

# PARKINSON'S VICTORIA ANNUAL REPORT 2014-15

#### **Our mission**

People living with Parkinson's have access to comprehensive, relevant and flexible services, encouraging independence and guality 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 vision**

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

### **Our values**

#### Sensitive

We understand the needs and challenges of people living with Parkinson's and their families, and ensure services and support is 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 a brain chemical called dopamine. The condition affects the nervous system and alters co-ordination and movement. 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 the quality of life for people with Parkinson's and Atypical Parkinson's conditions 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 30 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 health team also coordinates an extensive network of more than 60 Peer Support Groups across Victoria.

We are one of seven state-based associations working together with Parkinson's Australia to support more than 70,000 people living with Parkinson's nationwide. Collectively, we provide support and education, build community partnerships and capacity, increase awareness of Parkinson's, lobby government and 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.

Cover image: Mike and Heather Jobling photographed by Catherine de Wit

27,000 VICTORIANS ARE LIVING WITH PARKINSON'S

20% **OF PEOPLE WITH PARKINSON'S ARE UNDER 50 YEARS OLD** 

**AUSTRALIANS ARE DIAGNOSED WITH PARKINSON'S EVERY DAY** 

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# **2014-15 HIGHLIGHTS**

9,300 **PEOPLE WITH PARKINSON'S THEIR CARERS AND HEALTH PROFESSIONALS** REACHED



3,700

**PEOPLE** 

**PARTICIPATED IN** 

**A WALK IN** 

**THE PARK** 

3,786 **PEOPLE SUPPORTED THROUGH OUR INFORMATION SERVICE** 

> \$127,800 **INVESTED IN PARKINSON'S** RESEARCH



## CHAIRMAN AND CEO REPORT

#### In 2014-15, Parkinson's Victoria reached more members of the Parkinson's than ever before.

Our mission is for people living with Parkinson's to have greater access to services encouraging independence and improved quality of life, and increased research funding to help treat and advance the search for a cure.

To help us reach these goals, two strategic initiatives underpin our work: developing a sustainable organisation; and developing and delivering services to support the Parkinson's community.

We're proud to report that Parkinson's Victoria has made important strides towards meeting the objectives of our 2013-16 strategic plan this financial year. Growth in our multi-disciplinary team, and introduction of dedicated marketing resources, enabled us to develop and promote new and innovative programs, reaching 9,300 members of the Parkinson's community. This is an increase of 17 percent from the previous year.

We offered three new initiatives to our Peer Support Groups and regional Victorian communities - the RACV Safely Mobile education program, regional Recently Diagnosed Seminars and ParkinSong, an alternative peer support model. These programs increased community engagement and created important education and information sharing opportunities.

We delivered a new national training program targeting professionals in residential aged care and expanded our education seminars – delivering Living Well in September 2014. Growth in our programs is underpinned by development of three key revenue streams - trust and foundations, sponsorship and community fundraising.



Image: Parkinson's Victoria Chair Damien Farrell with CEO Emma Collin.

In August 2014, we held our sixth annual A Walk in the Park in Melbourne. The biggest and best yet, we experienced significant growth in participation, fundraising and community awareness raising activities. An impressive total of \$256,000 was raised from A Walk in the Park to fund our education programs and support services.

In February 2015, we completed our new research strategy, aspiring to increase investment and innovation in Parkinson's research. During the year, we established a new research partnership with Shake it Up Foundation, continued collaboration with the Florey Institute for Neuroscience and Mental Health and key universities – each providing critical building blocks for future research investment.

In an important step forward for the Parkinson's community, Parkinson's Australia - our national peak body - appointed a new Chief Executive Officer to lead our national advocacy campaigns. Collaborating with state associations, we also implemented a national brand identity and refreshed the look and feel of A Walk in the Park. These activities will help to unite and magnify our voice, and promote resource sharing. These achievements wouldn't be possible without our team of dedicated staff. Sensitive and responsive to the needs of the Parkinson's community, they go above and beyond, continuously inspiring and striving for improvement.

Finally, we'd like to thank the entire Parkinson's community – donors, partners, members, Peer Support Groups and volunteers - for their incredible support. We couldn't continue to grow and adapt to the needs of people living with Parkinson's without you.

