inmotion

ISSUE 4
SUMMER
2020/21

A MAGAZINE FOR THE PARKINSON'S COMMUNITY

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IN THIS TOGETHER
parkinson's
VICTORIA

CEO UPDATE

As 2020 comes to an end, I would like to take a moment to reflect on what has been described repeatedly as an 'unprecedented' year.

I ask that we pause and remember those in the Parkinson's community and broader community directly impacted by COVID-19, for the lives lost and families unable to properly grieve for their loved ones.

Our goal for the majority of this year has been to ensure Victorians living with Parkinson's and their families, were supported to navigate COVID-19. For some families it was to support a loved one to die with dignity, for others, it has been to stay safe, well and focused on the future.

As Victorians lived through lockdown during the second wave of COVID-19, we developed the concept of 27forParkinson's, an online event designed to create a sense of purpose, while incorporating the emotional and physical health benefits of walking and exercising.

With your support, it ended up becoming our most successful ever fundraiser. Helping to drive that success was an interactive Facebook community who came together to share stories and photos of where they were walking and who for. We share some of their photos in a pictorial spread on pages 10-11.

Everyone involved in this event contributed to its success, but I would like to acknowledge event Ambassadors John Eren and Steve Watts for their commitment and support to both fundraising and sharing their personal stories and experiences of diagnosis and living with Parkinson's in the media.

John was also instrumental in securing a $150,000 State Government donation, which pushed our final fundraising tally to $581,394. With a fundraising target of $100,000, we are truly blown away by your generosity during such a difficult time.

These funds will ensure continuation and growth of our services so that Victorians with Parkinson's and their families will be supported, educated and empowered to enhance their quality of life at every step of their personal journey.

This support is particularly important as we again adjust to a 'COVID normal life'. This year we commenced an outreach call program, developed in response to COVID-19 and Government restrictions to keep the community safe.

Through the outreach program we made more than 1000 calls and were able to support you directly, but were also able to use these discussions to inform development of new online education and Living Well with Parkinson's conversation series to better meet community needs.

This edition of InMotion includes information from the Living Well series, as well as a number of articles to support you to get back into the driver's seat, both literally, and figuratively, in a COVID normal world.

It is important to remember that just like the COVID-19 experience was different for people, so too will be the re-adjustment. Whether you want to jump straight into socialising or take it slow, there is no right or wrong.

This includes Christmas, which may be different for people this year. While it is a time of joy for many, for others it can be stressful or sad. Some people may be grieving a loss, others still kept apart from families, particularly from those who live overseas.

Not withstanding the pain COVID-19 has caused, some changes to the way we lived, worked and communicated were beneficial and can be modified and carried into next year and beyond.

Parkinson's Victoria CEO Emma Collin

COVID-19 restrictions propelled us into the online sphere. Between August and November, we offered 23 online events, including recently diagnosed seminars and the Living Well with Parkinson's conversation series that covered a wide range of topics, from intimacy and sleep to mobility and medication.

We also partnered with Maurice Blackburn to present a four-part series designed for people with Young Onset Parkinson's and focusing on topics relevant to them, including legal, insurance and employment.

There's no doubt an online offering will continue to be part of a new hybrid mix in 2021.

In recognition of the additional pressures of this year, we will offer a Health Information Line call-back service over the Christmas/ New Year period. This service is for Parkinson's advice and information.

Messages will be checked and returned at 9am, midday and 4pm on 29 and 30 December 2020. However, if you have any health-related concerns during this time, contact your GP or Nurse-on-Call, 1300 60 60 24.

Mental Health Support is available through Beyond Blue on 1300 22 4636 and if you experience a medical emergency, always call 000.

As we look forward, we also take the opportunity to look back. November 2020 marked 40 years since the first meeting of the organisation that we today know as Parkinson's Victoria. Our roots grew from the friendship and support of four women living with Parkinson's.

It is thanks to them and their families recognising the importance of sharing information and supporting each other than we are here for you today and into the future.

Emma L Collin

Emma Collin
CEO
Parkinson's Victoria

Cover: Rob Horsburgh formed the team, Rob's Gang, joining friends and family from around Victoria, to take part in 27forParkinson's. Story page 9.

NEWS & HIGHLIGHTS

DONATE TO MAKE A DIFFERENCE

Jenny and John Wilson are familiar faces at many Parkinson's Victoria events and keen Bentleigh Bayside Peer Support Group participants. Now, Jenny is fronting the Parkinson's Victoria 2020 Christmas Appeal.

After experiencing symptoms for three years, Jenny was diagnosed with Parkinson's in 2010. On diagnosis, her neurologist suggested she contact Parkinson's Victoria.

"I did not hesitate. Within a few days I received a big package filled with information on managing and living well with Parkinson's," Jenny said.

"I learnt so much about what I needed to do – how to keep moving, understanding the medications, managing my daily routines and affairs. And they encouraged me to get in contact with the local Peer Support Group."

Jenny puts a name and face to the thousands of people Parkinson's Victoria helps every year. Donating to our Christmas Appeal helps people to:

- access our expanding online education program to learn how to live well with Parkinson's, discover strategies to manage emotionally, physically and mentally, and take care of financial and legal affairs
- stay connected to each other via our Peer Support program, crucial to health and wellbeing, including via expanded online peer support
- receive vital support, information and care through our Outreach Phone Program, which will continue over the holiday season.

Donations also help us continue to progress life-changing clinical research such as ParkinDance and ParkinSong™.

Judy Wilson and her husband and 'rock', John.

Visit parkinsonsvic.org.au/christmas-appeal to make a donation, read more about Jenny's story and learn how your donation helps.

40 YEARS OF SUPPORTING VICTORIANS

It was poignant that the 2020 Parkinson's Victorian Annual General Meeting was held 40 years to the day after a determined group of 18 people attended the first ever meeting of what would become the Parkinson's Disease Association of Victoria on 27 November 1980.

The association had its roots in friendship – four women, all living with Parkinson's, who met each other at an outpatient group in the Occupational Therapy Department at Melbourne's Austin Hospital.

Finding they greatly benefited from sharing their experiences in a group situation, these inspirational women decided to establish an association that would provide information and support services to others living with Parkinson's.

With family participants, friends and health professionals, they formed the initial management committee and the association was officially launched in January 1981 with a TV advertisement featuring actor George Mallaby to increase public awareness of Parkinson's.

In April 1981, the first office - run by volunteers - opened in Collins Street, Melbourne and on 31 May 1982, the 2nd Annual General Meeting confirmed the organisation's constitution and tax exempt donation status. Formal registration was granted by the Health Commission in September 1982.

In 1984, a government grant of $87,000 enabled three staff to be employed. Approval was received to hang a sign on the front of the office, now located in Auburn Rd, Hawthorn.

Support groups were also being formed and running in Whittlesea, Geelong, Ringwood, Bentleigh, Kew, Heidelberg, Frankston, Ballarat, Swan Hill, Sunshine, Caulfield and Moe.

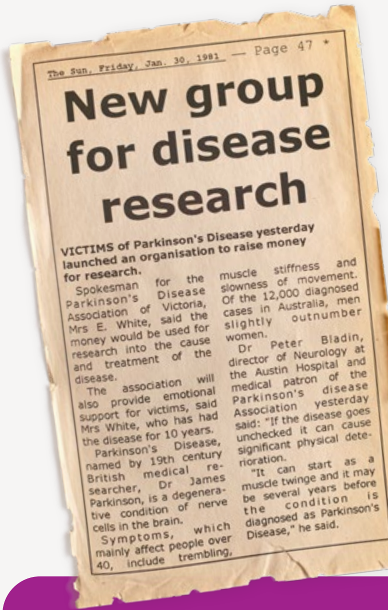
For the next few years, lack of recurrent funding was a problem as staff could only be employed for one year at a time. In 1996, there was a big breakthrough, when the Department of Human Services provided $36,000 for three years' funding for a telephone helpline.

Today, 40 years on, the telephone health information line remains a core service, while the number of peer support groups has grown to 75 around the state.

The organisation has continued to grow and evolve to meet the needs of the community, underpinned by a multi-disciplinary team of healthcare professionals, offering dedicated education programs and training for people with Parkinson's and the medical, health and aged care sectors.

We continue to support an extensive research agenda and raise community awareness of the condition through events such as A Walk in the Park and this year's 27forParkinson's, which also contribute to funding the work we do.

