

# LAYING FOUNDATIONS FOR INNOVATION IN GROWTH AND ENGAGEMENT





# 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 that improves the quality of life for people living with Parkinson's and Atypical Parkinson's conditions.

Our multi-disciplinary health 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.

Parkinson's Victoria is committed to supporting vital research into effective treatments that improve the quality of life for people living with the condition, and for 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 diagnosed. The most common symptoms include stiffened muscles, slowing movement and changing posture. Many people also experience resting tremor.

Other symptoms can include pain, depression, anxiety, speech changes and loss of facial expression. Medication and support from health care 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 today, with 20% of people living with Parkinson's diagnosed before they are 60. There is currently no known cause.

## 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 from occurring. 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 people living with Parkinson's to understand their needs and ensure services, supports and research are responsive, relevant and sympathetic.

We promote connection, participation and inclusion as a means to living an active and full life.

### 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.

### 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 services, methods and responses.

*Front page image: A Walk in the Park 10th anniversary celebrations*

# Our impact

**3400**

support group  
education attendees

**4648**

A Walk in the Park  
participants across  
Victoria

**151,766**

unique website  
users

**2965**

professional  
and community  
education session  
attendees

**5247**

personally advised via  
our health phone line  
and face-to-face

**1645**

members across  
Victoria

**7**

research projects  
supported

**72**

support groups  
across Victoria

**203**

health professional  
visits to support  
groups



2018 A Walk in the Park Ambassadors, actor Shane Jacobson and Howard Philpott.



# Chair & CEO Report

This year was one of progress as we built on the foundations laid in 2017-18 to increase capacity to deliver world-class Parkinson's health, education and research, while meeting growing demand for our services.

Moving from a focus on staff and resources, to improving our system capabilities, will ensure we are best positioned for growth and engagement within an ever-changing environment.

A key strategic priority is to develop a Parkinson's Centre of Excellence and build understanding of Parkinson's. To achieve this, and broaden our reach, will require a change in how we engage with our community.

We've commenced a major review of our processes and systems to understand how we can best position ourselves to innovate and grow services in the years ahead. This exciting project is a major step towards improved coordination and integration of our services and to set us up for growth in future digital engagement.

Aligned to this, we created a Chief Operating Officer role to oversee systems, processes and teamwork across the organisation. Importantly, this new role will allow Parkinson's Victoria to have greater resources to focus on advocacy on behalf of the Parkinson's community.

We have represented people living with Parkinson's on royal commissions and reviews underway at both the Federal and State levels.

Being a voice for Parkinson's is particularly important within the context of changes in the disability and health sectors. This year we continued to engage with the Department of Health and Human Services over the withdrawal of information line funding from 1 July 2019.

This extensive negotiation resulted in an election commitment to fund Parkinson's Victoria for 12 months – until 1 July 2020 – to develop a proof of concept education initiative to elevate the understanding of Parkinson's in health and community environments.

However, the fact is that demand for information via our phone service, email and face-to-face continues to grow.

In 2018-19 our health team responded to 5247 information requests – a 12% increase on the previous year. There was also a 32% increase in the number of unique visitors to the Parkinson's Victoria website.

Our membership program remains a core part of our engagement and support strategy. We grew our membership base with the re-launch our membership program in early 2019, resulting in a 10% increase to 1645 members.



Prof. David Finkelstein (L) Emma Collin (R)

Informing and supporting those living with Parkinson's is only part of the picture. We remain committed to increasing knowledge, skills and capacity within health, community, disability and aged care environments through several collaborative and self-funded initiatives.

While we continue to support research, the changing research environment has led us to commence a review of our current research strategy.

We want to ensure optimal use of our research funds, not only in the search for a cure, but for effective treatments that can improve quality of life for people now.

An example of this is ParkinDance a 2-year, randomised control trial looking at the specific dose of physical activity, in the form of dance, needed to have a positive benefit on the symptoms of Parkinson's.

In June, we were proud to be part of a group of Victorian participants in Japan at the World Parkinson Congress (WPC), a unique event bringing together world-leading scientists, physician's, clinicians, advocates, peak bodies and people living with Parkinson's and their families.

Almost 60 Victorians attended WPC, many of whom took the opportunity to attend a welcome function we hosted, where people could connect with each other to ensure they had a few familiar faces in the crowd.

This is an important event on the international Parkinson's calendar and also a valuable opportunity to meet other world leaders in Parkinson's healthcare, providing potential future collaborations and information-sharing.

Finally, we would like to thank our dedicated staff who work with purpose and pride to help others. With our valued corporate and community partners, volunteers, fundraisers and donors, they have collectively made a vital contribution to delivering our vision.

A handwritten signature in black ink that reads "David Finkelstein".

Prof. David Finkelstein  
Chair

A handwritten signature in black ink that reads "Emma Collin".