**Damien Farrell** 

Chair Parkinson's Victoria

Enna Aldlin

Emma Collin Chief Executive Officer Parkinson's Victoria

# PARKINSON'S VICTORIA BOARD



#### **Damien Farrell**

Chair Parkinson's Victoria's representative on Parkinson's Australia Board Vice President of Parkinson's Australia B.A., ACU, FAIM, MAICD Appointed: November 2012 Andrew Suggett OAM Vice Chair

Vice Chair Chair of Governance & Research Committee Dip. Acc., Cert. Retail Management Appointed: November 2011



Adam Conrad Treasurer Chair of Finance & Investment Committee B. Comm., CPA Appointed: November 2012



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

Appointed: May 2014



Karyn Spilberg Member of Governance & Research Committee B.Ed., Grad. Dip. Computer Education, Grad. Dip. English as a Second Language Appointed: June 2014

#### Joanna Hill (retired February 2015)

Secretary Member of Finance & Investment Committee B.App.Sc. Appointed: November 2011



Sue Harper Member of Finance & Investment Committee B.A., Grad. Dip. Ontological Coaching Appointed: November 2013

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# HEALTH EDUCATION

#### Tailored education seminars provide important information for people living with Parkinson's, carers and health professionals.

Parkinson's Victoria provides a variety of education programs to help people living with Parkinson's and professionals to better understand symptoms, treatment options and improve selfmanagement. Last year, Parkinson's Victoria provided education to 2,900 people across the state.

#### Recently Diagnosed Seminars

We tripled the delivery of our targeted education seminars for people recently diagnosed with Parkinson's, last year. For the first time, our health team delivered two Recently Diagnosed Seminars in regional locations – Geelong and Shepparton – and one in metropolitan Melbourne. These sessions were attended by almost 190 people diagnosed with Parkinson's in the last five years, their families and carers.

Partially funded by the Pierce Armstrong Foundation, these seminars provided a supportive environment to access valuable information about diagnosis, medications, treatments, well-being, and locally-based community services. They provided opportunity for people with Parkinson's to have their questions answered by experts, and to meet others facing similar daily challenges.

#### Living Well

In September 2014, Parkinson's Victoria delivered the Living Well seminar in Melbourne – the first event of its kind in Australia. With almost 230 participants, the unique format included a stream for people living with Parkinson's and education sessions for health care professionals.

Living Well empowered people – diagnosed with Parkinson's for seven or more years – and their families, the opportunity for improved symptom management, increased understanding of treatment options and strategies for improving their quality of life. It also provided an opportunity for people impacted by Parkinson's to explore topics related to travel and financial planning.

# Health professional education

Building the knowledge and skills of health care professionals is imperative to improving symptom management and the well-being of patients with Parkinson's. In the last 12 months, we've educated 1,760 health care professionals through approximately 80 sessions.

We delivered a national training package to residential aged care facilities, and our first national Parkinson's and Movement Disorder Nurse meeting was held in partnership with UCB. With more than 50 nurses attending, each received continuing professional development (CPD) points. Similarly, we provided educational opportunities for 160 health professionals and general practitioners in Albury/Wodonga.

#### Last year, we travelled:

(~ ) 27,293

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#### **RACV Safely Mobile program**

Supported by the RACV Community Foundation, our multi-disciplinary health team delivered a new comprehensive education program to our Peer Support Groups. The RACV Safely Mobile education program is designed to support safe mobility on the road, and at home.

Since February, 14 sessions were delivered to almost 380 attendees at our Parkinson's Peer Support Groups across Victoria, including metropolitan Melbourne, Grampians, Horsham, Geelong, Ballarat and Leongatha.

Sometimes quite confronting, this program aims to increase the understanding of driving safely with Parkinson's, including topics on legal requirements, insurance and safety considerations, preparing for driving assessments, and alternative community transport options.

The program also stimulated peer discussion and information sharing about appropriate support and mobility aids for improving independence.

# SUPPORTING THE PARKINSON'S COMMUNITY

#### Being diagnosed with Parkinson's is a personal experience that no one should face alone.

In 2014-15, we expanded our support services to reach more people across metropolitan, regional and rural Victoria.

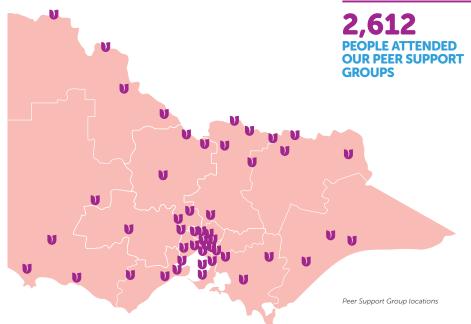
As everyone's journey with Parkinson's is different, providing a range of support services to meet individual needs is critical.