This move allowed us to extend our reach and will form an important part of our future offering to ensure more people than ever will have access to information, education and individualised support and services.



The Sun, Friday, Jan. 30, 1981 — Page 47 *

New group for disease research

VICTIMS of Parkinson's Disease yesterday launched an organisation to raise money for research.

Spokesman for the Parkinson's Disease Association of Victoria, Mrs E. White, said the money would be used for research into the cause and treatment of the disease.

The association will also provide emotional support for victims, said Mrs White, who has had the disease for 10 years.

Parkinson's Disease, named by 19th century British medical researcher, Dr James Parkinson, is a degenerative condition of nerve cells in the brain.

Symptoms, which mainly affect people over 40, include trembling, muscle stiffness and slowness of movement. Of the 12,000 diagnosed cases in Australia, men slightly outnumber women.

Dr Peter Bladin, director of Neurology at the Austin Hospital and the medical patron of the Parkinson's disease Association yesterday said: "If the disease goes unchecked it can cause significant physical deterioration.

"It can start as a muscle twinge and it may be several years before the condition is diagnosed as Parkinson's Disease," he said.

Further details from the 2020 AGM, including Parkinson's Victoria Award recipients, will feature in the Autumn 2021 edition of InMotion.

EDUCATION

BUILDING ONLINE COMMUNITIES VIA EDUCATION@HOME

As COVID-19 continued to impact Victorians, reducing interaction with medical and health practitioners, Parkinson's Victoria explored how we could move to support the community online.

Through our outreach program, and calls to our health information service, we identified a key focus area: to help people living with Parkinson's, or caring for someone with Parkinson's, navigate COVID-19 to stay safe, well and focused on the future.

In August, we introduced the *Living Well with Parkinson's* conversation series. This informative weekly presentation was designed to provide advice and tools to help people continue to optimally manage their Parkinson's symptoms during COVID-19 restrictions.

Held on the online Zoom platform, participants were able to come together as a community and ask questions during and after the presentation, with more than 500 attendances by almost 200 individuals attending the first 11 sessions.

Below is a summary of the topics covered and key messages from each presentation.

BUILDING YOUR TEAM

Parkinson's is a complex condition, so seeking support from a range of healthcare professionals provides the best symptom management approach. Examples of where a healthcare professional can help are:

- movement, exercise, reducing and managing falls - Physiotherapist
- medication management, continence - Parkinson's Nurse
- independence, fatigue management - Occupational Therapist
- communication, swallow, and saliva - Speech Pathologist
- mood, depression, emotional support - Psychologist
- emotional support, accessing benefits - Social Worker.

STAYING ACTIVE

Regular exercise is important and can have a positive impact on your Parkinson's symptoms. However, you should check with your GP and physiotherapist about your fitness to exercise and what exercises are best for you.

Mix up your exercise routine to keep interested and motivated and plan ahead to make sure you are ready to exercise. This includes having a safe, decluttered space and letting someone know you are exercising.

MANAGING YOUR WELLNESS

Feelings of depression, low mood, and anxiety are symptoms of Parkinson's. These symptoms are sometimes heightened in reaction to significant life events.

Anxiety and depression can be effectively treated, so seek support from a counsellor or psychologist. You can also speak to your neurologist about other treatments for anxiety and mood.

Other measures include making sure your Parkinson's medications are up to date and taken on time, eating and sleeping well and undertaking regular exercise.

MEDICATION AND MYTH-BUSTING

There are a range of treatments for Parkinson's – consulting a specialist will help find what's right for you.

It's important to get into good habits early, including taking your medication on time, every time. Remember, side effects can be managed – your doctor or Parkinson's Victoria can provide information about this.

People often consider a dietary supplement or complementary therapy, in addition to the medications prescribed by their neurologist.

It's important to remember that complementary therapies reside alongside your medically prescribed regime, so let your doctors know what you are taking as some complementary medications can interact with Parkinson's medications.

SAFELY MOBILE

Parkinson's may impact your mobility and driving. You also have a legal obligation to report you have Parkinson's to VicRoads, or the licensing body in your home state.

Help is available to keep you driving and/or to stay mobile in the community and you can involve an Occupational Therapist in the conversation for guidance and expertise.

DEEP BRAIN STIMULATION

Deep Brain Stimulation (DBS) is an evidence based surgical treatment for Parkinson's. It provides continuous electrical stimulation to the part of the brain most effected by Parkinson's, smoothing out symptoms.

DBS is commonly performed early in your Parkinson's journey, but can still be considered later on. Not everyone will need DBS, but it's always good to discuss this with your Neurologist.

Parkinson's Victoria hosts a dedicated DBS peer support group for people who have had DBS or are considering it at a treatment.

RESEARCH UPDATE

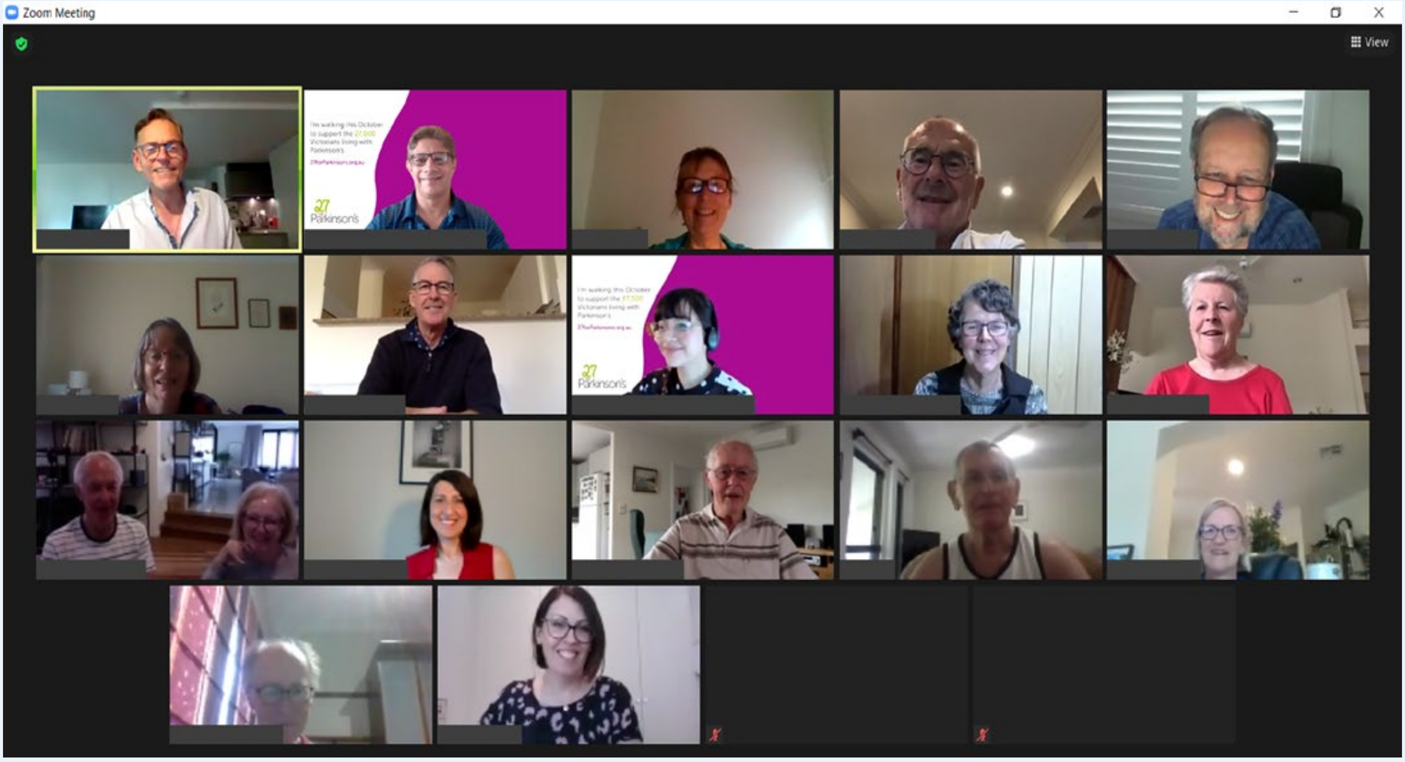
This session provided insights into current Parkinson's research and featured highlights from the recent (virtual) International Movement Disorder Society meeting.

