## Help for today, Hope for tomorrow



Parkinson's Victoria Annual Report 07/08

### 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. We achieve this by providing information, education, advocacy and support services to all those living with this chronic, progressive, neurological condition, their families, carers and allied health professionals.

### **Our values**

**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 business.
- Innovative through valuing new ideas, knowledge, experience and research.
- National in our outlook. We are committed to a vibrant, national organization.
- Caring for people in the delivery of our services.
- We value integrity through acting with honesty and according to our values.

### **Our services**

Parkinson's Victoria is the peak body representing the needs and interests of people living with Parkinson's in Victoria. 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 (by way of telephone counselling, fact sheets and information kits, web site, resource library and newsletters), and referrals to health specialists.
- Help in accessing government assistance schemes and support.
- Peer support through affiliated Support Groups.
- 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, a renowned Dutch horticulturalist, Mr J W S Van Deer Wereld, 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's, who is credited as being the first to formally recognize and document the symptoms of the condition in *An Essay on the Shaking Palsy* (1817). Parkinson's disease was then known as *paralysis agitans*. The term "Parkinson's disease" was coined later by French neurologist, Jean-Martin Charcot.Today, the tulip has been adopted as the world-wide symbol for Parkinson's and Parkinson's organisations.

Patron

The Governor of Victoria

### Board members 2007/08

Royce Pepin, President AM, MBE, GCSJ, Ph.C Kate Brown, Vice President Peter Walker, Chairperson Finance Committee Sandra Eisner Fred Van Ross Mary Jones Peter Raymond

### Staff members

Glenn Mahoney, Chief Executive Officer Amanda Spillare, Client Services Coordinator Victor McConvey, Parkinson's Nurse Specialist Catherine Watson, Community Development Worker Judith Mooney, Marketing Coordinator Donna Willis, Administration Officer Douglas Rochlin, Finance Officer Denise Perkins, Administrative Assistant Jackie Jenkins, Project Worker, "Bridging the Gaps' Lauren Cowling, Project Worker, "Get Connected" Anne Atkin, Volunteer Librarian

### **Our Support Groups**

Bairnsdale Ballarat Beechworth **Bellarine** Peninsula Benalla Bendigo Bentleigh/Bayside Bright Camberwell Charlton Cobram Cohuna Colac Cranbourne Echuca Eltham Epping (Plenty Valley) Essendon Frankston Geelong Grampians/Stawell Hamilton Horsham/Wimmera Kyneton (formerly Woodend) Lakes Entrance

Mansfield Mildura Moe Monash/Glen Waverley Orbost Parkies with a Purpose Portland **PSP Support Group** Ringwood Rosebud Sale/Maffra San Remo Seymour Shepparton South Gippsland (Leongatha) Swan Hill Wangaratta Warragul (formerly Bunyip) Warrnambool Werribee Yarra Valley Yarrawonga Young at Park

### Parkinson's Victoria Inc.

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### Front cover images

Highlights from 2007/08, from L-R, top row:

- Parkinson's Victoria President, Royce Pepin, with Lady Mayoress of Melbourne, Wendy Cheng and Lord Mayor of Melbourne, John So, at the Lord Mayor's Charitable Fund grant ceremony.
- Volunteers assist in mailing out Signpost, our quarterly newsletter, to more than 1500 members and supporters.
- Rhonda Kennedy, Bendigo Support Group Leader and Winner of the 2007 Sir Zelman Cowen Award for outstanding volunteer service to the Parkinson's Community, with members of her family and Support Group.
- Members of the Shepparton community listen to Dr David Williams during one of the 2007 Regional Seminars.
- Parkinson's Victoria CEO Glenn Mahoney, Jill Goss (co-leader of the Essendon Parkinson's Support Group) and Professor Mal Horne during the announcement of the Parkinson's Victoria Research Register, at the Florey Neuroscience Institutes (formerly the Howard Florey Institute).
- Volunteers collect donations from train commuters during National Parkinson's Awareness Week.
- Banners adorn iconic Flinders Street Station during Awareness Week.

### President's Report

As Parkinson's Victoria moves towards the conclusion of its 27th year, we can look back with satisfaction on the foundation and development of services and support for people living with Parkinson's. We have grown from early, modest beginnings to become a statewide organisation providing quality services and support for people diagnosed with Parkinson's, their carers, families, the community at large and health professionals.

