











PARKINSON'S VICTORIA ANNUAL REPORT 2009/10















About Parkinson's Victoria

Our Vision

A world without Parkinson's

Our Mission

That all people living with Parkinson's have access to comprehensive and relevant services, encouraging independence and improved quality of life.

Our values underpin everything that we do.

We are:

- Sensitive to the needs of people living with Parkinson's.
- Accountable to our stakeholders and transparent in the way we do
- Innovative: Valuing new ideas, knowledge, experience and research.
- National in outlook, committed to an effective, vibrant, national organisation.

Our Kev Result Areas

- The provision of innovative, relevant and quality services, which are available to all people living with Parkinson's throughout Victoria.
- Increased public awareness.
- Advocacy which results in better services and improved treatments 3. and quality of life.
- The advancement of Parkinson's research. 4.
- Financial sustainability. 5.
- Excellence in corporate governance.

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 of health professionals 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.

The significance of the Tulip

In 1981, Mr J.W.S. Van Deer Wereld, a renowned Dutch horticulturalist who had been diagnosed with Parkinson's, registered the Dr James Parkinson's Bulb, a prize cultivar with distinctive red and white petals. This was in honour of both the International Year of the Disabled and Dr James Parkinson, who is credited as being the first person to formally recognise and document the symptoms of the condition in An Essay on the Shaking Palsy (1817). Parkinson's was then known as paralysis agitans. The term "Parkinson's disease" was coined later by French neurologist Jean-Martin Charcot. Today, the tulip is recognised as the world-wide symbol for Parkinson's and Parkinson's organisations.

Patron

The Governor of Victoria

Board members 2009/10

Royce Pepin, President AM, MBE, GCSJ, Ph.C

Kate Brown, Vice President

Peter Walker, Chairperson Finance Committee

Fred Van Ross Mary Jones Peter Raymond Brendan Lourey

Staff members as at 30 June 2010

Glenn Mahoney, Chief Executive Officer

Judith Mooney, Marketing and Fundraising Coordinator

Denise Perkins, Administration Officer

Ian Hosking, Finance Officer

Victor McConvey, Parkinson's Nurse Consultant Catherine Watson, Community Development Worker

Michelle Wootton, Client Services Officer

Shelley Pollak, Physiotherapist Lesley Speirs, Database Officer

Jo Berthelemy, Administrative Assistant/Volunteer Coordinator

Jackie Jenkins, Project Worker, Bridging the Gaps and PSP Project

Anne Atkin, Volunteer Librarian

Pam Fox, Volunteer Administrative Assistant

Our affiliated, state-wide Support Groups

Albury/Wodonga Melton Bairnsdale Mildura Ballarat Moe

Beechworth Monash/Glen Waverley

Bellarine Peninsula Orbost

Benalla Painting with Parkinson's

Bendigo Portland

Bentleigh/Bayside **PSP Support Group**

Bright Ringwood Camberwell Rosebud Sale/Maffra Charlton San Remo Cobram Cohuna Shepparton

Colac South Gippsland (Leongatha)

Echuca Swan Hill Wangaratta Eltham Plenty Valley Warragul Warrnambool Essendon Frankston Werribee

Wimmera (Horsham) Geelong Grampians/Stawell Yarra Valley Yarrawonga Hamilton

Young at Park – Geelong Lakes Entrance Young at Park - Melbourne Mansfield

Parkinson's Victoria Inc. ABN 68 038 728 034

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TOLL FREE: 1800 644 189 www.parkinsonsvic.org.au info@parkinsons-vic.org.au

The faces and places of the Parkinson's Victoria community:

(Top) Clockwise from top left: Brenden Judge is smiles all 'round at the Parkinson's Victoria Unity Walk; Awareness Week banners adorn Flinders Street train station; Staff from the Wantirna Health Movement Disorders Clinic; Staff and volunteers during our annual city loop tin rattle; Mayor Steve Staikos with Spring Valley Charity Golf Day Committee Member Terri Farrell, Peter Raymond and Club President, John Philp following the annual Charity Golf Day.

(Bottom) Clockwise from top left: Top to Bottom cyclist John Vaughan-Fowler (who rode from Darwin to Melbourne raising funds for Parkinson's Victoria) on his arrival in Melbourne; Our *Health Team*; One of our youngest Unity Walkers; *Pedal 4 Parkinson's*: Sarah McDonald arrives at Federation Square; Staff from the *Wantirna Health* Movement Disorders Clinic; Bunnings Moorabbin Charity Sausage Sizzle Volunteers; Support Groups during Unity Walk.

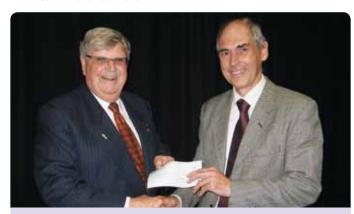
President's Report



| am pleased to report that this past financial year has been one of continued development and achievement. The services we provide for people living with Parkinson's have continued to grow to meet increasing demand. This growth in demand is due to both the increasing number of people being diagnosed, and the success of our community awareness initiatives.

- Service development is fundamental to our mission, and to this end we increased our team of health professionals. We are seeing real benefits already, with major workshops for allied health professionals attracting over 250 attendees from across Victoria. The calibre of our information and education services is a valued resource, not only in Victoria, but nationally and overseas.
- Our advocacy for improved services in western metropolitan Melbourne has seen Western Health fund and resource a Movement Disorder Clinic, enabling people with Parkinson's in the west access to this service for the first time.

The report Living with Young Onset Parkinson's Disease: The issues and impact of Young Onset Parkinson's disease in Australia, commissioned by Parkinson's Victoria, was launched at Parliament House Canberra. One of the major recommendations of this report was the development of a national conference for those living with Young Onset Parkinson's, which Parkinson's Victoria will host in November 2010.