A key focus area for researchers is around exercise and diet.

A good diet helps support a health microbiota and regular exercise is important and has a positive impact on sleep and thinking and may even slow the progression of Parkinson's.

The gut microbiota (healthy bacteria) and its link with inflammation may play a role in developing Parkinson's and may also be a future target for treatment.

If you would like to participate in research, you should discuss this with your neurologist or Parkinson's Victoria.



COGNITIVE CHANGES AND COMMUNICATION

Communication matters – it's a significant part of our daily life and connects us with other people.

If you experience communication changes, you can do something about it - the earlier the better. This includes requesting referral to a Speech Pathologist. Parkinson's Victoria can discuss options to best suit you.

COGNITION AND THINKING

Living with Parkinson's does not mean you will experience Dementia or significant memory problems.

However, some cognitive change can occur in Parkinson's – these are usually problems with word finding and completing complex tasks or multi-tasking.

If you are worried about changes to your thinking, discuss them with your neurologist, who may use a Parkinson's specific screening tool to assess memory and thinking.

Thinking or cognitive changes can be managed by:

- getting a medication review
- addressing other health conditions such as infections
- sleeping well.

Strategies, external cues and prompts can help overcome memory problems. If you are worried, speak with your neurologist or contact Parkinson's Victoria.

GETTING CREATIVE

Many people with Parkinson's find some symptoms, such as fine motor coordination, improve while they are concentrating on a creative activity

Finding an activity you can immerse yourself in can be a great way of supporting wellness and makes a positive contribution to managing Parkinson's symptoms.

If you are starting a creative activity, explore a range of activities and find one that suits you.

If you are interested in painting, contact us about joining a Painting with Parkinson's Peer Support group.

Living Well with Parkinson's **conversation series will continue in 2021.**

See www.parkinsonsvic.org.au/events for details.

If you have a question about any of the topics mentioned in this article, call our Health Information Line on 1800 644 189 to speak to a Parkinson's health professional.

You can also check out the Living Well post-seminar video series, featuring session presenters giving an overview of what was discussed.

View them on the *Living Well with Parkinson's* 2020 playlist on our YouTube channel, youtube.com/ParkinsonsVic

27 for Parkinson's

ONLINE FUNDRAISER HELPS BRING COMMUNITY OUT OF THE COVID CLOUDS

What was created as an event to virtually bring people together to lift spirits after months of COVID-19 restrictions that kept so many apart, became our most successful ever fundraiser.

27forParkinson's this year replaced the traditional A Walk in the Park events in Melbourne and regional Victoria.

As the State experienced a second wave of COVID-19 infections mid-year and the Government responded with measures to reduce community transmission, we reached out to the community, and responded to their issues

“Lack of access to vital support and medical services, no access to regular exercise programs and ongoing social isolation were taking a toll,” said Parkinson's Victoria CEO Emma Collin.

> *“"So we created a virtual fundraiser. Our goal was to revitalise people, with a focus on health and movement, and planning for better health, post restrictions.”*

People were asked to walk at their own pace 27 times, across 27 days in October. This number was chosen to represent the 27,000 Victorians with Parkinson's. A fundraising goal of $100,000 was set.

More than 800 fundraisers came on board, supported by 5777 donations and when donations officially closed on 27 November, $581,394 had been raised – more than $250,000 higher than the record amount raised from A Walk in the Park 2018.

“This increase in fundraising has come at a perfect time, with so much government funding channelled into the COVID-19 response. Our own State Government funding is only guaranteed to the end of this year,” Emma said.

“Having said that, we were grateful for the unexpected *27forParkinson's* donation of $150,000 we received from the State Government,” she said.

The reality of living with Parkinson's was brought home to many MPs and the wider Victorian community after the State member for Lara, John Eren, publicly disclosed his diagnosis in August. He agreed to join us as a *27forParkinson's* Ambassador.

John and FRV Commander Steve Watts were the public faces of the event, but many of the hundreds of people who took part shared their experiences on social media.

“We can't underestimate what this event meant to so many people. We received many messages about how it had come at a perfect time, lifting them out of a COVID-19 related slump,” Emma said.

“It was particularly heart-warming to see the engagement between participants on the closed event Facebook group we created. This was appreciated by those who took part, who were able to share stories and pictures of the gorgeous places they were walking and exercising.”

This included people who posted to a theme, including Yarra Peer Support Group leader Sheenagh Bottrell (pictured), who walked everyday wearing or displaying a dress, including her mid-80s Royal London Hospital nurses' uniform.

STATE GOVERNMENT BOOST TO FUNDRAISING TOTAL

John Eren

The final day of the *27forParkinson's* fundraising and community connection campaign was marked with the welcome boost of a $150,000 State Government donation in recognition of the information and support services Parkinson's Victoria provides to people with Parkinson's and their families.

“We welcome the Victorian Government's generous donation in support of the Parkinson's community, who have been managing a chronic and life-changing condition within the confines of COVID-19 restrictions and limitations,” Emma said.

“Parkinson's can be an isolating condition in itself. Since March, our priority focus has been on helping people living with Parkinson's, or caring for someone with Parkinson's, to navigate COVID-19 to stay safe, well and positively focused on the future.

“This donation – and the phenomenal efforts of John, who bravely disclosed his diagnosis and shared his story with the wider Victorian community throughout the *27forParkinson's* campaign – reinforces to people that they are not alone.”

John said he was proud of the Government's investment in this very important fundraiser.

“This donation will go a long way to help Parkinson's Victoria continue the great work they do in raising awareness for education, support services and research that improves quality of life for people living with Parkinson's and Atypical Parkinson's conditions.

“Congratulations to Emma, the entire team of Parkinson's Victoria and to everyone who worked together to raise money for this great cause. It has been a fantastic result.”

VICTORIAN FIREFIGHTERS AGAIN ACCEPT THE CHALLENGE

The Fire Fighters Charity Fund donated $26,920 to the *27forParkinson's* campaign, in support of Fire Rescue Victoria (FRV) firefighters and staff who walked and ran in a treadmill challenge from 5-9 October.

The FRV 48 Hours Parkinson's Challenge was organised by Commander Steve Watts, who joined John Eren at Kardinia Park to kick off the campaign.

Steve, who is also a Parkinson's Victoria Board member, has been actively involved in raising awareness and funds for Parkinson's after he was diagnosed in November 2017.

Last year, he was joined by MFB and CFA firefighters at the A Walk in the Park fundraiser, and with the support of the Firefighters Charity Fund, raised $20,000. This was on top of $7500 he helped raise in 2018 at a fundraising BBQ.

This year, he secured the support of the newly formed, Fire Rescue Victoria to support *27forParkinson's* with a treadmill challenge, for which participants from all FRV fire stations and workplaces clocked their kilometres in support of people living with Parkinson's across the state.

John Eren (left) joined Steve Watts at the launch of the FRV 48 hour challenge, a 27forParkinson's fundraiser.

Just over 500 people took part across FRV fire stations and workplaces, walking 5384km, with an initial cheque for $6182 presented to Emma on 16 October at the completion of the challenge (pictured top of page).

We extend our appreciation to the Fire Fighters Charity Fund for this generous support and those who actively took part in the challenge, as well as the United Firefighters' Union and Steve's colleagues for their involvement, donations and support.

27FOR PARKINSON'S TOP FUNDRAISERS

We can plan an event, but its success or otherwise comes down the contribution and commitment of the community.

We are so proud that *27forParkinson's* was embraced by so many. Some people had previously been part of A Walk in the Park, others had not and were first time fundraisers.

From the walkers, to their supporters and donors, we express our gratitude to everyone who took part in *27forParkinson's*.

Across the 27 days, we learned more about people's stories and who they were walking for. We were also privy to seeing the beauty of so many locations around the state where people walked.

We acknowledge our Top 5 fundraisers and teams, but also acknowledge each of the more than 5700 who donated to improve the lives of people with Parkinson's. Thank you!

