

**Parkinson's**  
SMART HEALTH



# About Parkinson's Victoria

## WHO WE ARE

Parkinson's Victoria is a not-for-profit, member-based organisation raising awareness and funds for services and research to improve quality of life for people living with Parkinson's and Atypical Parkinson's conditions.

Our multi-disciplinary team provides specialist advice and support to people living with Parkinson's, their families, carers, and health care professionals through:

- tailored health education programs and seminars
- a free and confidential health information service
- comprehensive web-based information
- an extensive Peer Support Group network.

We are committed to supporting vital research into effective treatments that improve the quality of life for people living with the condition, and the pursuit of a cure.

## WHAT IS PARKINSON'S?

Parkinson's is a chronic neurological condition with a range of complex symptoms unique to each individual. The most common symptoms include stiffened muscles, slowing movement and changing posture. Many people also experience tremors when resting.

Other symptoms can include pain, depression, anxiety, speech changes and loss of facial expression.

Medication and support from healthcare professionals can help manage these symptoms, however there is no way to slow progression or cure Parkinson's.

Parkinson's is the second most common neurological condition seen in our community. Cause is still unknown. It's estimated that 27,000 Victorians are living with Parkinson's, with 18% diagnosed while still of working age.

## ATYPICAL PARKINSON'S

Atypical Parkinson's are rare conditions that initially present like Parkinson's, but which have different causes, symptoms, and rates of progression. They include **Progressive Supra-Nuclear Palsy (PSP)**, **Multiple System Atrophy (MSA)** and **Cortico Basal Syndrome (CBS)**.

There are currently no known treatments to cure or slow the progression of PSP, MSA or CBS, or to prevent them. Treatments, therapies and strategies are available to help people manage their symptoms to make the most of living with these conditions.

## OUR VISION

A world without Parkinson's.

## OUR MISSION

To enable people living with Parkinson's to lead active and full lives.

To support the development of more effective treatments and a cure for Parkinson's.

## OUR VALUES

### Engagement and Inclusion

We engage and connect with people living with Parkinson's to understand their needs and ensure services, support and research are responsive, relevant and sympathetic to their needs.

We promote connection, participation and inclusion to help people live active and full lives.

### Knowledge and Empowerment

We understand the needs and challenges of people living with Parkinson's and their families and use evidence and best practice to inform, increase understanding and build individual capacity to manage their condition.

### Innovation and Excellence

We provide quality services and support in an environment that is committed to continuous improvement and establishing industry standards for people living with Parkinson's, their families, and carers.

We promote a learning culture within our organisation, the community and health sector, to ensure that advancements in research are reflected in improved services, methods and responses.

*Front page image: Prof. Bastiaan Bloem (right), consultant neurologist at the Department of Neurology, Radboud University Medical Centre, The Netherlands and co-founder of the ParkinsonNet model of multi-disciplinary care in Parkinson's, joined a team discussion about optimal symptom management for a Parkinson's patient, Russell (left) live on stage at Parkinson's Victoria Smart Health event in November 2019.*

# OUR IMPACT

**5726**

personally advised  
via our Health  
Information  
Service

**4220**

A Walk in the Park  
participants

**6**

research projects  
supported

**21**

peer support groups  
connecting via  
Facebook

**75**

peer support  
groups across  
Victoria

**96%**

increase in average  
phone call  
duration

**141,957**

unique website  
users

**2048**

peer support  
group education  
attendees

**685**

calls made via  
COVID-19 member  
outreach  
program

**1965**

professional and  
community  
education session  
attendees

Long-time supporter and fundraiser  
Judy Phelan was the face of our  
2019 Festive Season Appeal.

# Chair & CEO Report

Ensuring Victorians with Parkinson's were supported to navigate vast social change as the world responded to the COVID-19 global pandemic was key to our service offering in the second half of 2019-20.

It was an extraordinary turn of events that divided the year into two very different halves – the first saw thousands come together at major events including the Smart Health series, biennial Atypical Parkinson's seminar and A Walk in the Park.

By January, bushfires raged in parts of Victoria and just as people were recovering from the fires and the widespread smoke, a new threat, a deadly virus, was emerging. This virus came to define how we operated for the remainder of 2019-20 and beyond.

We commenced monitoring the potential impact of an escalating coronavirus in February. As the World Health Organisation declared a global pandemic on 11 March, and the Victorian Government a State of Emergency five days later, we were well-prepared to respond.

We took action to cancel face-to-face programs and events and directed Peer Support Group leaders to cancel meetings.

Anxiety increased as people become isolated and felt vulnerable to the virus; as allied health services were cancelled and medical specialists moved to telehealth. In response, we initiated an outreach program to make sure members were coping and managing their symptoms.

## THE SHIFT TO ONLINE

COVID-19 has taught us many things, not least that our organisation and community are adaptable and able to respond quickly to significant challenges and changes.

Our phone information line was seamlessly directed from the office to individual staff, who worked from home to collaboratively deliver our service and programs.

In line with our 2019-20 Operating Plan, digital learning, already under development as a complementary offering, became essential.

There will always be a place for face-to-face engagement, but online meetings, presentations and training extends access for those living in remote areas or unable to travel.

## FUNDING INTO THE FUTURE

With Government funding uncertain and only guaranteed until the end of 2020, fundraising for core business, including research, remains a key strategic focus.

This became even more critical as revenue streams reduced as events were cancelled and our appeal impacted by bushfire-related campaigns. Despite the challenges, extraordinary bequest revenue has contributed to our positive financial result.



We remain optimistic and continue to advocate strongly to ensure politicians and health officials understand the true value and impact of our services. We are also happy to report a successful \$1.7M Federal Government grant with the Western Region Primary Health Care Network to support four Movement Disorder Nurses for three years.

## A NEW APPROACH TO TREATMENT

In November, we hosted renowned Dutch neurologist, Dr Bastiaan Bloem, to speak at three special events. Prof. Bloem is co-founder of ParkinsonNet, a Parkinson's healthcare network formed in the Netherlands. He spoke of the multi-disciplinary care model that underpins ParkinsonNet and evidence of its improved clinical outcomes and reduced health costs.

As a supporter of this model, we will undertake a research project investigating how ParkinsonNet can be adapted for implementation in Australia. This is due to be delivered in 2020-21 and aligns with our Smart Health online education investment.

## OUR PURPOSE REMAINS THE SAME

Looking ahead we know further change is certain. We will focus on strategic, operational and financial resilience to enable us to further respond to, and recover from, the impact of the pandemic.

What this year has shown is that we can evolve and learn from our experiences to identify new ways of delivering proven programs and support.

What remains unchanged is our resolve to ensure all Victorians with Parkinson's and Atypical Parkinson's and their families, are supported and empowered to live their lives to the fullest.

Finally, we express gratitude to our dedicated staff, Peer Support Group leaders, donors, sponsors and fundraisers, for their efforts and willingness to support us through what was also a difficult year for many of them.

A stylized, handwritten signature in black ink, appearing to read 'Philip Thomas'.

**Philip Thomas**  
Chair

A stylized, handwritten signature in black ink, appearing to read 'Emma Collin'.

**Emma Collin**  
Chief Executive Officer

# Parkinson's Victoria Board

The Board and management is committed to Parkinson's Victoria's mission of enabling people living with Parkinson's to lead active and full lives, and to support the development of more effective treatments, and a cure, for Parkinson's.

The Board has three committees to ensure it satisfactorily discharges its responsibilities and duties. The committees are: Research; Governance and Risk; and Finance and Investment.



