stiffness and rigidity. After 6 years Geoff was finally diagnosed with Parkinson's at the age of 55. However, Geoff's medical records suggest his first symptoms may have started as early as age 30. Geoff works full time and he and his wife Julie have three young adult daughters, Emma, Kaitlin and Jessica.

Andrew Lindsay: Andrew has been living with Parkinson's for 4 years. His early symptoms were stiffness through his left hand, forearm, shoulder and back. After regular Physio sessions did not relieve symptoms he was referred to a Neurologist. Following tests he was diagnosed with Parkinson's at the age of 46. Andrew is now 50, works full time and he and his wife Mandy have two young adult children, Alexandra and James.

Learn more:
www.facebook.com/YEOPAAustralia

SARAH'S REIMAGINED FUTURE

Darebin Painting with Parkinson's coordinator Sarah Lumley was one of 50 artists with a disability whose work was displayed and celebrated at an exhibition inspired by the International Day of Disability theme, The future is accessible.

A Reimagined Reality was held at SpACE@Collins, an accessible gallery in Melbourne's CBD in December. It was hosted by The Brotherhood of St Laurence, together with Arts Access Victoria and Footscray Community Arts Centre.

Sarah was also asked to speak at the exhibition opening, where she told those gathered how the theme had resonated with her.

"As this exhibition demonstrates, we have something to offer the world. Our skills may be hidden, but when you look around here, at the paintings and drawings, sculptures and photographs, a creative wealth becomes accessible.

"How much more is hidden, the world over, amongst others living with a disability? A reimagined future that is accessible to all will be enabling and inclusive. But more than that, it will reveal a wealth within."

Sarah recalled loving and engaging with art as a young child and drawing sketches of indigenous plants as a young botanist, but said she took up art, "in a meaningful way" after being diagnosed with Young Onset Parkinson's.

"I lost my academic careers to Parkinson's. Loss of my imagined future led me to explore the person I had become and taught me to reimagine my present. This led to a completely reimagined future that was deeply rooted in the past."

She is now a certified Art Therapist.

SURF COAST DANCING WITH PARKINSON'S

The new Surf Coast Dancing with Parkinson's group, led by Jacqui Dreessens, has proven popular and a range of dance types are being highlighted.

Participants have already enjoyed dancing and sharing the technically physical skills and social aspects of Celtic Dance, with their end of year event a social occasion with an Irish band, TradJam of the Iron Bark.

"I was in awe of (the participants') courage and commitment to dancing," Jacqui said.

"Their ability to explore with their full movement potential was wonderful to witness. There were magical moments of connection within the dance group.

"I also greatly appreciate the carers and supporters dancing with us too. The joy on their faces was priceless. I find this inspiring and I look forward to teaching every week," she said.

The new year started with a focus on Afrobeat, which was due to culminate this month with live music from local African pop musician, Immy Owusu.

Other genres to be experienced during the year are Latin American, Swing and Baroque.

Surf Coast Dancing with Parkinson's meets on Thursdays from 10.30am – 12.30pm at Torquay Senior Citizens Centre.

NEW PSG LEADER AT PORTLAND

John Wolf, the new leader of the Portland Parkinson's Peer Support Group, was featured in the *Portland Observer's 'People of Portland and District'* column. The following is an edited version of the original article written by journalist, Angela McFeeters:

The former aged care nurse, Volunteer Coast Guard and St John's Ambulance volunteer is now a Portland Aluminium medical fire, emergency and response officer, volunteer firefighter and Coast Guard member, so it's absolutely clear he's a person who cares about looking after others.

He has also been on a very personal journey to learn more about Parkinson's for the past few years after helping care for his father Fredi, who was officially diagnosed with the illness in 2007 before he sadly died on Christmas Eve, 2018.

Mr Wolf became connected to the local Parkinson's support group through Fredi, first driving his father there and later staying at the meetings with some encouragement from members. The pair ended up receiving invaluable information about the condition as a result of their participation in the group.

Knowledge-sharing and moral support were just what past leader Nola Matuschka wanted the group to provide.

She established the group when her husband John was diagnosed with the condition 20 years ago, and she didn't know what to expect day-to-day as he lived with the illness.

"The neurologists were busy; they encouraged me to join a support group," Mrs Matuschka said. However she discovered there was no such support group in Portland, so with the assistance of local primary healthcare advocate, Athalie Lane, she established a group herself 19 years ago.

Mr Matuschka died four years ago, and while Mrs Matuschka and Mr Wolf have both been continuing as a part of the group since their loved ones died, Mrs Matuschka said she had decided it was time to finish her time in the leadership position.

It's there that Mr Wolf stepped in, feeling a little daunted that he was now in a role carried out by ’energiser bunny‘ Mrs Matuschka, but pleased to know she is remaining a member to help guide him.

He is also pleased that he might be able to facilitate the sharing of some very important information and help others benefit just as his family had.

"Before becoming a part of the group I had been wondering, am I providing Fredi with the support he requires? I didn't know who to interact with, who to ask, and what services are available," he said.

The 20 support group members often talk about different everyday strategies or medications they are trialling, for example, allowing participants to learn more and perhaps even start new care conversations with their healthcare providers.