Individuals	
John Eren	$13,814
Daris Olsauskas	$10,980
Stephen Lake	$6004
Jason Karametos	$5583
Meredith (Mimi) Morgan	$5366
Teams	
Team John Eren	$29,171
Firefighters' Charity Fund	$27,276
Rob's Gang	$13,219
Yarra Parkinson's Support Group	$10,187
Team Biff	$9513

27 for Parkinson's

A SENSE OF PURPOSE

As the Parkinson's Victoria team sat down to discuss COVID-safe options for the much-loved community fundraiser, A Walk in the Park, discussion turned to how we could still bring people together and offer purpose and hope for so many isolated from family and friends.

That option was *27forParkinson's* – an online event asking people to walk 27 times across 27 days in October to raise awareness of the neurological condition that affects more than 27,000 Victorians.

Acknowledging that many Victorians were hurting financially, we set a realistic fundraising target of $100,000; our main purpose was to help stimulate people who were emotionally and physically hurting after months of social restrictions.

As the event rolled out, we saw many examples of how much people appreciated the opportunity, the focus and purpose that *27forParkinson's* was providing.

There are many touching examples of this, including the experiences of Lawrence Atley OAM – an 83-year-old aged care resident who embraced the event, alongside his wife Margaret, two daughters, Lisa and Celia, and their families.

Lawrence is a renowned commercial architect and was heavily involved in building the Victorian University at Footscray and the 1993 renovation of the Footscray Town Hall.

With Margaret they have a lifetime of caring for others behind them, particularly through Rotary, where he was a Rotary Club of Footscray member and held roles both in Australia and internationally. He was awarded an OAM in 2016 for this community service.

Lawrence and Margaret had moved into Japara Rye Sands Aged Care home in June, just days before Victoria's second COVID wave began. Soon they were in lockdown. It was hard for a couple who had spent their lives in the community helping others.

Outside, their daughters were also worried about Lawrence not coping well with the enforced isolation.

"Dad was down, with worsening pain. It was at a stage where it was getting real," Celia said, who by chance heard about *27forParkinson's* on the radio. So, they encouraged him to sign up and showed him how to use the *27forParkinson's* website.

"I thought it was a novel idea, not really understanding the whole event and how it all worked as an online fundraiser, but I was very happy to be involved and keen that Lisa & Celia had initiated it," Lawrence said.

He created a page and together with Margaret, they added photos and updates. Lisa and Celia shared photos with family and friends on their personal social media pages.

Staff at Japara Rye Sands also got involved, helping to make signage for Lawrence's walker and supporting a morning tea Lawrence and Margaret put on to mark the final day of the event on 27 October.

They also picked lavender for Margaret to make lavender bags to sell on the day.

"It's been a God-send in terms of keeping Dad's mind off isolation and in many ways, allowed us to talk more about his Parkinson's as a family than we usually would," Lisa said.

Lawrence agreed.

With the help of staff at Japara Rye Sands Aged Care home Lawrence and Margaret Atley had fun celebrating their involvement in 27forParkinson's.

"I was able to walk each day which I wasn't really doing and that became easier physically as I went on. The help from the staff was great and it gave me a purpose during ISO - and the donations from people made me feel appreciated."

Celia is also thankful of how the event has helped her Dad.

"Just the day before we started this, Dad said to me he felt his movement was deteriorating in ISO, but now he feels strong and his painful legs are much better. *27forParkinson's* gave him a real target to work towards."

Now the event is over, Lawrence is keen to keep moving. Fishing and swimming are on the list for when he can get out and go to the pier, as well as helping out in the aged care community's veggie patch and rose garden.

"I need a new walker – I could raise funds for that. Perhaps a November challenge…" he added laughing.

> *"If you ever doubted the benefit of exercise, just ask Dad who told me today the walking has really helped his pain. He does exercise regularly even at 83 years of age, but walking with purpose every day for Parkinson's Victoria helped both mentally and physically" - Lisa Atley*

SENSE OF HUMOUR SHINES THROUGH

Kyabram Peer Support Group leader Christine Anderson is not afraid to speak the truth about Parkinson's – and she does so with a touch of cheekiness and a sense of humour.

Whether it's sharing a poem about not being discharged from hospital until she emptied her bowels, speaking openly about Parkinson's and sex, or writing a song about *27forParkinson's*, Christine's wit and creativity shines through.

As avid supporters of A Walk in the Park, Christine admits it took a while for her family's Marshall Mega Team to get behind *27forParkinson's*.

Christine has travelled to Melbourne for the past three years to join her siblings, children and grandchildren to fundraise and walk from Melbourne's Fed Square

When A Walk in the Park 2020 was cancelled in response to the Government's COVID-19 restrictions, Christine lamented that "coronavirus is taking away my fun".

But her positive attitude came to the fore and a little over two months after she was in hospital undergoing an operation for duodopa infusion therapy, Christine was out walking, attending online seminars and sharing her experiences.

"I have walked 27 of the 27 days to support those with Parkinson's. I have walked with friends and family, I have written the lyrics to a song, contacted each of my support group, been on TV and in the newspaper.

"I have fallen asleep in a session on 'Parkinson's and sleep', and I have agreed to be interviewed on 'Parkinson's, Sex and Intimacy' (which I will probably giggle all the way through).

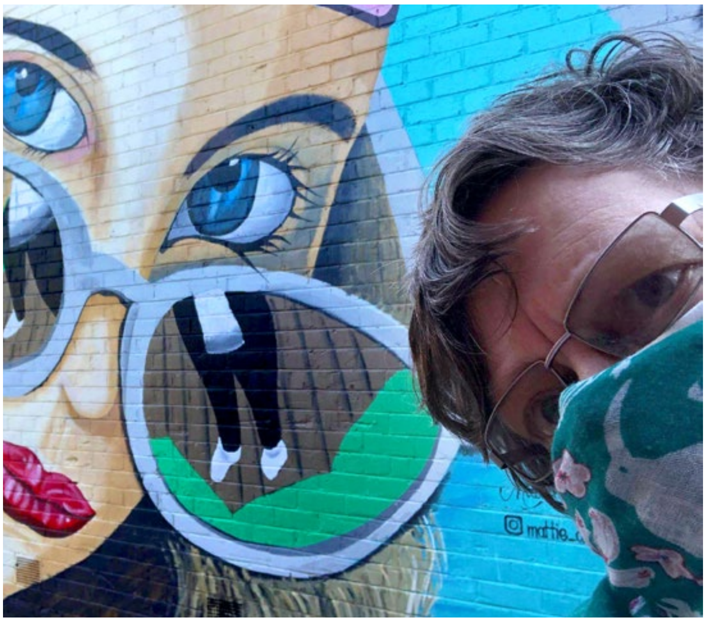
"I have experimented with ways to carry a Duodopa pump, finding the best way for me is in a tight vest.

"And I raised a little money for the wonderful Parkinson's Victoria.

"October has been a good month. Actually, October has been an excellent month. I think having people to share it with has made it extra excellent!"

Christine is always keen to promote Parkinson's awareness.

> *"It's interesting that when you have to replace an activity you have enjoyed with something different, you may start with an air of resignation but you can end with an air of triumph … because change provides learning opportunities. Parkinson's can be like that." Christine Anderson.*



STREET ART PHOTOS PROVE POPULAR

As *27forParkinson's* continued across October, people started to look out for Christine Challman's posts in the event's Facebook group.

Christine, who lives in Benalla and was supporting a dear friend's husband, decided to showcase the region's street and silo art, choosing a different location every day.

While people shared stunning photos from across Melbourne and regional Victoria, there's no doubt Christine's photos have encouraged a potential tourism boom from the *27forParkinson's* community.

Christine was part of 'Rob's Gang' – the team formed around Rob Horsburgh from Coleraine, who was diagnosed with Parkinson's seven years ago. Christine and Rob's wife Lona have been best friends since 1972.

Rob's Gang also included Rob and Lona's daughters Sarah and Laura, and David Rendell, Ric Purvis and Peter Schroder, who also have Parkinson's and live in nearby Hamilton. Together the team was the third highest fundraising team, raising more than $12,000.

"We were overwhelmed by the response and the beautiful messages from all over that we received," Lona said.

"We also loved the communication and connection with everyone through the Facebook page. We would say it was a very successful fundraiser but also promoted awareness that we haven't had before from the local community."