President Royce Pepin presents our research cheque to Professor Mal Horne for the Parkinson's Victoria Research Registry.

• Ongoing quality research into Parkinson's is vital. We have continued to fund the Florey Neurosciences Institute to develop the Parkinson's Victoria Research Registry, and we are pleased to advise that there are now six national research projects accessing the Registry for their respective projects.

Other projects we have supported include Louise Cooper's "Employment and Quality of Life" project through Swinburne University; the Mental Health and Research Institute Brain Bank; and projects with Melbourne, Latrobe and Monash Universities.

There will also be some exciting announcements made in the coming year as we establish annual grants for Parkinson's research projects.

The Parkinson's Victoria Unity Walk continues to grow, with Victoria having the largest participation in Australia, with close to 2,000 people at Federation Square in 2010. This is a wonderful

- opportunity for the Parkinson's community to come together, to raise awareness and much needed funds for research and services.
- The Board has commenced a review of our current accommodation. We have outgrown the leased house we have been in for the past 14 years, and criteria for future accommodation are being developed. This will include accessibility, public transport, functionality and
- Volunteers continue to be the cornerstone of Parkinson's Victoria. Over 300 volunteers have contributed 8,000 hours of service. conservatively valued at \$150,000.



(Clockwise from back left) Royce Pepin, Geoff and Margaret Alexander, Parkinson's Specialist Nurse and Parkinson's Victoria Board Member Mary Jones, Sir Zelman and Lady Cowen.

Geoff Alexander (above) was a most deserving recipient of the 2009 Sir **Zelman Cowen Award** for his outstanding contribution over many years as Coordinator of the Shepparton and District Support Group.

We thank all our volunteers for their dedicated service and friendship.

Financially we are in good shape. We have seen continued growth in income and continue to monitor expenditure carefully. Our thanks to Peter Walker, Chairperson of the Finance Committee, and Ian Hosking, Finance Officer, for their sound stewardship.

It is with sadness that the Board, staff and volunteers acknowledge the decision of our CEO Glenn Mahoney to resign his position due to ill health, and bring to an end 30 years of exemplary service to the not-forprofit sector. Glenn will be leaving us in March 2011. We thank Glenn for the significant contribution he has made to Parkinson's Victoria and the Parkinson's community over the past six years, and wish him well in his future years. I have formed a selection committee and the Board has retained Dakin Mayers and Associates, an executive recruitment firm, to assist us with the selection of our new CEO. We will have the new appointment in place while Glenn is still with us to ensure a comprehensive handover and smooth transition.

I acknowledge the valuable service and contribution of the members of the Board of Parkinson's Victoria. The performance of this organisation is in no small measure due to their hard work and dedication.

In closing, I take this opportunity to thank and acknowledge the service and contribution of all staff, donors, sponsors and supporters over the past year.

> Royce R Pepin AM, MBE, GCSJ, Ph.C President

The Year in Review

Education Services

We have been able to increase our services team in response to increased demand, and now have a multidisciplinary team of health professionals in the disciplines of nursing, social work, physiotherapy and health

We were delighted when two posters were accepted for presentation at the recent World Parkinson's congress in Glasgow.

Parkinson's Ambassador Anne Atkin had a poster accepted on her Painting with Parkinson's project, and Victor McConvey from our Health Team had a poster accepted on Palliative Care and Parkinson's. Victor and Catherine Watson, also from our Health Team, attended the Congress representing Parkinson's Victoria as we ensure our health team is conversant with best practice symptom management and treatments.

People with Parkinson's place high importance on our role of educating health professionals about Parkinson's symptom management, care and most importantly, medication management.

Our Health Team delivered 135 education sessions this year to health professionals in hospitals, community health, nursing homes and respite centres across Victoria.

Our successful series of *Community Seminars* for people with Parkinson's has continued, ensuring we reach out to and deliver education services in regional Victoria. We have also continued to educate GP's about Parkinson's and we are grateful to those GP Divisions throughout the state which have partnered with us to deliver professional development

We thank and acknowledge the Parkinson's specialist neurologists who have given their time to assist us this year, providing their services at these seminars free of charge: Professor Mal Horne, Associate Professor David Williams, Dr Richard Peppard, Professor Bob lansek, Dr Kate Kotschet and Dr Andrew Evans.

Pharmacists have an important role in the health system, and we have partnered with the *Pharmaceutical Society of Australia* in the delivery of Parkinson's seminars to community pharmacists in regional centres across Victoria and metropolitan Melbourne.

Victor McConvey has continued his excellent work collaborating with Palliative Care Victoria to develop Parkinson's and Palliative Care Guidelines, which will be disseminated throughout the sector.



Physiotherapist Shelley Pollak from our Health Team welcomes quests to our first ever dedicated education seminar for Physiotherapists.

Our physiotherapist Shelley Pollak coordinated our inaugural seminar for physiotherapists, with 135 professionals from Victoria and interstate attending the seminar. With the success of this seminar and feedback from participants we will look to placing this into our annual calendar of education events.

Special thanks to Professor Meg Morris, Head of the Melbourne University Department of Health Sciences and Professor Robert lansek for their contribution to this event.

Our *Recently Diagnosed Seminars* are always popular and this year 120 people attended to hear from our panel of experts, and for the opportunity to meet others who were recently diagnosed.

Information Services

Bridging the Gaps was the name of the project providing bi-lingual Parkinson's information in ten languages. Jackie Jenkins, Project Coordinator, did an outstanding job with this initiative, and she continued to promote the availability of the resources to Culturally and Linquistically Diverse (CALD) communities throughout the year. CALD resources were further enhanced by producing audio translations of print materials in Greek, Vietnamese, Cantonese and Italian. Our Ambassadors also promote the resources and our services to non-English speaking community groups by working with translators during their presentations.

