



PARKINSON'S VICTORIA ANNUAL REPORT

2012-2013

PRESIDENT'S REPORT

Reflections on the year



Peter Raymond,
President

Seven years ago, my Presidential predecessor reported that “together we make a difference”. Nothing has changed. Not since then. Nor in the 32 years since Parkinson's Victoria was founded.

“Together” we do empower and inspire.

Who are our partners?

Almost 2000 people walked along the Yarra to once again increase our media profile and raise money to help deliver our services.

They are our partners.

The hundreds of volunteers who not only support events like **A Walk in the Park**, but who give us their time, enthusiasm, spirit and initiative to conduct other successful events throughout Victoria.

They are our partners.

Our 57 Support Groups continue to astound as they venture from art into yoga, Tai Chi and singing.

We are also indebted to the sponsors and supporters who contribute financially, in-kind or pro-bono, to make our work possible.

You are all true partners – thank you.

Overall, our healthy surplus of \$1.06m FY12/13 bears testimony to prudent management and empowers us to respond positively to the needs of the Parkinson's community of carers, families and friends. Most importantly, it will help us continue to support the appointment of Movement Disorder Nurses, often in partnership with the local community.

To implement all this change is going to require more than just a bigger budget

We know that the number of people living with the daily complexities of Parkinson's has grown, along with their need for support and services.

How do we know? Because they tell us. Through market research and personal contact via social media (barely utilised seven years ago) and convergent digital technologies such as iPads, iPods, iPhones and cameras. Not to forget the ubiquitous email, which seven years ago was also less obtrusive and less powerful.

Friends and members, who came to be described more accurately as living with “Young Onset”, are now moving into the next phase of their lives with more strenuous demands on peak bodies, like Parkinson's Victoria and Parkinson's Australia. Equipped with more persuasive communication tools, they will expect us to take a more aggressive approach to government.

To implement all this change is going to require more than just a bigger budget. It will need a forward-thinking strategy.

Where do we start?

We have already grown our commitment to services and broadened our response to include Parkinson's-like conditions including: Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Cortico Basal Syndrome (CBD).

There is no doubt that we will see, in the future, a different organisation, but one still doing what it does best - supporting all people with Parkinson's, their families and carers.

In May, we welcomed Emma Collin as our new CEO. Emma came with excellent credentials, boundless enthusiasm and a sharp understanding of legislative changes taking place in the not-for-profit sector.

Together with the CEO, the Board is preparing for the significant reforms that will eventuate in the aged care and disability services sector. These reforms will demand that Parkinson's Victoria strengthens good governance, financial management and reporting. In readiness we have commenced a review of our rules and will undertake work in the coming year to review our legal framework.

Finally, I would like to thank my colleagues on the Board for their support during this challenging period. At this year's AGM, we honour the retirement of Fred Van Ross who has completed his maximum term of nine years service on the Board. Fred has tirelessly devoted his time and expertise and in the last two years has been a most supportive Vice President to me, personally and professionally.

Regrettably, we also accept the resignation of Professor Meg Morris whose work and travel commitments made the last two years very difficult for her. Meg's quiet wisdom and rich experience will be missed.

To our CEO, our talented and dedicated staff, our Support Groups, who continue to amaze with their innovation and enthusiasm, and all the volunteers without whom we would be unable to build such an effective and supportive organisation – I am proud to assert that “together we make a difference”.

Peter Raymond - President

Local Support

Lobbying government and local health care facilities to support funding for Movement Disorder Nurses has been a long-term priority of Parkinson's Victoria.

In recent years, some Support Groups have been proactive initiating and driving this at a local level, with varying degrees of success.

In July 2012, following months of collaborative work between Parkinson's Victoria, the Mildura Parkinson's Support Group and the Lower Murray Medicare Local, it was announced that a Movement Disorder Nurse would be employed to provide support ‘on the ground’ for the local community. The role was filled in August 2012.



Supporters from Mildura at
A Walk in the Park, 2012

NATIONAL CONFERENCE

National Parkinson's Conference, hosted by Parkinson's QLD. Staff attend to enhance their knowledge, deliver presentations and to network.

12th-14th July 2012

RUN MELBOURNE

68 members of Team Parkinson's hit the pavement for this major fun run and raise \$29,795.

21st July 2012



CEO'S REPORT

The year in review



Emma Collin,
CEO

The past year has delivered significant change: a slowing economy, tighter government purse-strings, and significant policy reforms within the disability, aged care and not-for-profit sectors.

This new landscape means our commitment to planning has never been more critical to delivering on the needs of people living with Parkinson's and their families. With this in mind, the Board and staff commenced the development of a new Strategic Plan, which was finalised in August this year.

While planning was a priority, so were the immediate and growing needs of the Parkinson's community. This was clear in the demand for our information helpline, educational seminars and Support Group services, which our research shows reached more than 7,000 people with Parkinson's, their carers and health professionals throughout the year. We also know more than 68,000 people visited our website and we will pursue increasing the development of our online platform next year.

This year, our peer support program launched a **Support Group Manual** to guide and advise leaders in the areas of coordination and administration, as building the capacity of the Parkinson's community had been identified as key work. The peer support program was quick to respond to community feedback, with the establishment of multiple groups based on mutual interest, including **yoga, Tai Chi, singing, painting** and a **Deep Brain Stimulation Support Group**. As a result, our overall number of Support Groups increased by 17 per cent; a really great result.

This year, we invested in the development and growth of support for people living with atypical Parkinson's conditions. With the ongoing support of a dedicated donor, we extended staff support and the development of targeted information kits. We can proudly state that this was an Australian-first and consequently all information has been shared with our national colleagues and now forms a national resource.