27 for Parkinson's

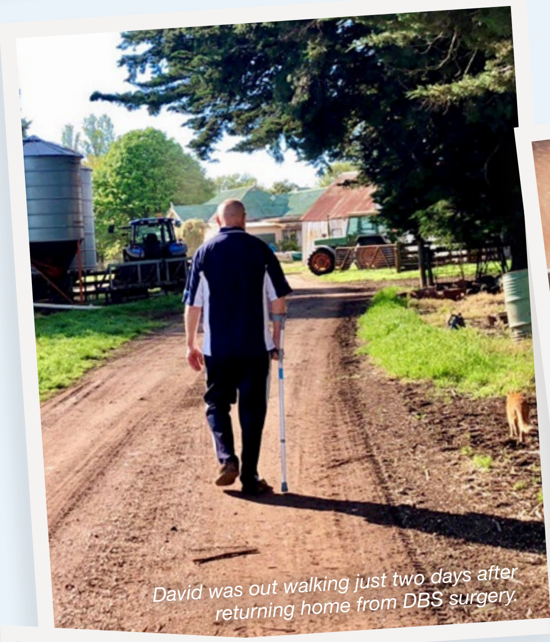
A highlight of 27forParkinson's was the sharing photographs on the event's Facebook page. This interaction was appreciated by many and created a true sense of community.

Kaye and Sandy shared photos –

– as part of the Sisterhood team.

Katrina walked for her mother-in-law, father-in-law and a friend with Parkinson's.

Dogs were walk companions for many people, including Ian.



David was out walking just two days after returning home from DBS surgery.

Libby loved walking with Maggie and Rodney.

Kirsten George rallied the Geelong community together for a virtual event.

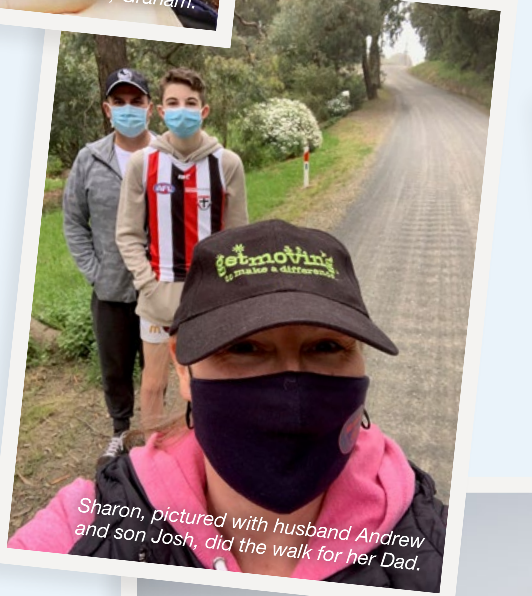
Fiona and Ella on her horse Maxx.


Helen walked in memory of her Dad, Graham.

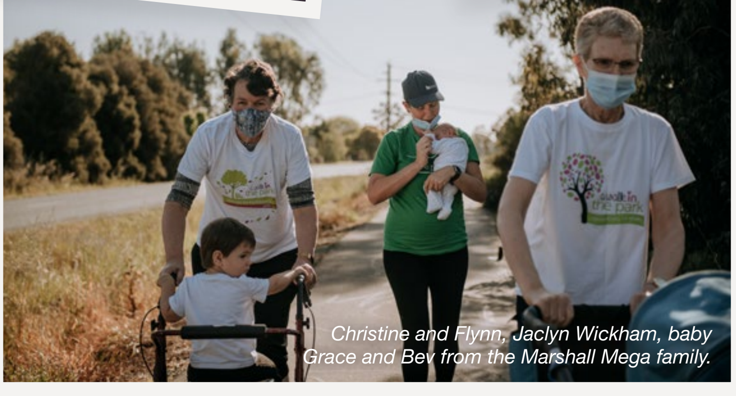

Lauren walked for her much-loved Pop in the aptly named, Team Pop.


With the support of family and friends, Mimi was a top fundraiser.


Cassandra walked for her mum, Kaye.


Sharon, pictured with husband Andrew and son Josh, did the walk for her Dad.


Christine shared silo and street art around Benalla.


Christine and Flynn, Jaclyn Wickham, baby Grace and Bev from the Marshall Mega family.


Pauline had some fun with her backdrop in Dromana.


Sally is a strong supporter of her mum, Judy.

COVID-19

GETTING BACK IN THE DRIVER'S SEAT

Lengthy lockdowns and travel restrictions have resulted in reduced confidence and heightened anxiety surrounding the resumption of driving, or driving for extended distances and periods.

Since March, car usage has been impacted by COVID-19 and associated government restrictions as non-essential activities were cancelled, travel distance limitations implemented and people opted for online services and delivered goods.

For some in the Parkinson's community, there may be feelings of being 'out of practice' or anxiety surrounding particular aspects of driving, such as merging onto the freeway, driving at night or parking the car.

For others, there may be more significant concerns as a result of changes in motor or non-motor symptoms over this time, causing them, or their loved ones, to doubt their abilities to manage a car again.

If you, or a family member, are concerned about resuming driving, the following tips and considerations may be helpful.

ANXIETY AND DRIVING

If you are anxious about resuming driving, maximise opportunities for success; prepare well and allow sufficient time to get to your destination.

Start with small journeys, on familiar roads in daylight hours and gradually increase the time and distance of each outing.

Given that anxiety can be a common symptom of Parkinson's, consider seeking professional advice. Relaxation strategies, mindfulness, cognitive behavioural therapy and a medication review may be beneficial, particularly if you are experiencing regular anxiety or it is affecting multiple aspects of your life.

CAR MAINTENANCE

If your car has remained idle for months, re-acquaint yourself with your vehicle and ensure essential maintenance checks are completed. Check that your insurance policy, vehicle registration and driver's licence are all still current.

DRIVING AT YOUR BEST

Driving is a complex task and requires the interaction of both cognitive and physical skills.

Cognitive abilities such as attention, scanning, concentration, spatial awareness, coordination, anticipation and responsiveness are utilised in combination with our physical ability to manage steering, braking, indicating and acceleration.

Motor fluctuations, fatigue, medications, pain and anxiety may impact on these skills, so try to schedule appointments and community outings at times of the day when you know you will be functioning at your optimum.

MINIMISE DISTRACTIONS

Minimise distractions to enable you to focus your attention on driving; switch off the radio and minimise conversations (including avoiding phone conversations, even on hands-free function). Try to avoid driving in inclement weather or at night and aim for quieter times, avoiding peak-hour and school traffic.

ENSURE SAFETY

Take your mobile phone, pen and paper, and torch with you in the car. Ensure you bring any medications or health supplies you will require and consider informing a loved one of your intended journey.

ROADWORKS AND ROUTE CHANGES

Be aware that you may encounter some roadworks or changes in road signage that may have occurred over lockdown period and to which you are unaccustomed. There may also be more cyclists and pedestrians to be aware of. Wherever possible, plan your route and allow plenty of time.

Brush up on your skills: If you feel out of practice and wish to optimise your driving skills and improve your confidence, consider reviewing the road rules via the Vic Roads website (www.vicroads.vic.gov.au/safety-and-road-rules/road-rules/road-to-solo-driving-handbook) or pursue some refresher driving lessons with a trained driving instructor. The dual-control vehicle may provide safety reassurance when refreshing your skills.

Ensure optimal health: If you have experienced changes in health or Parkinson's symptoms over the lockdown period, liaise with your medical and health team about management.

Cognition, vision and hearing play an important part in ensuring safety so if changes have been noted but regular health checks delayed, seek the relevant specialist review before resuming driving.

Motor changes may impact an individual's ability to perform car transfers, complete head checks or use car controls. A medication review and therapies such as Physiotherapy and Occupational Therapy, may improve mobility, posture, comfort and function and optimise the skills and movements required for driving.

Concerns surrounding confidence and driving are understandable at this time, and while these suggestions may be helpful, your individual health team is best positioned to give you tailored advice.

As motorists, we have a responsibility for ensuring our capability to drive and a legal obligation to report a permanent condition, such as Parkinson's or an Atypical Parkinson's condition to Vic Roads.

A good place to start is a discussion with your GP or you can contact our Health Information Line for advice on 1800 644 189.

PREPARING FOR A SMOOTH RIDE THIS CHRISTMAS

As Christmas fast approaches, the ‘silly season’ stress will be heightened this year as people adjust after many months of COVID-19 related isolation and uncertainty over what a COVID Safe Christmas may look like.

It’s been a difficult year for most people, so be kind to yourself and to others.