Emma Collin  
Chief Executive Officer

# Parkinson's Victoria Board

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



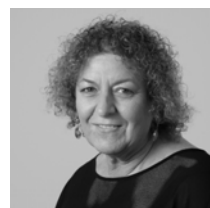
**Professor David Finkelstein**  
Chair

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



**Sue Harper**

Chair Governance & Risk Committee  
B.A., Grad. Dip. Ontological Coaching  
Appointed: November 2013



**Karyn Spilberg**

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



**Shane Murphy**

Member Governance & Risk Committee  
B. Applied Computing, Assoc. Dip.  
Electrical Engineering, Cert. Electrical  
Engineering, Grade A Electrician  
Appointed: November 2015  
Resigned: November 2018



**Philip Thomas**

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



**Dylan Hardy**

Member Finance and Investment  
Committee  
B.A.  
Appointed: July 2017



**Celia Robinson**

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



**Jason Karametos**

B Com/LLB (Hons), LL.M.  
Chair Finance and Investment Committee  
Appointed: April 2018



# Health Information Service

Supporting the complex information and health needs of people living with Parkinson's, their families, carers and healthcare professionals is core to the services provided by Parkinson's Victoria.

Clinical expertise across allied specialties including nursing, speech pathology and physiotherapy in our Health Team ensures the clinical, mobility and psychosocial needs of individuals are supported through a multi-disciplinary approach.

The number of people seeking support continues to grow, predominately via the free, confidential 1800 phone service, which operates weekdays from 9am – 5pm, with an after-hours message service.

Parkinson's Victoria was able to personally interact with 5247 individuals during the year – a 12% increase in the number of people directly seeking our advice and support.

Anxiety over access to, and navigation of, My Aged Care and the NDIS continued to be a key driver for this increase.

#### Key themes:

- Clarification around application rejection
- Access to community-based rehabilitation services outside My Aged Care and the NDIS.

Our team also experienced an increase in calls about symptom management and a notable increase in calls from General Practitioners and healthcare professionals seeking Parkinson's-specific information.

The Health Information team experienced a 12% increase in service contacts to

5247

116%  
increase over 5 years



John McKenzie, pictured with his wife Maria, was the face of the 2018 Festive Season Appeal.

"The support of Parkinson's Victoria has been essential. It's so good to have them so you can call up, to see if something or other is normal - to get help."

Maria McKenzie, whose husband John lives with Parkinson's

# Tailored Health Education

2965

professional  
and community  
education session  
attendees

18%

increase in  
2017-18

A cornerstone of our strategic direction is to build the understanding of Parkinson's. Key to achieving this is collaborating with the health, disability and aged care sectors to provide a range of education programs.

Building knowledge and capacity of professionals in these sectors is a key avenue through which Parkinson's Victoria can widen its positive impact on quality of life and improve health outcomes for people with Parkinson's.

## RECENTLY DIAGNOSED SEMINARS

Recently Diagnosed Seminars (RDS) remain a key initiative of our health education program, providing a safe environment where individuals and their families learn more about life after diagnosis and can connect with others.

The information delivered aims to help people recently diagnosed – and their families – to better understand the condition, treatments available to them and to build capacity for them to better self-manage their Parkinson's from the outset.

Attendees come away with symptom management strategies and information on the support services available to them.

**In 2018-19, the RDS program enabled the Parkinson's Victoria team to provide invaluable health education at seminars in Melbourne, Sunshine and Bendigo to 279 people newly diagnosed with Parkinson's.**

## NATIONAL NURSE MEETING

Parkinson's Victoria was proud to deliver the fourth annual National Movement Disorder Nurse Meeting. This meeting caters for the highly specialised professional development needs of Australian nurses who work with people living with Parkinson's and Atypical Parkinson's.

Delivery of this meeting, attended by 34 of the 42 Parkinson's and Movement Disorder Nurses in Australia was made possible through an unrestricted grant from a pharmaceutical industry partner, with the agenda shaped by the nurses themselves.

## PROFESSIONAL NETWORK SUPPORT

Parkinson's Victoria leads and supports professional special interest groups for physiotherapists, speech pathologists and movement disorder nurses.

Specialist health professionals from education institutions and public and private health sectors meet to share clinical practice and explore research and service improvement ideas.

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

## TAILORED TRAINING

Parkinson's Victoria's Health Team continued to respond to requests for training from a variety of health, community and aged care sector partners.

These requests often relate to patients with highly-specific needs or complex diagnosis and require the development of tailored solutions to specific care challenges.



Russell Joyce OAM and Victor McConvey.



## COLLABORATION

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

- Partnered with Albury Wodonga Health to deliver a free professional seminar for nurses, support staff and allied healthcare professionals.
- Took part in a live webinar with the MS Society, focusing on the role of the Healthcare professional in Parkinson's care.
- Spoke to 70 social work and psychology students at Swinburne University on current research into psychological and psycho-social considerations in Parkinson's.
- Joined an Aged Care Complaints Commission Live Stream presentation on Parkinson's treatments and symptom management with 90 Case Managers from around Australia.
- Presented to 120 Hospital Pharmacists Association members on complex and infused therapies in Parkinson's via webinar.
- Spoke to 50 Aged Care Workers from across the Barwon and South West regions about Parkinson's and considerations for community and residential care.
- Presented to 90 Disability Benefits Managers and other key Centrelink staff about treatment, care, challenges and support required for people living with Parkinson's.
- Continued to assist developing content for the Better Health Channel, Continence Foundation of Australia and Beyond Blue to provide information resources and to collaborate on community education, often covering subjects such as constipation, anxiety and sexuality.
- Worked with several state and independent high schools, providing education on Parkinson's as part of the VCE psychology syllabus.
- Provided education to more than 20 Aged Care Providers, primarily to address the challenges many people living with Parkinson's experience.