Signpost, our quarterly magazine, continues to be highly valued by readers. Circulation has increased and we receive many favourable comments on the quality of the information: Special acknowledgement to Editor Judith Mooney who combines the task with her role as Marketing and Fundraising Coordinator. Our thanks to all contributors to the publication who make it such a quality magazine.

Michelle Wootton joined us this year and her background in Health Promotion has been a welcome asset. Michelle and Catherine Watson have enhanced our information resources and developed our online information. We now have educational videos available via "Parkinson's TV" (YouTube) and we have commenced a Facebook social networking site, with 200 members to date.

We had a record 9,195 visitors to our website in March, our highest ever. Website visitors for the year topped 70,000 for the first time, with many people accessing our content from interstate and overseas.

In the coming year, we will be enhancing our website homepage in order to further improve functionality and provide the opportunity to conduct surveys to gain insight into the information needs and interests of people with Parkinson's.

We responded to more than 6,300 requests for information over the past 12 months via our toll free helpline, email, face-to-face visits and mail.

We continue to develop our library collection and have purchased new shelving to re-locate the collection to the office meeting room. We thank librarian Anne Atkin for coordinating our library service once again this past year.

Support Groups

Our 47 Support Groups continue to provide friendship, peer support and information to people with Parkinson's and their family members across

Support groups provide a vital link with local community health professionals and the general community.

This past year, many groups invited their local Federal and State Members to attend their meeting in order for them to learn more about Parkinson's

The Year in Review

and hear first-hand of the issues and impact of Parkinson's.

Our annual *Support Group Leader Day* was well attended and provided a forum to exchange ideas and meet other leaders with a common goal of reducing the impact of Parkinson's in their community.

Our thanks and appreciation to all Support Group Leaders, their leadership teams and volunteers for the valued contribution they make.

This past year, Warrnambool Support Group celebrated their 21st anniversary. Wimmera celebrated their 20th anniversary and Rosebud their 25th anniversary. Congratulations to you all and may there be many more years of service to come.

Research

We have continued to support the work of the *Florey Neurosciences Institute*, both financially and with recruitment of participants, with a view to developing and growing the *Parkinson's Victoria Research Registry*.

This project has been established to provide an efficient means of bringing together scientists and researchers with suitable participants (both people with Parkinson's and a control group) to advance research.

We continue to support the *Brain Bank at the Mental Health Research Institute*, as well as projects undertaken at *Melbourne*, *Swinburne*, *Monash* and *Latrobe Universities*.

Anne Atkin, in collaboration with the *Swinburne University Faculty of Life Sciences*, is undertaking a research project on the benefits of the *Painting with Parkinson's* program on individual well being. We look forward to sharing the results with you in 2011.



Anne Atkin, Painting with Parkinson's founder.

Volunteers

Volunteers are so important to Parkinson's Victoria. Whether it is volunteering at Support Groups, assisting with administration tasks in our office, presenting as an Ambassador or helping out at fundraising and other events, we are so appreciative of the contribution of all volunteers. Our thanks to Jo Berthelemy for her work in coordinating our volunteer services.

Advocacy

We launched our report into the issues and impact of *Young Onset Parkinson's* at Parliament House Canberra and will continue to advocate for improved services and support for people with Young Onset Parkinson's. Of those diagnosed with Parkinson's in Australia, 30 percent are of working age, and 10 percent are diagnosed under the age of 40.

We are pleased to be chosen to host the inaugural *National Young Onset Parkinson's Conference* in November. Catherine Watson will convene this conference with a working group of people with Young Onset Parkinson's.

Bill Shorten, in his capacity of *Parliamentary Secretary for Disability*

Bill Shorten, in his capacity of *Parliamentary Secretary for Disability Services*, visited our Essendon Support Group in his electorate and learned first-hand of the need for increased funding for services and support.



Bill Shorten was presented with a copy of the Access Economics Report Living with Parkinson's Disease: Challenges and Positive Steps for the Future. Above from left: Bill Shorten with CEO Glenn Mahoney and Essendon Support Group Leader Fred Van Ross during the Group's monthly meeting.

We were pleased that our advocacy initiatives for improving services in Western Metropolitan Melbourne have assisted with establishing a Movement Disorder Clinic in the West. However, we are disappointed that our call for ten Parkinson's specialist nurses to be funded and placed in major regional centres across Victoria has not been acted on by the state government.

In Victoria alone, 15,000 to 20,000 people have Parkinson's. A further six people are diagnosed every day of the year. The burden of disease cost is in excess of \$1.7 billion per year in Victoria alone. This is higher than Multiple Sclerosis, Huntington's Disease and Motor Neurone Disease combined, yet the amount of recurrent funding for specialist case coordination is nonexistent for people with Parkinson's. Parkinson's Victoria receives under \$200,000 recurrent funding from the state government each year for the provision of information services. The shortfall comes from fundraising, donations, bequests and events.

We are asking the state government to fund ten Parkinson's nurses at a cost of \$1.8 million per year to reduce hospital admissions, improve medication management, reduce emergency department admissions, improve quality of life, educate community health professionals and reduce health care costs.

Appreciation

This will be my final annual report as CEO. I will be leaving Parkinson's Victoria in March 2011 due it ill health. I have thoroughly enjoyed my time here and have met many inspiring individuals.

My thanks and appreciation to President Royce Pepin. To all members of the Board, thank you for your support and understanding. To the fantastic staff of Parkinson's Victoria, it has been a pleasure to work with you. Thank you for your commitment, energy and good humour. And to our members, feel confident that your Board and staff will continue to work hard to reduce the impact of Parkinson's.

