



# About Parkinson's Victoria

## OUR VISION

A world without Parkinson's. Help for today, hope for tomorrow.

## OUR MISSION

People living with Parkinson's have access to comprehensive, relevant and flexible services, encouraging independence and quality of life.

Funding for Parkinson's research supports improved quality of life outcomes for people with the condition, and the search for a cure.

## OUR VALUES

### Sensitive

We understand the needs and challenges of people living with Parkinson's and their families, and ensure services and support are sympathetic and responsive to their needs.

### Responsive

We provide timely, accessible and flexible services and support to people living with Parkinson's, their families, carers and health professionals.

### Innovative

We seek ways to improve outcomes for people living with Parkinson's and their families. We seek to promote a learning culture within our own organisation, the community and health sector to ensure advancements in research are reflected in new and original service methods and responses.

### Excellence

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

## ABOUT PARKINSON'S

Parkinson's is a chronic and progressive neurological condition. In Victoria alone, 27,000 people are living with Parkinson's, with more diagnosed every day.

Parkinson's symptoms result from the progressive degeneration of brain cells which produce a chemical called dopamine. The condition affects the nervous system and alters co-ordination and movement together with non-motor symptoms such as pain, cognitive change and problems with sleep. Parkinson's is not fatal or contagious, and there is no cure.

It affects people in different ways - no two people will have exactly the same symptoms or experience.

Atypical Parkinson's – sometimes known as Parkinson's Plus - are conditions that initially present like Parkinson's. The conditions include Progressive Supra-Nuclear Palsy (PSP), Cortico Basal Syndrome (CBS) and Multiple System Atrophy (MSA). These conditions have different causes, symptoms and rates of progression to Parkinson's.

## WHO WE ARE

Parkinson's Victoria raises awareness and funds for services and research to improve quality of life for people with Parkinson's and Atypical Parkinson's across the state.

Parkinson's Victoria was founded by four visionary women with Parkinson's in 1981. They provided information and support to others living with Parkinson's and their families. More than 35 years later, their vision continues to underpin everything we do.

Every day, our multi-disciplinary Health Team provides expert information, education and advice to people living with Parkinson's, their families and healthcare professionals. Our team also coordinates an extensive network of 65 Peer Support Groups across Victoria.

We are one of seven state-based associations working together across Australia to support more than 70,000 people living with Parkinson's nationwide. Collectively, we provide support and education, build community partnerships and capacity and increase awareness of Parkinson's within the community and government to encourage research to further our understanding of the condition.

Parkinson's Victoria is a not-for-profit organisation funded in part by the State Government of Victoria. We rely heavily on the generous donations from our community to grow and deliver our support services.

**27,000**

Victorians with Parkinson's

**3,780**

Community members used our Information Service

**3,708**

A Walk in the Park participants

**2,712**

Support Group attendees

**2,323**

Professional and community education participants

## 2015-16 AT A GLANCE

With a focus on granting access to people living with Parkinson's that encourages independence and quality of life – we continue to educate, build partnerships and invest in research. In 2015 – 2016, Parkinson's Victoria:

- INVESTED IN RESEARCH - partnered to award \$340,000 in fellowships and scholarships
- PARTNERED FOR THE FUTURE - formalised an agreement with Shake It Up Foundation
- STRENGTHENED OUR PROGRAM – expanded our multi-disciplinary Health Team that helped 21% more people living with Parkinson's
- SHONE A LIGHT ON ATYPICAL PARKINSON'S – over 170 participants from Australia and New Zealand joined our Managing Atypical Parkinson's symposium



# Chairman & CEO Report



**In 2015-16, due to greater community awareness and participation, Parkinson's Victoria partnered to deliver over \$502,000 in research.**

This year, we invested more money into research than ever before. In 2015-16, our total revenue was \$1.75 million, an increase of \$311,500 on 2014-15.

Our multi-disciplinary Health Information Service responded to 3,780 requests. There was a greater depth of service with the expansion of our Health Team to include a Physiotherapist and Social Worker, delivering excellence to clients, members, health professionals and the wider Parkinson's community.

Working collaboratively through partnerships with health services and specialists, our education program delivered comprehensive and relevant information to the community. In September 2015, we held our Innovation in Parkinson's seminar and National Young Onset Parkinson's conference and throughout the year continued meeting and educating those recently diagnosed. These targeted programs supported community engagement at critical points in their Parkinson's journey.

At our annual research forum - InSearch 2016 - we proudly announced the four recipients of our inaugural Fellowship and Scholarship program and jointly funded over \$340,000 in research with La Trobe University, The University of Melbourne, Murdoch Children's Research Institute and Alfred Health. We also announced a three-year commitment with Shake It Up Foundation, Michael

J Fox Foundation and La Trobe University to further research into a world-first blood test for Parkinson's.

In April 2016, we released our findings on the Prevalence of Parkinson's in Victoria: Research Report in collaboration with Monash University and the Florey Institute of Neuroscience & Mental Health. The findings contributed to greater awareness of the prevalence of Parkinson's in Victoria and the need for further funding to explore a cluster of Parkinson's in North Western Victoria.

In August 2015, we held our seventh annual A Walk in the Park in six locations across Victoria. While registrations and funds raised were not as strong as anticipated, there was a palpable feeling of celebration and hope. All funds raised were invested to provide information, education and support services to improve the quality of life for people with Parkinson's across the state and advance the search for a cure.

We continued to provide support for people living with Atypical Parkinson's conditions, such as Progressive Supra-nuclear Palsy (PSP), Multiple System Atrophy (MSA) and Cortico Basal Syndrome (CBS) with Support Group meetings and a targeted symposium, Managing Atypical Parkinson's, in May 2016.

A special mention to Anne Mooney (recipient of the Sir Zelman Cowan Award) and our sincerest thanks to our members, donors, partners, Peer Support Groups and volunteers for their incredible support. Alongside our team of dedicated staff, we can continue to grow and adapt to the needs of the community.