#### Peer Support Groups

Parkinson's Peer Support Groups provide the opportunity to learn more about living with Parkinson's connect with like-minded people, provide mutual support, and to share information about local resources.

Parkinson's Victoria continued to respond to community demand for new activity based and local groups, with the addition of three new groups last year. Our work extended to providing support to and building capacity of its leaders, co-ordinating activity and facilitating some special interest groups. Last year, we imparted valuable information and education to 101 Peer Support Groups.

In 2014-15, approximately 940 individual peer support and special interest meetings were held by 63 groups across Victoria. More than 2,610 people with Parkinson's, family members and carers attended these Peer Support Groups – an increase of 20% from the previous year.



#### Our special interest groups for people with Parkinson's include:

- Atypical Parkinson's Support Groups
- Painting with Parkinson's
- Tai Chi
- ParkinSong
- Deep Brain StimulationYoung Onset Parkinson's
- (Young@Park)
- Dancing with Parkinson's

#### **63** PEER SUPPORT GROUPS IN VICTORIA

**20%** INCREASE IN PEER SUPPORT GROUP ATTENDANCE

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#### Information Service

Parkinson's Victoria provides the only condition-specific Information Service in Victoria. This critical service responds to the needs of people living with Parkinson's and is partly funded by the Victorian Government. 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.

Acknowledging that we are often the first contact for people newly diagnosed, last year we expanded our health team to include a specialist nurse, occupational therapist, speech pathologist and health promotion officer.

"It's a pleasure to watch new ParkinSong groups unfold and to see people enjoying and expressing themselves in loud, strong voices,"

Heather Jobling, co-leader of ParkinSong Williamstown.



Staffed by Parkinson's Victoria's multi-disciplinary health team, our Information Service continues to make a significant and positive difference for people living with Parkinson's, their families and carers. It runs from 9am -5pm, Monday to Friday.

Last year, 3,786 people reached out for expert advice from Parkinson's Victoria via our toll-free and confidential Information Line, email and inperson – an increase of 25 percent from the previous year. We provided comprehensive information and advice on a range of topics including medications, symptom management, treatment options, mobility equipment and disability aids, peer and carer support and how to access health services and resources. **3,786** PEOPLE CONTACTED OUR INFORMATION SERVICE IN 2014-15

#### **2,870** PEOPLE CONTACTED THE SERVICE IN 2013-14

2,670 PEOPLE CONTACTED THE SERVICE IN 2012-13

#### Staying in tune with ParkinSong

We're bringing the power of song to more people with Parkinson's, their family members, and carers. Thanks to the generous support of the Hugh Williamson Foundation, we saw the exciting development of new ParkinSong groups in 2015.

In collaboration with Melbourne University Conservatorium of Music, we initiated a pilot study to measure the benefits of long-term benefits of singing and engaging through music for people with Parkinson's. We also developed a ParkinSong Research Steering Committee and collaborated with academics from various disciplines including representatives from the University of Melbourne, La Trobe University, Alfred Health, Monash Health and Monash University.

In March, ParkinSong Williamstown – the first special interest singing group for people with Parkinson's in Victoria – celebrated their second birthday. More than 30 people from the Parkinson's community came together to celebrate the group's successful beginnings with coleaders, Heather and Mike Jobling.

In response to community demand, ParkinSong Ashwood was established in May 2015. Ocean Grove's Parkinson's Peer Support Group is also transforming into a ParkinSong group, with trials expected to begin in late 2015.

Establishing and expanding our ParkinSong groups is providing exciting and important learning opportunities for Parkinson's Victoria. With high demand for new groups presenting challenges for ongoing facilitation, we are continuously refining our model to ensure they are sustainable and community driven.

# **SUPPORTING THE PARKINSON'S COMMUNITY**

#### Atypical Parkinson's

Atypical Parkinson's, sometimes known as Parkinson's Plus, are a group of disorders which often - early on - present like Parkinson's. These conditions include Progressive Supra-Nuclear Palsy (PSP), Cortico Basal Syndrome (CBS) and Multiple System Atrophy (MSA). Many people living with these conditions may initially receive a Parkinson's diagnosis. These conditions have different causes, symptoms and rates of progression to Parkinson's.

#### Progressive Supra-Nuclear Palsy

Currently, around 1,300 Australians are diagnosed with this rare condition. PSP affects the parts of the brain that control walking, eye movements, balance, speech and swallowing.