Glenn Mahoney Chief Executive Officer



Parkinson's Victoria Inc. Abridged Financial Statements 2009 - 2010 Full audited accounts are available to Members upon request

STATEMENT OF INCOME & EXPENSES 2010 INCOME 202,761 Government Grants Interest 60,298 Products Sales 16,692 Membership Subscriptions 41,363 171,017 Donations In Memoriam Donations 66,666 307,674 **Bequests** Education 20,909 Trusts and Foundations 70,047 Sponsorship 6,760 **Events** 168,365 Other Income 5,674 Project Income 35,561 1,717 **Ambassadors** TOTAL INCOME 1.175.504 **EXPENDITURE** Advertising 10,489 **Ambassadors** 2,672 Annual Leave 25,175

Audit Fees

Bank Fees

Catering

Events Insurance

Depreciation

Equipment

Building Maintenance

Computer Costs

Internet Services

Education Expenses

CARRY FORWARD EXPENSES	\$198,151
Merchandise	8,745
Miscellaneous	99
Motor Vehicle	14,052
Parkinson's Australia	23,794
Photocopier Maintenance	1,668
Postage & Courier	18,803
Printing and Stationery	42,612
Rent	19,890
Research	25,000
Salaries and Wages	382,204
Project Expenses	43,604
Staff Amenities	1,653
Payroll Expense	360
Subscriptions	146
Superannuation	30,305
Support Group Expenses	(228)
Telephone & Facsimile	16,364
Training	2,632
Travelling & Accommodation	11,920
Volunteer Costs	1,901
Workcover	4,294
YPH Expenses	23,658
Membership Expenses	95
Books & Publications	608
Awareness Week Expense	4,973
Facility Hire	3,467
Sponsorship	477
TOTAL EXPENSES	881,247
NET INCOME	<u>294,257</u>

ur recurrent government funding represents only 17 percent of our total income this financial U_year . We rely on donations, bequests and other forms of income in order to offset the shortfall needed for service provision. Beguests of \$307,674 represented a welcome addition to our income. While we encourage people to remember Parkinson's Victoria in their will, we cannot rely on this as a regular income stream each year. Our objective is to increase community support and recurrent government funding in order to meet increasing service demand.

4.100

3,464

2,639

16,542

1,095

12,653 106,900

2,471

5,251

2,485

2,215

In June 2006, the Board of Parkinson's Victoria established the Endowment Fund with the objective of securing donated funds to be invested for the purposes of capital appreciation and to produce income to support the mission of the organisation. This is represented in the Balance Sheet Current Assets as \$1,041,067. The Endowment Fund includes income from the following:

Ģ	The Hele	n Sophie	Gerstmann
	Bequest		

- The Henry Newell Bequest
- Mrs P. Di Battista Trust
- The Anastasia Coleman Beguest
- > The Joe White Bequest

- The Phyllis Macgregor Bequest
- The Frances Dumaresg Beguest
- Mr Gordon Moffatt, A.M., KSJ.
- **∽** The Sewell Family
- ∽ The Stella Hansen Bequest
- > The Trevor Scott Bequest

The 2009-2010 financial year end result was a surplus of \$294,257. Our continuing challenge is to build recurrent government income to meet the increasing demand for services, to increase our donor income and to build our membership base, while continuing to monitor our expenditure.

STATEMENT OF FINANCIAL POS	<u>ITION</u>
2010 CURRENT ASSETS Cash and Cash Equivalents Receivables Inventories Other Current Assets TOTAL CURRENT ASSETS	\$ 1,533,453 2,870 5,201 <u>42,455</u> 1,583,979
NON-CURRENT ASSETS Property & Equipment TOTAL NON-CURRENT ASSETS TOTAL ASSETS	44,039 44,039 1,628,018
CURRENT LIABILITIES Trade and Other Payables TOTAL CURRENT LIABILITIES	108,423 108,423
NON CURRENT LIABILITIES Trade and Other Payables TOTAL NON-CURRENT LIABILITIE TOTAL LIABILITIES NET ASSETS	10,810 S <u>10,810</u> 119,233
EQUITY Members Funds Research Funds YPH Funds TOTAL EQUITY	1,222,279 286,506 0 1,508,785

STATEMENT OF RECOGNISED INCOME AND EXPENDITURE FOR THE YEAR ENDED 30TH JUNE, 2010 MEMBERS FUNDS

	Þ
Balance at 30 June 2009	908,080
Surplus/ (Deficit) for the year	316,827
Transfer	(2,628)
Balance at 30 June 2010	1,222,279

STATEMENT OF RECOGNISED INCOME AND EXPENDITURE FOR THE YEAR ENDED 30TH JUNE, 2010 RESEARCH ACCOUNT

	Ψ
Balance at 30 June 2009	<u>285,418</u>
Surplus/ (Deficit) for the year	1,088
Balance at 30 June 2010	<u>286,506</u>

STATEMENT OF RECOGNISED INCOME AND EXPENDITURE FOR THE YEAR ENDED 30TH JUNE, 2010, YPH FUNDS

\$

Balance at 30 June 2009	21,030
Surplus/ (Deficit) for the year	(23,658)
Transfer	2,628
Balance at 30 June 2010	<u>0</u>

Our community

The sum of us

Parkinson's Victoria is the sum of its parts, and it is only when these parts come together that we truly begin to live our mission: That all people living with Parkinson's have access to comprehensive and relevant services, encouraging independence and improved quality of life – as we work towards our vision of a World without Parkinson's

Together, our staff, organisational members, supporters, volunteers, donors and health care partners are a community of passionate, caring, focused and committed people who share one aim: to reduce the burden of Parkinson's on individuals, families and the wider community and improve the lives of those living with Parkinson's. It is only with the support of the wider community that we are able to respond to the increasing need for support, education and information.