Our approach to research initiatives again had a strong partnership focus. Working collaboratively with Goulburn Valley Health and the Shepparton Support Group, we were able to fund and support the development of a two year demonstration project, employing a Movement Disorder Nurse in the region and measuring the benefit that localised clinical expertise can bring to regional and rural areas. The findings of this on-going project will provide much needed research data for our advocacy and funding submissions to Government and other funders in the future.

Our work with Monash University's **Essence Project: investing in research on the impact of 'wellness programs' on people living with Parkinson's**, also continued this year. In addition to project funding, we supported the recruitment of more than 70 participants for the program. We look forward to seeing the results of the research in the coming year.

Raising awareness of the needs of people living with Parkinson's in the wider community was and continues to be a key focus of our work. For the first time this year we celebrated World Parkinson's Day (11 April) at Federation Square. This event, together with **A Walk in the Park**, our major fundraiser, attracted over 2,000 participants and the coverage by local media was important to help raise the profile of Parkinson's throughout the community.

This year, through events such as these, as well as donations, we raised over \$568,000. We also received more than \$1.2 million in bequests.

Finally, I would like to thank the staff, Board, hundreds of volunteers and donors who have generously supported this year's work.

Emma Collin - CEO

A Walk In The Park

The Parkinson's Walk marked its 4th year in Victoria, when almost 2,000 friends and family came together at Federation Square.

Once again, our Walk was the largest of its kind for the Parkinson's community in Australia.

The event, which resulted in more than \$300,000 worth of free media across radio, television, print and online, was instrumental in raising awareness of Parkinson's in the broader community.

Most importantly, media stories highlighted the 'human story' behind the statistics.

We acknowledge the generous financial support of event sponsors: Outlook Financial Solutions, Segue Financial Services, Medtronic, Australian Unity, Martin & Pleasance and City of Melbourne.



"We're all in this together!" A Walk in the Park, 2012

MILESTONE:

388 calls logged to our Help Line

August 2012

SUPPORT GROUP LEADER DAY

This annual event sees the launch of our Support Group manual, filled with information and advice.

25th August 2012

A WALK IN THE PARK

Nearly 2,000 people Walk in a public show of support and raise \$50,000 to fund support and research initiatives.

26th August 2012

PARKINSON'S ANNUAL VICTORIA REPORT

WE VALUE ENGAGEMENT

Essential for today, and for the future



Our new exercise DVD was launched with a free Tai Chi demonstration at Federation Square on World Parkinson's Day, 11 April. We acknowledge the generous support of Tai Chi Australia.

Feedback from the Parkinson's and broader community, supporter networks and health sector is vital to gaining insight into key community issues and emerging concerns, as well as areas that require our attention regarding services and support, innovation and resource development.

Providing our stakeholders with opportunities to communicate openly with us will result in our work being more effective with greater impact. In the past 12 months, our Support Groups have continued to provide us with direct access to local communities and issues.

Throughout 2012-13, we worked with a number of Support Groups to facilitate meetings with their Medicare Local and local Members of Parliament, including Bairnsdale, Mildura, Shepparton and Warragul. The value of these meetings is significant as they combine the local and personal experience of those living with Parkinson's with the weight of the peak body that represents the Parkinson's community.

Local Advocacy

Parkinson's Victoria joined with the Bairnsdale Support Group to host a public meeting to highlight and discuss the benefits of a local Movement Disorder Nurse.

VIPs in attendance included the Mayor and MPs Tim Bull and Darren Chester.

We progressed our major Market Research project, where we are speaking directly with the Parkinson's and wider community, as well as the health sector about their experience of Parkinson's, Parkinson's Victoria and the services and support they've encountered.

The results are providing rich data that will improve our understanding of our community, key priorities, areas for improvement and opportunities for growth, and will ultimately translate into improved services. It is likely that the findings will also inform new areas of focus for our work and support initiatives.

It is likely that the findings will also inform new areas of focus for our work and support initiatives

Our annual 'road trip' program once again saw us deliver major education seminars to local communities across metro Melbourne and into regional Victoria. In 2012-13, we hosted seminars in Pakenham, Doncaster, Melton, Mildura and Kyabram, and visited each of our 57 Support Groups during their monthly meetings.

Following submission of our annual **service delivery report** to funding body, the Department of Human Services, our team had cause to stop and reflect on what was another busy year. The data captures the number of contacts our team has had with service users (members of the public and health sector), and the method of this contact over a 12-month period*. The report demonstrates the ongoing need for information and support by the Victorian community.

Phone contacts:	2328
Face to Face:	112
Email:	230
Support Group attendees:	1792
Professional Education Sessions/Seminar attendees:	2544
Website contacts (approx):	68,980
TOTAL contacts for year:	75,986

**The DHS reporting period is April-April.*

Professional Program

In 2012, Parkinson's Victoria, working with Southern Health, Cabrini Hospital, and the Movement Disorder Speech Pathology Special Interest Group, hosted the first ever workshop specifically exploring swallow and speech challenges: ***A Tough Act to Swallow***.

While it is acknowledged that many Speech Pathologists have a good understanding of dysphagia, the event provided an opportunity to enhance this knowledge base, with the aim of improving the quality of life and symptom management of patients and clients living with Parkinson's.

The event was attended by 83 speech pathologists.

NATIONAL PARKINSON'S AWARENESS WEEK

A TOUGH ACT TO SWALLOW

83 Speech Pathologists attend a dedicated full day seminar addressing speech and swallow challenges associated with Parkinson's.