I am pleased to report that this past year has been one of growth and development for our organisation. We are seeing continued growth in the number of people seeking help and support from Parkinson's Victoria, together with the fact that the role of our organisation is becoming better known and understood in the community. This has presented the challenge of providing increased services to meet demand.

The continued involvement and contribution of volunteers is a major strength of our organisation. Voluntary assistance in coordinating Support Groups, supporting fundraising activities, library services, community awareness and office administration is most welcome and appreciated.



Bendigo Support Group Leader and 2007 Sir Zelman Cowen Award Winner, Rhonda Kennedy, with Sir Zelman Cowen (left) and Royce Pepin.

Two years ago Sir Zelman Cowen generously allowed us to name our highest volunteer award in his honour. In 2007, the Award was presented to Rhonda Kennedy, a most worthy recipient, who started the Bendigo Support Group 21 years ago.

For some time we have been aware of the need to produce information in languages other than English for the significant population of people with Parkinson's from non-English speaking backgrounds. To this end, we were delighted to receive a major grant form the Lord Mayor's Charitable Fund for our **Bridging the Gaps** project, enabling the production of Parkinson's information in ten languages.

Our Client Services Coordinator, Amanda Spillare, was awarded a Churchill Fellowship to travel to the United States and UK to study service and support programs for young people diagnosed with Parkinson's. One person in five diagnosed with Parkinson's is of working age, and we look forward to implementing service initiatives for people with young onset Parkinson's over the coming years. We acknowledge and thank the Churchill Trust for making the scholarship available. Research is fundamental to the interests of people with Parkinson's. The launch of the *Parkinson's Victoria Research Registry* has been a positive step forward. The research registry is an exciting, collaborative project between the Florey Neurosciences Institute (formerly the Howard Florey Institute) and Parkinson's Victoria, providing a rich resource



of information to improve our understanding of the condition and as a further resource to improving treatment and symptom control.

Our national secretariat, based in Canberra, has enhanced our ability to lobby the Federal Government for funding for Parkinson's services and support. While we were not successful in achieving direct commitments of funding for Parkinson'srelated services during the 2007 Federal election, there have been several national initiatives that will prove beneficial, improving the knowledge of Parkinson's among health professionals in Australia. Through the support of Parkinson's Western Australia, a comprehensive Parkinson's manual for General Medical Practitioners has been produced. The manual will be distributed freely to GP's across Australia as a means to improve their understanding of Parkinson's. Rural GP's will also have access for the first time to an online Parkinson's education program, to be launched in 2009. In addition, a post graduate neurological nursing course will be offered for the first time in 2009 through the Notre Dame University. Nurses will be able to enrol via distance education, or at the Notre Dame University Campus.



From left: Joint Essendon Support Group leaders Jill Goss and Fred Van Ross, with former leader Ruth Steward and Royce Pepin during the Support Group's 25th Birthday celebrations in 2007.

While we celebrate and acknowledge the achievements of the past year, we recognize and commit to the need to further develop services and support in the face of increasing demand. Your continued financial support is vital.

In closing, I take this opportunity to thank and acknowledge the service and contribution of the members of the Board, volunteers, our Chief Executive Officer, Glenn Mahoney and staff, donors and supporters over the past year.

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

### **CEO's Report**

#### **Services**

We were delighted when two members of our services team were awarded major scholarships that will lead to further service development in the coming years. Client Services Coordinator Amanda Spillare was awarded a *Churchill Fellowship* to study services and programs for people with young onset Parkinson's in the United States and Europe, with a view to developing services in Australia. Parkinson's Nurse Victor McConvey was awarded the *June Allen Fellowship* for Practice Enhancement, an initiative of the Nurses Board of Victoria, to explore services for people diagnosed with Parkinson's Plus syndromes in the United Kingdom.