The spirit of community, empowerment and hope on which our organisation was founded, and which continues to inspire and motivate us, is bolstered by the continued recognition, involvement and assistance of our wide range of supporters.

We recognize and gratefully acknowledge the role our members and supporters have played over the years and in particular the past 12 months. To each of our members, volunteers, donors, event participants, Ambassadors, Support Group Leaders and corporate sponsors – thank you. Your contribution to our work is valued above all else. It has enabled us to grow as an organisation that provides a valuable service to the community, and with your continued support we will able to maintain the fight to reduce the burden on all those living with Parkinson's.

As long as there is the need to support and empower people living with Parkinson's, to advocate on their behalf, to fund research, to educate health professionals, and reduce stigma, we will be here to respond to this need on behalf of the community. We are better positioned than ever to provide *Help for Today and Hope for Tomorrow*, and we look to the future with confidence and hope.

The past 12 months have been a time of particularly strong growth in the areas of external support, community participation and initiative, fundraising opportunities, and increased awareness.

Fundraising & Special Events

We are pleased to say our calendar of events this year combined regular events, such as our Bunnings Charity Sausage Sizzles, Annual Appeals and Train Station Tin Rattles, with a number of new activities, including Fundraising Movie Nights, Fitness Challenges and Parkinson's Unity Walk. While these events generate substantial income, they also provide opportunities for people to show their support for the cause and to engage with the Parkinson's community. In addition, they provide us with the chance to connect with new supporters, educate the community about Parkinson's, and our role and services, which is vital if people are to access available support.

Public Support

We appreciate members of the public, business sector and community organisations who are keen to support our work, whether with financial



Parkinson's Victoria Unity Walk

2009 saw the launch of Parkinson's Unity Walk during National Parkinson's Awareness Week. The event drew a crowd of just over 1000 people from all walks of life, from all across the state. It was the largest ever gathering of Victorians in support of the Parkinson's cause and raised in excess of \$60,000, which will help us deliver and develop support services and fund research. Parkinson's Unity Walk is set to become a major annual event for the general community and on our awareness and fundraising calendar.

"We loved the very relaxed and family orientated feel to the event - no athletes there to prove themselves with times! It was also very sobering to see the number of people with Parkinson's who participated. We would like to do it again and involve more of our family members."

"It was wonderful being with so many other people in a common cause. I felt so encouraged by my friends joining me - it was a very happy day."

and in-kind donations, by volunteering their time, or organising a fundraising event on our behalf.

We gratefully acknowledge all those who have actively shown their support for the cause by supporting us, and in doing so, validate our valuable role in the community.

Charity Challenge

Our second Charity Challenge (March 2010) saw 4 fit and passionate fundraisers head off to cycle through Vietnam, after reaching their individual fundraising goals and raising more than \$30,000 between them! Thankyou to Ed and Matt Beesley, Dean Edwards and David Gibson.

Charity Challenges generate significant funds and are a unique way for supporters and adventurers alike to make a difference while stretching personal boundaries. Challengers help raise awareness of the cause within their networks and community, generate media stories with their local newspapers and radio station, and organise fundraising events all to the benefit of those living with Parkinson's. Challengers to date have raised close to \$200,000!

Our community



Tulip Ball

The Tulip Ball, established in 2008 and which took place in 2009 at the exclusive Melbourne Savage Club, continues to be a glamorous event that raises significant funds, which are donated to Parkinson's Victoria by event organisers Julie Sewell and Jo Hill. The mission of Tulip Ball Events is to raise awareness and funds to assist people living with Parkinson's disease. Julie and Jo are well and truly on their way to achieving this, with close to \$50,000 already raised and hundreds of people learning about Parkinson's while lending their support to the cause along the way. Congratulations and thank you to Julie and Jo.

Above from left: John Sewell, Judith Mooney (Marketing & Fundraising Coordinator), Jo Hill, Glenn Mahoney (CEO), Julie Sewell and Peter Raymond (Board Member and Ambassador Coordinator).

Communications, Awareness & Media

Thanks to those who have been media spokespeople on our behalf or who have initiated a news story with their local newspaper or radio station and shared their experience of living with Parkinson's. We have seen a dramatic shift in the media's focus in relation to Parkinson's, and it is encouraging and long overdue to see media stories highlight the triumphant spirit of people living with Parkinson's; recognise the value Support Groups have had for local communities; and celebrate creative talents. Working with individuals and journalists, we have been able to also stress key facts and figures about Parkinson's, which complement the personal stories and present a consistent message about the need for increased and improved services and funding.

Volunteers

"Volunteers don't get paid - not because they're worthless, but because they're priceless." Sherry Anderson

If you've been to a Parkinson's Victoria event you've most likely encountered one of our wonderful Volunteers. What you might not know is that we have volunteers behind the scenes too. They help keep the



Spring Valley Charity Golf Day

We are grateful for the ongoing support of the Spring Valley Golf Club and its members. This year's Charity Golf Day boasted another full capacity crowd and raised almost \$10,000 to help fund our services and support programs. Thank you to Club President John Philp (Above with President Royce Pepin) and members of the Charity Golf Day Committee, particularly Terri Farrell and Margaret Hancock for their hard work in organising such a successful event. We also thank the Kingston Charitable Trust and the Lord Mayor's Charitable Foundation.

cogwheels of our office turning smoothly, performing various essential, but often time-consuming administration tasks, such as collating information kits, photocopying and packing Christmas cards! We have also had terrific support from volunteers who assisted at events on our behalf, such as community expos.

We are proud to say our team of Volunteers continues to grow. Today, a volunteer may be a person living with Parkinson's, a university student, an employee from a large or small business or a member of the community looking to make a difference.