COMMUNITY EDUCATION

Introduction to Parkinson's seminar is attended by 40 members of the Melton and surrounding community.



WE VALUE INNOVATION

In our approach to service delivery and investment

Being ready and able to respond to the many and varied needs of each of our stakeholder groups – people diagnosed with Parkinson's, family members, the health sector, funding bodies, supporters, and the wider community - requires an innovative approach to service delivery, investment, allocation of resources and partnership.

Throughout 2012-13, our team explored enhanced service delivery methods and scope. The results included delivery of a number of specialist information seminars and the development of new resources, including an exercise DVD.

An exciting research project commenced in May 2013 to gather evidence of the value of a Movement Disorder nurse

Generalist seminars allow us to deliver key information on a range of Parkinson's-related content to a broad audience. Feedback we have received indicates there is also a desire for specialist knowledge on specific areas of Parkinson's and symptom management. In 2012-13, our team presented the following:

A Tough Act to Swallow

A seminar exploring the swallow and communication challenges of Parkinson's (83 attendees)

Revealing the Mysteries of Parkinson's

A multi-disciplinary approach to managing Parkinson's (80 attendees).

Nursing Care of the Patient with Movement Disorders

(40 attendees)

A-typical Parkinson's Seminar:

Investigating the spectrum of Parkinson's-like conditions (PSP, MSA, CBD) and a multi-disciplinary approach to care (85 attendees).

An exciting and significant research project was commenced and launched in May 2013. The purpose is to gather evidence that identifies the value of local communities having direct access to a Movement Disorder Nurse, as well as the potential impact on the wellbeing of people living with Parkinson's and their families and any associated economic-health benefit.

This ground-breaking project is the result of hard work and collaboration between the Shepparton Parkinson's Support Group, Parkinson Victoria and Goulburn Valley Health, and is the first of its kind in Australia.

People living with Parkinson's-like conditions are sometimes overlooked. These conditions, which include Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Cortico Basal Syndrome (CBD), are rare, rapidly progressive and disabling. They are commonly misdiagnosed initially as Parkinson's.

Parkinson's Victoria has been committed to supporting this group for many years and over time we have been able to improve this support, as a result of increasing need and funds. An a-typical Parkinson's Support Worker is now employed by Parkinson's Victoria for 6 hours per week and, to support increased awareness and provide families with up-to-date and relevant information, Parkinson's Victoria was pleased to launch comprehensive support manuals for all three conditions. This work is a world first and was made possible with the contribution of leading Australian Movement Disorder professionals.

A-Typical Parkinson's

In 2011, following several years of informal support for people diagnosed with 'Parkinson's-like conditions', including Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Cortico Basal Syndrome/Degeneration (CBS/D), Parkinson's Victoria received a significant donation, enabling the support program to be formalised.

The result included employment of a part-time support worker and two dedicated full day seminars: in March 2012 for 60 carers, and again in March, 2013 for 75 allied health professionals. Three information resources were also developed and launched (below). An Australian first, the manuals provide specific information on a-typical Parkinson's conditions that will assist individuals, families and health care professionals.



Shirley Milne, Health Team Administrator Jo Berthelemy, PSP Australia convenor Anne Mooney, and Parkinson's Nurse Consultant Victor McConvey.

MILESTONE:

Parkinson's Victoria
'Website Hits'
reach 27,390.

October 2012

PARKINSON'S VICTORIA WINS AWARD

Partnership with creative agency RAPP results in a **Rotary Community Service Award** and pro bono 'prize' from Disegno to re-develop our website.

15th October 2012

WE STRIVE TO BUILD CAPACITY

To help the community to help themselves

Empowering individuals and communities are key priorities which underpin our service program. Our work supporting individuals is an important investment, resulting in improved health outcomes, informed decision-making and self-advocacy.

While the traditional Support Group model has provided hundreds of Victorians with friendship, information and support over the years, feedback highlighted the need for new and alternative avenues of support. In 2012-13, in response to emerging areas of interest, an increasing body of knowledge to support the benefits of social/community engagement and certain complementary 'therapies', we were proud to launch 2 new Support Groups in Doncaster and Pakenham and the following special interest groups:

Yoga for Parkinson's:

A new program of *Yoga for Parkinson's* commenced with the support of Movement Disorder Neurologist Dr Sanjay Raghav, who generously donated his time to facilitate our inaugural group. The success of the program resulted in an on ongoing program being offered in Camberwell.

Tai Chi for Parkinson's:

Group facilitator, Tai Chi master Anastasia Yianni is passionate about the group and observes the participants improve balance and coordination, while participants comment on benefits that include improved movement and more control over symptoms.

Parkinsonsong:

The launch of our inaugural singing and Parkinson's group – *Parkinsonsong!* - has brought together people with Parkinson's, carers and speech pathology students who want to have fun while raising their voices.

Although located in Williamstown, the group continues to grow with new faces each meeting, and members coming from near and far. Participants have been overwhelming in their praise for the group and often comment that "they never realised that doing something which was fun, could also be good for you!"

Painting with Parkinson's:

An initiative of Ann Atkin, winner of the *2012 Sir Zelman Cowan Award for Outstanding Service to the Parkinson's Community*, the program was given a boost when it received a grant from FaCHSIA enabling 5 new Painting with Parkinson's groups to be established across the state. Groups are now active in Warrnambool, Mt Martha, Torquay, Koroit and Essendon, with the original group in Berwick continuing, despite a fire at their monthly meeting place, which destroyed materials and art works.