## ADVOCACY

### Deaths in institutional care

Members of the Parkinson's Victoria Health Team participated in focus groups held as part of the Disability Services Commissioner's review of disability services given to people who died in disability accommodation in 2017-18.

We provided professional input and case examples, bringing attention to some of the challenges experienced by people living with Parkinson's in institutional care.

These challenges often relate to not getting medication on time, which can exacerbate symptoms, causing swallow reflex to be slow, contributing to aspiration pneumonia.

### Aged Care Royal Commission

Parkinson's Victoria commenced a comprehensive response to the Royal Commission into Aged Care Quality and Safety.

Key to this response has been our ongoing community engagement that has enabled us to provide illustrated examples of the challenges experienced by people with Parkinson's living in residential and community aged care.

### Minimum safety standards

Parkinson's Victoria was pleased to be invited to contribute to the Victorian Government's review of minimum quality and safety standards in Victorian Aged Care, highlighting the medication challenges experienced by people living with Parkinson's in the aged care sector.

### Building knowledge

Parkinson's Victoria advocated directly to the Federal Health Minister, Mr Greg Hunt, to support health education to build the capacity of the healthcare sector to better understand and assist in the management of Parkinson's symptoms to improve outcomes and quality of life for people with the condition.



Parkinson's Victoria speech pathologist Caterina Marigliani speaking at a PSG meeting.





Victorian attendees at the World Parkinson Congress.

## INTERNATIONAL COLLABORATION

### World Parkinson Congress

Parkinson's Victoria was proud to be part of a small, but influential group of Victorian participants at the World Parkinson Congress (WPC), a unique event bringing together world-leading scientists, physicians, clinicians, advocates, peak bodies and people living with Parkinson's and their families.

The WPC was held in Kyoto in June 2019, attracting more than 3700 delegates from around the world.

Parkinson's Victoria was proud to play a key role in the event, with board members and staff represented on the organising committee, leadership forum and as presenters and conference contributors.

As a result of attending this conference, Parkinson's Victoria formed a number of international collaborations:

- Secured world-renowned Dutch neurologist Bas Bloem to speak in Melbourne in November 2019
- Confirmed a project with the Parkinson's Disease Association of India to develop a program including cultural sensitivity training, publication translation and referral pathways for people in Australia with a family member living with Parkinson's in India.
- Committed to work with representatives from Kenya to help with the translation of resources.

Almost 60 Victorians attended WPC, many of whom took the opportunity to attend a welcome function we hosted, where people could connect with each other to ensure they had a few familiar faces in the crowd.

Importantly, we proudly stood alongside members of the Victorian Parkinson's community, some of whom were WPC Ambassadors, others whose posters were accepted into the Poster Display or who wanted to learn as much as possible and connect with others from around the world living with Parkinson's.

### INTERNATIONAL MOVEMENT DISORDER SOCIETY

Parkinson's Victoria continued its international activities through attendance at the International Congress of Parkinson's Disease and Movement Disorders.

Members of the Parkinson's Victoria team participate in the International Movement Society in a number of capacities, including chairing the Global Taskforce on Palliative Care and the Healthcare Professionals section of the Society. Parkinson's Victoria staff are also involved in developing and leading an education program for Health Professionals in developing nations.

# Investing in Research

Parkinson's is a complex condition for which there is no known cause or cure. Parkinson's Victoria actively supports a research program, partnering with institutes and universities to support:

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

Importantly, it also ensures that Parkinson's Victoria's research investment fits within the aims of our strategic plan and Mission.

A review of our research strategy commenced in 2018-19. The review explored how we can best use our research funds in the search for a cure, and the impact on people's quality of life during their lifetime.

## PARKINSONG

Parkinson's Victoria has contributed to the body of evidence for ParkinSong™, through our involvement in *ParkinSong™: A Controlled Trial of Singing-Based Therapy for Parkinson's Disease*, published in the *Neuro-rehabilitation and Neural Repair Journal* in May 2019.

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

The research trial found ParkinSong™ participants made a statistically significant improvement in:

- vocal intensity (voice loudness)
- maximum expiratory pressure (respiratory strength)
- voice-related quality of life (more positive perceptions about their voice and communication).

The study was conducted in 2015-16, funded by the Hugh Williamson Foundation, Parkinson's Victoria and Melbourne University.