And having the opportunity to debrief about the difficult aspects of experiencing Parkinson's with peers is most valued.

"This is a very personal process and journey, but being in the support group you journey along other people's paths with Parkinson's and don't always have to be the pioneer.

"I took this up mainly to expand the advocacy aspect of the group: I'd like to be giving out information, and get guest speakers in that can assist with living with the condition and also talk about general life skills that they may miss out on due to the condition.

"There's so much even I have to learn as well."

The Portland Parkinson's Support Group meetings are held at 10am on the first Tuesday of every month at the Fawthrop Community Centre.

NEW SUPPORT GROUP FOR WESTERN SUBURBS

A new western suburbs Peer Support Group officially launched this month, offering local support and activities for people with Parkinson's living in Melbourne's west.

The group will meet in Altona North and is expected to draw in members from Hobsons Bay, as well as Maribyrnong and Brimbank council areas, which currently have no Parkinson's PSGs.

In addition to offering support and a place to share information and experiences, ParKanDo aims to offer a variety of activities identified and driven by members.

Group coordinator Pam West, said the idea for the new group started after four people, three of them living with Parkinson's and the fourth a carer, met for a coffee and a chat last year.

"Even though each of our journeys were quite different, we shared a great deal of enthusiasm and a common goal – to positively contribute to peer support in the under-represented west. The idea of forming ParKanDo was born."

Launched mid-February, ParKanDo will meet monthly on the fourth Tuesday of the month, during school terms, at Walker Close Community Centre, Altona North.

Pam said how people chose to be a member was up to the individual.

"They could do as little as joining a mailing list to receive notification of guest speakers or new activity groups through to attending peer support and social gatherings or actively participating at ParKanDo meetings to contribute and assist with the development of new ideas and activities."

A new network of PSG leaders from the west, including ParKanDo, Wyndham, Melton and ParkinSong Williamstown, has also been formed, to stay connected, share information and mentor each other.

Pam has certainly been busy supporting Parkinson's, holding a Lunch with Twitch fundraiser in November as part of the William Angliss Great Chef's Series event, where Angliss restaurant students get to work alongside recognised award-winning Australian chefs.

Pam's guests were treated to a delectable three-course meal overseen by Tony Twitchett from Taxi Kitchen, who is pictured with Pam (left) and PV CEO Emma Collin.

Interested in joining a local or specialist Parkinson's Peer Support Group – or even starting a group in your area? Contact us on 1800 644 189 and we can help link you into the right group for you.

OTHER NEWS:

- Essendon PSG provided a range of exercise activities and showcased the work of the Painting with Parkinson's group at the Active Multicultural Seniors Festival held in Braybrook. The event was held to celebrate the Moving for Life – The Way I Like It project and showcase a range of activities the program has to offer seniors in the community, including rock 'n' roll dancing, archery, tai chi and more.
- A Geelong Community Tea, sponsored by St John of God Geelong Hospital, was held in October, attracting people from across the Barwon region, including representatives from Geelong East Peer Support Group and Geelong Painting with Parkinson's, which hosted the event. As well as providing the opportunity to meet people from the wider region, the event also helped create awareness of the services available for people and their families impacted by Parkinson's.
- The Victorian Painting with Parkinson's Network received a Victorian Government health condition support grant to provide professional development sessions and to update the Victoria Painting with Parkinson's Peer Support Group Manual (authored by Anne Atkin, Founder of Painting with Parkinson's in Victoria).
- Did you know Parkinson's Victoria runs specialist peer support groups for those who have undergone, or are planning to undergo, infusion therapy and deep brain stimulation? Call our health information team on 1800 644 189 for details.
- The 2020 Recently Diagnosed Seminar (RDS) program is now underway. All RDS sessions are listed on our website for prior registration. See www.parkinsonsvic.org.au/events

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UPCOMING EVENTS

Parkinson's Victoria raises awareness and funds for services and research that improves the quality of life for 27,000 people with Parkinson's in Victoria.

To stay up-to-date with upcoming events, and for registration details, go to:
www.parkinsonsvic.org.au/events

DATE	NAME	LOCATION	TIME
Tuesday 3 March	**Community Seminar**	Grampians Community Health, Stawell	10.30am – 12.30pm
Friday 20 March	**InSearch research series**	Mercure Port of Echuca	2pm – 4.30pm
Thursday 26 March	**InSearch research series**	The Florey Institute, Parkville	2pm – 5pm 6pm – 9pm
Monday 30 March	**Recently Diagnosed Seminar**	Lucas Community Hub, Ballarat	10am – 2pm
Tuesday 31 March	**InSearch research series**	Glen Logan, Horsham	2pm – 4.30pm
Wed - Fri 1 - 3 April	**INSIGHT into Parkinson's 2020**	Online: www.insightintopd.com/	9am – 7.30pm
Thursday 30 April	**Community Seminar & Recently Diagnosed Seminar**	The Swan Hill Club (The Glencoe Room), Swan Hill	1pm – 3pm
Friday 15 May	**Recently Diagnosed Seminar**	Parkinson's Victoria, Surrey Hills	2pm – 6pm