While some are excited to be out and about, others are understandably concerned about the virus still being in the community, or grieving over lost time and opportunities.

Others still bear the worry of family members living overseas, particularly in countries where COVID-19 cases are again climbing.

This year, more than ever, is the time to be sensitive to people’s needs and fears and if you have Parkinson’s, to be assertive in communicating these to your family.

Your health is important and with a bit of foresight, you can plan for how to keep calm and connected and enjoy Christmas:

- Try not to over-do-it and remember to be kind to yourself. COVID-19 associated restrictions kept many people in, or close to home, for much of the year. Smaller, more frequent festive gatherings may make communication easier, but don’t forget to pace yourself.
- Plan your Christmas shopping for quieter times. With social distancing, things may take longer and there may be more queues.
- Suggest catch-ups with family and friends that suit you and correlate with your ‘on’ periods. With summer upon us, you have the option of meeting in a park or utilise some of the extended outdoor dining options available this summer.
- Christmas can be a lonely time and this could feel worse this year as traditional face-to-face events are cancelled and some families remain apart. Ask family members or friends who are confident internet users for tips and pre-arrange a festive online celebration with those who are interstate or overseas.
- It can be normal to feel a bit more stressed or anxious during the festive period and more so this year, so take time out to relax. Meditation or going for a walk can help clear your mind.
- Maintain healthy eating habits and remember to factor your medication into your Christmas lunch or dinner schedule.

Our Health Team can provide you with tips to manage anxiety, diet and medication over the holiday season.

Call 1800 644 189.

COVID NORMAL EXPERIENCE NOT THE SAME FOR EVERYONE

COVID normal is a phrase used by some officials to describe the stage when restrictions are eased to allow people to go about their business in an environment in which COVID-19 still exists without treatment or prevention.

However, we need to recognise that coming out of months of COVID-19 restrictions and lockdown might be as hard for some people as it was going in.

With our lives still impacted by the global pandemic, and with a number of people reporting an increase in their Parkinson's symptoms during the restrictions, it is normal is to feel a range of emotions at this time.

You may be experiencing:

- fear of catching COVID until there is a vaccine
- anxiety around leaving the 'security' of home and your local bubble
- frustration as some regular activities remain cancelled
- sadness over not being able to visit family interstate and overseas and jealousy of those who can
- social anxiety and loss of confidence as you re-engage with social activities for the first time since March
- the need to put on a face and 'stay strong' for others no matter how you are feeling
- grief over not being able to visit or mourn dying family or friends or for the precious time lost to COVID-19.

Or you may feel none of this – you might be energised and ready to rush out to celebrate the easing of restrictions and get on with life again.

What is certain is that everyone will react differently. Jump in, or ease in – but follow the guidelines, adhere to the restrictions and remember, if you are feeling anxious about re-engaging with your family, friends and community, help is available. There are a number of ways you can access help to manage anxiety and depression and get on with your COVID normal life.

The Federal Government is supporting an additional 10 Medicare subsidised psychological therapy sessions available for people subjected to further restrictions in areas impacted by the second wave of the COVID-19 pandemic, including Victoria, until 31 March 2021.

You are required to have a Mental Health Treatment Plan and a review with your GP to access the additional sessions. Your GP will be able to provide information about this process.

The Government has also established 15 new HeadtoHelp mental health clinics to further support Victorians. The hubs are located in six Primary Health Network regions in Melbourne and regional Victoria.

The service is available for people seeking support, as well as those caring for and supporting people with existing or developing mental health conditions.

HeadtoHelp is a free service. You can visit a hub in person or talk to a mental health professional via the central phone service.

Visit headtohelp.org.au or phone 1800 595 212

Further resources can also be found at:

Beyond Blue: coronavirus.beyondblue.org.au/

Black Dog Institute: blackdoginstitute.org.au/resources-support/coronavirus-resources-for-anxiety-stress/

Keep up to date on the latest **COVID-19** restrictions at: dhhs.vic.gov.au/coronavirus

Not everyone has an extended network of family and friends to turn to for support.

The Community Visitors Scheme (CSV) provides friendship to isolated older Australians, matching a volunteer visitor with an older person across Australia.

The service is free for anyone who receives Government-subsidised residential aged care or a Home Care Package. This includes people are approved and on waiting lists for these types of care.

More information: health.gov.au/initiatives-and-programs/community-visitors-scheme-cvs

GETTING YOUR HEALTH ROUTINE BACK ON TRACK

One of the consequences of protecting the community against a global health pandemic has been the impact on people undergoing treatment for other health conditions.

As early as April, then National Chief Medical Officer Brendan Murphy urged people not to neglect other health conditions after some GPs reported of sudden drops in patient numbers.

There is no doubt the health response to containing the spread of COVID-19 has impacted other areas, including allied health treatments used by many people to help manage their Parkinson's symptoms.

Physiotherapy and speech pathology, both of which traditionally involve in-person visits and active on-site exercises with the healthcare practitioner, are often used to help manage movement and voice-related symptoms.

In addition, many people had regular appointments with their neurologist over a phone call, which reduces the opportunity for any changes in movement to be observed.

Phone calls to our health information line and via our member outreach service indicated that months of restricted access to medical and health facilities was taking a toll.

Now is the time to start thinking ahead re-establishing contact with the services and systems that support your symptom management.

You can take a number of proactive and positive steps to better health as we move into COVID normal:

1. Call your neurologist to schedule your next face-to-face appointment now as there may be a delay. If you need to speak to your neurologist before this, ask for a telehealth appointment in the meantime
2. Contact your allied healthcare providers, most of whom are again meeting clients face-to-face with COVID Safe plans in place
3. Make an appointment with your GP for an overall health check up
4. Follow up any postponed appointments with other doctors you may see regularly
5. Register to attend a Parkinson's Victoria Living Well with Parkinson's session. See parkinsonsvic.org.au/events
6. Seek support if you are struggling
7. Reinstate My Aged Care and any home help you may have cancelled during restrictions
8. Keep up good walking habits established during *27forParkinson's*
9. If you are a gym member, keep up to date with the re-opening schedule.

If you have any questions or concerns, we are here to help. Call our Health Information Service on 1800 644 189 or email, info@parkinsons-vic.org.au

WEEKEND SUPPORT

Acknowledging the crisis in residential aged care in Victoria's second wave of COVID-19 cases in August and September, Parkinson's Victoria activated a weekend on-call phone service to support the acute and aged care sector staff in their clinical management of people with Parkinson's.

The service, promoted via the Department of Health and Human Services, supported a number of calls covering a range of topics. At the same time, we also spoke to a number of family members unable to communicate with loved ones in aged care as many facilities went into full lockdown.

"Issues surrounding timing of medication or how to respond to a missed dose or to manage complex multiple symptoms featured in a majority of calls," said Parkinson's Victoria Health Team, Clinical and Support Services Manager, Victor McConvey. "Calls from the aged care sector often came from staff who were unfamiliar with a particular resident."

There were also several calls requesting information on initiating palliative care and managing end of life care, with some of these calls regarding patients with Parkinson's and COVID 19.

"Supporting complex discharging planning was also a feature as people with Parkinson's were admitted to unfamiliar areas or public patients were transferred to private hospitals as part of the COVID-19 response," Victor said.

In October/November, we also delivered online training to just under 120 personal care assistants and clinical and executive managers at aged care provider, Estia. This included three modules, covering an introduction to Parkinson's, common challenges and complications, and medication management.

"Considering up to 8% of residents in aged care may be living with Parkinson's, providing accessible education in a time of lockdown is of huge benefit to the staff and for the residents who they care for," Victor said.

In October, the Federal Government announced a Grief and Trauma Response Package to support those affected by COVID-19 across the aged care sector. The package was developed to provide direct support to aged care residents and their families. The Australian Centre for Grief and Bereavement will provide specialist information and support to residential aged care and home care recipients and their families who have been affected by COVID-19 through:

- a national toll-free telephone service linking callers with specialist bereavement practitioners
- telehealth and face-to-face counselling services; and
- specialist grief and bereavement information including online training and webinars.

Call: 1800 22 22 00.

RESEARCH

CAN LOSS OF SMELL BE USED TO DETECT PARKINSON'S?

The COVID-19 global pandemic has thrust science and research into the spotlight. Research gives hope for the future and when it comes to Parkinson's research, Prof. David Finkelstein, says "quiet evolution is occurring".