In a controlled trial, a proportion of the 75 participants attended ParkinSong™ and the control participants attended other groups such as regular Parkinson's Peer Support groups, Tai Chi groups, dancing groups or Painting with Parkinson's groups.

Benefits were evident at the 3-month point of the study and maintained at 12 months. The more frequent the singing group participation, the more significant the improvement.



Caterina Marigliani and Prof. Meg Morris contributed to the ParkinSong™ research.

**The study concluded that high dosage (weekly), therapeutically informed, intensive effort singing increased vocal intensity, MEP and voice-related quality of life.**

There are now eight ParkinSong™ groups in Victoria, and strong interest in developing several other groups across Victoria. These groups will be supported by a comprehensive training and support package currently being developed.

## INSEARCH LECTURE SERIES

InSearch provides a unique opportunity for Victorians to learn first-hand about research being carried out with the potential to greatly enhance the lives of people living with Parkinson's.

The program commenced in 2015 in response to the community's demand for knowledge about current research into Parkinson's.

The 2019 series, with the theme, *Help for Today, Hope for Tomorrow*, launched on 11 April, World Parkinson's Day, and drew record numbers, with 520 people attending four lectures in Geelong, Wangaratta and Melbourne.

Attendees heard from Professor Meg Morris and Professor David Finkelstein about research positively impacting people living with Parkinson's now, as well as hope for new treatments that may be able to stop or slow progression in the future.

- Professor Finkelstein provided insights into future treatments and research that is helping us better understand Parkinson's, including the future potential of tailored stem cell therapies.
- Professor Meg Morris announced her ParkinDance research project investigating dance as a safe and accessible physical activity as well as trying to identify the 'dosage' of dance that may slow the progression of Parkinson's.



## PARKINDANCE

There is growing evidence that physical activity is neuroprotective and may have the capacity to slow the symptoms of Parkinson's.

ParkinDance is a two-year, randomised control trial looking at the specific dose of physical activity, in the form of dance, needed to have a positive benefit on the symptoms of Parkinson's.

This collaborative research project with La Trobe University is being led by internationally-recognised physiotherapist and researcher, Professor Meg Morris and commenced in February 2019 with the first group of participants.

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

ParkinDance has been generously supported by the Pratt Foundation and community fundraising led by Isa Adams.

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.

## BRAIN BANK

Parkinson's Victoria continues to support the Victorian Brain Bank Network (VBBN), auspiced by Melbourne University and the Mental Health Research Institute.

The VBBN collects and supports brain donation which provides vital tissue samples supporting research into Parkinson's and Atypical Parkinson's throughout the Asia-Oceanic region.

From 1 July 2018 – 30 June 2019 the Brain Bank collected, processed and stored 48 new brain donations, 11 cases were confirmed neuropathologically as either Parkinson's or Atypical Parkinson's.

Eight new or continuing Australian and international research projects have applied and been granted access to Parkinson's-related tissues, quantifiable by the provision of 340 diseased and control brain samples.



Prof. Meg Morris and Prof. David Finkelstein spoke at the InSearch lecture series.

## TREAT TO TARGET

The Treat to Target clinical trial aims to support medical decision making with objective data collected by the Parkinson's Kinetograph Watch (PKG) a wearable sensor able to detect tremors, slowness of movement, additional movement and sleep.

This trial is a collaboration between Global Kinetics, Parkinson's Victoria, The Michael J. Fox Foundation and Shake it Up Australia Foundation and was announced in April 2018.

Parkinson's Victoria provided \$127,000 towards this landmark research project in 2017-18 and this year continued to promote the clinical trial to the Victorian Parkinson's community. At the end of December 2018, 55 Victorians had taken part in the trial.



Former Parkinson's Victoria Board member Shane Murphy (right) with InSearch attendees at the Geelong lecture.

"I'm very grateful these events are provided for people with Parkinson's – and that these clever people are prepared to deliver the lectures."

InSearch attendee



# Supporting the Parkinson's community



## PEER SUPPORT PROGRAM

Peer Support Groups (PSGs) remain a key service offering for Parkinson's Victoria, providing a vital channel through which community members connect, share information and reduce social isolation.

Currently Parkinson's Victoria auspices 72 PSGs across Victoria – up from 70 on the previous year and including 10 new groups, with a small number discontinued.

The most significant growth has been in specialist and activity-focused peer support.

Specialised PSGs focus on a specific therapy or treatment, in particular Deep Brain Stimulation and Infused Therapies.

There has also been substantial growth in the numbers of people seeking connection through a group based around an activity, such as painting, dancing and singing.

Parkinson's Victoria's Health Team delivered more than 200 face-to-face PSG sessions to keep community members informed and up-to-date with current research, treatments and implementable strategies to live well with Parkinson's.

We welcomed 14 new PSG Leaders and numerous volunteers, supporting them to build their capacity to grow their groups and to support their local members.

Parkinson's Victoria also supported 12 PSGs to secure government funding to enable them to continue to offer a high level of peer support to people locally.

## YOUNG ONSET PARKINSON'S

Providing and strengthening peer support opportunities for the 20% of people diagnosed with Parkinson's before the age of 65 is a priority.