**Assoc. Prof. David Finkelstein**  
Chair

**Emma Collin**  
Chief Executive Officer

## INCREASING ACCESS, BUILDING PARTNERSHIPS

Parkinson's Victoria moved to Surrey Hills in March 2016. The facility allows for increased access for the Parkinson's community including a training room for over 60 to support our education delivery and member's library.

The building is shared with other non-Government agencies and during 2015-16 delivered a reduction in overhead costs and extra administrative leverage from the sharing of resources.



# Parkinson's Victoria Board



**Assoc. Prof. David Finkelstein**  
Chair

Member of Governance & Research Committee,  
B.Sc., Grad. Dip. Scientific Instrumentation,  
M. Sc., Ph.D.

Appointed: May 2014



**Andrew Suggett OAM**  
Vice Chair

Chair of Governance & Research Committee,  
Dip. Acc., Cert. Retail Management

Appointed: November 2013



**Adam Conrad**  
Treasurer

Chair of Finance & Investment Committee,  
B. Comm., CPA

Appointed: November 2012



**Damian Farrell**

Member of Finance & Investment Committee,  
B.A., FAIM, MAICD

Appointed: November 2012



**Sue Harper**

Parkinson's Victoria's representative on  
Parkinson's Australia Board,  
B.A., Grad. Dip. Ontological Coaching

Appointed: November 2013



**Karyn Spilberg**

Chair of Engagement & Representation Working Group,  
B.Ed., Grad. Dip. Computer Education, Grad. Dip.  
English as a Second Language

Appointed: June 2014



**Shane Murphy**

Member of Engagement & Representation  
Working Group  
B. Applied Computing, Assoc. Dip. Electrical  
Engineering, Cert. Electrical Engineering

Appointed: November 2015



**Philip Thomas**

M. ComLaw, B.Bus., Grad. Dip. CSP., ASA,  
FCSA, FCIS, F.Fin, MAICD

Appointed: June 2016

## NEW ENGAGEMENT AND REPRESENTATION WORKING GROUP

Between February and May 2016, the working group met with 16 rural and metro Parkinson's Peer Support Groups to understand the priorities, concerns, opportunities and barriers to supporting the Parkinson's community. People living with Parkinson's shared a diverse range of concerns, including a lack of access to local neurological services and other health supports and the need for greater carer supports. Community feedback along with other research sources, support the evidence base for education program development, systemic policy change and the development of our research agenda.

This new group meets for three hours bi-monthly and is comprised of two Board Members, a volunteer committee representative, the CEO and one team member. The group's role is to develop and implement engagement strategies, conduct community engagement activities and report outcomes to the Parkinson's Victoria community and Board.

**"In 2015-16, Parkinson's Victoria further enhanced their client focus by creating the Engagement and Representation Working Group. The charter of the working group is to ensure that the voice of our community shapes the agenda, activities and communication with all Parkinson's Victoria stakeholders."**

Dylan Hardy  
Volunteer Committee Representative



# Tailored Health Information Service

Our Health Information Service provides tailored support to help people living with Parkinson's and health professionals better understand the clinical side of Parkinson's (symptoms, treatment, management etc.), navigate the health system and access our referral pathway for local and other community support services.

Through tailored support we can engage, educate and empower both health professionals and people living with Parkinson's (including their families and carers) to take the lead on diagnosis and treatment, enhancing independence and quality of life for those living with the condition.

## Parkinson's Victoria Health Information Service

### What's the service?

Who can access?	Health Information Line 1800 644 189	Secondary Consultation	Education Seminars	Peer Support Groups	Research	Raising Community Awareness
People living with Parkinson's, carers and family	✓	✓	✓	✓ Over 65 Peer Support Groups in Victoria	✓	✓
Professionals incl. practitioners, clinicians, therapists, specialists	✓	✓ Inter-professional consultancy	✓		✓	✓
Parkinson's Victoria affiliates	✓		✓ e.g. Nurse Education, Aged Care training		✓	✓ e.g. A Walk in the Park, Parkinson's Australia network, Ambassador Program
	Telephone and email Information Service with access to a Clinical Nurse, Speech Pathologist, Physiotherapist and Social Worker		e.g. Recently Diagnosed, Living Well, Young Onset, Managing Atypical Parkinson's seminars		e.g. InSearch 2016, community partner collaborations in research, participant recruitment and presenting outcomes	

### Outcomes

Support, professional development, capacity building and improved self-management



# Expert Health Education

In 2015-16, our team of multi-disciplinary health specialists delivered comprehensive, relevant and flexible education sessions to 2,323 people, encouraging independence and quality of life.

## NATIONAL YOUNG ONSET PARKINSON'S CONFERENCE

SEPTEMBER 2015

20% of people diagnosed with Parkinson's are under the age of 60. This two-day conference provided almost 100 people with Young Onset Parkinson's and their partners information on the latest treatments, research, support and practical solutions to continue vocational and lifestyle choices. It included a special networking dinner featuring an address on the latest technological developments useful for those with Parkinson's by neurologist Dr Katya Kotschet.

Assoc. Prof. David Williams, Dr Sanjay Raghav, National Disability Insurance Agency, Disability Employment Australia and Maurice Blackburn presented to participants practical advice for managing emotional changes, managing symptoms, treatment options, relationships, diet and nutrition. Attendees were encouraged to try singing, dancing and personal training. This multi-faceted model of education enabled attendees to receive comprehensive information encouraging them to try new, easily accessible activities that can improve quality of life.