The grant also funded an art show of students' creative works - *A Walk through our Art*. The art exhibition and "birthday party for Dr James Parkinson" (after whom Parkinson's is named), was a key event on World Parkinson's day, 11 April, most notably because former Prime Minister Kevin Rudd attended and spoke openly of his mother's life with Parkinson's.



Members of our Young Onset Group (Barwon Region) and family at A Walk in the Park, 2012

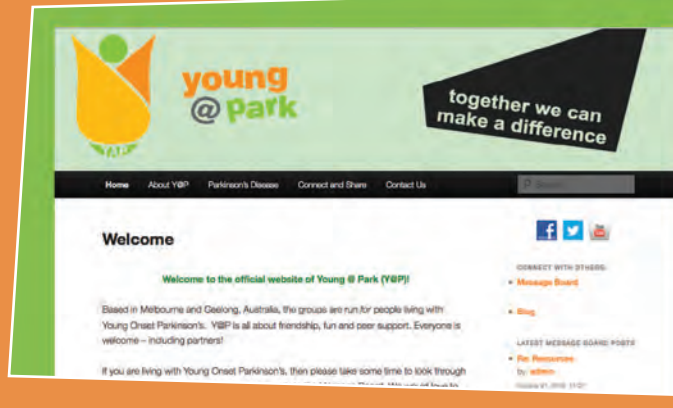
A *Deep Brain Stimulation (DBS) Support Group* was established following an information seminar on the procedure.

The importance of our Support Groups in providing local, peer support is well known. To assist group leaders to continue their invaluable work, we launched a comprehensive *Support Group Manual* during our 2012 *Support Group Leader Training Day*. This ever-evolving document supports our leaders by providing a clear and concise guide to managing all matters related to their group.

Online Support

In November, we commenced re-development of the Young Onset website. Working with volunteers and students from Swinburne University, the project will deliver a revitalised website aimed at improving online support for those living with Young Onset Parkinson's.

Around the same time, we undertook a survey to understand how we can improve support for the Young Onset community. Targeted at those diagnosed under the age of 60, we sought feedback about priority needs, current support services, preference for new services, and how the community wants to engage.



PROFESSIONAL EDUCATION

Revealing the Mysteries of Parkinson's provides general and expert information, while debunking the myths. Attended by 80 health professionals.

ONLINE RESOURCE DEVELOPMENT

Collaboration between our Young @ Park group, Swinburne University and Parkinson's Victoria begins. Aim: Revitalise Young Onset website.

RECENTLY DIAGNOSED

67 people attend this annual full day seminar.



WE FOCUS ON AWARENESS

It is integral to everything we do



Shepparton Support Group Chairman, Robin Squires (left) and Group Coordinator, Geoff Alexander (right), with Parkinson's Victoria President, Peter Raymond at the Group's fundraising lawn bowls event, 2013.

Improving the landscape for those living with Parkinson's begins with raising awareness.

Parkinson's Victoria helps many hundreds of people every year, but there are still so many people who don't reach out to us, in many cases because they are unaware of our support services. While we continue to provide support and services **today**, our awareness raising work is integral to our long-term strategy to connect with all those who need us today, and in the future.

Our work, programs and campaigns focus on increasing the visibility of Parkinson's, education of the broader community, reducing stigma, helping the Parkinson's community to 'speak up', and being a voice for those who cannot speak for themselves.

In the financial year ending 2013, our approach emphasised changing perceptions, highlighting the specific needs of those living with Parkinson's, and delivering key information about "the facts" – what Parkinson's is, and isn't.

Our programs and campaigns focus on increasing the visibility of Parkinson's

Parkinson's is more than just statistics. While numbers are important to validate the impact and need, behind every statistic is a real life experience, a human story.

This year, we've created and responded to a number of media opportunities, resulting in hundreds of thousands of dollars in free media interviews and stories.

As a peak body and front line service provider, Parkinson's Victoria is often called upon by members of the media to provide information and commentary on various matters related to Parkinson's. Media inquiries may be related to new or emerging technologies/treatments, funding and demographic/statistical information, Parkinson's Victoria events, activities and initiatives, viewpoints, positions and comment on topical and relevant issues, and the impact of external activities/announcements, just to name a few.

Parkinson's Victoria is also contacted by media who wish to interview members of the public regarding their personal perspective of living with Parkinson's. Personal stories are powerful in highlighting the human 'face' behind the statistics and provide an opportunity to celebrate the achievements and the courageous, positive and inspiring attitude of the Parkinson's community. We are always pleased to facilitate these interviews.

Our education program - for both the community and health professionals - aims to increase understanding and awareness of the condition in order to improve quality of life. While we provide individuals and families with access to information about services, treatment options, assistance programs and how to 'navigate the system', we also educate those working in the health/aged care sector so they can improve the quality of care they provide.

We are fortunate to have an amazing team of Ambassadors and Support Groups who support our awareness raising efforts by undertaking activities in their own communities.

Activities, which include hosting information stands, participating in speaking engagements to local schools, social and service clubs, as well as media interviews, help to raise awareness, improve local support and reduce the stigma associated with the condition.

In recent years, we have seen a significant increase in the number of people wishing to support our work through fundraising.

In 2012-13, these supporters alone contributed more than \$60,000 to help fund our day-to-day support services and program initiatives, as well as research. In addition, they were invaluable advocates for the cause, reaching community groups and corporates that we would not otherwise have access to.

Our fundraisers are proud to share with their networks why the fight against Parkinson's is important to them. In many cases, it is only after attending, or reading about one of these fundraising events, that people have reached out to us and we have been able to provide support, information and assistance.