#### Cortico Basal Syndrome

CBS is characterised by a gradual loss of nerve cells and shrinkage of tissues in the parts of the brain controlling movement and thinking. Only 150 Australians are diagnosed with this progressive condition.

#### Multiple System Atrophy

MSA involves shrinkage or damage of cells and structures that control multiple functions and parts of the brain. Approximately 2,500 Australians are living with MSA.

#### Supporting people with Atypical Parkinson's

Last year, our support included facilitating 10 meetings at our two Peer Support Groups in Melbourne and Mornington to ensure our personal support for the often complex and difficult discussions on symptom management.

Nationally recognised for supporting people with Atypical Parkinson's, our health team regularly receives calls about these conditions from around Australia on our Information Line. Forty carers also attended a unique education seminar that included information on symptoms, support services, behavioural management, continence and advance care planning

A range of resources - including articles in InMotion magazine, factsheets and the sale of comprehensive information kits for each condition provided valuable information and support for people with Atypical Parkinson's, family members and carers.

1,300 **AUSTRALIANS ARE CURRENTLY DIAGNOSED** WITH PSP

150 **PEOPLE HAVE CBS** 

#### 2,500 **PEOPLE IN AUSTRALIA ARE LIVING WITH MSA**

## **IN OUR** COMMUNITY

In 2014-15, individual donors, community fundraisers and corporate partners contributed more than \$900.000 to Parkinson's Victoria.



Image: Moira Lewis bakes macarons



Image: Grant Rowe reaches new heights. Image courtesy of Shepparton News

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

#### Appeals

Fundraising appeals provide a critical revenue stream for Parkinson's Victoria. We ran two appeals in 2014-15, raising a combined total of \$138,000 for our education programs and support services.

Moira Lewis shared her personal journey of living with Parkinson's for our end-of-year appeal. Whether it's focusing on her next batch of macarons or celebrating Christmas with family and friends, she chooses to stay positive and engaged in the future by setting goals. Moira's story helped Parkinson's Victoria raise \$40,000 to secure a health specialist for our multi-disciplinary health team.

Diagnosed with Parkinson's at 39, Grant Rowe shared his inspirational story for our mid-year appeal. Since diagnosis, he's met and married his wife Lisa, welcomed her three children into his life and plays an active role in the Shepparton Parkinson's Peer Support Group.

Our mid-year appeal raised almost \$98,000 to support our growing number of calls, emails, face-to-face contacts and tailored community education sessions. For the first time, our mid-year appeal reached out to our most engaged donors via mail and email, with almost 10 percent of donations made online.

#### Christmas catalogue

Parkinson's Victoria celebrated the festive season with a Christmas Catalogue filled with fantastic gifts such as tea towels, books, calendars and Christmas cards. With gifts selling out well before Christmas, we raised more than \$21,000 to support people with Parkinson's.

#### Maior donors and bequests

generous support of individuals to deliver support services to the Parkinson's community. We greatly appreciate the invaluable contributions made by the following individuals, families, trusts and foundations, and bequests this year:

#### Major donors

- Fiona and Stephen Cole
- Graham Robilliard
- Anonymous (7)

#### Bequests

- Estate of the Late Eveline Elizabeth Dawn Cutler
- Estate of the late Colin & Sheila Marshall
- Estate of the late Mrs Jean Lillian Paynter
- Estate of the late Mrs Barbara Kathleen Waters
- Estate of the Late Joe White

#### Trusts and Foundations

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CHRISTMAN

parkinson

- G&I Meagher Charitable Trust
- Hugh Williamson Foundation
- Joy Smith Family Foundation
- Pierce Armstrong Trust Foundation
- RACV Community Foundation



#### No secrets here

a regular at our Young@Park -

"I tend to not dwell on it and handle it with typical Aussie humour – laugh at it and treat it with the contempt it deserves,"

"My new lifestyle means that I'm in a much better state of mind than I was two years ago."

medication and peer support has



# Parkinson's Victoria relies on the

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# IN OUR COMMUNITY

#### Community fundraising

Fundraising is a simple and meaningful way for the community to get involved and to support people with Parkinson's. From participating in triathlons to hosting charity dinners, the inspirational fundraising efforts of our community help to improve the lives of people with Parkinson's in Victoria.