Prof. Finkelstein is Head of the Parkinson's Disease Laboratory at Melbourne's Florey Institute of Neuroscience and Mental Health and a Parkinson's Victoria Board member.

"In Melbourne and around the world, scientists and clinicians are successfully identifying Parkinson's and parkinsonian disorders in the laboratory many years before people were traditionally diagnosed," Prof. Finkelstein said.

Traditional clinical diagnosis of Parkinson's currently relies on presentation of clinical symptoms, but research shows by this time significant cell loss in the brain has already occurred.

Scientists at the Florey want to establish a simple, web-based, cost-effective screening protocol aimed at identifying people at risk of developing Parkinson's, or who are in early stages of the disease, and are seeking funding from the Federal Government's Medical Research Future Fund.

"The earlier we are able to diagnose people, the greater the potential therapies have to prevent onset of the symptoms that cause difficulty in daily life," Prof. Finkelstein said.

"Surprisingly there are changes in the body many years, even decades, before people go to the doctor. Constipation and loss of smell present in a high percentage of people in the early stages of Parkinson's.

"We believe by using a number of web-based tests, we can detect someone's risk of developing Parkinson's much earlier, at a time when neuroprotective therapies have a higher chance of success," he said.

"We are very excited that the Florey, together with international drug companies, have developed two compounds that have been successful in safety trials in people and are now going into trials to see if they are neuroprotective."

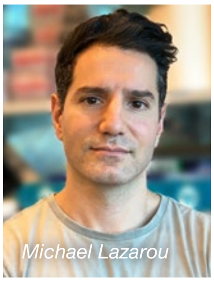
VICTORIAN RESEARCHERS COLLABORATE ON INTERNATIONAL TEAMS

Victorian researchers have key roles in a new international research collaboration program.

They include two researchers from The Florey Institute of Neuroscience and Mental Health and one from Monash University, who are on teams assembled in the first round of projects funded by the US-based Aligning Science Across Parkinson's (ASAP) Collaborative Research Network.

A total of 21 teams from 60 institutions across 11 countries are part of the initial $161million international collaborative research program. Projects funded come under the platforms of the biology of Parkinson's-associated genes (14 teams) and interaction between the nervous and immune system (7 teams).

The 5-year ASAP program is focussed on building an international network of scientists to uncover the basis of Parkinson's – how it originates and progresses – to fuel development of new treatments.


Michael Lazarou


Clare Parish


Lachlan Thompson

Victorian researchers working on the internationally recognised teams include Prof. Clare Parish PhD & Assoc. Prof. Lachlan Thompson PhD of The Florey Institute, who will look at the role of gene mutation.

Parkinson's has been studied for more than 200 years and although it is not heritable, we do know genetics plays a role in making people susceptible to the disease. We need to understand more about the biological process that governs initiation and progression of the disease, in order to develop new drugs and interventions.

"The work will generate neurons from stem cell lines derived from patients with Parkinson's and will study how the disease develops in the environment of the living brain. This unique approach, moving out of the petri dish and into an integrated nervous system, will enable us to assess how different genetic mutations in Parkinson's disease drive the dysfunction and loss of specific cell types," Prof. Clare Parish.

Dr Michael Lazarou PHD from Monash University, is on a team looking at the relationship between Parkinson's and damaged mitochondria.

Mitochondria are tiny structures within our cells that provide us with the chemical energy that keeps us alive, that is why they are often referred to as the powerhouse of the cell.

Mitochondria are also very important in maintaining our cell's health. For example, when mitochondria become damaged they can activate cell death and inflammation pathways. It is therefore important to maintain optimal mitochondrial health.

Using advanced imaging techniques developed in his laboratory at Monash University, Dr Lazarou will help visualise how two specific genes that are mutated in Parkinson's can 'clean up' damaged mitochondria in human neurons. It is by improving our understanding of this clean up response, that we can look at developing drugs and treatments to help maintain healthy mitochondria.

Sydney-based researcher, Joseph Powell PhD from The Garvan Institute of Medical Research is on another team using technology to learn more about the complex interplay of genes, molecules, cells and age-related factors that trigger Parkinson's.

INTERESTED IN READING MORE?

Early detection and smell:

florey.edu.au/about/news-media/neurological-consequences-of-covid-19-the-silent-wave

ASAP research network:

florey.edu.au/about/news-media/international-funding-received-to-advance-research-into-the-genetic-basis-of-parkinsons-disease

garvan.org.au/news-events/news/parkinson2019s-trigger-in-focus-for-new-international-research-project

SUPPORT FOR YOU

MAINTAINING SUPPORT IN 2020 AND BEYOND

There's no doubt 2020 has been a challenge for many Parkinson's Peer Support Group leaders as COVID-19 put a temporary halt to the traditional community-based support system that has helped so many for the past 40 years.

In March, we supported PSG leaders to cancel face-to-face meetings, a responsible move in response to Government restrictions announced after the global health pandemic was officially confirmed by the World Health Organisation.

Since then, our focus has been on helping leaders maintain other forms of communication with group participants, while ensuring the leaders themselves, many of whom have Parkinson's or care for someone with Parkinson's, were also supported.

One of the first things we did was create private Facebook groups to help PSGs stay connected safely online. More than 20 now have their own Facebook group.

In developing new ways to communicate, we also recognised the need to upskill those new to Facebook and online communication platforms, such as Zoom.

In response, we ran online training on the basics of navigating these platforms, including how to host a Zoom meeting and the basics of managing a Facebook Group.

However, not all groups were able come together this way – some have used the more traditional 'phone tree' concept to keep in touch, others communicated via email.

Specialist online peer support groups coordinated by Parkinson's Victoria, including Young Onset, Deep Brain Stimulation and Atypical Parkinson's, were also able to move online.

For Atypical Parkinson's, this resulted in an increase in attendees as people were able to join online, including some interstate attendees (Parkinson's Victoria offers Atypical Parkinson's support nationally).

SAFELY SINGING TOGETHER

Another offering for PSG participants in September/October was weekly online open singing sessions. The benefits of singing range from the physical and psychological, while singing together creates a heightened sense of belonging and connection.

Held each Friday in September and October, our Music Therapist facilitated these open singing sessions. The last session for 2020 will be held on Friday 18 December. Register your interest by phoning our health information line on 1800 644 189.

PAINTING WITH PARKINSON'S

The move to online services in response to COVID-19 restrictions has created opportunities for people to come together and access resources no matter where they live. One such opportunity is the development of a Painting with Parkinson's Facebook group. This new group is open to anyone with an interest in painting and artwork. More information is available via our Health Information Service.

LOOKING AHEAD

As restrictions eased in November, we began contacting leaders to commence discussions around transitioning back to face-to-face meetings. Many PSGs are keen to meet again soon, but we need to plan how to do this safely and within COVID Safe guidelines. We also want PSG leaders to support each other at a regional level, so a new focus going into 2021 will be encouraging leaders to connect.

Regional support networks provide a great opportunity to further develop leadership and communication skills and to share ideas and advice with peers and has already proven successful in Melbourne's West. The Parkinson's Peer Support Group network remains a vital support offering and we look forward to growing and evolving the network to provide a sense of community and as a source of strength and knowledge at the local level.

Thank You!

2020 has been a difficult year for everyone. But you were there, offering leadership and support.

To our valued Peer Support Group volunteer leaders...

we say THANK YOU.

parkinson's VICTORIA IN THIS TOGETHER

www.parkinsonsvic.org.au

1800 644 189

facebook.com/parkinsonsvic

PERSONAL STORIES

AROUND THE WORLD IN 2 WEEKS – A COVID-19 TRAVEL TALE

Most of us are familiar with the saying, 'when life gives you lemons, make lemonade'.

This describes perfectly what Dave and Jill Price did when COVID restrictions forced them to cancel their Queensland winter escape. Instead, they set about planning a virtual holiday that took them on a journey around the world – all from the comfort of their own home.

"We had a wonderful holiday," Jill said.

"We used the internet to research places to go and where to stay, and as no money was involved and there were no problems with accessibility, we could choose the best and most luxurious hotel rooms!"

The couple allocated budget to buy special treats along the way. They researched recipes from countries they were visiting, stocked the freezer with meals and made some online purchases to enhance the experience.