**Professor David Finkelstein**  
Chair Research Committee  
B.Sc., Grad. Dip. Scientific Instrumentation, M. Sc., Ph.D.  
Appointed: May 2014



**Dylan Hardy**  
Member Finance and Investment Committee  
B.A.  
Appointed: July 2017  
Six month leave of absence: July - December 2019.  
Resigned: January 2020



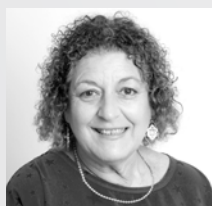
**Sue Harper**  
Chair Governance & Risk Committee  
B.A., Grad. Dip. Ontological Coaching  
Appointed: November 2013  
Resigned: June 2020



**Jason Karametos**  
Chair Finance and Investment Committee  
B Com/LLB (Hons), LLM  
Appointed: April 2018



**Celia Robinson**  
Member Finance and Investment Committee  
Member Research Committee  
M.Pub&IntLaw, B.Bus (Local Government)  
Appointed: August 2017



**Karyn Spilberg**  
Member Research Committee  
B.Ed., Grad. Dip. Computer Education, Grad. Dip. English as a Second Language  
Appointed: May 2014



**Faye Spiteri**  
B.A., GradCert PubRelations  
Appointed: October 2019



**Philip Thomas**  
Chair  
Member Governance & Risk Committee  
M. ComLaw, B.Bus., Grad. Dip. CSP., ASA, FCSA, FCIS, F.Fin, MAICD  
Appointed: June 2016



**Orlando Viola**  
Member Governance and Risk Committee  
Member Finance and Investment Committee  
BBus (Bachelor of Business - Accounting)  
Appointed: September 2019



**Steve Watts**  
Member Governance and Risk Committee  
Grad. Cert. Applied Management. Adv. Dip. Business Management  
Appointed: September 2019



# Health Information Service

The fundamental need for a dedicated Parkinson's health information service was reinforced in the second half of 2019-20 as many Victorians confronted bushfires and the COVID-19 pandemic.

Our health service incorporates clinical expertise across a range of healthcare specialties, enabling us to offer a multi-disciplinary service to support clinical, mobility and psycho-social needs.

The health team advises people with Parkinson's, family members, carers, employers and medical, health and aged care professionals.

We also provide a national service of tailored support and information for people with Atypical Parkinson's.

As Victorians were affected by the COVID-19 global pandemic and associated government restrictions, we saw a significant increase in call complexity and duration – from an average of 12 to 23.5 minutes.

A change in call purpose was also identified, driven by bushfire-associated air pollution and an increase in general anxiety around the global pandemic.

In April, we introduced a new outreach call program to Parkinson's Victoria members, in response to the reduction in services, reduced connection and increased isolation being experienced by many in the community.

This allowed us to reach out to 685 individuals around Victoria, to check that they were managing in the constantly changing environment, and provide guidance and support to initiate or remain engaged with health and community support services.

COVID-19 restrictions also led to an increase in complex professional consultancy services.

As health and aged care services managed COVID-19 restrictions and changes in available staff, we were able to provide peer-to-peer health professional support and advice to facilitate greater coordination and support of the condition and its symptoms.

In total, the Health Information Service managed 5725 calls in 2019-20, a 9% increase on the previous year.

This is a 136% increase over the past six years.



## COMMON QUERIES TO THE HEALTH INFORMATION SERVICE INCLUDED:

- Medication management and side effects
- Access to skilled allied health professional support
- My Aged Care and NDIS support
- Secondary consultation with health care professionals.



## COVID-19 RESPONSE

Parkinson's Victoria commenced work on a COVID-19 response plan in February 2020. This saw us well-replaced to respond to government decisions announced in March after the World Health Organisation officially declared a global pandemic.

Our advanced planning for business continuity in the event of a global pandemic allowed us to ensure continuation of services and seamlessly transfer our phone information service to staff working from home when we closed our Surrey Hills office in early March.

At the same time, we reviewed our face to face programs, in line with restrictions and health concerns for our community, cancelling our planned InSearch research lecture series, and all Community and Recently Diagnosed Seminars. Parkinson's Peer Support Group leaders were also supported to suspend their meetings.

To ensure community access and equity and in recognition of the significant financial hardship being experienced across the community, membership fees were waived by the Board from April 2020 to March 2021.

This initiative provided an opportunity for greater engagement, facilitating our ability to reach and support more people through the e-version of the member magazine, *InMotion*, which dedicated 5 pages to 'Coping with COVID-19' in its May edition.

In addition, we created a COVID-19 update page on the Parkinson's Victoria website, viewed by 1238 people between mid-March and 30 June. Updates were shared via tailored posts on our Facebook page.

The COVID-19 member outreach program also enabled us to explore the capacity of members to connect online and helped us develop an online support offering, the *Living Well with Parkinson's* online conversation series, which rolled out from August 2020.

"The call came at the perfect time, and it was so reassuring to know that Parkinson's Victoria was interested in how I was, and how I was managing when everything is so strange and frightening"

OutReach program call recipient

## COPING THROUGH COVID-19

The COVID-19 restrictions have placed extra pressure on people living with Parkinson's – but has also opened up a new world of connectivity and communication.

The following five pages are dedicated to helping you navigate restrictions imposed to reduce the risk of COVID-19 spreading throughout the community.

If you have any questions, the Parkinson's Victoria Health Team is here for you.

Call them on 1800 644 189 for information and advice (after hours phone calls will be returned the next day).

### STAYING CONNECTED

Our ability to communicate with others affects our enjoyment of all aspects of our life. This makes social distancing a challenge – impacting our relationships with family, friends and colleagues.

Social distancing, let alone social isolation, is challenging and can impact not only our physical, but our mental wellbeing.

But when viewed from a 'glasses half full' perspective, it can be seen as an opportunity to explore other tools and strategies we can use to enable us to continue to communicate and stay connected.

- seeing family who do not live with us
- catching up with friends
- accessing health services and other appointments
- shopping
- maintaining community supports, ie, personal care
- participating in work, activity groups and exercise programs
- engaging in Parkinson's Peer Support Networks.

When you list the many interactions we have, it's easy to understand why we've been quick to find different ways to stay connected through the use of existing digital technology.

### MAINTAIN COMMUNICATION SKILLS

In addition to receiving speech pathology therapy services to help you with your speech, there are ways you can actively help maintain communication skills:

- Make a conscious decision to **use your communication** – remains active in your real-life use of speech and language
- **Set 1 or 2 goals** to communicate each day. For example: phone a friend, write an email, or FaceTime a family member
- If you have trouble hearing the other person over the phone or vice versa, check if your telephone provider has a selection of phones with **built in amplifiers**
- Our use of the **phone is currently more important than ever**. If you find it difficult to talk on the phone or via a computer screen, ask your speech pathologist to work with you, specifically on these skills
- If your hearing has deteriorated, **consider an assessment with an audiologist**. A hearing loss can be a significant barrier to communication and staying connected
- If your Parkinson's affects your communication, **consider contacting a speech pathologist** to arrange an assessment and a suitable therapy program, tailored to meet your needs

- Work with your speech pathologist on designing a **'communication maintenance routine'** you can follow on an ongoing basis to reinforce your skills
- **Consider activities** you enjoy, which require you to communicate, express yourself or exercise your speech and voice, eg, singing, reciting poetry, reading a book or newspaper out loud
- Consider the **range of aids and equipment** to assist with everyday communication, eg, voice amplifiers, apps or devices that speak a typed message or communication boards can sometimes be helpful.

### WHAT IF I'M NOT AN INTERNET USER?

Talking on the phone, or writing a letter or card, are important and effective means of communication. Emails are also a popular and highly convenient way to interact with others.

More sophisticated digital tools such as applications on a smart phone, tablet or computer, are efficient and powerful, enabling the user to connect virtually with others, almost as though in the same room.

If you're open to using the internet and applications but don't yet have the skills, ask family or friends if they can help get you started. It may be easier than you expect. Ask them to introduce you to tools you can use together.

If you don't have a smart phone, iPad or computer, family or friends may have a device they no longer use they could give to you. People who like to access the latest technological devices are sometimes keen to upgrade and make their older devices available to share with others.

Even beginner skills in using the internet can open doors to a wealth of information, activities, and tools to help you stay connected. If you find them useful, you may choose to keep using them post this current 'new normal'.