Pilot Project

Heavily supported by the fundraising efforts and advocacy work of the Shepparton Support Group, in December 2012 Parkinson's Victoria committed to part funding a Movement Disorder Nurse for the Goulburn Valley region.

Positioned as a pilot project that will generate research data as evidence to support the value of a nurse for local communities, the initiative took several months of discussion and fine-tuning before resulting in a role being established (and filled in May 2013).

The ground-breaking project has been made possible with the financial support of three key players; Parkinson's Victoria, the local Shepparton Support Group and Goulburn Valley Health.

MILESTONE:

Our Professional Education program reaches out to 1,270 health professionals.

December 2012

THANKS A BUNCH

Parkinson's Victoria acknowledges the contribution of volunteers at our annual *Thanks a Bunch* event.

2nd December 2012

MOVEMENT DISORDER NURSE

Development of the *Shepparton Nurse Pilot Project* commences; a partnership between Parkinson's Victoria, Goulburn Valley Health and Shepparton Support Group.

3rd December 2012

WE PROMISE ROBUST INVESTMENT

To prepare for the future



The Parkinson's Victoria team and Ambassadors at the National Parkinson's Conference in Brisbane. From L-R: Judith Mooney, Karyn Spilberg, Victor McConvey, Peter Raymond, Breanna Wotherspoon, Linda Walsh and Sharon Daborn.

With more than 30,000 Victorians relying on us for support, it's vital that we are ready to respond. Your support is critical to help us deliver and develop programs.

Thanks to the support of hundreds of donors every year, Parkinson's Victoria is able to invest in much-needed and effective solutions that enable us to empower and support people living with Parkinson's. Our focus in 2012-13 has been on program growth, infrastructure and system development, staff development and research.

Areas of investment reflect new and emerging areas of need, as well as unmet need, including but not limited to, Young Onset Parkinson's, regional Victorians, Culturally and Linguistically Diverse Communities (CALD), atypical Parkinson's, and advanced-stage Parkinson's. These have been identified as a priorities by our team and will continue to inform our programs moving forward.

Specialist Support

Responding to growing interest in Deep Brain Stimulation Surgery, Parkinson's Victoria hosted a dedicated seminar in May.

Attended by 58, the event led to the establishment of a DBS Support Group for those who have undergone the procedure, providing a chance for them to connect with others and share experiences.

A post-event survey revealed that the majority of attendees had been considering DBS surgery from anywhere between 1 month and five years, with their understanding of the procedure increasing from 'poor' to 'excellent' as a result of the seminar.

Feedback also highlighted the degree to which the community views Parkinson's Victoria as a trusted source of relevant information and support.

During the 2012-13 year, we have also invested internally: in improved systems; equipment and software including upgrades to our supporter database and IT infrastructure; increasing staff, as well as staff development in key areas including fundraising, media training and knowledge to improve our support services; and in strategic planning and business development.

- In July 2012, the National Parkinson's Conference took place in Brisbane and provided an excellent opportunity for the Parkinson's Victoria team to hear presentations from Australia's leading Movement Disorder professionals. Parkinson's Victoria staff actively participated in the conference, delivering papers and chairing interactive sessions. This meeting was also the first occasion for Parkinson's health teams across Australia to meet, network and share experiences, and this has strengthened relationships and fostered national collaboration.
- Prize money awarded to a member of our Development Team was also invested, at the request of the staff member, in the services of a professional consultant to help improve our fundraising programs and administration. The result has meant improved stewardship of donors and donations and more effective fundraising programs. It is also laying the groundwork for more robust fundraising in the future - in the face of increased competition in the charity space - and enhanced relationships with our supporters.
- Our research investment program means we focus on promising research that will improve our understanding of Parkinson's and lead to improved quality of life, better symptom management and ultimately a cure. In 2012-13, we had the opportunity to demonstrate our continued support of research with some exciting projects, including:
 - A program headed up by researchers at Melbourne University, which investigated the impact of 'dance' on Parkinson's symptoms.
 - A partnership with **The National Health and Medical Research Council (NHMRC)**, Australia's peak body for supporting health and medical research, to offer a TRIP fellowship. To support this partnership, NHMRC and Parkinson's Victoria representatives met to identify a strategy to recruit suitable Research Fellows.
 - Continued financial support of the Victorian Brain Bank Network, with a total of 144 brains having been donated by people with Parkinson's. Tissue samples contribute to research occurring across Australia and internationally.

Parkinson's Victoria continues to rely on the financial support of the community and our members to help fund our everyday support programs, program development and research.

Ways to give:

- Make a donation or ask about making a regular monthly donation
- Remember Parkinson's Victoria in your will with a bequest
- Organise your own fundraising activity
- Volunteer your time or skills

For more information about ways to support Parkinson's Victoria, contact our Development Team: info@parkinsons-vic.org.au

MILESTONE:

Our annual *End of Year* appeal raises almost \$40,000.

MILESTONE:

Parkinson's Victoria 'road trips' to Support Groups equate to helping 1,484 members during local meetings.

MILESTONE:

1,300 calls logged to our Help Line.



WE VALUE STRATEGIC PARTNERSHIPS

They enhance our work and what we are able to achieve

We believe that growth through excellent relationships is not only valuable, but essential. They enhance our work and what we are able to achieve.

Strategic partnerships are about bringing together the knowledge, experience and resources of Parkinson's Victoria and that of corporate enterprise, health organisations, individuals, community groups and research institutes to address shared priorities; improving the lives and future of those living with Parkinson's.