## INNOVATION IN PARKINSON'S SEMINAR

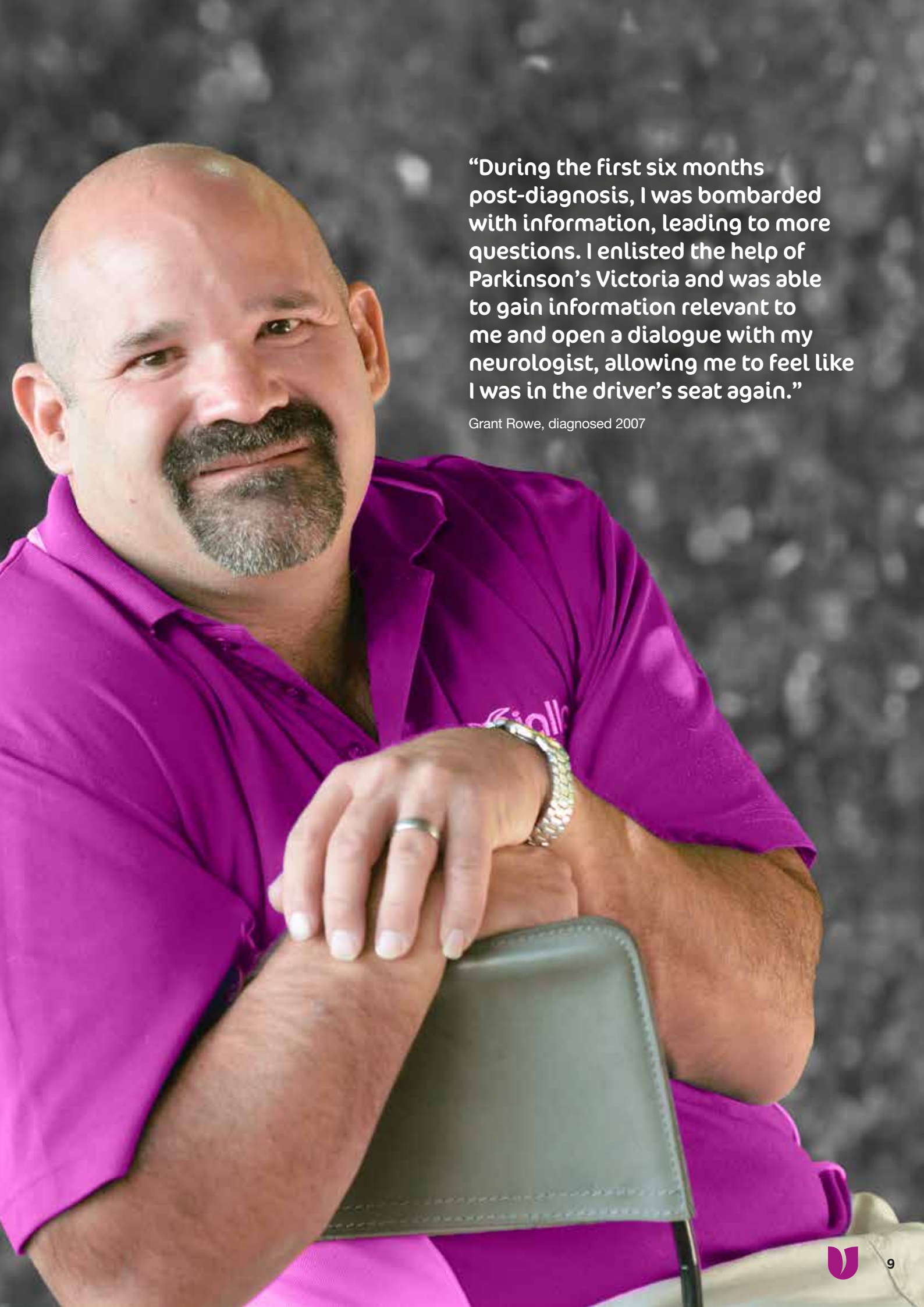
SEPTEMBER 2015

More than 20 presenters including Dr Wesley Thevathasan and Prof. Meg Morris donated their time to this health professional seminar focussed on the latest Parkinson's research, new therapies and best practice in Parkinson's. A multi-disciplinary approach was discussed in the morning and participants spent the afternoon divided between four discipline-specific streams: speech pathology, nursing care, physiotherapy & occupational therapy and social work & psychology.

Innovation in Parkinson's was designed to expand the knowledge and skills of over 130 healthcare professionals, enabling them to deliver the most contemporary care.







**“During the first six months post-diagnosis, I was bombarded with information, leading to more questions. I enlisted the help of Parkinson’s Victoria and was able to gain information relevant to me and open a dialogue with my neurologist, allowing me to feel like I was in the driver’s seat again.”**

Grant Rowe, diagnosed 2007

# Expert Health Education

## MANAGING ATYPICAL PARKINSON'S SYMPOSIUM

MAY 2016

The Managing Atypical Parkinson's symposium for 125 healthcare professionals provided insights and practical strategies to enhance clinical practice. It was an engaging forum for discussing challenges amongst peers and specialist clinicians and allowed attendees to facilitate networking opportunities.

The symposium included a dedicated stream for 41 people living with Atypical Parkinson's, their families and carers, and focused on improving the understanding of Atypical conditions, providing practical strategies for managing symptoms and fostering the sharing of personal experiences.

## HEALTH PROFESSIONAL EDUCATION COLLABORATIONS

Parkinson's Victoria has continued to lead delivery of Parkinson's and Atypical Parkinson's healthcare professional education across Victoria, including:

- Collaborations with the Multiple Sclerosis Society of Australia, Peninsula Health, Bendigo Health and La Trobe University to deliver Parkinson's specific content into their education initiatives and teams
- Collaboration with Goulburn Valley Health to deliver a regional study day for health professionals and people living with Parkinson's
- Coordination and delivery of Parkinson's training to care managers and senior nursing personnel nationally for Regis Aged Care
- Active partnerships with a range of industry partners to deliver education to general practitioners, with educational dinners occurring in Mildura, Wodonga, Shepparton and Tasmania.

## NATIONAL AGED CARE EDUCATION DELIVERY

Parkinson's Victoria supported the development and delivery of the National Aged Care Education presentation, as a result of a Department of Health Australia grant.

Delivered to over 1,500 aged care workers across Victoria, the presentation focused specifically on the learning needs of aged care workers with the key aim of improving care for people who reside in aged care facilities.

Parkinson's Victoria delivered sessions in metropolitan and regional Victoria.