### KEEPING ENGAGED

Taking conscious steps to stay connected is an important part of looking after ourselves:

- Post or arrange someone to personally deliver a note or card to family or friends
- Contact at least one person each day to check how things are going. Send a photo or video clip to family or friends
- Consider using social media tools such as Facebook or WhatsApp – your children or grandchildren could teach you how to use these
- If you have a smart phone, FaceTime allows you to see each other whilst you talk

Five pages of the May edition of *InMotion* were dedicated to managing Parkinson's through COVID-19 changes and restrictions.



# Health Education

Building understanding of Parkinson's is a cornerstone of our strategic direction.

This is achieved through an extensive range of programs developed for both the community and the health, disability and aged care sectors, including the popular Community Seminar and Recently Diagnosed Seminar Series and sector-specific education and training.

In second half of 2019-20, COVID-19 restrictions advanced the evolution of plans for delivery of a digital learning program. What was planned as a complementary platform became essential.

The groundwork done between March and June 2020 has laid the foundation for several online education offerings to be rolled out in 2020/21.

## RECENTLY DIAGNOSED SEMINARS

Our Recently Diagnosed Seminar (RDS) program has been pivotal to our community education program for more than 17 years.

The program connects individuals and their families with our supports and services, helping them to build understanding of condition and provide them with trusted information and tools to build a foundation for improved self-management.

These sessions are usually attended by an individual diagnosed with Parkinson's within the previous five years, as well as a family member or friend. A Young Onset Parkinson's-specific RDS is held annually.

In 2019-20, the RDS program was delivered to 287 individuals and their families at locations in Melbourne, Hamilton, Traralgon and Echuca.

The face-to-face program was temporarily postponed due to COVID-19 restrictions. An online pilot successfully trialled with 18 participants in June, has enabled us to develop a robust product for online delivery in 2020-21.

"So much useful and practical information along with the relevant clinical information. I hope to be able to use the information you provided to better support people living with Parkinson's."

professional education attendee



John Young has spoken about his personal journey with Parkinson's at a number of Recently Diagnosed Seminars and as the face of our 2020 Mid-Year Appeal.

## MANAGING ATYPICAL PARKINSON'S

Parkinson's Victoria provides information and support for people living with Atypical Parkinson's nationwide, as well as their carers and families.

Progressive Supranuclear Palsy (PSP), Multi-System Atrophy (MSA) and Cortico Basal Syndrome (CBS), may initially present like Parkinson's, but the way they progress and affect people is different.

There are currently no known treatments to cure or slow the progression of PSP, MSA or CBS, or to prevent them from occurring. Treatments, therapies and strategies are available to help people manage their symptoms.

Doctors and health workers may have limited knowledge of, and experience managing, Atypical Parkinson's symptoms due to the rarity of these conditions.

Key to improving this is delivery of the biennial Managing Atypical Parkinson's conference.

Offering two streams – one for healthcare professionals and the other for people with Atypical conditions, their families and carers – this conference is designed to increase understanding, and therefore more effective self and professional management of condition.

Facilitated by Parkinson's Victoria in collaboration with leading healthcare practitioners and patient advocates since 2007, it provides continuous professional development and community education on Atypical Parkinson's.

The August 2019 conference was attended by more than 120 people.



## EDUCATION COLLABORATION AND DELIVERY

Parkinson's Victoria worked with education, health and aged care sectors to improve understanding of Parkinson's in the following ways:

- Delivered La Trobe University and Bendigo Health Graduate Certificate of Gerontology Unit on Parkinson's care, treatments and the role of the healthcare professional
- Presented to social workers and psychologists at Swinburne University about current research into Parkinson's and psychological and psychosocial considerations
- Collaborated on a discussion panel on Deep Brain Stimulation at the General Practice Continuing Education Conference
- Delivered an introduction to Parkinson's and symptom management as part of the Hospital Pharmacists' Association's Continuous Professional Development Program
- Presented to the Continence Foundation of Australia nurses about the impact of Parkinson's on continence and intimacy
- Continued to collaborate in development of information and resources for the Better Health Channel, Continence Foundation of Australia and Beyond Blue.

## PROFESSIONAL NETWORK SUPPORT

Parkinson's Victoria supports and leads a number of professional special interest groups for physiotherapists, speech pathologists, movement disorder nurses and more recently, occupational therapists.

Specialist Health Professionals from across the university, public and private health sectors regularly meet to share clinical practice and explore research and service improvement ideas.

These groups have also collaborated in the development of patient education and information, contributing to increased awareness and influencing improvements in care delivery and the capacity of people living with Parkinson's to better understand and manage symptoms.

A tangible example was the production of information developed by the physiotherapists' network about how to safely exercise at home during the COVID-19 restrictions. This was published on our website and in *InMotion* member magazine.



Parkinson's Victoria Health Team Manager Victor McConvey with social worker Amanda Spillare and Atypical Parkinson's advocate Anne Mooney.

## AGED CARE TRAINING

Parkinson's Victoria continues to provide tailored programs for the aged care sector to increase awareness of symptoms, treatments and best practice care.

This includes an emphasis on identifying the challenges many people living with Parkinson's face such as not getting medication and essential treatments on time.

As we identified as part of consultation for our Aged Care Royal Commission submission, there can often be a perception that a person with Parkinson's has cognitive change or behavioural issues when in fact, they have simply not received essential medication on time.

More than 1000 aged care personnel took part in the Aged Care Education program between July 2019 and March 2020. Since then, the provision of this education has continued online, on request.

Consideration of continued online delivery of such training is being included in future service delivery planning.

# Collaboration & Advocacy



Collaboration at national and international levels is key to ensuring Victorians living with Parkinson's are exposed to information from world-leading researchers and practitioners to provide hope for the future, as well as tangible help for their lives today.

This collaboration saw us support and drive two innovative major events to benefit Victorians living with Parkinson's in 2019-20.

## SMART HEALTH

Prof. Bastiaan Bloem, consultant neurologist at the Department of Neurology, Radboud University Medical Centre, Nijmegen, The Netherlands, is co-founder of the ParkinsonNet model of multi-disciplinary care in Parkinson's, and is an internationally renowned neurologist and expert on Parkinson's care.

As keynote speaker at Parkinson's Victoria's inaugural Smart Health event, his only public speaking event on his Australian visit, Prof. Bloem demonstrated the benefits of the multi-disciplinary healthcare model.

His message – healthcare in Parkinson's should be patient-centric, with a coordinated approach by a treating team of specialists across multiple medical and allied health disciplines.

The Smart Health program ran across two days in November and was attended by more than 400 participants.

The community event, Parkinson's Life – Putting you in the centre, incorporated a full day program of informative sessions for people with Parkinson's, including a specific stream for Young Onset Parkinson's.

Prof. Bloem's presentation culminated with a live demonstration of the multi-disciplinary model in action. He was joined by eight medical and allied health professionals focussing on how to enhance quality of life for a 'real' person with Parkinson's, who joined them on stage.

More than 100 health care professionals attended the Smart Health presentation at the Florey Institute the next day. This event encouraged them to think in a broader, multi-disciplinary way and identify how collaboration can improve patient outcomes.

Thank you to the following patient and healthcare professionals who took part in the multi-disciplinary panel:

- Russell Joyce – Person with Parkinson's
- Dr David Blumberg – GP
- Assoc. Prof. Jennifer McGinley – Physiotherapist
- Caterina Marigliani – Speech Pathologist
- Natalie Delac – Occupational Therapist
- Dr Luke Smith – Neuropsychologist
- Victor McConvey – Parkinson's Nurse
- Amanda Spillare – Social Worker
- Amanda Longo – Dietician

## Applying ParkinsonNet in Australia

While in Melbourne, Prof. Bloem joined Parkinson's Victoria CEO Emma Collin and Chair Professor David Finkelstein to showcase the ParkinsonNet model.

This multidisciplinary care model has demonstrated improved care and clinical outcomes for people living with Parkinson's in the Netherlands, while independent economic evaluation also found cost savings for the health system.

After this event, the Parkinson's Victoria Board approved the investment of \$200,000 across two years to take the next steps to develop and introduce the ParkinsonsNet model in Victoria.