The **Progressive Neurological Disease Project**, facilitated by Calvary Health, is a significant state-wide, government-funded project investigating better models of care for progressive neurological conditions. This year, working in collaboration with representatives from other neurological organisations, including MS Australia, MND Victoria (Motor Neurone Disease), Muscular Dystrophy Foundation Australia, and Huntington's Disease Association, Parkinson's Victoria joined the steering committee to help expand the pilot project into the Barwon region, through the local health services. This project will support us in developing a new interface between health services, commonly accessed by people with Parkinson's, and disability services in the Barwon launch site of the **National Disability Insurance Agency (NDIA)**.

Our partners also include hundreds of supporters who **'Get Moving to Make a Difference'** and in doing so, play a vital role enhancing our own awareness raising and fundraising activities. Our supporters connect us with the general public and work with us to create positive change. Importantly, they extend our reach into the community, promoting our services and our role as the peak body representing those living with Parkinson's. Their efforts, which include story sharing, raising awareness, reducing stigma, fundraising, engaging with their local networks and corporate Australia, and speaking with media, are not only invaluable but integral to our work reaching out to those who need us, and on behalf of those who rely on us.

Every year, we are overwhelmed by the support we receive from individuals, families, companies, social clubs, schools and Support Groups, who undertake fundraising activities, everything from garage and bake sales, to fun runs and music events.

Just some of the highlights from 2012-13 were:

- Joanne Tremonti who competed in the **Comrades 89km Ultra Marathon** in South Africa and raised over \$6,000.
- Alan Barber, on his way to running the famed **New York Marathon** for Parkinson's Victoria in late 2013, clocked up \$10,000 (so far) from donations and fundraising events.
- Melanie Franks and Fabienne Parr hosted **Intimo Lingerie Parties** and donated proceeds of \$525 and just over \$2000 (respectively)
- Gideon Goldberg celebrated his bar mitzvah and asked friends and family to donate to Parkinson's Victoria in lieu of gifts. A total of \$7,207 was donated.
- From Sydney, Belinda Nussbaum has been running **Punch4Parkinsons** kick boxing classes. Participants donate to Parkinson's Victoria, instead of paying Belinda for the weekly class. Donations continue to come in with around \$300 already donated.
- Jason Lavery held a garage sale and raised over \$500.
- Linda Walsh asked her local newsagency, SupaNews, to host a Parkinson's Victoria collection tin and in recent months close to \$500 has been donated in loose change.
- We once again had a very fit bunch of people participating in various fun runs, including **Run Melbourne**, the **Melbourne Marathon** and the **City to Sea** (over \$40,000 was raised through these events).
- We also had tremendous support from the corporate sector, including the NAB and Baulderstone, and school students, including Kilbreda College and Essendon Keilor College.
- And, we received generous support from many of our Support Groups, including those who undertook a fundraising BBQ or other activity.

The energy, enthusiasm and creativity of all our fundraisers is inspirational and we gratefully acknowledge their incredible efforts.

It really is only when we work together - with all our partners - that we can make a real difference.



Our partnership with creative agency RAPP, who created 'A message from Jennifer' (short film) resulted in a Rotary Community Award. From L-R: Jennifer Alison (who featured in the film), Parkinson's Victoria President, Peter Raymond with Tess Doughty and Richie Taaffe from RAPP DDB Group.

Supporting Research

Committed to funding innovative, evidence-based research that has the potential to improve quality of life, in 2011 Parkinson's Victoria announced a collaboration with researchers from Monash University for the Essence Project.

The 2-year project involves the recruitment of participants from our Camberwell and Essendon Support Groups and is investigating the impact of "wellness programs" on people living with Parkinson's.

It is hoped that the outcomes of such a program are beneficial for people living with Parkinson's and their carers.

COMMUNITY SEMINAR

People living in the Doncaster area have the chance to hear from experts about Parkinson's and local support during an information seminar.

15th February 2013

LAUNCH OF 'PARKINSONG'

For the first time, thanks to the enthusiasm and commitment of Parkinson's Victoria members, a Parkinson's singing group is launched.

21st February 2013

COMMUNITY SEMINAR

We host an information session for those living in the Pakenham area. The seminar is a great success and results in the establishment of a local Support Group.

28th February 2013

PARKINSON'S ANNUAL VICTORIA REPORT

PARKINSON'S VICTORIA INC.

Financial statements

PROFIT AND LOSS ACCOUNT FOR THE YEAR ENDED 30 JUNE 2013

INCOME	2013	2012
OPERATING	\$	\$
Advertising	3,400	-
Ambassador	1,605	1,475
Donations	192,749	136,655
Education	22,967	19,264
Events / fundraising	320,978	291,428
Grants – government	221,164	215,025
In memoriam donations	55,163	74,826
Memberships and subscriptions	41,393	43,324
Merchandise and product sales	10,896	12,597
Other income	6,398	1,943
Sponsorship	2,500	2,879
	879,213	799,416
NON OPERATING		
Bequests	1,209,764	243,018
Donations for Equipment	-	1,100
Interest		
- General	88,109	115,924
- Research	32,306	-
Profit on sale of fixed assets	768	-
Project income	20,228	7,454
Research donations	19,305	5,871
Trusts and foundations	20,000	-
PSP Income	56,670	38,199
Sheila Marshall Lecture	-	743
	1,447,150	412,309
TOTAL INCOME	2,326,363	1,211,725