Other highlights of the year included

- The launch of the **Parkinson's Victoria Research Registry** in collaboration with the Howard Florey Research Institute.
- Our World Parkinson's Day Let's Talk: Parkinson's and Depression seminar, with special thanks to keynote speaker Associate Professor Mal Hopwood. The seminar, sponsored and supported by Beyond Blue, was sold out and greatly valued by attendees.
- Regional Forums for people living with Parkinson's in Horsham and Shepparton, including separate seminars for GP's, improving their understanding of Parkinson's. Our thanks to members of the Horsham and Shepparton Support Groups for their assistance, and to Dr David Williams for his participation.
- The Lord Mayors Charitable Fund major grant, enabling our **Bridging the Gaps** initiative, producing Parkinson's information in ten languages.
- The AUDA Foundation awarded us a grant to develop a web-based information portal, enabling people to access local information via our website.
- The launch of the **Lewy Body Dementia DVD and booklet**, produced in partnership with Alzheimer's Australia.
- In partnership with the Parkies with a Purpose Support Group, we commissioned Dr Chris Fyffe and Jeffrey McCubbery to prepare a report into the housing and support needs of young people with Parkinson's. This



Members of the Art for Parkinson's group getting creative in the studio.

### The Year in Review

has been a valuable advocacy tool in discussions with government and funding bodies.

- The development of the **Art for Parkinson's** program, coordinated by Anne Atkin.
- Fred Van Ross successfully completed the Leadership Plus program in 2007. Parkinson's Victoria is a sponsor of this course, which is auspiced by RMIT to develop the leadership and advocacy skills of people with a disability. Moira Lewis is undertaking the course in 2008.

### **Education Services**

Last year we conducted a survey of people with Parkinson's to identify their main issues. Overwhelmingly, the major priorities were to improve medication management in hospitals and accommodation centres, and to improve the knowledge of community health professionals about Parkinson's.

To this end, in the last financial year we conducted 120 education sessions for health professionals across Victoria. These sessions targeted staff at hospitals, community health centres, nursing homes, aged care centres, respite and accommodation facilities, the Royal District Nursing Service, general practitioners and allied health students. Presentations were also given to Disability Support Workers and Palliative Care Victoria.

One hundred and thirty people attended the Recently Diagnosed Seminar in 2007, one of the most valued seminars we provide in our education calendar. As one attendee commented, "Thank you so much for this seminar. So much good information told in an interesting way. Such a great feeling that we are supported and are not alone."

Following the success of our regional forums last year, we are currently coordinating major seminars for people with Parkinson's and General Practitioners to be held in Traralgon and Geelong in the coming year.



Client Services Coordinator, Amanda Spillare with her **Churchill Fellowship certificate** and Board Member Fred Van Ross.



Dr David Williams, keynote speaker at the Horsham Regional Seminar with Des Hewitt of Warracknabeal and Stuart and Isabel McNally of Donald. Photo courtesy of the Wimmera Mail Times.

### Making a Difference

### **Information Services**

For people diagnosed with Parkinson's and their families, timely, accurate information is a fundamental need. We have responded to more than 5,000 requests for information during the past year. This has been provided via our toll free information line, information packs (newly diagnosed, carers, volunteers, students and health professionals), brochures, emails, letters and via face-to-face visits.

Many people access our website for information, with over 4,000 visitors each month.

**Signpost**, our quarterly magazine, is valued highly by readers as an important information resource. Special thanks to editor, Judith Mooney, and to all who contribute articles.

Our weekly radio program continues to be broadcast on **1179 Vision Australia Radio**, networked across Victoria.

Our resource library collection has been developed over the past year with the addition of new titles. Thanks to librarian Anne Atkin, who has volunteered her time for this valuable service.

### **Support Groups**

Our network of 47 Support Groups across Victoria continues to provide friendship, information and education, and to raise community awareness about Parkinson's. A new Support Group was established in Beechworth, in partnership with the Wodonga Regional Health Service. Following a public meeting, we are hopeful that another group will commence in Melton, a growth corridor in the western metropolitan region.

We were pleased to join with the Essendon Support Group to celebrate its 25th anniversary in 2007.



**2007 Leadership Plus** participant Fred Van Ross (far right) with (from L-R): Parkinson's Victoria President Royce Pepin and CEO, Glenn Mahoney, Leadership Plus Program Director Steven Gianni and 2008 Leadership Plus Program participant Moira Lewis.

We conducted a **Support Group Leaders Workshop** during the year, with representatives attending from across Victoria.

It has been pleasing to see the increasing advocacy role of Support Groups, with many groups making representations to local politicians for improved services and support, and inviting politicians to attend their meetings. Our sincere thanks and appreciation to all Support Group leaders and their teams of volunteers for providing such a valuable community service.