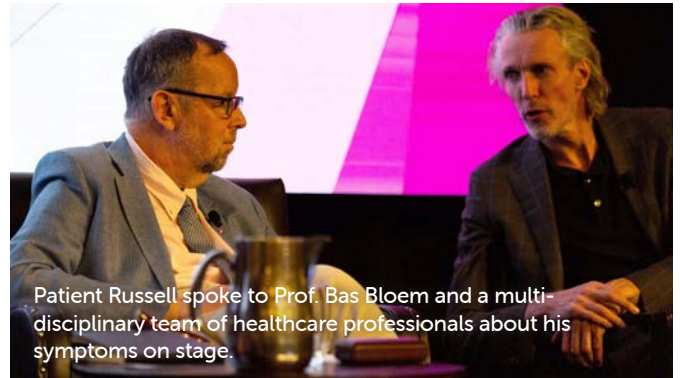
## What is ParkinsonNet?

ParkinsonNet is a patient-centred and network-based healthcare model now operating across the Netherlands, Germany, Belgium, Norway, Czech Republic, parts of California and the UK, where it has been adapted for the respective health systems in each country or jurisdiction.

The healthcare professionals are supported by the ParkinsonNet coordination centre at Radboud University Medical Centre in Nijmegen, led by Prof. Bloem and Dr Marten Munneke.

The model trains and educates healthcare professionals, seeking to make them Parkinson's disease experts and create a team of professionals around those people living with Parkinson's.

The Parkinson's Victoria Research Committee is overseeing a scoping project to review, evaluate and assess the application of the model in the Victorian and national healthcare environments to recommend how it could be adapted here to deliver new and improved outcomes for people living with Parkinson's.



Patient Russell spoke to Prof. Bas Bloem and a multi-disciplinary team of healthcare professionals about his symptoms on stage.



Members of the community were able to connect with Parkinson's Victoria staff, including music therapist Fiona Sham.

"A holistic approach, as modelled today, shows more accurate strategies and diagnosis. This will be a great help for Parkinson's patients and their families."

Smart Health attendee



The Smart Health series was attended by more than 400 people. However, face-to-face events were cancelled from March 2020 in line with COVID-19 restrictions.

## INSIGHT 2020

Parkinson's Victoria was proud to join the 2020 INSIGHT into Parkinson's conference as a Platinum sponsor. The value of this was reinforced as Victoria moved into staged COVID-19 restrictions.

This provided a pivotal opportunity for the Parkinson's community to come together to connect and learn, as face-to-face events across Australia and internationally were cancelled as the global pandemic worsened.

INSIGHT into Parkinson's, organised by the founder of PD Warrior, Sydney-based Melissa McConaghy, is the largest online global conference for people living with Parkinson's.

Access to quality information and experts from around the world was behind our decision to collaborate with the organisers to sponsor the event. Our sponsorship helped enable everyone to stream the three-day conference free of charge.

More than 9440 people from around the world, including 923 from Victoria, were able to listen to, and ask questions of renowned presenters from the medical, scientific and advocacy fields.

Our CEO Emma Collin facilitated the live Future Frontiers panel, while Health Team Manager and Clinical Nurse Consultant, Victor McConvey presented on the topic, Between the Sheets.

## WORLD PARKINSON CONGRESS

Following on from its key role in organisation and delivery of the 2019 World Parkinson Congress (WPC) in Kyoto, Parkinson's Victoria is proud of our continued collaboration in support of development of the WPC 2022, scheduled to be held in Barcelona.

WPC is a unique event held every three years, bringing together scientists, physicians, clinicians, advocates, peak bodies and people living with Parkinson's and their families.

We are represented on the leadership forum and advocacy, comprehensive care and pre-congress education committees.

## INTERNATIONAL MOVEMENT DISORDER SOCIETY

Parkinson's Victoria continued its international activities through attending the International Movement Disorder Congress.

Members of our team participate in the Congress in a number of capacities, including chairing the Global Taskforce on Palliative Care and the Healthcare Professionals section and developing and leading an Education Program for Health Professionals in developing nations.

# WESTERN DISTRICT MOVEMENT DISORDER NURSE PILOT

In February 2019, the Federal Government committed \$6.4M over four years to fund a national Movement Disorder Nurse pilot program through its primary health networks.

We responded by partnering with Western Victoria Primary Health Network Western, Rural North West Health, Wimmera Health Care Group, South West Healthcare and Grampians Community Health to develop a pilot program and grant application.

In January 2020, we submitted the \$1.7M Western Region Movement Disorder Better Care pilot to provide specialised care for people living with movement disorders in rural and remote western Victoria, where a Parkinson's prevalence cluster has been previously identified.

The Federal Government grant was awarded in June 2020, providing funding for four movement disorder nurses in Horsham, Warracknabeal, Stawell and Warrnambool.

The pilot aims to build local specialist clinical support and knowledge so people living with complex movement disorders can better manage their condition, with increased access to referral pathways, treatments and therapies in order to deliver better health outcomes.

# DEPARTMENT OF HEALTH AND HUMAN SERVICES

Parkinson's Victoria continues to lobby the State Government for recurrent funding on its own behalf and as a leading member of the Victorian Neurological Alliance in conjunction with the Epilepsy Foundation. This funding is essential to provide our health information and education services including the Parkinson's Smart Health online education program.

With funding due to cease in June 2020 and handing down of the State Budget delayed until the last quarter of 2020 due to COVID-19, a commitment was made to extend our Government funding arrangement until the end of 2020.

We continue to advocate on behalf of all Victorians with Parkinson's to secure ongoing commitment of State Government funding to fill the health and service gaps identified in 2018 as state-based disability funding was directed through the NDIS.



PD Warrior and INSIGHT into Parkinson's founder Melissa McConaghy (right) visited Parkinson's Victoria CEO Emma Collin to discuss our sponsorship of the online event.

# AGED CARE ROYAL COMMISSION

Parkinson's Victoria's submission to the Commonwealth's Royal Commission into Aged Care Quality and Safety called for ongoing investment to support the professional development of those working with people with Parkinson's and Atypical Parkinson's.

This is essential in order to improve understanding of the conditions, treatment options and the many challenges faced by patients and their families.

Our recommendations included:

- better support for online and face-to-face educational programs for general practitioners and aged care professionals covering the fundamentals of Parkinson's
- specialised modules to help them to better understand symptoms and learn best-practice ways to manage Parkinson's

We believe such investment will increase access to services for people with Parkinson's, upgrade the skills of multi-disciplinary professionals within the aged care sector, reduce unnecessary transfers to acute care services and support better identification and management of palliative symptoms and care.

"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. Bastiaan Bloem, founder of ParkinsonNet.

# Investing in Research



## Parkinson's Victoria actively supports a research program, partnering with universities and institutes to support

- applied research to improve the lives of people living with Parkinson's and Atypical Parkinson's
- scientific research to discover more about the cause, and potential cure, of Parkinson's and Atypical Parkinson's.

The Parkinson's Victoria Research Committee reviews all requests for research support to ensure the proposal has scientific rigour and is underpinned by appropriate ethics approval. This process ensures our research investment fits within the aims of our strategic plan and mission.

## PARKINDANCE

The two-year ParkinDance randomised control trial continued into 2019-20 before being suspended due to COVID-19 restrictions.

This research project partnership with La Trobe University, led by internationally-recognised physiotherapist and researcher, Professor Meg Morris, aims to identify the level of activity needed to stabilise or improve Parkinson's symptoms.

The randomised placebo-controlled clinical trial commenced in April 2019, with two groups of 24 participants taking part in the 12-week program before it was suspended in March.

Recruitment for a Young Onset Parkinson's trial group was also postponed.

Since March, Parkinson's Victoria, in conjunction with Prof. Morris, has been working on a way to take the research project online, which would see a world-first online delivery of research into physical activity.

An additional benefit of this trial will be the establishment of guidelines to develop ongoing safe and accessible dance-based exercise programs for Victorians living with Parkinson's.

## PARKINSONG™

The 12 month results of the ParkinSong™ controlled trial of singing-based therapy for Parkinson's were submitted to the Journal of Parkinson's Disease in May 2020.