STATEMENT OF FINANCIAL POSITION AS AT 30 JUNE 2013

CURRENT ASSETS	2013	2012
	\$	\$
Cash and Cash Equivalents	3,175,069	2,077,747
Trade and Other Receivables	22,712	8,310
Inventories	10,625	4,829
Other Current Assets	78,201	91,410
TOTAL CURRENT ASSETS	3,286,607	2,182,296
NON-CURRENT ASSETS		
Property, Plant and Equipment	55,094	59,278
TOTAL NON-CURRENT ASSETS	55,094	59,278
TOTAL ASSETS	3,341,701	2,241,574
CURRENT LIABILITIES		
Trade and Other Payables	218,531	188,176
TOTAL CURRENT LIABILITIES	218,531	188,176
NON-CURRENT LIABILITIES		
Trade and Other Payables	21,194	9,237
TOTAL NON CURRENT LIABILITIES	21,194	9,237
TOTAL LIABILITIES	239,725	197,413
NET ASSETS	3,101,976	2,044,161
MEMBERS' FUNDS		
Members Funds	2,572,577	1,542,024
Research Funds	529,399	502,137
TOTAL MEMBERS' FUNDS	3,101,976	2,044,161

Full audited accounts are available to Members on request.

EXPENDITURE

OPERATING	2013	2012
	\$	\$
Advertising – other	1,277	4,139
Advertising – staff	20,493	259
Ambassador expenses	108	170
Annual General Meeting & Report Expenses	8,385	-
Annual leave	34,541	31,985
Audit fees	5,192	4,030
Awareness week expenses	3,515	500
Bad Debts	136	318
Bank Charges	47	-
Bank – merchant fees	4,073	1,591
Board expenses	1,681	303
Books and publications	1,602	1,894
Building maintenance and cleaning	10,023	11,737
Catering	469	3,145
Computer software and hardware expenses	3,901	3,808
Computer maintenance	14,543	10,599
Conference Expenses	10,032	-
Consultancies	5,000	27,134
Depreciation	28,762	-
Education expenses	9,108	9,296
Equipment and equipment hire	533	581
Event fundraising	166,705	166,678
Facility hire	46	3,512
Insurance	3,730	2,578
Internet services	2,917	4,500
Legal fees	3,159	250
Light and Power	11,801	8,948
Long service leave	4,835	1,966
Market Research	2,260	16,711
Membership Parkinson's Australia	1,485	1,257
Membership expenses	26,557	245
Merchandise and product sales	1,864	15,068
Miscellaneous	3,075	5,243
Motor vehicle	7,207	6,224
Motor vehicle – lease	-	-
Parkinson's Australia – Membership, Travel	31,175	29,913
Photocopier maintenance	2,626	2,487
Postage and courier	14,609	22,736
Printing and stationery	15,685	44,797
Public relations	26,750	8,081
Rates & Water	3,751	2,396
Rent & Car Parking	73,009	70,150
Salaries and wages	515,729	466,857
Staff amenities	1,118	1,603
Sponsorship	-	-
Subscriptions	1,909	1,648
Superannuation	76,700	46,966
Support group expenses	3,565	3,767
Telephone and facsimile	12,916	10,210
Theft expenses	-	-
Training	5,792	1,973
Travel and accommodation	13,633	5,752
Volunteer costs	1,097	2,788
Work cover	8,995	8,881
	1,208,121	1,075,674
NON OPERATING		
Legal expenses	1,950	-
Project expenses	3,236	7,454
Research project	17,850	17,850
Victorian Brain project	6,500	6,500
Moving expenses	-	3,934
Painting with Parkinsons	15,098	5,000
Shepparton Support Group	5,833	-
PSP Expenditure	9,960	7,974
Sheila Marshall Lecture	-	15,505
	60,427	64,217
TOTAL EXPENDITURE	1,268,548	1,139,891
SURPLUS	1,057,815	71,834

MILESTONE:

Donations for the financial year to date reach \$500,000.

WORLD PARKINSON'S DAY

Former Prime Minister Kevin Rudd helps mark the occasion during an art exhibition, hosted by *Painting with Parkinson's*.

MILESTONE:

We reach out to almost 57,000 individuals and health care workers.

A DAY ON THE GREEN

A charity golf day - hosted by Tim Diamond to honour mum 'Tessie' - results in a \$10,000 donation.



TREASURER'S REPORT

Our financial position



*The Parkinson's Victoria Board 2012-13.
From L-R: Andrew Suggett, Peter Walker, Secretary Jo Hill,
President Peter Raymond, Damian Farrell, Vice President
Fred Van Ross, Treasurer Adam Conrad, Professor Meg Morris.*

On behalf of the Board, I am pleased to report an operating surplus of \$1,057,815 for the year end 30 June 2013.

The Financial Position/Balance Sheet indicates a substantial increase on the previous year's result, primarily due to the receipt of bequests in non-operating income of \$1,209,764.

This year's slowing economy, tight Federal budget and new community sector policy reforms were challenging for Parkinson's Victoria and the not-for-profit community sector as a whole.

There were limited opportunities for new government funding and significant competition in the lobbying space for chronic illness dollars in the lead up to the Federal election.

Despite these challenges, there were minor increases in operating income through donations and general fundraising activities, demonstrating an increase in awareness of, and commitment to Parkinson's, by the community. Government support remained stable, with only a small grant increase received to support the expansion of the **Painting with Parkinson's** Support Group program.

In the Financial Year ending 2013, the Board has approved new staff resources, as well as system development across the organisation. This has increased output, including the growth of Support Group numbers by 17 per cent, and a 12 per cent increase in donations and fundraising income, which is partially offset by increased operating expenditure.