We thank those who have helped out at education and fundraising events, especially our early morning train station tin rattles, our Bunnings (Moorabbin) Charity Sausage Sizzles, our Fundraising Movie Nights and Parkinson's Unity Walk. Their professional, friendly and enthusiastic contribution ensures our events run smoothly, but most importantly that the experience for our members and guests is a positive and enjoyable one. We are proud to have our volunteers represent us at these events, and we thank them for *choosing* to volunteer their valuable time, skills and smiles!

Continued on Page 10

Our Supporters

We gratefully acknowledge all those who generously supported us this year*.

Individual donors \$4000+

Mary Kentish Fiona Lourey

Individual donors \$2000+

Paul & Elizabeth Atkinson Matthew & Tara Beesley Deirdre Collier Dean & Kate Edwards Barry Williams

Individual donors \$1000+

RJ Allica Robert Buckle Peter Craig Stuart Cumming Ellen Hall Warwick Hall Pauline Hurley Harold Jarvis Alan Michael Geoff Mitchell Elizabeth Nicol Dorothy Norton Peter O'Dea Sue Ploog David & Mary Shuttle Yvonne Sullivan Edmond Ip & Teh Family Brian & Margaret Weeks

Individual donors \$500+ Daniel Atkin Brian Audsley Stephen Audsley Bruce Barker Fave Clarke Pamela Crosthwaite Caroline Dew George Dore Vicki Duffy Peter & Lesley Dyer Elliot & Beverley Elliott Craig & Amanda Gemmell Leonie Gibson Diana Grav Peter Griffiths Jason Grollo Beryl J. Height Wendy Heisler Rex & Jan Hutchison Mike & Heather Jobling Michael Kirby Tom Matthews The Donald & Jill Morrison Bequest

Allan Penney Margaret Saunders Deborah Smith Phillip Smith Newton & Mavis Thompson Keith Williams Rohan Worland

Parkinson's Support **Groups**

Bairnsdale Ballarat Beechworth/Yackandandah Camberwell Essendon Hamilton Mildura Portland PSP Australia Rosebud Shepparton Warragul Wimmera YAP - Young at Park

Special event hosts & participants

Charity Challenge Ed Beesley Matt Beesley Dean Edwards David Gibson Pedal 4 Parkinson's Sarah McDonald Run Melbourne 2009 Andrew Bromell Jason Cheong Ashlev Deans Michael Dorman Kellie Emmerson Tania Freer Benjamin Higgins Gary Swanton Top to Bottom Bike Ride John Vaughan-Fowler Tulip Ball Jo Hill Julie Sewell

Bequests

Patricia Annie Bauld Frances Mary Castle Robyn Jaap Doreen Merle Gardener Stella Margaret Hansen Audrey MacDonald Trevor Scott Lilly Smith The Joe White Bequest

In Memory of...

Fred Appelbe Valerie Audsley Bruce Bennett Harold Boulnois Ennio Cacchione Chris Chong Edilbert Corsaletti Ken Evely Ronald Fallow Claire Filson Noel Gough Murray Graham Anne Haagsma Keith Hall Janet Hughes Jordanis Ignatiadis William Leek Stephen Leong Elio Martin Shirley Mcutchen Daryl Mooney Nick Plevritis Alex Porteous Noel Tucker Barbara Williams Jim Winchester

In Celebration of...

Margaret Beaver Cassie Goffin Ella Goldberg Kaher (Dolly) Manjit June Oldham Peter Thiele Mr Tabacco

Endowment Fund

The Endowment Fund includes income from the following:

- The Helen Sophie Gerstmann Bequest
- The Henry Newell Bequest
- Mrs P. Di Battista Trust
- The Anastasia Coleman Bequest
- The Joe White Bequest
- The Phyllis Macgregor Beauest
- The Frances Dumaresq Bequest
- Mr Gordon Moffatt, A.M., KSJ.
- · The Sewell Family
- The Stella Hansen Bequest
- The Trevor Scott Bequest

Foundations, Grants & **Trusts**

The Danks Trust Harry Secomb Foundation William Angliss (Vic)

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The Curves (Hampton & Brighton) Dartmore Uniting Fellowship Dawson's Australia Ptv Ltd Deck Bar & Restaurant Deer Park/Sunshine Network Colleagues Dendy Palace Cinemas Diocese of Sandhurst Development Fund Douta Galla Ladies Badminton Club Egialian Association Ego Pharmaceuticals Endota Spa (Brighton Beach) **Evolve Accounting Solutions** Federation Square FHB Holdings Pty Ltd Field Group Financial Planning, The Flash ID Fleetworks Mobilty Florentine Restaurant Friends from Creative Writing U3A Waverley Friends of Morwell Rose Garden. The Geelong Street Rodders Inc George Fethers & Co Trading Pty Ltd Go Shop Around Tours Good Guys Discount Warehouse, The GPG (No.3) Pty Ltd Greensborough Country Womens Association Hancock Victorian Plantations P/I Hawaii Tourism Hawaiian Airlines Heatherhill Primary Heinz Heralds No 2 Group Masonic Masters Highton Amcal Pharmacy IGC Dorel Production InTouch Direct Interchem Pty Ltd James Clyne Accounting John Crane Australia Korowa Anglican Girls' School La Manna Direct