## RECENTLY DIAGNOSED SEMINARS

2015, 2016

In this reporting period and supported by the Pierce Armstrong Foundation, Parkinson's Victoria was able to expand our Recently Diagnosed seminars to regional centres including Shepparton, Wodonga, Lakes Entrance and Geelong, as well as a metropolitan seminar.

These seminars reached over 200 newly diagnosed people and their families.

For over 20 years, these meetings have provided information and hope to people who have received a recent Parkinson's diagnosis and their families. These seminars provide access to valuable information about diagnosis, medications, treatments, well-being and Parkinson's Victoria's services including support, secondary consultation and referrals to other service providers.

## NATIONAL NURSE EDUCATION MEETINGS

2015, 2016

In collaboration with Parkinson's Western Australia and supported by UCB, Parkinson's Victoria developed and presented at the National Parkinson's Nurse Meetings held in 2015 and 2016. These meetings focused on the specific needs of nurses who work primarily with people living with Parkinson's and other movement disorders. This is a highly specialised area of nursing and there are less than 50 movement disorder nurses (MDN) nationally.

# Supporting the Parkinson's Community

Parkinson's is individual in its symptoms and progression, but the journey towards a world without Parkinson's is one we take together.

In 2015-16, approximately 764 peer support and special interest meetings by 65 groups were held across Victoria. Parkinson's Victoria provided leadership support, printed materials, tailored education content and presentations, assistance in the coordination of meetings, recruitment of new members and development of new ideas.

## PEER SUPPORT GROUPS

Attended by over 2,700 people living with Parkinson's during 2015-16, our Peer Support Groups provided a source of information, social connection, hope and support for people living with Parkinson's.

As agreed with individual Support Groups, a set number of meetings were attended by a Parkinson's Victoria Health Team specialist who presented an education module of the Support Group's choosing, ensuring a further value-add that was relevant and comprehensive for each group.

The Safely Mobile education module, funded by the RACV Foundation, continued to be delivered across the state to educate the community about driving with Parkinson's and mobility options.

Other Support Group topics include well-being, research and treatments, movement and exercise, communication and navigating the legal/healthcare systems.

180

visits by  
Parkinson's  
Victoria

65

groups across  
Victoria

764

support  
meetings held

### "HEALTH TEAM IS OUR SECURITY BLANKET"

Even though her husband Jonathan passed away three and a half years ago, Elaine Maberly continues to lead the Ballarat Parkinson's Peer Support Group and encourages members to actively manage their symptoms and to contact Parkinson's Victoria's multi-disciplinary Health Team for support and advice:

"It's our security blanket," says Elaine, "I make sure everyone has the number".



# Supporting the Parkinson's Community

## PEER X-CHANGE

Peer x-change commenced during 2015-16, so that via conversation and Parkinson's Victoria's quarterly member magazine *InMotion*, Peer Support Groups can inspire each other with ideas, speakers and topics for their meetings.

In 2015-16, original and inspiring initiatives included:

- Local dietetic students presented on healthy eating (Benalla)
- "Living alone safely" talk presented by the Bellarine Police Community Support Register (Ocean Grove)
- Tai Chi trial and podiatry/occupational therapist talk (Lakes Entrance)
- Early evening meeting trial (La Trobe Valley)
- Lunch in honour of partners and carers (Warragul)



## TAILORED INFORMATION AND ADVICE

Partly funded by the Victorian Government, Parkinson's Victoria's Freecall Information Service continued to provide tailored information and advice to respond to the needs of people living with Parkinson's.

A best-practice model recognised by the International Movement Disorder Society, our multi-disciplinary Health Team provides specialised information and support to help people living with Parkinson's better manage their symptoms.

This year, 3,780 people (including health professionals, those with the condition, their families and carers) confidentially reached a:

- Clinical Nurse who provided information on managing Parkinson's symptoms, as well as medications and treatments
- Speech Pathologist who helped with communication-related symptoms such as speech, facial expressions and swallowing
- Physiotherapist who assisted with symptoms that affect movement including walking, freezing and falls
- Social Worker who provided support for emotional changes such as anxiety and depression, stress and apathy.


## PARKINSONSONG

Singing can be both physically and emotionally invigorating, especially when it's experienced with others who share the same motivation and enthusiasm.

70-90% of people experience communication changes with Parkinson's – so Parkinson's Victoria encourages its community members to attend a local monthly session where participants can find their voice in a group setting, and attend without singing experience in a safe environment facilitated by music therapists and speech pathologists.

During 2015-16, our ParkinSong groups continued to grow with five new groups created in this reporting period.

In 2016, Parkinson's Victoria partnered on a research project called "Staying in Tune with Parkinson's Communication: Investigating the effects of long-term participation in ParkinSong singing groups for people with Parkinson's disease and their caregivers" with the University of Melbourne Conservatorium of Music and National Music Therapy Unit led by researcher Dr Jeanette Tamplin. Other major contributors include the University of Melbourne Speech Pathology, La Trobe University and Monash Health. The 12 month study attracted 116 participants.

A middle-aged man with short, light brown hair is smiling slightly. He is wearing a light blue polo shirt with dark horizontal stripes. He is using a black walker. The background is a blurred outdoor setting with trees and foliage. The lighting is bright, suggesting a sunny day.

**“I wanted to find my voice again. I wanted to sing and learn new songs. I also wanted to go to an activity where I could help my speech and enjoy other people’s company.”**

John Strugnell, diagnosed 1994

Supported by a significant grant from the Hugh Williamson Foundation, the development of ParkinSong has begun.



# In our Community

In 2015-16, individual donors, community fundraisers and corporate partners contributed more than \$1,028,000 to Parkinson's Victoria.

The combined efforts and commitment of our generous donors, regular givers, trusts and foundations, and corporate partners, enabled Parkinson's Victoria to make important strides towards our vision of a world without Parkinson's.