People living with Young Onset Parkinson's have some very distinct and diverse needs. Addressing these needs requires dedicated peer support with regular informally-moderated meetings accommodating working people.

This year we began a review of the way people living with Young Onset Parkinson's want to connect with us and what information they need to better help them manage their life with Parkinson's.

## ATYPICAL PEER SUPPORT

Atypical Parkinson's conditions are rare and people impacted encounter complex and rapidly-progressing symptoms that can be isolating for them and their families.

For more than 10 years, Parkinson's Victoria has run the only 'in-person' peer support program for people with Atypical Parkinson's in Australia.

This year, we worked with the group to develop a new meeting model, in which those in the carer role meet in a dedicated space, supported by an experienced movement disorder social worker, to share and discuss how these conditions have impacted them.

People living with the condition are supported in a parallel session and have a chance to share and discuss information in a facilitated and safe space. At the end of 2019 this group delivery model will be formally evaluated.



## PSG MILESTONES

- Inaugural leaders of the Williamstown ParkinSong™ group, Heather and Mike Jobling (pictured right), retired after six years. Heather established this successful group and also played a key role helping Parkinson's Victoria achieve a Hugh Williamson Foundation grant to develop the ParkinSong™ program more widely.
- Warrnambool PSG celebrated its 30th anniversary in November, a testimony to the committed individuals dedicated to supporting their community and being prepared to adapt and evolve to meet changing needs.



Narelle Fraser with Echuca PSG member Jeannette Branch at the Echuca Community Seminar.



June Bowen, Andrew Suggett and Emma Collin at the Warrnambool 30th anniversary celebration.

- A new PSG was launched in Wonthaggi in November, with almost 20 people impacted by Parkinson's attending the inaugural meeting.
- New Painting with Parkinson's PSGs were formed in Geelong and Darebin and the long-running Mount Martha group was re-launched.



Judy Hayes at the new Geelong Painting with Parkinson's PSG.

## COMMUNITY SEMINARS

We collaborated with community and health stakeholders, Victorian Neighbourhood House networks, community service organisations (i.e. Rotary, Australian Men's Shed Association) and local government to host professional and community seminars that attracted over 2965 attendees.

These 'plain English' seminars commenced following many requests from local Parkinson's communities and are now held throughout Victoria each year, helping hundreds of attendees better understand Parkinson's.

The seminars also assisted promoting the profile of local Parkinson's PSGs, which provide an important opportunity for people living with the condition to connect, reducing isolation and loneliness. The seminar program kicked off in September 2018 in Castlemaine.

In March, more than 70 people attended the Mornington Community Seminar. Guest speaker Russell Joyce OAM shared his story of diagnosis and how he is choosing to live well with Parkinson's and help others on the Parkinson's journey.

The Echuca Community Seminar attracted more than 100 attendees, where guest speaker, former Victoria Police Detective, Narelle Fraser talked about building resilience and living well with a life-changing condition.

The Echuca Community Seminar was made possible through a successful Campaspe Shire Council grant application by the local support group – a great show of community connectedness and support.

"Painting with Parkinson's offers the chance to learn a new skill with no right or wrong and provides personal value whilst fostering confidence and optimism."

Ros Pollard, Geelong Painting with Parkinson's PSG leader



Andrew Suggett with his wife Betty and family.

## SIR ZELMAN COWEN AWARD

Warrnambool Parkinson's PSG Coordinator and community leader Andrew Suggett OAM was named the 2018 recipient of the Sir Zelman Cowen Award, in recognition of his invaluable voluntary contribution to the Parkinson's community.

Andrew has been committed to supporting regional Victorians impacted by Parkinson's at both local and state levels.

He has been involved with the Warrnambool PSG for 18 years and was a Parkinson's Victoria board member from 2011-2016, including time as Vice-Chair.

He regularly engages the local media, businesses and politicians to raise awareness of Parkinson's and fundraising efforts, including leading the Warrnambool *A Walk in the Park*. He also played a key role in creating a local Parkinson's Men's Shed.

At the same time, he is also there to help others – whether it be one-on-one or within a wider community context.

A strong family man, Andrew is an active member of the local golf and Rotary clubs and has been a member of the local Chamber of Commerce and several advisory bodies.



## 2018 VOLUNTEER RECOGNITION AWARDS

The annual Parkinson's Victoria Volunteer Recognition Awards recognises individuals and groups for their contribution to the Parkinson's community.

### Years of Service Awards

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

#### 15 Year Service Awards:

Elaine Maberly – Ballarat Support Group  
Ray McClusky – Ballarat Support Group  
Margot Adams – Ballarat Support Group  
Edith Weaver – Essendon Support Group

#### 10 Year Service Awards:

Gordon Townsend – Essendon Support Group  
Ingrid Camille – Eltham Support Group

#### 5 Year Service Awards:

Anne Simpson – Eltham Support Group  
Clarrie & Hwa O'Brien – Essendon Support Group  
Nu & Vien Lieu – Essendon Support Group  
Sue & Franz Schnellman – Essendon Support Group  
Robert & Sharyn Mains – Essendon Support Group  
Jenny & John Wilson – Bentleigh Bayside Support Group  
Mike Atkinson

### Community Recognition Award

Contribution of an individual or organisation to events or activities:

Geoff Constable  
Kim Goodridge  
Shane Jacobson

### Certificate of Appreciation

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

Kirsten George  
Adam Conrad





# Fundraising

Donations, bequests and community fundraising represented 64% of our operating revenue.