This year, community fundraisers contributed more than \$115,500 to Parkinson's Victoria – almost double the revenue from the previous year. We recognise the incredible energy, determination and voluntary efforts of our community fundraisers and thank them for their generous support. We'd like to make special mention of the following individuals and groups who raised more than \$2500 in 2014-15:

- City Kids Early Learning Centre
- Graeme Love and Ian Cuttler
- Owen Lewis
- Mark and Rhia Milligan
- Order of St John of Jerusalem Knights Hospitaller – Australia

Volunteers

Parkinson's Victoria is extremely grateful to our passionate, loyal and hardworking volunteers who generously donate their time and skills. Thank you to Jessica Singh for her invaluable contribution as a dietican to the health team. Special thanks to Pam Fox, a long-standing volunteer who has been a reliable, regular and important part of our team for more than eight years.



#### A Walk in the Park 2014

A Walk in the Park is Australia's most iconic event for the Parkinson's community. On the last Sunday in August 2014, we held our sixth annual event at Federation Square in Melbourne. More than 3,200 participants walked under a glorious spring sky in support and celebration of people living with Parkinson's, and in memory of loved ones.

It was our most successful yet, demonstrating compounding yearon-year growth. Media coverage for A Walk in the Park reached 3.8 million people across TV, print and radio, creating an important opportunity to increase awareness and understanding of Parkinson's. A significant amount of coverage was also achieved through members of the Parkinson's community and key spokespeople sharing their stories in local newspapers.

Parkinson's Victoria is grateful for the outstanding fundraising efforts of participants, supporters and corporate partners who helped to raise a record breaking \$256,000. Special acknowledgement goes to our top individual fundraisers: Judy and lan Phelan, Peter Raymond, and Andrew Maxwell from Global Kinetics Corporation, our A Walk in the Park platinum partner.

Not only did thousands of people come together for A Walk in the Park in Melbourne, there was also a number of events in regional Victoria. More than 500 participants walked to raise awareness of Parkinson's in their local communities of Mansfield, Mildura, Shepparton and Warrnambool A Walk in the Park achievements:

**3,700** PARTICIPANTS ACROSS VICTORIA

**3.8M** PEOPLE REACHED THROUGH MEDIA COVERAGE

\$256,000 RAISED TO SUPPORT PEOPLE WITH PARKINSON'S

And the set of the set

#### **Milligan Benefit Dinner**

In October 2014, Mark Milligan and his wife Rhia brought 160 guests together for a special benefit dinner at the Grand Hyatt in Melbourne. Socceroo and former captain of Melbourne Victory Football Club, Mark was inspired by his grandfather

Mark's grandmother Maria shared her story with guests, providing a personal account of how Parkinson's has

Image: Socceroo Mark Milligan with grandmother, Maria Image courtesy of Mark Milligan d to fund sp ducation of kinson's in

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# INVESTING IN RESEARCH

#### In 2014-15, Parkinson's Victoria more than doubled the research investment made in the previous financial year.

Developing a stronger Australian research agenda is central to Parkinson's Victoria's mission. This year, we invested \$127,800 to promote a better understanding of the condition, treatment options and ultimately to advance the search for a cure.

#### Research agenda

Parkinson's Victoria has developed a new research strategy to provide clear direction for increased investment in Parkinson's research.

The research strategy provides a platform within the research sector through scolarships, fellowships and strategic partnerships to:

- Better understand the impact of living with Parkinson's;
- Raise awareness with respect to the benefits of research investment;
- Seek participation from the Parkinson's community in research trials;
- Increase reporting of research with the community (including supporters) of outcomes, results and breakthroughs; and
- Contribute to innovative, world leading research that advances the search for a cure.



#### Victorian Brainbank Network

Parkinson's Victoria continues to invest in the Victorian Brainbank Network (VBBN) to ensure continued collection and donation of brains and tissue. The Victorian Brainbank Network (VBBN) links clinicians, neuropathologists and research scientists working to understand the cause of Parkinson's.

The VBBN collected, processed and stored 72 new brain donations last year, with 22 cases neuropathologically confirmed as Parkinson's or Atypical Parkinson's. Six Australian and international research projects were granted access to enable further understanding of these conditions.

#### Goulburn Valley Health

Partnering with Goulburn Valley Health and the Shepparton Parkinson's Peer Support Group, we've completed a two-year research project in the Goulburn Valley region. With \$70,000 invested over three financial years, the Movement Disorder Nurse (MDN) project was established to evaluate the benefits of a movement disorder nurse in regional areas.

The project evaluation found the MDN model to be highly valued and responsive to the needs of the rural community. The service provided support for people with Parkinson's and their carers, and had a positive impact on their quality of life and confidence in managing the condition.