### Research

We continued our support for research with the launch of the Parkinson's Victoria Research Registry. Other projects we have supported over the past year include:

- Deakin University study into the Economic Impact of
   Neurological Disease
- Monash University Parkinson's and Driving study
- Swinburne University Project Employment, Quality of Life and Parkinson's.
- **Falls Prevention** research, undertaken by Melbourne University and sponsored by a grant from the Michael J Fox Foundation.

### Volunteers

We value immensely the skills, experience and friendship volunteers bring to Parkinson's Victoria. Volunteers assist in a variety of roles, including coordinating or assisting in the smooth running of Support Groups, administration, fundraising, auxiliaries and the Ambassador's program. Over the past year, more than 200 volunteers have given an estimated 7,500 hours of service, conservatively valued at \$125,000. We also acknowledge the work of Donna Willis, our Administration Officer who coordinates our volunteer services.



Professor Bob lansek, keynote speaker for the 2007 **Recently Diagnosed Seminar,** with the Parkinson's Victoria Client Services team, Amanda Spillare, Catherine Watson and Victor McConvey.

### **Advocacy**

Until we achieve a significant increase in recurrent government funding, we will continue to advocate vigorously for a better deal for people living with Parkinson's. Current recurrent government funding we receive represents just \$9 for each person with Parkinson's in Victoria, which is inadequate.

The recent Access Economics Report identified the cost-burden of Parkinson's as \$6.8 billion each year, with 25 Australians diagnosed every day. There are more Australians with Parkinson's than MS, Motor Neurone disease, Huntington's disease and Muscular Dystrophy combined, yet state government funding is a fraction of that provided for these other chronic, progressive, neurological conditions. We have made representations to state and federal parliamentarians and departments, forwarded budget submissions advocating for change, and will continue to do so until the inequity is addressed. People with Parkinson's deserve a better deal.

#### Awareness

Improving community awareness about Parkinson's is a priority. There is a perception that Parkinson's is "an old person's condition". This is not the case. 80,000 Australians are diagnosed with Parkinson's: 16,000 of these people are of working age.

During Awareness Week 2008 we will launch new posters, to be distributed nationally, addressing this issue. (The poster can be seen on the back cover of this report). This will coincide with national community service announcements.

We acknowledge the continued support of Nerissa Mapes (diagnosed age 28) in raising Parkinson's awareness and for her fundraising through the POP Foundation she established. We also thank The Age newspaper for giving us free advertising space throughout the year with a commercial value in excess of \$200,000.

We appreciate the support of Connex who continue to provide us with advertising space for banners and posters to promote Parkinson's awareness.

Marketing Coordinator, Judith Mooney has achieved a high number of print and television media stories over the past year raising Parkinson's Awareness.

We have continued to promote the **Get It on Time** awareness campaign, focusing on improved medication management in hospitals.

We appreciate the work of our Ambassadors who continue to raise community awareness through public speaking engagements.

### **Appreciation**

I would like to thank Royce Pepin, President of Parkinson's Victoria and members of the Board for their support. I would also like to thank and recognize the hard working staff of Parkinson's Victoria for the significant contribution they continue to make to reduce the impact of Parkinson's.



Glenn Mahoney, CEO

The launch of the **Parkinson's and Dementia with Lewy Bodies** resource kit during National Parkinson's Awareness Week (2007). From L-R: client Parkinson's Nurse Consultant, Victor McConvey, Parkinson's Australia CEO, Norman Marshall, Professor Bob lansek, Alzheimer's Australia General Manager, Strategic Policy and Projects Jack Sach..

### Spreading the word: the Ambassadors Program

### PETER RAYMOND, Ambassador Coordinator, provides an update on the program's impact during 2007/08.

In my role as the Coordinator of the Ambassador Program, I am pleased to report that once again Parkinson's Victoria has been well-served by its Ambassadors and their professional contribution to community understanding and awareness.

Over the past 12 months, Ambassadors have presented to nearly 600 people in organisations such as Rotary, Probus, Lions, Aged Care Centres, TAFE Colleges, Schools, Churches, the Country Women's Association, Masonic Lodges, Migrant Centres, Carers Groups and Support Groups.

Although the Ambassador Program does not focus on fundraising, some organisations have been so appreciative and touched by the message that they have generously donated to support the work of Parkinson's Victoria.

Most of the activity occurs in and around metropolitan Melbourne but we have also been well-served in Shepparton, Kerang, Gippsland, Warrnambool, Geelong and the Surf Coast.