ParkinSong™ is an activity-based peer support group program involving vocal warm-up and exercise, practical communication activities, group singing and social engagement that commenced in Williamstown in 2013.

The 2015-16 research project was funded by Parkinson's Victoria, together with the Hugh Williamson Foundation and Melbourne University.

We have now funded lead researcher Dr Jeanette Tamplin to collect pilot data for a NHMRC grant application for the next stage of research, a randomised controlled study to verify the validity of research results.

We have also been investigating opportunities to take ParkinSong™ online to enable the program to be offered to a wider cohort in more isolated regions and those who can't attend in person.

## EXERCISE AND PROGRESSIVE SUPRANUCLEAR PALSY (PSP)

In 2018, Dr Susan Slade, Senior Research Fellow at La Trobe University, commenced a research project aimed at broadening understanding of factors that may influence participation in exercise and physical activity by people with PSP.

The project was funded through the Argyrou Family Atypical Fellowship, awarded at Parkinson's Victoria's 2018 Insearch lecture series.

In 2019-20, Parkinson's Victoria funded an extension of this project to allow for:

- extended data collection
- publication of two new manuscripts on focus group results in peer-reviewed international journals
- data collection for a new element led by Prof. Meg Morris: worldwide clinical guidelines for exercise and physical activity in PSP
- development of information resources for people living with PSP including exercise and physical activity recommendations.

## HAND FUNCTION AND DEXTERITY IN PARKINSON'S

Physiotherapist and University of Melbourne researcher Dr Elizabeth Proud has been supported to undertake a pilot looking at the feasibility of a home-based, task-related hand training program for people with Parkinson's.

Although decreased dexterity and problems with hand function are Parkinson's symptoms, there has been limited research into exercise interventions targeting dexterity.

Dr Proud's research project will involve a randomised controlled trial that will investigate the effects of a home-based dexterity exercise program

## INSEARCH LECTURE SERIES

The InSearch Lecture Series was developed in response to the Parkinson's community's desire to increase their awareness of current research into Parkinson's and presents translational research to the community.

In its sixth year, the 2020 lecture program was to feature researchers Prof. Malcolm Horne, Dr Scott Ayton and Dr San San Xu presenting at community lectures in Melbourne, Echuca and Horsham in March. Prof. Simon Lewis, Director of the Parkinson's Disease Research Clinic at the Brain and Mind Centre and

Emeritus Professor Deborah Theodoros from The University of Queensland, were due to present at the Healthcare Professionals lecture.

In response to the introduction of COVID-19 associated restrictions from March, we made the responsible decision to cancel the lectures, instead encouraging attendees to attend the INSIGHT into Parkinson's online conference, which offered research-based presentations.

## BRAIN BANK

Parkinson's Victoria's support for the Victorian Brain Bank Network (VBBN), auspiced by the University of Melbourne and the Mental Health Research Institute, continued in 2019-20.

The VBBN collects and supports the storage of donated brains and provides tissue samples which support research into Parkinson's and Atypical Parkinson's.

In 2019-20 the Brain Bank collected, processed, and stored 37 new brain donations, of which nine were confirmed as being affected by Parkinson's or Atypical Parkinson's.

Two Victorian research projects were granted access to 76 Parkinson's-related and control brain tissue samples which are used throughout the Asia-Pacific region.

Brain donations were suspended in mid-March during the COVID-19 pandemic.

Research gives me hope that families like ours will one day be spared the heartache we've endured. This is the reason I started fundraising for Parkinson's Victoria every year via the 'Walk in the Park' events. I don't want our community to just rely on the faint hope of a cure, I want them to benefit from groundbreaking research that improves how they live now."

Judy Phelan, 2019 Festive Season Appeal Ambassador.



# Supporting the Parkinson's community



## PEER SUPPORT GROUP PROGRAMS

The Peer Support Group (PSG) program is a key service offering, providing a safe forum for people with Parkinson's and their families to connect at the local level. Our model is education and information focused, aimed at providing participants with the knowledge to:

- better self-manage their symptoms
- understand their rights and responsibilities
- locate and use services effectively.

Importantly, these groups also provide a vital channel through which community members connect locally, reducing social isolation.

These groups are led by local community volunteers, supported by a dedicated co-ordinator at Parkinson's Victoria. They are also supported by our Health Team.

An increased network of 75 Peer Support Groups, including community-based and activity based programs ParkinSong™ and Painting with Parkinson's adapted to meet the challenges of COVID-19 restrictions.

Since face-to-face meetings were suspended in March, we worked closely with PSG leaders to build supports and programs to move into online engagement and other avenues of communication to maintain contact with group participants.

This included creation of closed Facebook groups, providing a dedicated online platform through which they could continue to share information and hold discussions.

In addition to two PSGs with an established Facebook presence, another 19 created new Facebook groups, with 223 PSG participants joining.

## YOUNG ONSET PARKINSON'S

With 18% of people diagnosed with Parkinson's under the age of 65, providing and strengthening peer support opportunities for this cohort is a key strategic focus area.

People living with Parkinson's while still of working age have some very distinct needs, often facing challenges relating to employment and raising a family. Issues around accessing the NDIS and superannuation are also common.

We coordinate a dedicated Young Onset Parkinson's Peer Support Group that meets regularly on Sunday afternoons. This group continued to connect online in response to COVID-19 restrictions.



In addition, we are supporting the new Early and Young Onset Parkinson's Alliance (YEOPA), an independent, family-friendly support group formed by Geoff Constable and Andrew Lindsay.

The immediate needs of these groups were addressed during COVID-19 restrictions, with a further review of the specific resources and information people with Young Onset Parkinson's require, to be undertaken in 2020-21.

Suspending face-to-face meetings also provided an opportunity to review and pilot the future potential of continued online support and delivery into 2020-21.

## ATYPICAL PEER SUPPORT

Parkinson's Victoria continues to support the community affected by the Atypical Parkinson's conditions – Progressive Supranuclear Palsy, Multiple System Atrophy and Cortical Basal Syndrome.

There are currently no known treatments to cure or slow the progression of PSP, MSA or CBS, or to prevent them from occurring. Treatments, therapies and strategies are available to help people manage their symptoms.

Parkinson's Victoria continues to run the only Australian 'in-person' peer support group for people with Atypical Parkinson's. An average of 30 people attend the bi-monthly meetings in Melbourne.

This group's move to online at the end of March in response to COVID-19 restrictions was welcomed by some group members, who said it was easier to attend. It also extended access to those who cannot travel or live too far away from the traditional meeting location.

The option of continued online support post-COVID will be part of an overall ongoing review of service delivery.



From left: Melton, ParKando and Werribee PSG leaders Helen Lyne, Pam West and Noala Flynn at the Wyndham Community Seminar.

## PSG MILESTONES

- The clinically focused Specialist Peer Support Groups (DBS and Infused Therapies) continued to maintain focus on the complex or advanced therapy choices available and grew in attendance when the meetings moved online
- New PSGs were launched in Moorabbin, the City of Yarra PSG and City of Hobsons Bay and surrounds
- Essendon PSG provided a range of activities and showcased the work of the Painting with Parkinson's group at the Active Multicultural Seniors Festival in Braybrook
- Victorian Painting with Parkinson's Network received a Victorian Government grant to provide professional development sessions and update the Painting with Parkinson's PSG manual
- Victoria's longest-serving PSG leader, Harold Waldron retired as leader of the Geelong PSG. In recognition of Harold's extended care, compassion and support of the community, a new Parkinson's Victoria Carer's Award in his name was announced at the 2019 Annual General Meeting
- Inaugural Portland PSG leader Nola Matuschka handed over the reins after 20 years. John Wolf, whose father had Parkinson's, took over the leadership role
- 19 PSGs moved to online communication via Facebook during COVID-9 restrictions.

## COMMUNITY SEMINARS

The 'plain English' Community Seminar program provides an opportunity for people to learn more about Parkinson's to better understand the condition.

More than 350 people were able to attend eight face-to-face seminars in 2019-20 until we suspended the program in late March in line with government COVID-19 restrictions.