## APPEALS

Each year, Parkinson's Victoria conducts a Tax and Christmas Appeal heroing members of our community. By sharing their story and the important role Parkinson's Victoria plays in their life, donors confidently continue to support delivery of our essential Health Education Services:

- \$45 helps three people to access professional advice via phone
- \$75 provides a Peer Support Group with two annual visits from our Health Team
- \$150 supports a person living with Parkinson's to attend an education seminar

Raising almost \$100,000 thanks to the kindness of over 900 donors, these appeals supported our growing number of calls, emails, face-to-face contacts and tailored community education sessions.

## CHRISTMAS CATALOGUE

Parkinson's Victoria supporters demonstrated their support by 'giving a gift that matters' via our Christmas fundraiser. Through the sale of linen tea towels, books, calendars and Christmas cards, more than \$18,000 was raised to support people living with Parkinson's.

## MAJOR DONORS & BEQUESTS

Many generous individuals make invaluable contributions to enable Parkinson's Victoria to deliver support services to the Parkinson's community. We greatly appreciate contributions made by the following individuals, families, trusts and foundations.

### Bequests

- Estate of the Late Mr Peter John Craig
- Estate of the Late Mr Keith Williams
- Estate of the Late Joe White

### Businesses

- Hickory Group Pty. Ltd.
- Bensons Property Group
- Dellermay Pty. Ltd.
- Segue Financial Services Pty. Ltd.

### Individuals

- Mr & Mrs Chris & Trish Reardon
- Vale Mr Hermann Schulz
- Ms Olivia Romano
- Mr & Mrs Graeme & Barbara Love, with Mr Ian Cuttler
- Anonymous (3)

### Major donors

- Quill Club Inc.
- Fox Classic Car Collection
- Hoppers Crossing Sports Club
- Corryong Sporting Complex Inc.
- Montmorency Bowling Club

### Trusts & Foundations

- G & I Meagher Charitable Trust
- Hugh Williamson Foundation
- O'Sullivan Family Gifts-Australian Philanthropic Services Foundation
- Epsilon Research Fund
- The Barbara Luree Parker Foundation Ltd
- Scanlon Foundation



## SIR ZELMAN COWAN AWARD

Each year, Parkinson's Victoria presents the Sir Zelman Cowan Award to an individual in recognition of their invaluable contribution to Parkinson's Victoria and people living with Parkinson's.

Anne Mooney was our 2015 recipient. At 68, Anne's husband Daryl was diagnosed with PSP. As well as providing care for her husband, Anne took on the role of convenor of a Peer Support Group for people living with Atypical Parkinson's and family members in 2008. Six and a half years after Daryl's passing, Anne remains the convenor of PSP Australia.

Anne has worked tirelessly to ensure people with Atypical Parkinson's have access to information and support, and has advocated for the creation of Atypical Parkinson's information kits, which are distributed nationally.

Working closely with Parkinson's Victoria and the Rotary Club of Huntingdale, last year Anne helped raise awareness and funds for Atypical Parkinson's, raising more than \$60,000 for PSP research.



# In our community

## FUNDRAISING

Incredibly inspiring and meaningful, spanning across dinners, fun runs, sausage sizzles and hours of volunteering, the Victorian Parkinson's community helped raise funds to improve the lives of people with Parkinson's and to bring the journey closer to a cure.

We recognised the incredible energy, determination and voluntary efforts of our community fundraisers and thank them for their generous support.

Almost  
**60**  
events

Over  
**\$135K**

raised via the  
community

Almost  
**\$12,000**  
raised in  
celebration

### ROTARY CLUBS FUNDRAISING DINNER FOR PARKINSON'S

In July 2015, the Rotary Clubs of Huntingdale and Clayton hosted a fundraising dinner to increase the awareness of Atypical Parkinson's conditions. They raised \$45,000 of their aimed \$60,000 towards a Research Fellowship to investigate Atypical Parkinson's.

Guests heard from esteemed Parkinson's neurologists, Assoc. Prof. David Williams and Dr Kelly Bertram who drew on their extensive experience working with people with Atypical Parkinson's. They gave the audience insights into these debilitating conditions and why future research is so critical. Cheryl Jones shared her story as a carer.

Bree Wolany, whose father was diagnosed with PSP last year, raised a further \$25,000 for Parkinson's Victoria to contribute towards the Fellowship.



### QUILL CLUB LUNCHEON

In August 2015, 380 guests attended the Quill Club 9th Annual Charity Luncheon. Master of ceremonies Joe Dolce was incredibly engaging and patrons were eager to win the donated raffle items. Judy Phelan – a long time fundraiser and supporter of Parkinson's Victoria – shared her inspiring experiences of living with Parkinson's. A generous \$28,000 was raised to support people living with Parkinson's.



**“This year brought together the Rotary Clubs of Huntingdale and Clayton, Parkinson's Victoria and our Support Group to raise funds for our aim to find a cure for PSP,” says Anne. “Due to some amazing fundraising, we secured a fellowship to study the conditions and we are on our way with world research to find a cause, medication that works, and hopefully a cure.”**



# A Walk in the Park 2015

A Walk in the Park is Australia's largest community event dedicated to improving the lives of people with Parkinson's.

On Sunday 30 August 2015, Parkinson's Victoria held its seventh A Walk in the Park in Melbourne, and regionally in Bendigo, Mildura, Shepparton, Warrnambool and Wodonga.

Evaluation of the event demonstrated:

- 52% of participants knew about A Walk in the Park from previous years
- 32% joined after receiving information from Parkinson's Victoria
- 36% walked in support of a friend or family member with Parkinson's
- 18% of registered walkers honoured the memory of someone with Parkinson's
- 21% of participants had Parkinson's.

With almost \$210,000 raised, including \$4,500 from Bendigo at its inaugural walk, Parkinson's Victoria is committed to investing these funds by providing information, education and support services to improve the quality of life for people with Parkinson's across the state, and to advance the search for a cure.

We would like to sincerely thank our ambassadors who donated their stories and time to the 2015 campaign and in turn supported media growth and community engagement: Ben Zipper, Clare Gleeson-Maguire, Geoff Constable, Grainne Murphy, Jenny Hanson, Mike Atkinson and Shane Murphy.