Parkinson's Victoria supports around 15 registered Ambassadors with audio-visual materials, information and logistical support such as laptop, data projector and overhead projector. Some presentations involve working with an interpreter, which can be a real challenge.

Since the Ambassador Program started in 2004, our Ambassadors have received nothing but praise and positive feedback for being professional informative communicators. They deserve to be congratulated on how well they have "spread the word".

Of course, there are many other people with Parkinson's, particularly in areas outside Melbourne, who are informing and educating the community every day and every week. It's just that we don't hear about their efforts.

If you are one of these "anonymous" Ambassadors, we'd love to hear about your work and the people you have reached. We may be able to help you present more effectively or you may help me and the Parkinson's Victoria staff improve the program. We are always looking for contacts, opportunities and new initiatives.

Certainly, the biggest challenge remains finding opportunities to present.

Please take every opportunity to tell your friends, colleagues and families about the Ambassador Program and if you have any ideas as to how we might expand it, please let us know: Peter (pdr@netspace.net.au) or Donna at Parkinson's Victoria



(03) 9551 1122 or donna@parkinsons-vic.org.au).

Peter Raymond

Peter Raymond, Coordinator of the Parkinson's Victoria Ambassador Program, is also a Board Member of Parkinson's Victoria. Peter was diagnosed with Parkinson's in 2001.

### Financial Report

### Abridged Financial Statements 2007 – 2008.

Full audited accounts are available to Members upon request

STATEMENT OF INCOME & EXPENSES		CARRY FORWARD EXPENSES	\$77,378	STATEMENT OF FINANCIAL POSITION	
2008 INCOME	\$	Merchandise Motor Vehicle	17,358 17,251	2008 CURRENT ASSETS	\$
Government Grants Interest Products Sales Membership Subscriptions Donations In Memoriam Donations Bequests Education Trusts and Foundations	217,421 84,920 39,279 48,939 148114 37281 88,388 18,704 31,426	Parkinson's Australia Photocopier Maintenance Postage & Courier Printing and Stationery Rent Research Projects Salaries and Wages Staff Amenities	28,401 4,410 19,907 41,529 22,308 55,000 374,787 2,552	Cash at bank Cash on Hand Investment account Endowment Fund Receivables Stock Prepayments	21,809 300 509,928 728,610 11,308 11,020 1,139
Sponsorship Events	8,300 10,935	Subscriptions Superannuation Support Group Expenses	1,826 25,310 511	TOTAL CURRENT ASSETS	1,284,114
TOTAL INCOME EXPENDITURE	733,707	Telephone & Facsimile Training Travelling & Accommodation	15,993 4,392 8,274	Plant & Equipment TOTAL NON-CURRENT ASSETS	55,461 <b>55,461</b>
Advertising Annual Leave Audit Fees	1,048 12,654 936	Volunteer Costs Workcare YPH Expenses	562 11,037 12,644	TOTAL ASSETS CURRENT LIABILITIES	1,339,575
Bank Fees Computer Consumables Computer Maintenance Depreciation	3,214 819 14,847 14,843	Membership Expenses Books & Publications Awareness Week Expense Facility Hire	1,685 346 12,688 6,894	Trade and Other Payables TOTAL CURRENT LIABILITIES	182,633 182,633
Events General Expenses Insurance Internet Services	10,881 2,787 908 7,402	Sponsorship Office Expenses	3,234 1,973	TOTAL LIABILITIES	182,633
Equipment Education Expenses CARRY FORWARD EXPENSES	1,385 5,654 <b>77,378</b>	TOTAL EXPENSES	768,250 (34,543)	EQUITY Members Funds Research Funds	1,001,616
				YPH Funds TOTAL EQUITY	32,951

Our recurrent government funding represents only 28% of our total income this financial year. We rely on donations, bequests and other forms of income in order to offset the shortfall needed for service provision. Bequests of \$88,388 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.

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 organization. This is represented in the Balance Sheet Current Assets as \$728,610. The Endowment Fund includes income from the following:

The Helen Sophie Gerstmann Bequest The Henry Newell Bequest The Anastasia Coleman Bequest The Joe White Bequest The Phyllis Macgregor Bequest The Frances Dumaresq Bequest Mrs P. Di Battista Trust Mr Gordon Moffatt, A.M., KSJ.