"To give us that real holiday feeling, we changed the house around to make it feel like a holiday apartment – re-arranged the furniture, put out new cushions, magazines and a tea-making station, stocked up the minibar with treats, put out the fluffiest guest towels and some luxurious toiletries and off we went." Jill said.

The stress-free holiday, with-no queues delays or jet lag plus a comfortable bed every night, was perfect for someone with Parkinson's.

"All we had to pack was our sense of fun and our imagination. We landed in perfect weather and "checked in" for our first night, where we celebrated Christmas in July with a Christmas dinner and gifts under the tree to open each day of our two week break.

"We visited a different country every day, mostly countries we have never been to but would love to see. In 14 days we travelled to Iceland, Spain, the Maldives, India, South Africa, Russia, Alaska, The Grand Canyon, Wales (for our wedding anniversary), the Greek Islands, Egypt, Austria and the UK ('home' for Dave's birthday)."

Bags packed and ready to holiday – at home.

Jill and Dave virtually visited 14 countries in 14 days.

It was the wealth of resources available online that helped them make it more realistic.

"We even had coffee and cake with the background noise of a Spanish café. We did guided tours on YouTube, a virtual safari in the Serengeti, a virtual trek along the Grand Canyon, virtual visits to landmarks like the Taj Mahal, the Pyramids and La Sangria Familia in Barcelona.

"We enjoyed watching movies like "Eurovision", set in Iceland, and listened to music specific to each country, like the Vienna New Year's Day concert or the Red Army choir."

They also learned local dances, including Icelandic folk dancing, a bit of Bollywood, a Viennese waltz and their favourite, Zorba the Greek, which "had us in fits of laughter!" They even had a Nana Mouskouri karaoke night!

"I think the absolute privacy gave us more confidence to have a go than if people had been watching!" they both admitted.

They incorporated games and art and craft, playing chess in Russia and the ancient game of Senet in Egypt; building a kit volcano in Greece, painting nesting dolls in Russia, drawing lions in Africa and making pottery in the UK.

And each day, they ate food from the country they were visiting, including Icelandic Lamb Soup, Happy Marriage Cake and Welsh cakes.

"I think our favourite night was the Greek night, when we had moussaka and melamokarona biscuits with Ouzo, then ended the evening by smashing plates, Greek style, outside. We had to explain that one to the neighbours," Jill said laughing.

"We both had loads of fun, tried some new things, relaxed, didn't listen to the news (apart from checking the latest restrictions) and at the end of the two weeks, felt we had had a real break. We even had that feeling, at the end, of coming home from holiday," Dave added.

"We have been blessed to be able to travel fairly extensively over the years, even since diagnosis, and have some lovely memories of wonderful places in the world.

"We have had to adjust our expectations as time has gone on and now look forward to a more local holidays when restrictions are lifted. We live in a beautiful country and there is still plenty to explore!"

'PURL' OF A FUNDRAISER

Rene Vivian is a familiar face in the Parkinson's community, whether it has been helping coordinate A Walk in the Park in Horsham or supporting tulip fundraisers.

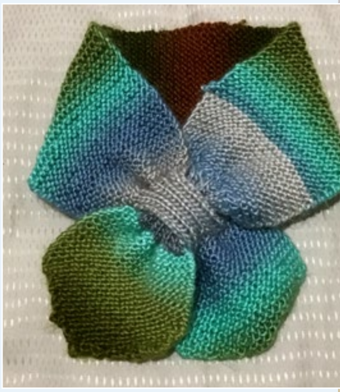
At 81 years of age, and diagnosed with Parkinson's six years ago, Rene admits each year gets a little harder to fundraise for both Parkinson's and Cancer research.

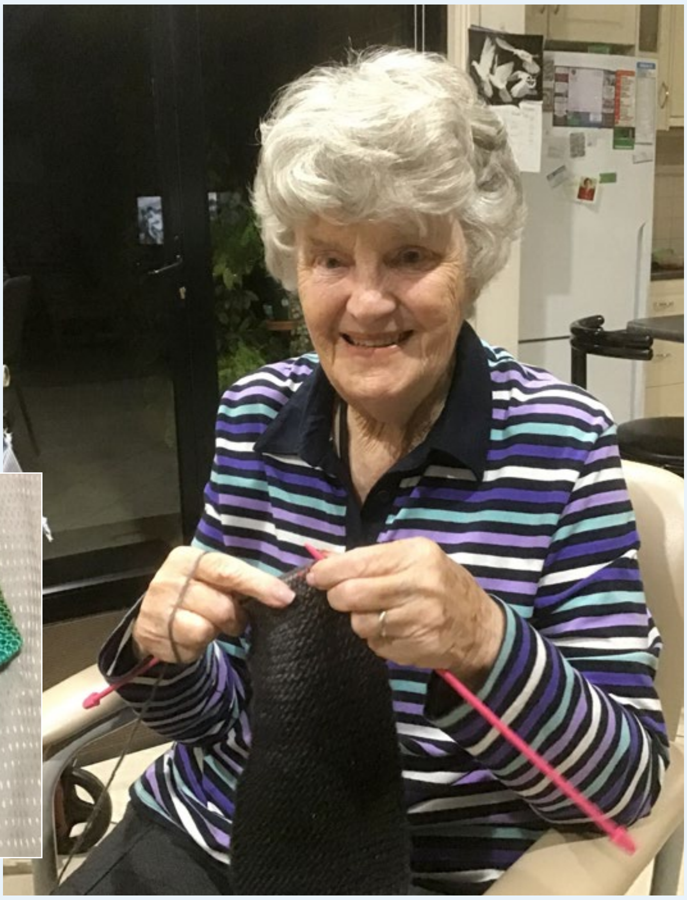
Not even cancellation of face-to-face events this year could keep Rene down. With no Horsham walk to join, Rene spent the winter knitting some beautiful scarves.

"My knitting, like me, is not perfect now and I knit with my 'dancing hand' (tremor) pinned inside a bucket chair to hold my work more firmly," Rene said.

In total, she knitted 39 scarves and raised $400, selling 25 of them mainly to Facebook friends and donating others to charity.

Thank you Rene for once again creatively fundraising for the Parkinson's community!





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ABOUT INMOTION

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While submissions for inclusion in InMotion are welcome, 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.

UPCOMING EVENTS

In line with Victorian Government COVID-19 restrictions, all Parkinson's Victoria face-to-face events remain suspended. However, a number of online events will be held. Register for all events at; parkinsonsvic.org.au/events

DATE	NAME	EVENT DETAILS
Wednesday 23 December	Carols via ZOOM-light	Join the Parkinson's Victoria team for a festive season open sing-along
Thursday 4 February, midday	Young Onset online series in conjunction with Maurice Blackburn	Engaging legal services
Thursday 11 & Friday 12 February, 4-5.30pm	Online Recently Diagnosed Seminar	A safe environment in which individuals and their families can better understand diagnosis and have their questions answered by a clinical Parkinson's Nurse.
Commences in February	Living Well with Parkinson's conversation series	The popular online series will continue in 2021. Confirmed dates and topics will be listed on the Parkinson's Victoria website.
Commences in February	NEW Ask the Expert online panel	Hear from guest speakers in an online panel discussion. Confirmed dates and topics will be listed on the Parkinson's Victoria website.
Thursday 18 February, midday	Young Onset online series in conjunction with Maurice Blackburn	Super and insurance
Thursday 4 March, midday	Young Onset online series in conjunction with Maurice Blackburn	Wills and delegated decision making
Thursday 18 March, midday	Young Onset online series in conjunction with Maurice Blackburn	Advanced care planning
Thursday 25 & Friday 26 March, 4-5.30pm	Online Recently Diagnosed Seminar	A safe environment in which individuals and their families can better understand diagnosis and have their questions answered by a clinical Parkinson's Nurse.
Thursday 8 April, midday	Young Onset online series in conjunction with Maurice Blackburn	Employment rights

HOLIDAY SEASON OFFICE HOURS

The Parkinson's Victoria office will close from 5pm Wednesday 23 December, re-opening at 9am on Monday 4 January 2021.

Our health information phone line will offer a call-back service on Tuesday 29 and Wednesday 30 December. All calls made after this time will be returned from 4 January.

If you have a health-related concern, contact your GP or Nurse-on-Call, 1300 60 60 24. If you experience a medical emergency, always call 000.