Parkinson's Victoria was proud to partner with the following corporations for A Walk in the Park 2015: Global Kinetics Corporation, St John of God Frankston Rehabilitation Hospital, Abbvie, City of Melbourne, Federation Square, Lundbeck, Medtronic and UCB.

Over **770** participants in five regional walks across Victoria

Almost **3,000** participants in Melbourne

Almost **\$210K** in donations raised to support people with Parkinson's

**4.9m** people reached through media coverage

Over **130** engaged volunteers donated their time



# Investing in research

Parkinson's Victoria is committed to supporting vital research that improves quality of life for people with the condition, and the search for a cure.

While significant advances have been made in understanding Parkinson's and developing better treatment options and therapies, Australian and international researchers continue to search for a cure.

## FELLOWSHIP SCHOLARSHIPS

At InSearch 2016, Parkinson's Victoria announced the four recipients of our inaugural Fellowship and Scholarship program, and funded \$340,000 in partnership with La Trobe University, The University of Melbourne, Murdoch Children's Research Institute and Alfred Health. The 2016 Fellowship and Scholarship Awardees were:

### The Argyrou Family Fellowship (\$70,000)

**Dr Joanne Wittwer, School of Allied Health, La Trobe University**

Undertaking research to improve gait in people living with Progressive Supranuclear Palsy (PSP) and Alzheimer's disease through exercise using music cues.

### The Community Fellowship (\$30,000)

**Dr Kelly Bertram, Alfred Hospital**

Investigating Neurophysiological parameters measured by Transcranial Magnetic Stimulation as diagnostic clues in Atypical Parkinson's.

### The Argyrou Family Scholarship (\$15,000)

**Ms Sonia Rao, The Florey Institute of Neuroscience & Mental Health**

PhD studies investigating the pathological interaction between iron and tau proteins in Progressive Supra-Nuclear Palsy (PSP).

### The Atypical Fellowship (\$55,000)

**Dr Sarah Stephenson, Neurogenetics Laboratory, Murdoch Children's Research Institute**

Identifying the genes underlying Alpha-synuclein and tau variability in Parkinsonian disorders.

## WORLD-FIRST DIAGNOSTIC BLOOD TEST

In April 2016, Parkinson's Victoria and Shake It Up Foundation announced a commitment to jointly fund Prof. Paul Fisher (La Trobe University) and his team to develop a world-first diagnostic blood test.

Parkinson's Victoria, Shake It Up Foundation, US based Michael J Fox Foundation for Parkinson's Research (MJFF) and La Trobe University have invested \$640,000 over three years to develop a diagnostic blood test for Parkinson's. Currently, no clinical biomarker test exists for Parkinson's and the only means of diagnosis is a neurological examination. By the time patients develop symptoms and undergo the exam, large numbers of vital brain cells have already been destroyed.

A blood test, which detects abnormal metabolism within blood cells, may become a definitive diagnostic tool. Early diagnoses will enable early intervention, limiting the number of brain cells destroyed. The test could be available to the public in as little as five years if sufficient additional funds can be raised for its rapid development.

## INSEARCH: WORLD PARKINSON'S DAY RESEARCH SYMPOSIUM AND PUBLIC LECTURE

To commemorate World Parkinson's Day on April 11th, Parkinson's Victoria in partnership with the Florey Institute of Neuroscience & Mental Health, presented the InSearch lecture series in metropolitan and regional Victoria with the aim to increase awareness of Parkinson's research, foster the research community's commitment to Parkinson's and promote the importance of Parkinson's research in Australia.

The Melbourne public lecture - held at The Grand Hyatt - was attended by almost 390 people including fellowship and scholarship awardees, sponsors, Parkinson's Victoria members and their guests.

### InSearch 2016 presenters included:

- Professor Ashley Bush, Head of the Oxidation Biology Unit at the Florey Institute of Neuroscience & Mental Health and Chief Scientific Officer of the Cooperative Research Centre for Mental Health
- Dr George Mellick, an interdisciplinary scientist working on all aspects of neurodegenerative disease with an emphasis on Parkinson's and related disorders
- Associate Professor David Finkelstein, Head of Parkinson's Disease Laboratory at the Florey Institute of Neuroscience & Mental Health
- Dr Wesley Thevathasan, a Melbourne based neurologist who helped to develop a new form of deep brain stimulation for Parkinson's and has managed this innovative therapy on hundreds of patients.

In conjunction with the InSearch lecture series, this year's scientific symposium was attended by 120 like-minded researchers and clinicians with a focus on sharing information, current research and networking.

InSearch 2016 was made possible by the generous support of our sponsors: Medtronic, STADA, UCB, TEVA, The Grand Hyatt (in kind support) and MLC Insurance who volunteered to support registration and arrival of guests.

**MELBOURNE**

**APRIL 11 2016**

Scientific symposium for

**120**

researchers/  
clinicians

**MELBOURNE**

**APRIL 11 2016**

Public lecture for

**386**

people with an  
interest in  
Parkinson's  
research

**SHEPPARTON**

**APRIL 12 2016**

Public  
lecture for

**60**

people

**WARRAGUL**

**APRIL 12 2016**

Public  
lecture for

**40**

people



# Investing in research

## GOULBURN VALLEY HEALTH AND PARKINSON'S VICTORIA NURSE PROJECT - EVALUATION

The Movement Disorder Nurse project was funded by Parkinson's Victoria, Goulburn Valley Health and the Shepparton Parkinson's Peer Support Group to evaluate the benefits of establishing a Movement Disorder Nurse to support people living with Parkinson's and other movement disorders in the Goulburn Valley community.

More than 200 people living with Parkinson's and other movement disorders received services from the Movement Disorder Nurse during the two year project and its evaluation found that these visits improved the confidence of people living with Parkinson's and carers to manage their symptoms and medications. The project also helped to reduce travel to metropolitan areas and reliance on specialist visits.