The seminars were in collaboration with community and healthcare stakeholders in Moorabbin, Endeavour Hills, City of Wyndham, Kingston City, Brooklyn, Essendon, Stawell and Monash University.

In response to the ongoing COVID-19 restrictions, we commenced looking into how to re-shape presentation of this information about treatments, symptom management and more into an online offering.

This culminated in the Living Well with Parkinson's online series, a one hour, weekly, topic-based presentation that commenced roll-out in August 2020.



## SIR ZELMAN COWEN AWARD

From sky-diving, to seeding an idea that become the landmark ParkinSong™ program earned long-time and passionate volunteer Heather Jobling the prestigious 2019 Sir Zelman Cowen Award, Parkinson's Victoria's highest honour.

First presented in 2006, the award recognises an individual's outstanding service to people living with Parkinson's.

Heather's idea for ParkinSong™ came after she heard an address by a speech pathologist – it got her thinking: if people were to exercise their voices through singing, it could assist with speech and swallowing.

Working with Parkinson's Victoria staff and funds from Hobson's Bay Council's Mayoral Fund, the first group began singing on Thursday 21 March 2013.

Since then, ParkinSong™ has grown with more groups created and the concept continuing to evolve as groups were forced to cancel their meetings from March.

As well as being instrumental in developing the ParkinSong™ concept, Heather and her husband Mike remained leaders of the Williamstown ParkinSong™ peer support group until the end of 2018.

Heather is a much-loved member of the Parkinson's community and has inspired others through the happiness and social connection she has brought to so many.



Mildura Peer Support Group participant Cynthia Parker received her 5 Year Service Award at the 2019 AGM.

## 2019 VOLUNTEER RECOGNITION AWARDS

Parkinson's Victoria's annual Volunteer Recognition Awards acknowledge their service and support of the Parkinson's community.

### Honorary Life Members

Trevor & Pearl White  
Judy Phelan

### Years of Service Awards

Continuous service of volunteers in an administrative, project or service capacity, particularly PSG coordination:

#### 10 Year Service Awards:

Louise and Paul Zajac (Geelong Young@Park)

#### 5 Year Service Awards:

Mildura Peer Support Group  
Darryl Keeble  
Cynthia Parker  
Kyabram Peer Support Group  
Christine Anderson  
Joy Shortis  
Kathy Kukuljan

### Community Recognition Award

Contribution of an individual or organisation to events or activities:

Judy Russell  
Richard Grimmatt  
Mike Atkinson  
Christine Anderson

### Certificate of Appreciation

Contribution of an individual or organisation to a community event or activity to support/raise awareness of Parkinson's:

Kirsten George  
Peter Walsh  
Dr John Locke  
Fred Van Ross  
Shane Murphy

# Fundraising

Donations, bequests, and community fundraising represented 84% of total income.

We rely on fundraising and donations to deliver our world’s best practice multi-disciplinary approach to health education, information and support services for people living with Parkinson’s and Atypical Parkinson’s conditions.

Fundraising also plays a key role in raising community awareness of the conditions.

New funding continues to be sought to support future programs to meet the growing and diverse needs of the community, and the move into online models, which all indications suggest will remain a growing and consistent trend.

## A WALK IN THE PARK 2019

A Walk in the Park is Australia’s largest Parkinson’s community event and the major annual fundraiser for Parkinson’s Victoria.

It provides a platform which brings together people living with Parkinson’s, their family, friends and colleagues, as well as medical and health care supporters, creating a tangible sense of community, belonging and support.

A total of 2569 registered walkers came together at Federation Square in August 2019, with an additional 1651 walking at seven regional events across Victoria between August and October. Together, they raised \$237,562 to support our education, programs and services.

Media Ambassador Shane Jacobson once again played a key role in event promotion, providing video content for a registration-focused digital campaign, which reached 60,800 people via Facebook. Shane also had key roles on the day, including his much-loved on-stage welcome and the official race start.

Olympian Steve Moneghetti was also interviewed on stage and took part in the walk with his family in support of his Mum.

Strong media coverage was this year driven by the MFB, which came on board to support firefighter – and new Parkinson’s Victoria Board member – Steve Watts.

With his story of Young Onset Parkinson’s and adapting at work with the help of a supportive employer, Steve was a strong Ambassador for the event. He was joined by community Ambassadors Sheenagh Bottrell and John Young, who featured in their local newspapers.



Actor Shane Jacobson and his mum, Jill Goss

Steve’s personal story was shared in an extended segment that aired on the Channel 7’s House of Wellness, which also included in-studio interviews with Shane Jacobson, his mum Jill Goss, who has Parkinson’s and neurologist Dr Richard Blaze.

This segment, combined with coverage in metropolitan TV news and radio, as well as extensive coverage in suburban and regional press, saw our media reach extend to 4.8 million – an increase of 500,000 compared to the previous year.

### Fundraising champions

The fundraising success of this event is due to the efforts of 765 committed individuals who actively raised sponsorship dollars on top of their registration fees, including 37 who raised more than \$1000.

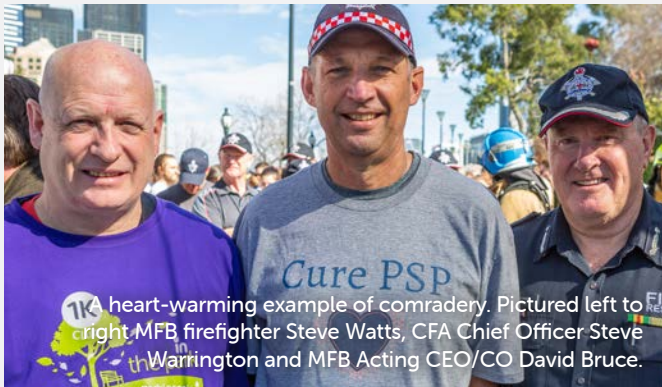
Every dollar contributed to this event is appreciated, but we acknowledge the contribution of the top 10 fundraisers in 2019:

Steve Watts	\$6926	Margaret Anderson	\$2235
Judy Phelan	\$5197	Damian Rann	\$2130
Isa Adams	\$3062	Sue Harper	\$2120
Vanessa Guerrisi	\$2775	Darryl McInerney	\$2050
Christine Anderson	\$2680	Sandra Turner	\$1914

We also extend our appreciation to the following organisations that voluntarily supported the event: Melbourne Institute of Massage Therapy & Myotherapy, Glenferrie Rotary Club and Swinburne University’s exchange students from Northeastern University, Boston, USA.



# Fundraising cont...



TKA heart-warming example of comradeship. Pictured left to right: MFB firefighter Steve Watts, CFA Chief Officer Steve Warrington and MFB Acting CEO/CO David Bruce.



## FIRIES TURN OUT TO SUPPORT THEIR OWN

We acknowledge the heartfelt support of the MFB to promote awareness of Parkinson's across the fire service, while raising funds in support of one of their own and the wider Parkinson's community.

The MFB has proactively supported Commander Steve Watts after his Parkinson's diagnosis and with the support of the Melbourne Firefighter's Charity Fund, drove awareness of A Walk in the Park and Parkinson's in the workplace.

With the support of workmates and friends, Steve emerged as the leading individual fundraiser with \$6926 and his team, The Steve Brigade, raised an impressive \$34,653, including \$20,000 donated by the Firefighters' Charity Fund.

## REGIONAL WALKS

More than 1650 people stepped out for Parkinson's in seven regional walks held between 18 August and 13 October, raising \$20,767 towards the overall event total.

The regional walks are a labour of love for dedicated volunteers who tap into the community spirit which often comes from knowing a person with Parkinson's.