Ladies Probus Club of Rye

Lan 1 Pty Ltd

Landpartners

Langham Hotel, The

Our Supporters

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Latown Sequence Dance Group Latrobe City Council Link Pumps Lioness Club of Yarrawonga Lions Club of Berwick Lions Club of Moorabbin Lotas Pty Ltd Magic 1278 Maroondah City Council Medtronic Melbourne Cricket Club Melbourne Welsh Church Midwood Roses/Treloar Roses Monash-Aires. The Morris Meats Mount Martha Golf Club National Australia Bank Ltd Navarre Football/Netball Club Neurosolutions Nikos Tavern **Novartis** Oil Patch Containers Outrigger Enterprises Group Pallotti College Pascoe Vale Italian Bocce Club, Pathways Australia Pty Ltd Pharmacy Guild of Australia, The Public Trransport Safety Victoria Puma RAPP Ritchies Supermarkets Rotary Club of Ballarat East Rotary Club of Oakleigh Rotary Club of Prahran Rotary Club of Warrandyte & Donvale Incorporated RSL Angling Club Russell Investment Goup Pty Ltd Sandringham Baptist Church Scicluna's Secure Parking Shepparton RSL (Sub Branch) Inc Slape & Sons Sorrento Social Savvys, The South Gippsland Parkinson's Support Group South Gippsland Secondary College Sportstex Pty Ltd SpringValley Golf Day St Andrew Opportunity Shop St Andrew's Uniting Church St Paul's Christmas Card Shop Stirling Fildes

Tabtimer Pty Ltd Telstra Townsville City Council Turks Sports Bar Pty Ltd Ultra Tite Waterproofing Uniting Church - Synod of Victoria & Tasmania Vermont Secondary College Vietnam Veterans Club of Shepparton WAM Personal Training Warrawee Senior's Club Inc Warren Opportunity Shop Incorporated Wattle Valley Golf Club Inc. Wellington Latrobe Lions Club Woolworths/Safeway World Ship Society Victoria Branch Yodgee Footwear

Legal & Financial Support

Bentleys Freehills Maurice Blackburn

Governement

Magistrates Court of Victoria Victorian Department of Human Services

Research Partners

Deakin University Florey Neurosciences Institute La Trobe University Melbourne University Monash University Swinburne University Victorian Brain Bank Network

We would also like to acknowledge all those who gave anonymously throughout the year and all who gave In Memoriam donations. We extend our sympathies to those who have lost loved ones in the past year.

*Covers the period 1 July 2009 to 30 June 2010. Unfortunately, due to the overwhelming number of supporters we are unable to list them all here. Listed are those individuals, organisations and businesses which donated \$500 or more (including those in whose name In Memoriam donations of \$500 or more were received), and businesses which gave in-kind support.

Our community

Continued from Page 8

We also value the contribution of our Volunteer Ambassadors and Support Group Leaders. We especially acknowledge Pam Fox, who has become a greatly valued volunteer member of our Administration Team and Bronwyn Betro who has taken a number of fundraising events to heights we hadn't dreamed of, thanks to her attention to detail, passion for the job and her enthusiasm.

We thank the Herald Sun for the opportunity to run awareness advertisements. We are also grateful to those who requested Parkinson's information for a display in their workplace or local community.

To our members and supporters, thank you for joining with us as we make every effort to initiate and respond to opportunities that will increase public awareness and support, including increased funds to aid the delivery of our service programs.

We encourage you to continue to get involved in our fundraising, special events and awareness programs, whether directly or indirectly.

With your support - we can, and will make a difference for those living with Parkinson's.

Parkinson's Skill Tester

During Awareness Week, in the lead up to Parkinson's Unity Walk, the famous clocks of Flinders Street train station were adorned with eye catching banners, asking the question "Would you walk around the block to support someone with Parkinson's?"

The banners were generously designed by RAPP creative advertising agency.

RAPP's creative team, led by Glenn Dickson and Ruben Ciruqeda, and assisted by Melissa Fullerton, also came up with a novel way to help

the general public 'experience' what it can be like to live with Parkinson's.

The Parkinson's Skill Tester, based on the traditional "arcade" machine, was designed to give members of the general public a personal experience of what it can be like to live with the symptoms of Parkinson's. To highlight symptoms, traditional prizes of soft toys and candy were replaced with 'everyday items', such as milk cartons, mobile phones and remote controls. Passers-by were then encouraged to 'try their luck' using the machine's claw to pick up an item, and the slogan was "Parkinson's Disease makes easy things hard." The concept later won RAPP a Gold Award at the International DMA Echo industry awards in

We are extremely grateful to the RAPP team for giving their time and expertise to help raise awareness, especially during Awareness Week. RAPP continue to support us and we are grateful for their creativity. enthusiasm and commitment.

Swinburne University of Technology

Syspro Software

Support Groups

e recognise the tremendous contribution our Support Groups continue to make to those living with Parkinson's and their families.

To acknowledge all the individual achievements of our 47 Support Groups over the past 12-months would be impossible, mostly because the list would extend well beyond the limits of this page. However, we would like to highlight a selection of initiatives and activities undertaken in the past year.



Catherine Watson (far right) with members of the Moe Support Group during a community education seminar.

Across the state, there are more than 1000 people who regularly attend one of our regional or metro Parkinson's Support Groups. That's a significant number of people to have experienced first-hand the value of peer support and who have benefitted from the friendship, sharing of information and the sense of 'not being alone' that comes with being a member of a Support Group.

Our Support Groups offer individuals the chance to create supportive. interpersonal relationships with members of one's own community. They also foster increased resiliency to face the day-to-day challenges of living with Parkinson's. Members are uniquely able to help others by listening empathically and sharing invaluable coping strategies.

In addition to providing support at the "coalface", there are many Support Groups who have also undertaken fundraising and awareness raising activities in their local communities. We are encouraged by - and value - their enthusiasm and actions which benefit not only their own group, but also Parkinson's Victoria, and which greatly support our own work and initiatives.

- ADVOCACY: Local Members of Parliament accepted invites from their local Support Group to attend a meeting and hear directly from group members - the people that vote - about issues they're concerned about with respect to accessing services and support.
- EDUCATION: Each year, we host major community seminars in locations throughout the state and the success of these events is

very much dependant on the support and participation of the local Support Group.