76% of patients surveyed reported that their quality of life was maintained or improved as a result of Movement Disorder Nurse support.

The key to the success of the Movement Disorder Nurse model has been its multi-disciplinary and collaborative approach with health partners. The Movement Disorder Nurse role increased knowledge of 150 local healthcare providers through 23 education sessions and improved clinical care through the introduction of advanced therapies at Goulburn Valley Health.

**“It was not only the cost of the specialist, but travel and the need to take the day off work to go to Melbourne. In between specialist visits, the Movement Disorder Nurse gives you guidance and information about the services, exercises, and supplements to manage the incidentals. The Movement Disorder Nurse is the valuable link that keeps it all together, and keeps you on track.”**

Paul, diagnosed 1998

## RESEARCH REPORT SHEDS NEW LIGHT ON POSSIBLE CAUSES OF PARKINSON'S

To coincide with World Parkinson's Day, Parkinson's Victoria released the key findings of a joint Monash University and Florey Institute of Neuroscience & Mental Health report uncovering the prevalence of Parkinson's in Victoria.

In the survey of the state of Victoria, the researchers identified that four neighbouring local government areas in North Western Victoria are exceptions to the rule that Parkinson's prevalence does not differ between urban and rural locations.

The report – focusing on one possible cause – suggested that research exploring the potential link between the use of pesticides in the farming of pulses and an increased risk of Parkinson's is needed.

## BRAIN BANK AND REGISTRY

Parkinson's Victoria continued to provide ongoing financial and in kind support to the Brain Bank and Registry. The Brain Bank provides researchers with tissue samples providing valuable insights into the pathogenesis of Parkinson's and Atypical Parkinson's contributing significantly to numerous research projects.

Sixty-four new brain donations were processed between August 2015 and July 2016, with twelve neuropathologically confirmed as Parkinson's or Atypical Parkinson's. Six Australian and international research projects were also granted access to 193 Parkinson's, Atypical Parkinson's and normal control tissues to enable further understanding of these conditions.

Supporting the Brain Bank not only aids in research for a cure but we hope, through new initiatives and findings, will provide improved quality of life outcomes for people with the condition.

# Treasurer's Report

2015-16 has been another successful year, delivering a deficit of \$18,342. This result exceeded budget expectations, with a 22% increase in our total revenue offset by a 4% growth in expenditure.

This year our commitment to research was met with a strong response from the community, with research revenue growing by 267% to \$218,103. In addition, a bequest of a \$250k contributed to our strong revenue result. A Walk in the Park revenue was down from the previous year, however community fundraising events contributed over \$135,000 to our programs.

Operating expenses were down \$46,420, this included our relocation to Surrey Hills and a 21% growth in our health information and education program reach. Careful management of staff costs and targeted program efficiencies supported this positive outcome. Our planned research investment, which was up 88% to \$240,497, delivered projects in partnership to the value of \$502,054 and was the main area of expense increase.

Our financial position remained strong with net assets of \$2.7 million. Research funds remained at a healthy \$484,565 with a plan to maintain the same level of investment in research next year.

The implementation of the investment policy commenced and will be finalised in 2016-17. The budget for next year predicts a surplus of \$355,000, anticipating the receipt of a bequest of \$540,000 in the second half of 2016/17.



# Auditor's Report



Advantage Advisors Audit Partnership  
Audit & Assurance Services  
Level 7, 114 William Street  
Melbourne VIC 3000  
Australia  
GPO Box 2266  
Melbourne VIC 3001  
Australia  
ABN 47 075 804 075  
T +61 3 9274 0600  
F +61 3 9274 0660  
audit@advantageadvisors.com.au  
advantageadvisors.com.au

## AUDITOR'S INDEPENDENCE DECLARATION TO THE DIRECTORS OF PARKINSON'S VICTORIA LIMITED

In accordance with the requirements of section 60-40 of the Australian Charities and Not for Profits Commission Act 2012, as auditor for the audit of Parkinson's Victoria Limited for the year ended 30 June 2016, I declare that, to the best of my knowledge and belief, there have been:

- a) no contraventions of the auditor independence requirements as set out in the Australian Charities and Not for Profits Commission Act 2012 in relation to the audit; and
- b) no contraventions of any applicable code of professional conduct in relation to the audit.

*Advantage Advisors*

ADVANTAGE ADVISORS AUDIT PARTNERSHIP  
CHARTERED ACCOUNTANTS

*Ben Bester*

BEN BESTER  
PARTNER

Dated in Melbourne on this 27 day of October 2016



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under professional standards legislation.



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

Advantage Advisors Audit Partnership

Audit & Assurance Services

Level 7, 114 William Street  
Melbourne VIC 3000  
Australia

GPO Box 2266  
Melbourne VIC 3001  
Australia

ABN 47 075 804 075

T +61 3 9274 0600

F +61 3 9274 0660

[audit@advantageadvisors.com.au](mailto:audit@advantageadvisors.com.au)

[advantageadvisors.com.au](http://advantageadvisors.com.au)

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

We have audited the accompanying financial report of Parkinson's Victoria Limited, being a special purpose financial report, which comprises the statement of financial position as at 30 June 2016, and 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, notes comprising a summary of significant accounting policies and other explanatory information and the directors declaration.

### Directors' Responsibility for the Financial Report

The directors are responsible for the preparation and fair presentation of the financial report and have determined that the basis of preparation described in Note 1, is appropriate to meet the financial reporting requirements of the *Australian Charities and Not-for-profits Commission Act 2012 (ACNC Act)* and is appropriate to meet the needs of the members. The directors' responsibility also includes such internal control as the directors and management determines is necessary to enable the preparation and fair presentation of the financial report that is free from material misstatement, whether due to fraud or error.

### Auditor's Responsibility

Our responsibility is to express an opinion on the financial report based on our audit. We have conducted our audit in accordance with Australian Auditing Standards. Those standards require that we comply with relevant ethical requirements relating to audit engagements and plan and perform the audit to obtain reasonable assurance about whether the financial report is free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial report. The procedures selected depend on the auditor's judgement, including the assessment of the risks of material misstatement of the financial report, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial report 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 entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by management, as well as evaluating the overall presentation of the financial report.