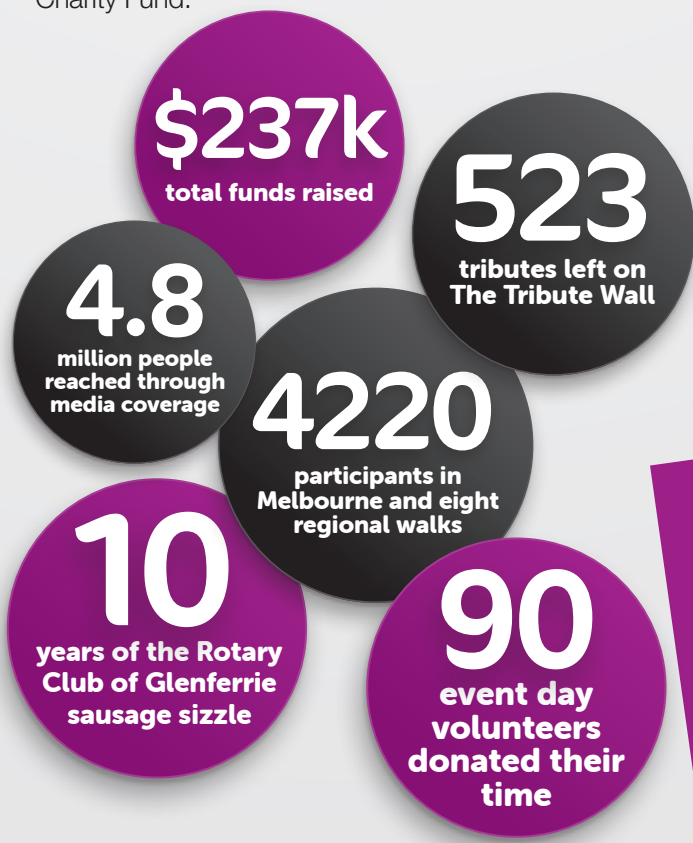
These dedicated people put many hours into organising and staging these events. We truly appreciate their amazing efforts and contribution.

The Mildura walk (pictured above) is a wonderful example of this community spirit, with event organiser Cheryl Barnes and her team celebrating 10 years. This walk traditionally asks participants to wear red, creating impact and drawing widespread local support.

This year's walk at Mildura attracted 200 registrations and raised \$1276.

We acknowledge and thank Cheryl and the other walk organisers for hosting another season of successful regional events:

- Frankston – Karen Begg
- Geelong – Kirsten George
- Horsham – John McRoberts
- Warrnambool – Andrew Suggett
- Wodonga – Leanne Torpey
- Yarrawonga – Judy Ramsdale



"This is a wonderful event. Some people, like myself, have personally benefited from the funds raised by Parkinson's Victoria. I hope the event will go on for a long time and get better every year."

2019 AWITP participant

## DONATIONS AND BEQUESTS

Parkinson's Victoria relies on donations and bequests so it can support individuals and families affected by Parkinson's.

We are particularly grateful for the generosity shown by the following individuals, organisations, trusts and foundations whose support allows Parkinson's Victoria to grow and evolve to meet the increasing and changing needs of our community.

### Trust and Foundations

- Handelsman Charitable Trust
- MacKenzie Family Foundation
- The G & I Meagher Charitable Trust
- The Orloff Family Charitable Trust

### Bequests

- Estate of the Late Joe White
- Estate of the Late Esme Lloyd Mitchell
- Estate of the Late Margaret Wilkinson
- Estate of the Late Norman Kaye
- Estate of the Late Crystal Maud Downward Dunn
- Estate of the Late Rudolf Guehr
- Estate of the Late Jennifer Ethel Harte
- Estate of the Late Colleen Margaret Wallace
- Estate of the Late Craig Johnston
- Estate of the Late Alfred Noel Curphey

### Community Fundraisers

- Richard Langridge – English Channel swim
- Andrew Lindsay – Melbourne Marathon
- Rotary Club of Oakleigh, Clayton and Huntingdale – Spring Auction



Andrew and Amanda Lindsay at the Melbourne Marathon

# Corporate Partnerships

The generosity and commitment of our corporate, community and government partners is vital to the successful delivery of our comprehensive range of support and education programs for people living with Parkinson's and their families.

We thank the following companies and organisations for their support in 2019-20.

### Corporate partners



### Community partners

- BrainBank
- Epilepsy Foundation
- Maurice Blackburn
- World Parkinson's Coalition
- PD Warrior

### Research partners

- La Trobe University
- University of Melbourne
- The Florey Institute of Neuroscience and Mental Health

### In-kind support

- Bayview on Eden
- Go Natural Australia
- Maurice Blackburn
- Montalto Vineyard & Olive Grove
- Treloar Roses

### Government partners

- Western Victoria Primary Health Network

The Parkinson's Victoria Information Line is supported by the Victorian Government.



# Financial Report

Parkinson's Victoria reported a very strong net surplus of \$1,302,176 for FY20, an increase of \$1,015,561 on the previous year. This financial performance was primarily due to higher than expected bequest revenue of \$2,147,379 an increase of \$1,780,110 on FY19.

Largely as a result of COVID-19 and the cancellation of a Walk in the Park, Parkinson's Victoria's donations from events and appeals decreased in FY20 compared to FY19 which was partially offset by better investment income. Further government support of \$167,000 through Job Keeper and other measures supported Parkinson's Victoria's financial performance for FY20.

Investment in research resulted in additional expenditure of \$94,679 compared to FY19, supporting an invigorated agenda with increased funding for existing and new research initiatives.

Our Investment portfolio continued to perform, however given significant global market volatility driven COVID-19, at 30 June 2020 it was sitting on an

unrealised loss of \$323,835. The Board continues to carefully monitor Parkinson's Victoria's investments and is in regular dialogue with our investment manager.

Victorian Government funding of \$300k was secured as well as a further funding commitment for FY21, however recurrent funding for Parkinson's specialist health services remains a priority.

Our net assets remain at a healthy position of \$4,949,401, an increase of \$1,302,176. In a year of extraordinary events, Parkinson's Victoria's sound financial management and strong balance sheet means that despite the uncertainty caused by COVID-19, it is well positioned financially to meet the needs of our community and deliver on the priority programs during FY21.



**Jason Karametos**

Chair Finance and Investment Committee



# Auditor's Report



Chartered Accountants & Advisors

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## INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF PARKINSON'S VICTORIA LIMITED

### Opinion

We have audited the accompanying financial report of Parkinson's Victoria Limited, which comprises the statement of financial position as at 30 June 2020, the statement of profit or loss and other comprehensive income, statement of changes in equity and statement of cash flows for the year then ended, and notes to the financial statements, including a summary of significant accounting policies and the directors declaration.

In our opinion the financial report of Parkinson's Victoria Limited has been prepared in accordance with Division 60 of the *Australian Charities and Not-for-profits Commission Act 2012*, including:

- (a) giving a true and fair view of the company's financial position as at 30 June 2020 and of its financial performance and cash flows for the year ended on that date; and
- (b) complying with Australian Accounting Standards to the extent described in Note 1, and Division 60 the *Australian Charities and Not-for-profits Commission Regulation 2013*.

### Basis for Opinion

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Report section of our report. We are independent of the Entity in accordance with the ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110 Code of Ethics for Professional Accountants (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our other ethical responsibilities in accordance with the Code.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

### Emphasis of Matter - Basis of Accounting

Without modifying our opinion, we draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared for the purpose of fulfilling the responsible entities' financial reporting responsibilities under the ACNC Act. As a result, the financial report may not be suitable for another purpose.



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under professional standards legislation.



Independent Member of  
Walker Wayland Australasia Limited,  
a network of independent accounting firms



# Auditor's Report cont...



## **INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF PARKINSONS VICTORIA LIMITED (Continued)**

### **Directors' Responsibility for the Financial Report**

The directors of the company are responsible for the preparation of the financial report that gives a true and fair view and have determined that the basis of preparation described in Note 1 to the financial report is appropriate to meet the requirements of the ACNC Act, and for such internal control as the directors determine is necessary to enable the preparation of a financial report that gives a true and fair view and is free from material misstatement, whether due to fraud or error.

In preparing the financial report, the directors are responsible for assessing the Entity's ability to continue as a going concern, disclosing, as applicable, matters relating to going concern and using the going concern basis of accounting unless management either intends to liquidate the Entity or to cease operations, or has no realistic alternative but to do so.