This year our Ballarat Group did a terrific job promoting and supporting our regional community seminar.

Special mention goes to the *Frankston Group* who undertook the organisation of their own community seminar, and the result was of an excellent standard.

AWARENESS: We are always amazed at the initiative shown by Support Groups during National Parkinson's Awareness Week in September, when they work hard to raise funds for - and awareness of- the cause.

The following groups organised a planting of Parkinson's Passion (our rose) in their local town gardens, with the support of the local Mayor and media: Barwon Young at Park Group (with Geelong Support Group), Moe Support Group (with the participation of South Gippsland, Warragul and our Sale/Mafra Support Groups) and Portland Support Group.

RESEARCH: Many support group members have played an important role participating in research studies.

In particular, a researcher from Monash University visited the Mildura Support Group to work with group members gathering data for a project.

Other groups, such as *Essendon*, have been involved in trials that required ongoing participation over a series of weeks.

Participation in research studies help to advance the understanding of Parkinson's and is another way to get involved, show your support and make a difference.

GETTING CREATIVE: An exciting development to take place within the Support Group environment - and certainly the newest - has been the introduction of *Painting with Parkinson's* workshops, which have stemmed from the recently established *Painting with* Parkinson's support group.

Over the past 12 months, Anne Atkin, Coordinator of *Painting with* Parkinson's, has run many workshops across the State, as part of regular Support Group meetings. Their success has resulted in several smaller art groups being set up within the main support group.

The concept has proven to be not only enjoyable to participants but beneficial, so much so that Swinburne University is currently undertaking a research project exploring the benefits of art as a therapy in relation to Parkinson's.

- FUNDRAISING: Coinciding with the launch of *Victoria's Parkinson's* Unity Walk in August 2009, the Mildura, Warrnambool and Albury/ Wodonga Support Groups each hosted a Walk inviting local community members to take part.
- > VOLUNTEER RECOGNITION: Special congratulations go to Geoff Alexander, leader of our Shepparton Support Group for being awarded the prestigious Sir Zelman Cowen Award for Outstanding Voluntary Service to the Parkinson's Community, acknowledging his years of service to the group.

Support Groups

.Ambassadors



LOCAL SUPPORT: It was encouraging to see Geelong residents, with our support, establish a second Young at Park Support Group (specifically for those diagnosed with Young Onset Parkinson's) and it continues to grow in numbers.

Likewise, the recently formed *Melton Support Group* has really found its feet and continues to flourish.

To all Support Groups who have welcomed new members, provided friendship and support, invited quest speakers, organised social events, raised money and awareness, and spoken with their local radio station or newspaper, we are truly grateful for the work you do for - and with - your local communities.

For those not yet convinced of the positive impact and benefits that being a member of a local Parkinson's Support Group can have, consider this: Parkinson's Victoria itself started 30 years ago as a Support Group. In that same year, a handful of other groups started up in both regional and metropolitan areas and most have stood the test of time. We have recently, proudly witnessed several groups celebrate milestone anniversaries, particularly "25 years of service and beyond". What a tremendous effort and affirmation of the value of Support Groups to those living with Parkinson's.

Whether a group has a long history or is just starting out and finding its feet, the contribution our Support Groups make to the Parkinson's community is to be admired, valued, supported and encouraged. Support Groups and group members successfully provide the most important grass-roots support to people living with Parkinson's and their families; local peer support from someone who not only understands, but can empathise.

Our Support Groups greatly enhance the work we undertake, providing information, support and advocacy. Support Groups and our members are the lifeblood of Parkinson's Victoria and we thank you for your support and contribution.



Parkinson's Victoria conducts annual workshops for Support Group Leaders to provide them with an opportunity to get together, learn new skills and share ideas. (Above) Support Group leaders attend our 2010 Workshop.

here is nothing more powerful than hearing a personal story. Our Ambassador Program provides people with Parkinson's the opportunity to share their story while raising awareness in the general community. These inspirational people honestly and publicly share their experiences - the challenges, heartaches, triumphs and intimate details of living with Parkinson's – with audiences around the state because they are passionate about increasing understanding and support for the cause. Ambassador Coordinator PETER RAYMOND reports.

I am pleased to report once again that after four years, our *Ambassadors* of Hope Program continues to educate and inform the community. Every week an Ambassador, wearing an official Ambassador Polo shirt and armed with brochures, booklets and posters, shares their personal story with a community organisation. They may also be armed with laptop, projector and slideshow. Most important of all will be their sincerity, enthusiasm and good humour, which never fail to impress.

Typically, we receive comments such as "[This] presentation was one of the best I have heard in my 30-plus years involved in service clubs. [The] explanation and insight into Parkinson's was eye-opening, but more importantly was the message of hope and positive outlook.



Peter Raymond during an Ambassador presentation to students at Korowa Anglican Girls School.

Although Ambassadors undertake speaking engagements free-of-charge, it is not uncommon for organisations to be inspired to make a donation to Parkinson's Victoria as a result of an Ambassador's powerful presentation. Over the years we have received more than \$12,000 in such donations. The most common audiences are service clubs such as Rotary and Probus, although in the last 12 months we have been much more involved with linguistically diverse community groups and it is now not uncommon for an Ambassador to work cooperatively with an interpreter.

Since 2006, 38 different Ambassadors have generously donated their time to 233 organisations. While most presentations take place in Melbourne and metro suburbs, 30 percent are in rural and provincial Victoria and we are indebted to those Ambassadors who travel long distances to spread the message and share their story.

The most compelling fact of all is that through our Ambassador Program we have reached out to over 9,000 people. That means 9,000 people who are now more understanding and aware when it comes to Parkinson's.

> Peter Raymond Coordinator, Ambassador Program