Parkinson's Victoria relies on fundraising and donations to deliver its world's best practice multi-disciplinary approach to health education, information and support services for those living with Parkinson's and Atypical Parkinson's conditions.

Our contract with the Victorian Department of Health and Human Services to fund our health information line, contributing 13% of our total revenue, has been extended until June 2020.

New funding continues to be sought to support future programs.



## DONATIONS AND BEQUESTS

The generosity shown by the following individuals, organisations, trusts and foundations allows Parkinson's Victoria to grow and evolve to reach even more people who need our help.

### Bequests

- Estate of Joan Carter
- Estate of Bernadette Claire Rogers
- Estate of Nance Veronica Ebery
- Estate of Bessie Mary Thompson
- Estate of Elsie Joyce Spicer
- Estate of Charlotte Edith Tooke
- Estate of Craig Johnston
- Estate of Alfred Noel Curphey



### Community Fundraisers

- Isa Adams, Linda Gandel & Brenda Steinberg
- Olga Hilton and Rotary Club of Flemington
- Kim Goodridge
- Anne-Marie McDonnell
- Karen Kirsten Family
- Caulfield Alma Park Bowls Club
- Robbie Sherwill
- Andrew Lindsay
- HD Entertainment



### Trusts and Foundations

- Estate of Joe White
- G & I Meagher Charitable Trust
- MacKenzie Family Foundation
- The Mary Elinor Harris Fund
- O'Sullivan Family Gifts



# Fundraising cont...

## A WALK IN THE PARK 2018

A Walk in the Park, Australia's largest community event dedicated to improving the lives of people with Parkinson's, celebrated its 10th anniversary in 2018.

This milestone year attracted a record number of participants, with 2848 people taking part in the flagship Melbourne walk on Sunday 26 August – 88 of whom have been part of every walk since its inception.

Another 1800 people joined nine regional events around Victoria. This was an increase on the six regional walks held in 2017, and included the inaugural A Walk in the Park Geelong.

### Highlights:

- 11% increase in Melbourne walk participants
- 10% increase in the number of fundraisers
- 6% increase in total funds raised.

### Fundraising record

We were overwhelmed by the generosity of those participating in A Walk in the Park – as well as the family, friends, community organisations and businesses supporting them. Thanks to their efforts, our fundraising target was once again exceeded.

As our major fundraising activity, A Walk in the Park was a record breaker, raising just under \$329,000.

The importance of this uplifting event is two-fold: For those living with Parkinson's, it creates a sense of belonging, of being part of a community who understand and support each other.

On a broader level, it enables Parkinson's Victoria to improve community understanding of the condition and raises vital funds to enable us to continue delivering our valued services and support.

Strong media coverage is integral to the success of the event. We rely on the generous and inspirational members of our community who publicly share their personal stories in the media.

In 2018, this included our 10 Walk Ambassadors: Geoff Constable, Kim Goodridge, Jill Goss, Mary Jones, Steve Moneghetti, Meg Morris, Peter Raymond, Karyn Spielberg and Geoff Wilkinson.

This year's 4.3 million media reach was boosted by live interviews on Channel 7's The Daily Edition, ABC Radio National and 3AW. In total, 128 individual items were reported across all media channels at the national, state, regional and local levels.

The Melbourne walk was also supported by Steve Moneghetti, who walked for the first time in a public show of support for his mum. Despite performing on the same day, actor Shane Jacobson was also able to stop by to welcome everyone and get the walk on its way.

## FUNDRAISERS

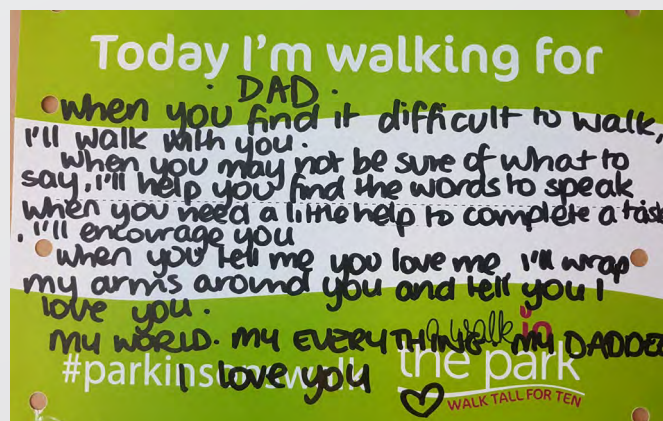
We particularly extend our appreciation to the 730 committed fundraisers who contributed to the fundraising efforts, including the 59 people who raised more than \$1000 to achieve special \$1K Club status.