### **Auditor's Responsibility**

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with the Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

As part of an audit in accordance with the Australian Auditing Standards, we exercise professional judgment and maintain professional scepticism throughout the audit.

We identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

We obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Company's internal control.

We evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the directors.

We conclude on the appropriateness of the directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the Company to cease to continue as a going concern.





**INDEPENDENT AUDITOR'S REPORT  
TO THE MEMBERS OF PARKINSONS VICTORIA LIMITED (Continued)**

We evaluate the overall presentation, structure and content of the financial report, including the disclosures, and whether the financial report represents the underlying transactions and events in a manner that achieves fair presentation. We communicate with the directors regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

**Independence**

In conducting our audit, we have complied with the independence requirements of the *Australian Charities and Not-for-profits Commission Act 2012*. We confirm that the independence declaration required by the *Australian Charities and Not-for-profits Commission Act 2012*, which has been given to the directors of Parkinson's Victoria Limited, would be in the same terms if given to the directors as at the time of this auditor's report.

A handwritten signature in blue ink that reads 'Walker Wayland Advantage'.

A handwritten signature in blue ink that reads 'Awais Ur Rehman'.

**WALKER WAYLAND ADVANTAGE AUDIT PARTNERSHIP  
CHARTERED ACCOUNTANTS**

**AWAIS UR REHMAN  
PARTNER**

Dated in Melbourne on this 30<sup>th</sup> day of October 2020

# Financials

<b>STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME FOR THE YEAR ENDED 30 JUNE 2020</b>	<b>2020</b>	<b>2019</b>
	<b>\$</b>	<b>\$</b>
<b>Income</b>		
Revenue	3,143,539	1,754,590
Research Revenue	121,482	120,503
Victorian Dept of Health and Human Services Grant	300,000	275,095
<b>Total Income</b>	<b>3,565,021</b>	<b>2,150,188</b>
<b>Expenditure</b>		
Employee Benefits expense	(1,352,431)	(1,062,346)
Depreciation amortisation expenses	(26,533)	(15,844)
Operating Lease expense	(61,184)	(53,478)
Finance costs	(21,338)	(18,517)
Research expenses	(118,679)	(24,000)
Other expenses from ordinary activities	(682,680)	(689,390)
<b>Total Expenditure</b>	<b>(2,262,845)</b>	<b>(1,863,575)</b>
<b>Surplus for the year before income tax</b>	<b>1,302,176</b>	<b>286,615</b>
Income tax expense	-	-
<b>Net surplus for the year</b>	<b>1,302,176</b>	<b>286,615</b>
<b>Other comprehensive income:</b>		
<b>Items that will not be reclassified subsequently to profit or loss</b>	-	-
<b>Items that will be reclassified subsequently to profit or loss when specific conditions are met</b>	-	-
<b>Total other comprehensive income for the year</b>	<b>-</b>	<b>-</b>
<b>Total comprehensive income for the year</b>	<b>1,302,176</b>	<b>286,615</b>
<b>Total comprehensive income attributable to members of the entity</b>	<b>1,302,176</b>	<b>286,615</b>
<b>STATEMENT OF CASH FLOW FOR THE YEAR ENDED 30 JUNE 2020</b>	<b>2020</b>	<b>2019</b>
	<b>\$</b>	<b>\$</b>
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>		
Receipts from donations, bequests and other income	3,251,263	1,626,936
Government grant	300,000	275,095
Payments to suppliers and employees	(2,156,515)	(1,821,990)
Interest received	8,631	10,997
<b>Net cash generated from operating activities</b>	<b>1,403,379</b>	<b>91,038</b>
<b>CASH FLOWS FROM INVESTING ACTIVITIES</b>		
Purchase for plant and equipment	(20,153)	(28,313)
Investment in Financial Assets	117,506	(131,062)
Income from Investments	(63,835)	168,182
Management fees for Investments	(15,295)	(15,110)
Purchase of Right to Use assets – premises	(592)	-
<b>Net cash (used in)/generated from investing activities</b>	<b>17,631</b>	<b>(6,303)</b>
<b>CASH FLOWS FROM FINANCING ACTIVITIES</b>		
Finance Costs	-	-
<b>Net cash (used in)/generated from Financing activities</b>	<b>-</b>	<b>-</b>
Net decrease in cash held	1,421,010	84,735
Cash on hand at the beginning of the financial year	820,093	735,358
<b>Cash on hand at the end of the financial year</b>	<b>2,241,103</b>	<b>820,093</b>

<b>STATEMENT OF FINANCIAL POSITION AS AT 30 JUNE 2020</b>	<b>2020 \$</b>	<b>2019 \$</b>
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash and cash equivalents	2,241,103	820,093
Accounts receivable and other debtors	60,042	41,681
Inventories	899	473
Other current assets	75,432	110,452
<b>TOTAL CURRENT ASSETS</b>	<b>2,377,476</b>	<b>972,699</b>
<b>NON-CURRENT ASSETS</b>		
Plant and equipment	55,331	61,666
Right of Use assets	101,771	-
Financial Assets at fair value through Profit or Loss account	2,782,423	2,899,929
<b>TOTAL NON-CURRENT ASSETS</b>	<b>2,939,525</b>	<b>2,961,595</b>
<b>TOTAL ASSETS</b>	<b>5,317,001</b>	<b>3,934,294</b>
<b>LIABILITIES</b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable and other payables	99,221	131,140
Lease Liability	67,072	-
Provisions for Employee Benefits	142,384	93,542
Revenue received in advance	15,000	43,597
<b>TOTAL CURRENT LIABILITIES</b>	<b>323,677</b>	<b>268,279</b>
<b>NON-CURRENT LIABILITIES</b>		
Lease Liability	37,012	-
Provisions for Employee Benefits	6,911	18,790
<b>TOTAL NON-CURRENT LIABILITIES</b>	<b>43,923</b>	<b>18,790</b>
<b>TOTAL LIABILITIES</b>	<b>367,600</b>	<b>287,069</b>
<b>NET ASSETS</b>	<b>4,949,401</b>	<b>3,647,225</b>
<b>MEMBERS' FUNDS</b>		
Members' funds	4,288,399	2,973,231
Research Funds	661,002	673,994
<b>TOTAL MEMBERS' FUNDS</b>	<b>4,949,401</b>	<b>3,647,225</b>

<b>STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDED 30 JUNE 2020</b>	<b>Members' funds \$</b>	<b>Research funds \$</b>	<b>Retained surplus \$</b>
<b>Balance at 1 July 2018</b>	<b>2,812,974</b>	<b>547,636</b>	<b>3,360,610</b>
<b>Comprehensive income</b>			
Surplus for the year	160,257	126,358	286,615
Other comprehensive income for the year	-	-	-
<b>Total comprehensive income attributable to members of the entity</b>	<b>160,257</b>	<b>126,358</b>	<b>286,615</b>
<b>Balance at 30 June 2019</b>	<b>2,973,231</b>	<b>673,994</b>	<b>3,647,225</b>
<b>Comprehensive income</b>			
Surplus/(deficit) for the year	1,315,168	(12,992)	1,302,176
Other comprehensive income for the year	-	-	-
<b>Total comprehensive income attributable to members of the entity</b>	<b>4,288,399</b>	<b>661,002</b>	<b>4,949,401</b>
<b>Balance at 30 June 2020</b>	<b>4,288,399</b>	<b>661,002</b>	<b>4,949,401</b>

## HOW YOU CAN HELP

### Give

Your donations mean we can continue to offer vital information, support and education services to Victorians affected by Parkinson's.

### Leave a gift in your Will

A gift in your Will is a valuable way to help create a brighter future for Victorians living with Parkinson's.

### Fundraise

Get involved in one of our fundraising events—or organise your own.

### Partner with us

There are many ways we can work together to help more people with Parkinson's live their best life possible. Find out how your organisation can be part of our achievements.

### Volunteer

There are many ways you can volunteer with us. Help with administrative tasks, share your professional skills or help at an event. Contact us for more information.

## CONNECT WITH US



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