Key to the success of the MDN model is its multi-disciplinary model and collaborative approach with health partners, bringing a wealth of combined expertise. The MDN has enabled service expansion in the rural setting that would not otherwise be achievable. It has also provided a strong base for future advocacy initiatives and duplication in other rural health settings.

# INSEARCH: PARKINSON'S RESEARCH SERIES

# Unlocking the Secrets to Parkinson's

With the aim of strengthening research in Victoria, we launched InSearch, a series of research lectures and events in partnership with the Florey Institute of Neuroscience and Mental Health on World Parkinson's Day 2015.

The first in a three-year research lecture series, *InSearch: Unlocking the Secrets to Parkinson's* provided a unique opportunity for people living with Parkinson's, families, carers and health professionals to learn about current international and Australian research from leading researchers and clinicians.

The 2015 series included public lectures in Melbourne, Warrnambool and Bendigo, as well as a scientific symposium attended by 180 clinicians and researchers – reaching 700 people from the Parkinson's community.

Professor Ted Dawson, a leading neurologist from Johns Hopkins University in the United States, was the keynote speaker for our Melbourne event. Dedicating much of his career to researching Parkinson's and other movement disorders, Professor Dawson shared his studies and insights into the relationship of mutant or altered brain proteins linked to the condition.



Image: Dr. Ted Dawson presents his research at the InSearch series in Melbourne

Guest speakers for our regional lectures, Melbourne-based neurologist Dr Wesley Thevathasan and Associate Professor David Finkelstein (from the Florey Institute of Neuroscience and Mental Health) showcased the latest Parkinson's research, and improved the understanding of the complex interplay between clinical treatments for Parkinson's and research for a cure.

#### The 2015 InSearch series was made possible by the generous support of five corporate partners: Medtronic, Lundbeck, UCB Australia, AbbVie and the Cooperative Research Centre for Mental Health.

#### **Funded research projects**

In 2014-15 funded research projects included:

- Goulburn Valley Health -Movement Disorder Nurse Project
- La Trobe University -Physiotherapy Practice for Parkinson's Research Project
- Victorian BrainBank Network Program funding
  - Deloitte Access Economics -Living with Parkinson's Disease: An updated Economic Analysis 2014

Monash University -Estimating the prevalence of Parkinson's disease in Victoria

- InSearch Series - Florey Institute of Neuroscience and Mental Health
  - Monash University -Essence Research Project



Image: Members of the Parkinson's community attend InSearch lecture in Melbourne

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# RAISING PUBLIC AWARENESS

Providing current, accurate and easily accessible information to support the Parkinson's community is a significant focus of our work.

To ensure people living with Parkinson's, their families and health care professionals can access a variety of resources, we've worked hard to deliver more targeted, professional and relevant communications materials.

In conjunction with other state associations, Parkinson's Victoria rebranded in September 2014. This national initiative supports the promotion of Parkinson's in the wider community and led to the release of new resource materials including a refresh of InMotion - our quarterly membership magazine, numerous factsheets and launch of a new website.

#### Parkinson's Victoria launches new website

Improving the organisation's systems and technology has enabled Parkinson's Victoria to provide people living with Parkinson's, carers, and health professionals with better access to current and relevant information. Recognising the increasing community need for web-based information resources, we launched a new website in September 2014.

A significant undertaking for a small organisation, the project was funded by a generous bequest from the late William Regan. Consultations with the Parkinson's community were conducted to understand how best to provide support, information and advice. External developers and a large internal project team were also assigned to ensure consistency, relevancy and accessibility.

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Image: Parkinson's Victoria's new website homepage.

The new website includes an extensive range of information about addressing symptoms, available treatments, living with Parkinson's, and current Australian and international research. It also includes details about our Peer Support Groups across Victoria, other ways to access support, and how to get involved with Parkinson's Victoria.

The responsive design is more accessible - enabling use on computers, tablets and mobile phones. In the first six months, we had more than 17500 unique visits to the website.

#### 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. In 2006, Sir Zelman Cowen generously gave permission for the award to be presented in his name, allowing Parkinson's Victoria the honour of recognising his outstanding community service and support of people living with Parkinson's.

Fred Van Ross was the deserved recipient of our highest honour in 2014. Diagnosed in 2003, Fred has made significant contributions to the Parkinson's community, including serving as a Parkinson's Victoria Board member for nine years. Fred is also President of the Essendon Peer Support Group - a position he's held for more than eleven years.