Every cent counts, but we would like to acknowledge the top five individual fundraisers in 2018:

• Kim Goodridge	\$20,042
• Debbie Sheldon-Collins	\$8221
• Angela Di Paola	\$8110
• Peter Raymond	\$7098
• Maria Ibrido Lucca	\$6624

We also acknowledge the following individuals for their support organising and hosting the nine successful regional A Walk in the Park events.

• Bendigo	Glenis Gordon
• Frankston	Karen Beggs
• Geelong	Kirsten George
• Horsham	John McRoberts
• Mildura	Cheryl Barnes
• Timboon	Pam Robb
• Warrnambool	Andrew Suggett
• Wodonga	Alys Cummings
• Yarrawonga	Judy Ramsdale





4648

participants in Melbourne and nine regional walks

106

volunteers donated their time

\$329K

in donations raised to support people with Parkinson's and their families

98%

of people said they would return or might walk in 2019

4.3m

people reached through media coverage

"The feel of community on the day is brilliant and I always find finishing the walk an emotional experience"

2018 AWITP participant

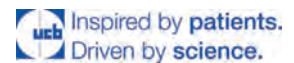


# Corporate Partnerships

The generosity and commitment of our corporate and community partners are vital to the successful delivery of our comprehensive support programs for people living with Parkinson's and professional education events.

We thank the following companies and organisations for their support in 2018-19:

## Corporate partners



## In-kind support

- Activate Strategy Group
- Advantage Advisors
- Maurice Blackburn
- MLC

## Community partners

- Alfred Health
- Brainlink
- Calvary Health Care Bethlehem
- Epilepsy Foundation
- Florey Institute of Neuroscience & Mental Health
- Goulburn Valley Health
- Monash Health
- Monash University
- La Trobe University
- Shake It Up Foundation
- University of Melbourne

## Information Line

- Victorian State Government



# Financial Report

Parkinson's Victoria reported a surplus of \$286,615 for the financial year 2018-19, due to higher than expected bequest revenue and better investment returns. Research expenditure was significantly down, as Parkinson's Victoria reviewed its research agenda in response to significant change in the national research policy and funding landscape in Australia.

The financial performance this year reflected an overall increase in net revenue of \$251,054 as compared to the previous year, attributing from an increase in total bequests and grants received by \$134k. Our Investment Strategy continued to perform, and achieved a growth of 16% resulting in \$26k increase in the investment income. The organisational review of the research agenda resulted in a reduction of \$339k in the funding expenditure and a corresponding decrease in the major gifts tied to research. A renewed research agenda and program will be relaunched in 2020 with investment expected to grow.

This year marked the celebration of the 10th Anniversary of Parkinson's "A Walk In The Park". The event also surpassed expectations and contributed significantly to the increase in the operating revenue for the year.

Year two of the Strategic Plan 2017-2020 saw the commencement of our business systems' review project with the development of new systems to be implemented in the upcoming year.

Our net assets remain at a healthy position of \$3.65 million. Research funds remained strong at \$673,994 with plan to increase the investment in research next year.

Budget for 2019-20 forecasts a deficit of \$81K, as we continue to invest in the growth of our programs and support for the Parkinson's community.



**Jason Karametos**  
Chair Finance and Investment Committee



Lyn, Cynthia, Cheryl and Lois from Mildura PSG.



Guest speaker, neurologist Richard Blazé.



Parkinson's Victoria Chair Prof. David Finkelstein speaking at the AGM.



# Auditor's Report



Chartered Accountants & Advisors

Walker Wayland Advantage Audit Partnership

Audit & Assurance Services

Level 7, 114 William Street  
Melbourne VIC 3000  
Australia

ABN 47 075 804 075

T +61 3 9274 0600

F +61 3 9274 0660

audit@wwadvantage.com.au

wwadvantage.com.au

## 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 2019, 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 2019 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 of 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.



Independent Member of

**BKR**  
INTERNATIONAL

Liability limited by a scheme approved  
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'.

**WALKER WAYLAND ADVANTAGE AUDIT PARTNERSHIP  
CHARTERED ACCOUNTANTS**

A handwritten signature in blue ink that reads 'Ben Bester'.