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



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# Financials

<b>STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME FOR THE YEAR ENDED 30 JUNE 2016</b>	<b>2016 \$</b>	<b>2015 \$</b>	
Revenue	1,285,404	1,139,500	
Research Revenue	218,103	59,432	
Victorian Dept of Human Services Grant	241,640	234,713	
Employee Benefits expense	(910,383)	(903,243)	
Depreciation amortisation expenses	(16,300)	(20,818)	
Operating Lease expense	(81,012)	(79,334)	
Finance costs	(2,614)	(4,857)	
Research expenses	(240,497)	(127,752)	
Other expenses from ordinary activities	(512,683)	(561,358)	
<b>Current year surplus/(deficit) before income tax</b>	<b>(18,342)</b>	<b>(263,717)</b>	
Income tax expense	-	-	
<b>Net current year surplus/(deficit)</b>	<b>(18,342)</b>	<b>(263,717)</b>	
<b>OTHER COMPREHENSIVE INCOME</b>			
Items that will not be reclassified subsequently to profit or loss	-	-	
Items that will be reclassified subsequently to profit or loss when specific conditions are met	-	-	
<b>Total other comprehensive income for the year</b>	<b>-</b>	<b>-</b>	
<b>Total comprehensive income for the year</b>	<b>(18,342)</b>	<b>(263,717)</b>	
Total comprehensive income attributable to members of the entity	(18,342)	(263,717)	
<b>STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDED 30 JUNE 2016</b>	<b>Members' funds \$</b>	<b>Research funds \$</b>	<b>Retained surplus \$</b>
<b>Balance at 1 July 2014</b>	<b>2,399,036</b>	<b>575,280</b>	<b>2,974,316</b>
<b>COMPREHENSIVE INCOME</b>			
Surplus/(deficit) for the year	(195,397)	(68,320)	(263,717)
Other comprehensive income for the year	-	-	-
<b>Total comprehensive income attributable to members of the entity</b>	<b>(195,397)</b>	<b>(68,320)</b>	<b>(263,717)</b>
<b>Balance at 30 June 2015</b>	<b>2,203,639</b>	<b>506,960</b>	<b>2,710,599</b>
<b>COMPREHENSIVE INCOME</b>			
Surplus/(deficit) for the year	4,053	(22,395)	(18,342)
Other comprehensive income for the year	-	-	-
<b>Total comprehensive income attributable to members of the entity</b>	<b>4,053</b>	<b>(22,395)</b>	<b>(18,342)</b>
<b>Balance at 30 June 2016</b>	<b>2,207,692</b>	<b>484,565</b>	<b>2,692,257</b>



**STATEMENT OF FINANCIAL POSITION  
AS AT 30 JUNE 2016**

**2016      2015**  
**\$      \$**

**ASSETS**

**Current assets**

Cash and cash equivalents	2,870,351	2,793,891
Accounts receivable and other debtors	28,964	15,279
Inventories	6,550	8,016
Other current assets	52,016	71,285

**TOTAL CURRENT ASSETS      2,957,881      2,888,471**

**Non-current assets**

Plant and equipment	23,215	34,184
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**TOTAL NON-CURRENT ASSETS      23,215      34,184**

**TOTAL ASSETS      2,981,096      2,922,655**

**LIABILITIES**

**Current liabilities**

Accounts payable and other payables	134,995	106,601
Provisions for Employee Benefits	83,111	65,971
Revenue received in advance	63,109	30,351
<b>TOTAL CURRENT LIABILITIES</b>	<b>281,215</b>	<b>202,923</b>

**Non-current liabilities**

Provisions for Employee Benefits	7,624	9,133
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**TOTAL NON-CURRENT LIABILITIES      7,624      9,133**

**TOTAL LIABILITIES      288,839      212,056**

**NET ASSETS      2,692,257      2,710,599**

**MEMBERS' FUNDS**

Members' Funds	2,207,692	2,203,639
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Research Funds	484,565	506,960
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**TOTAL MEMBERS' FUNDS      2,692,257      2,710,599**

# Financials

<b>STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 30 JUNE 2016</b>	<b>2016 \$</b>	<b>2015 \$</b>
<b>CASH FLOWS FROM OPERATING ACTIVITIES</b>		
Receipts from donations and bequests	1,475,976	1,162,666
Grants	241,640	234,713
Payments to suppliers and employees	(1,701,296)	(1,737,263)
Interest received	65,470	94,941
Net cash (used in)/generated from operating activities	81,790	(244,943)
<b>CASH FLOWS FROM INVESTING ACTIVITIES</b>		
Payment for plant and equipment	(5,330)	(4,373)
Net cash (used in)/generated from investing activities	(5,330)	(4,373)
<b>CASH FLOWS FROM FINANCING ACTIVITIES</b>		
Finance Costs	-	-
Net cash (used in)/generated from financing activities	-	-
Net increase in cash held	76,460	(249,316)
Cash on hand at the beginning of the financial year	2,793,891	3,043,207
<b>Cash on hand at the end of the financial year</b>	<b>2,870,351</b>	<b>2,793,891</b>

# Increasing impact through partnership

It is the generosity and passionate commitment of our corporate and community partners that makes it possible for Parkinson's Victoria to support people living with Parkinson's.

From partnerships for our seminars to raising awareness of Parkinson's research in 2015-16, we were proud to partner with:

## In-kind support

- Maurice Blackburn
- MLC
- The Grand Hyatt

## Community partners

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

## Information Line

- Victoria State Government

## Corporate partners





For more information and support, contact Parkinson's Victoria:

587 Canterbury Road  
Surrey Hills VIC 3127

Freecall: 1800 644 189

T: (03) 8809 0400

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

[parkinsonsvic.org.au](http://parkinsonsvic.org.au)