Fred has attended countless health conferences and seminars to increase his knowledge of Parkinson's and to support others. He is a seasoned media spokesperson and Parkinson's Victoria Ambassador, freely sharing his knowledge and personal experiences to increase community awareness. Fred is an active fundraiser and a regular participant of A Walk in the Park, our major community event. He is a truly exemplary member of the Parkinson's community.



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Image: Fred Van Ross presented with Sir Zelman Cowan Award.

## INCREASING IMPACT THROUGH PARTNERSHIPS

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

From partnerships for A Walk in the Park to raising awareness of Parkinson's research, in 2014-15, we were proud to partner with:

#### Corporate partners

#### In-kind support

- Jack Gallagher
- Philippa Hurford
- Adam Patching
- Belinda Piccirillo
- Darren Singh

#### Community partners

- Australian Medical Association
- Brainlink
- Calvary Health Bethlehem
- Cooperative Research Centre for Mental Health
- Epilepsy Foundation
- Florey Institute of Neuroscience
  and Mental Health

#### Goulburn Valley Health

- Melbourne University
- Monash University

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- National Network of
  Parkinson's Associations
- Shepparton Parkinson's Peer Support Group

#### Information Line

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





## TREASURER'S REPORT

#### Parkinson's Victoria remains in a strong financial position with net assets of \$2.7 million at year end.

In 2014-15, total revenue was \$1.4 million, almost \$100,000 higher than last year. A Walk in the Park, our signature fundraising and awareness raising event continued to grow, enabling enhancements in health program delivery.

Increased investment in staffing and our organisational structure demonstrates our commitment to supporting and delivering improved outcomes for the Parkinson's community. Predicting an operating deficit of approximately \$222,000, we closed the 2014-15 year with an operational loss of \$263,717. This was due to an unbudgeted increase in research investment of \$56,000. Parkinson's Victoria's dedication to research is evidenced by investment of \$127,805, with \$68,320 coming from our research reserves. With our research reserves remaining at a healthy \$506,960 and another ambitious funding research agenda for 2015-16, we anticipate a further drawdown on funds.

Last year, a significant increase in operating expenses was primarily due to investment in human resources, with additional expertise recruited for our fundraising and health teams. This investment has resulted in growth of our education and information services and increased reach to a broader population through investment in our digital platforms.

We also developed and adopted a conservative investment policy. Becoming the basis for appointing a fund manager to guide the consolidation and investment of our considerable financial reserves, it has the potential to offer us an improved rate of return.

#### Where the money comes from

- **61%** Donations/Fundraising
- 22% Grants
- 6% Investments
- 2% Other
- 2% Memberships
- 4% Sponsorships
- 3% Education

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2016 will see the implementation of this policy which is expected to deliver increased annual returns while enabling us to continue meeting our obligations.

The 2015-16 budget predicts a reduced deficit as we continue to invest in systems and resources that lay foundations for sustainable revenue streams that increase long-term support for the Parkinson's community.

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Adam Conrad Treasurer

# AUDITOR'S REPORT

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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 2015, 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.



## AUDITOR'S REPORT



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

#### Independence

In conducting our audit, we have complied with the independence requirements of the Australian Charities and Not-for-profils Commission Act 2012. We confirm that the independence declaration required by the Australian Charities and Not-for-profils 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.

#### Opinion

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 2015 and of its financial performance and cash flows for the year ended on that date; and

(b) complying with Australian Accounting Standards to the extent described in Note 1, and Division 60 the Australian Charities and Not-for-profits Commission Regulation 2013.

#### Basis of Accounting and Restriction on Distribution and Use

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 director's financial reporting responsibilities under the ACNC Act. As a result, the financial report may not be suitable for another purpose.

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CHARTERED ACCOUNTANTS

ADVANTAGE ADVISORS AUDIT PARTNERSHIP

RSHIP BEN BESTER PARTNER

Dated in Melbourne on this /3 Iday of November 2015

#### Statement of Profit or Loss and other Comprehensive Income for the Year Ended 30 June 2015

	2015	2014
	\$	\$
Revenue	1,139,500	1,012,768
Research Revenue	59,432	89,880
Victorian Dept of Human Services Grant	234,713	237,034
Employee benefits expense	(903,243)	(714,677)
Depreciation amortisation expenses	(20,818)	(26,069)
Operating lease expense	(79,334)	(76,384)
Finance costs	(4,857)	(4,103)
Research expenses	(127,752)	(43,999)
Other expenses from ordinary activities	(561,358)	(602,110)
Current year surplus/(deficit) before income tax	(263,717)	(127,660)
Income tax expense	-	-
Net current year surplus/(deficit)	(263,717)	(127,660)
Other comprehensive income:		
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		
Total other comprehensive income for the year	-	-
Total comprehensive income for the year	(263,717)	(127,660)
Total comprehensive income attributable to members of the entity	(263,717)	(127,660)