**BEN BESTER  
PARTNER**

Dated in Melbourne on this 25 day of October 2019

# Financials

<b>STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME FOR THE YEAR ENDED 30 JUNE 2019</b>	<b>2019</b>	<b>2018</b>
	<b>\$</b>	<b>\$</b>
Revenue	1,754,590	1,566,332
Research Revenue	120,503	235,488
Victorian Dept of Human Services Grant	275,095	263,786
Employee Benefits expense	(1,062,346)	(942,277)
Depreciation amortisation expenses	(15,844)	(16,620)
Operating Lease expense	(53,478)	(51,920)
Finance costs	(18,517)	(14,004)
Research expenses	(24,000)	(362,834)
Other expenses from ordinary activities	(689,390)	(642,391)
<b>Current year surplus/(deficit) before income tax</b>	<b>286,615</b>	<b>35,560</b>
Income tax expense	-	-
<b>Net current year surplus/(deficit)</b>	<b>286,615</b>	<b>35,560</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>Total comprehensive income for the year</b>	<b>286,615</b>	<b>35,560</b>
Total comprehensive income attributable to members of the entity	<b>286,615</b>	<b>35,560</b>
<b>STATEMENT OF CASH FLOW FOR THE YEAR ENDED 30 JUNE 2019</b>	<b>2019</b>	<b>2018</b>
	<b>\$</b>	<b>\$</b>
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>		
Receipts from donations and bequests	1,626,936	1,502,964
Government grant	275,095	263,786
Payments to suppliers and employees	(1,821,990)	(1,997,833)
Interest received	10,997	13,484
Net cash (used in)/generated from operating activities	91,038	(217,599)
<b>CASH FLOWS FROM INVESTING ACTIVITIES</b>		
Purchase for plant and equipment	(28,313)	(18,603)
Investment in Financial Assets	(131,062)	(152,412)
Income from Investments	168,182	145,215
Management fees for Investments	(15,110)	(11,871)
<b>Net cash used in investing activities</b>	<b>(6,303)</b>	<b>(37,671)</b>
<b>CASH FLOWS FROM FINANCING ACTIVITIES</b>		
Finance Costs	-	-
Net cash (used in)/generated from Financing activities	-	-
Net decrease in cash held	84,735	(255,270)
Cash on hand at the beginning of the financial year	735,358	990,628
Cash on hand at the end of the financial year	820,093	735,358



<b>STATEMENT OF FINANCIAL POSITION AS AT 30 JUNE 2019</b>	<b>2019 \$</b>	<b>2018 \$</b>
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash and cash equivalents	820,093	735,358
Accounts receivable and other debtors	41,681	89,691
Inventories	473	3,118
Other current assets	110,452	96,515
<b>TOTAL CURRENT ASSETS</b>	<b>972,699</b>	<b>924,682</b>
<b>NON-CURRENT ASSETS</b>		
Plant and equipment	61,666	49,196
Financial Assets at fair value through Profit or Loss account	2,899,929	2,708,905
<b>TOTAL NON-CURRENT ASSETS</b>	<b>2,961,595</b>	<b>2,758,101</b>
<b>TOTAL ASSETS</b>	<b>3,934,294</b>	<b>3,682,783</b>
<b>LIABILITIES</b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable and other payables	131,140	120,876
Provisions for Employee Benefits	93,542	83,221
Revenue received in advance	43,597	100,635
<b>TOTAL CURRENT LIABILITIES</b>	<b>268,279</b>	<b>304,732</b>
<b>NON-CURRENT LIABILITIES</b>		
Provisions for Employee Benefits	18,790	17,441
<b>TOTAL NON-CURRENT LIABILITIES</b>	<b>18,790</b>	<b>17,441</b>
<b>TOTAL LIABILITIES</b>	<b>287,069</b>	<b>322,173</b>
<b>NET ASSETS</b>	<b>3,647,225</b>	<b>3,360,610</b>
<b>MEMBERS' FUNDS</b>		
Members' funds	2,973,231	2,812,974
Research Funds	673,994	547,636
<b>TOTAL MEMBERS' FUNDS</b>	<b>3,647,225</b>	<b>3,360,610</b>

<b>STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDED 30 JUNE 2019</b>	<b>Members' funds \$</b>	<b>Research funds \$</b>	<b>Retained surplus \$</b>
<b>Balance at 1 July 2017</b>	<b>2,685,640</b>	<b>639,410</b>	<b>3,325,050</b>
<b>Comprehensive income</b>			
Surplus/(deficit) for the year	127,334	(91,774)	35,560
Other comprehensive income for the year	-	-	-
<b>Total comprehensive income attributable to members of the entity</b>	<b>127,334</b>	<b>(91,774)</b>	<b>35,560</b>
<b>Balance at 30 June 2018</b>	<b>2,812,974</b>	<b>547,636</b>	<b>3,360,610</b>
<b>Comprehensive income</b>			
Surplus/(deficit) 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>

## HOW YOU CAN HELP

### Give

Your donations mean we can continue to offer vital information and support services to people impacted by Parkinson's and Atypical Parkinson's.

### Leave a gift in your Will

A gift in your Will is a valuable way of helping to 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

 [linkedin.com/company/parkinson's-victoria-inc/](https://www.linkedin.com/company/parkinson's-victoria-inc/)

 [facebook.com/parkinsonsvic](https://www.facebook.com/parkinsonsvic)

 [@parkyvic](https://www.instagram.com/parkyvic)



IN THIS TOGETHER  
**parkinson's**  
VICTORIA

ABN: 59 604 001 176

587 Canterbury Road  
Surrey Hills VIC 3127

T: (03) 8809 0400

E: [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au)

[parkinsonsvic.org.au](https://www.parkinsonsvic.org.au)