In addition to increased staffing head count, the Board also supported mandatory award increases and the implementation of a management structure at the year's commencement, reflecting the majority of increases in operating expenses for the period.

In comparison to the previous year, there was a lower than expected return on investment, with interest rates recorded at their lowest levels in recent memory.

With the prospect of returns on investment remaining low for cash reserves and other unpredictable income in long term deposits, the Board commenced work in June to develop its first Finance and Investment Strategy. This work commenced with a comprehensive review of the current financial process, policies and procedures; and a commitment in the coming twelve months to restructure and redevelop internal financial systems.

This initiative will run concurrently with a new governance structure to administer a targeted and prudent investment strategy with a share portfolio able to generate a reliable annual income for both research and program investment.

As at the 30 June, Parkinson's Victoria held cash and cash equivalents of \$3,175,069, including amounts held for research and the Parkinson's Endowment Fund.

The Board believes with this strong financial base, the development of an investment strategy and a commitment to a new Strategic Plan in the coming year, the organisation will be able to meet its existing commitments, expand its health and education programs, and contribute to proactive research to improve quality of life outcomes and the pursuit of a cure for Parkinson's.

Adam Conrad - Treasurer - November 2013

Movie Marathon

In October, the Parkinson's community and **Back to the Future** fans came out in droves to see the trilogy on the Astor's big screen and have their photo taken sitting in the Time Machine DeLorean. Almost \$10,000 was raised.



*Parkinson's Victoria staff and volunteers at our
Back to the Future Mega Movie Marathon.*

BEYOND THE MASK

Mildura Support Group hosts *Beyond the Mask II*, resulting in a \$1,400 donation.
A community seminar is also organised (4 May).

3rd May 2013

CHARITY GOLF DAY

Now in its sixth year, the Spring Valley Golf Club's generosity results in a donation of just over \$7,000.

24th May 2013

COMMUNITY SEMINAR

More than 58 people attend an information day on Deep Brain Stimulation surgery for Parkinson's.

30th May 2013

ABOUT PARKINSON'S VICTORIA

Who we are, what we do

OUR VISION

A world without Parkinson's.

Help for today, hope for tomorrow.

OUR MISSION

To provide people living with Parkinson's access to comprehensive, relevant and flexible services, encouraging independence and improved quality of life.

To facilitate and fund research projects which seek to improve both quality of life outcomes for people living with Parkinson's 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 supports are sympathetic and responsive to their needs.

Responsive: We provide timely, accessible and flexible services and supports to people living with Parkinson's, their families and carers and service providers.

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

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

OUR SERVICES

Parkinson's Victoria is the peak body representing the needs and interests of people living with Parkinson's in Victoria.

Through our multi-disciplinary team we provide a range of support services to assist in managing the condition, improve quality of life, and to reduce the impact of Parkinson's on individuals, families and the wider community.

Specific services include:

- Information and advice (through the provision of telephone counselling, fact sheets and information kits, website, resource library and newsletters), and referrals to health specialists.
- Help in accessing government assistance schemes and support.
- Peer support through affiliated Support Groups.
- Professional education of the health sector.

We are also active in the areas of community education, advocacy, research and community awareness.

PATRON

The Governor of Victoria.

BOARD MEMBERS 2012/13

Peter Raymond, *President*
Fred Van Ross, *Vice President*
Adam Conrad, *Treasurer*
Joanna Hill, *Secretary*
Damian Farrell
Professor Meg Morris
Andrew Suggett
Peter Walker (*resigned 2012*)

STAFF MEMBERS AS AT 30 JUNE 2013

Emma Collin, *Chief Executive Officer*
Ian Hosking, *Finance Officer*
Melissa King, *Office Manager*
Judith Mooney, *Development Manager*
Victor McConvey, *Health Team Manager/Clinical Nurse Consultant*
Breanna Wotherspoon, *Health Promotion Officer*
Alisha Chand, *Client Services Officer*
Dianne Rayner, *Client Services Officer/PSP Support Worker*
Lesley Speirs, *Database Administrator*
Jo Berthelemy, *Health Team Administrator*
Joelle Metcalf, *Data Entry Officer*
Pam Fox, *Volunteer Administrative Assistant*

World Parkinson's Day

Occurring annually on 11 April, the birthday of Dr James Parkinson, we marked World Parkinson's Day 2013 with two special events, which each gained significant media coverage.

We launched our very own Parkinson's-specific exercise DVD with a Tai Chi demonstration at Federation Square.

And, *Painting with Parkinson's* founder, Ann Atkin hosted a birthday party for Dr Parkinson's at her group's art exhibition; *A Walk through our Art* at the Kingston Art Centre. Former Prime Minister Kevin Rudd accepted an invitation to 'blow out the candles'!



Kevin Rudd addresses guests during A Walk through our Art, to mark World Parkinson's Day, 11 April, 2013.



Tulip Ball

The 2012 Tulip Ball at the Regent Theatre's Plaza Ballroom resulted in a donation of \$18,200. Since its inception in 2008, the event has raised \$97,000.

MILESTONE:

Three Bunnings charity BBQ's raise almost \$3,000 but not without the support of our amazing volunteers!

MOVEMENT DISORDER SOCIETY

The 17th International Congress takes place in Sydney.

PARKINSON'S VICTORIA INC.

ABN 68 038 728 034
8b Park Road [PO Box 2606], Cheltenham, VIC, 3192
Tel: (03) 9581 8700 Fax: (03) 9583 9952

TOLL FREE: 1800 644 189

WWW.PARKINSONSVIC.ORG.AU