# Statement of Changes in Equity for the Year Ended 30 June 2015

	Members Funds	Research Funds	Retained Surplus
	\$	\$	\$
Balance at 1 July 2013	2,572,577	529,399	3,101,976
Comprehensive income			
Surplus/(deficit) for the year	(173,541)	45,881	(127,660)
Other comprehensive income for the year	-	-	-
Total comprehensive income	(173,541)	45,881	(127,660)
attributable to members of the entity			
Balance at 30 June 2014	2,399,036	575,280	2,974,316
Balance at 1 July 2014			
Surplus/(deficit) for the year	(195,397)	(68,320)	(263,717)
Other comprehensive income for the year	-	-	-
Total comprehensive income attributable	(195,397)	(68,320)	(263,717)
to members of the entity			
Balance at 30 June 2015	2,203,639	506,960	2,710,599

# Statement of Financial Position as at 30 June 2015

	2015	2014 \$
	\$	
ASSETS		
CURRENT ASSETS		
Cash and cash equivalents	2,793,891	3,043,206
Accounts receivable and other debtors	15,279	4,030
Inventories	8,016	8,016
Other current assets	71,285	97,282
TOTAL CURRENT ASSETS	2,888,471	3,152,534
NON-CURRENT ASSETS		
Plant and equipment	34,184	50,629
TOTAL NON-CURRENT ASSETS	34,184	50,629
TOTAL ASSETS	2,922,655	3,203,163
LIABILITIES		
CURRENT LIABILITIES		
Accounts payable and other payables	172,572	176,780
Revenue received in advance	30,351	48,356
TOTAL CURRENT LIABILITIES	202,923	225,136
NON-CURRENT LIABILITIES		
Accounts payable and other payables	9,133	3,711
TOTAL NON-CURRENT LIABILITIES	9,133	3,711
TOTAL LIABILITIES	212,056	228,847
NET ASSETS	2,710,599	2,974,316
MEMBERS' FUNDS		
Members' Funds	2,203,639	2,399,036
Research Funds	506,960	575,280
TOTAL MEMBERS' FUNDS	2,710,599	2,974,316

# Statement of Cash Flows for the Year Ended 30 June 2015

	2015	2014
	\$	\$
CASH FLOWS FROM OPERATING ACTIVITIES		
Receipts from donations, bequests	1,162,666	1,034,781
Grants	234,713	237,034
Payments to suppliers and employees	(1,732,406)	(1,493,506)
Net cash (used in)/generated from operating activities	(335,027)	(221,691)
CASH FLOWS FROM INVESTING ACTIVITIES		
Payment for plant and equipment	(4,373)	(22,291)
Net cash used in investing activities	(4,373)	(22,291)
CASH FLOWS FROM FINANCING ACTIVITIES		
Interest	94,941	116,222
Finance Costs	(4,857)	(4,103)
Net cash used in Financing activities	90,084	112,119
Net decrease in cash held	(249,316)	(131,863)
Cash on hand at the beginning of the financial year	3,043,207	3,175,069
Cash on hand at the end of the financial year	2,793,891	3,043,206

## LOOKING AHEAD

With stronger organisational foundations, we are well placed to embrace future opportunities.

#### In 2015-16 we will:



To improve our efficiency and effectiveness we will pursue new opportunities for partnership and resource sharing with organisations servicing the neurological community.



To ensure greater investment by government in services, support and Parkinson's research, we will campaign alongside the community, Parkinson's Australia and like-minded organisations.



To enable research funding growth in Australia, we will undertake collaborative projects with organisations such as the Shake it Up Foundation.



To ensure our support services are relevant, accessible and ultimately improve outcomes for the Parkinson's community, we will continue to expand our multi-disciplinary health team.



To increase awareness of the needs and aspirations of the PSP, MSA and CBS community, we plan to deliver our first combined health professional and community education seminar.

# How you can help

Parkinson's Victoria relies on support from individuals, corporations, the government and community groups to help improve the quality of life for people living with Parkinson's and advance the search for a cure.

You can help Parkinson's Victoria continue to support people living with Parkinson's in Victoria by making a donation.

#### **Parkinson's Victoria**

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