The 2007-2008 financial year end result was a deficit of \$34,543. Our challenge is to build recurrent government income to meet the increasing demand for services, to increase our donor income, to continue to build our membership base, while continuing to monitor our expenditure.

#### STATEMENT OF FINANCIAL PERFORMANCE - YPH ACCOUNT FOR THE YEAR ENDED 30TH JUNE, 2008

2008 INCOME	\$
Interest	2,819
Donation	
TOTAL INCOME	2,,819
EXPENDITURE	
YPH Expenses	12,644
TOTAL EXPENSES	
SURPLUS (DEFICIT) FOR THEYEAR	(9,825)

#### STATEMENT OF FINANCIAL PERFORMANCE – RESEARCH ACCOUNT FOR THE YEAR ENDED 30TH JUNE, 2008

2008 INCOME Donations Interest	<b>\$</b> 71,388 8,315
TOTAL INCOME	79,703
EXPENDITURE Research Projects TOTAL EXPENDITURE	55,000
SURPLUS/(DEFICIT) FOR THE YEAR	24,703

### Changing hearts and minds

"My husband's symptoms started in his right arm, and there were mood swings and depression. I think Neil had an idea what the problem was, but it was not until we saw the neurologist that it was confirmed as the beginning of Parkinson's.

After being diagnosed in 2003, the neurologist suggested we join a support group. Neil got in touch with Parkinson's Victoria and spoke with one of the health professionals on the team. The information and support was so helpful and gave Neil so much encouragement. We also found out about – and joined – two support groups; Bunyip, which is now the Warragul Support Group, and Moe. We are still members of both.

We received plenty of information in those early days from Parkinson's Victoria and it was good to know that so much is being done to help people with Parkinson's get on with life.

Since then, the team continues to keep us up to date on new services, developments and advances in lifestyle and social welfare. This is why it is so important to be a member.

We get a lot of satisfaction out of volunteering for the organisation. We always have plenty to chat and laugh about, which makes the time fly by. Also, whenever you phone, you always know the voice on the other end is going to brighten your day.

For the past five years we've found the organisation's help, support and friendship great – they've made such a difference. Thank you Parkinson's Victoria.''

Norma

Below left: As part of the AGE newspaper's program of support for worthy charities, Parkinson's Victoria has had the opportunity to run a series of free advertisements in the paper, highlighting the day-to-day impact of Parkinson's, the increasing prevalence of the condition, and the need for community support. Pro bono support of this kind is worth thousands of dollars and greatly enhances our general marketing and awareness campaigns.

Early 2008 saw the launch of the inaugural Team Parkinson's Challenge, where members of the community take on the personal challenge of fundraising for Parkinson's, while raising awareness of the condition within their network. The additional challenge is getting fit and joining a 13 day tour/5 day bike ride through Vietnam in 2009.



From left: President of the South Gippsland Support Group, Noelle Bright, Parkinson's Victoria CEO, Glenn Mahoney, team Parkinson's Challengers Kim Harris and Sue Dutton, and Support Group Secretary, Treasurer and Coordinator Trevor White, as featured in The Star newspaper in May, 2008.

The team currently numbers 18, with a joint fundraising goal of \$120,000.

The Challenge is an innovative and inspiring fundraising and awareness raising

**HELP SHAKE PARKINSON'S** 

Today, 25 Australians will be told they have Parkinson's disease. Your donation will help reduce the impact of symptoms such as tremors, stiffness, impaired balance, fatigue and depression.

Parkinson's Victoria



initiative: The network of "ambassadors" enables Parkinson's Victoria to increase its reach into the community, spreading the message about awareness and increasing funds in ways that we could never do on our own, given our limited resources. In addition, several team members have been featured in their local newspaper – which is valuable in keeping Parkinson's in the public spotlight.

Whether it's helping in our office to pack Christmas cards and newsletters, nominating the organization for a business grant or employee donation matching program, or providing goods and professional services in-kind, our volunteers and corporate supporters make a valuable contribution to our efforts. Without their support, we would not be able to achieve all that we do.



Volunteer Coordinator and Admin Officer, Donna Willis accepts a cheque for \$4000 from Derek Lyons of the NAB, as part of the bank's Employee Volunteer Grants program.

In 2008, we were excited to form a partnership with renowned rose supplier, Treloar Roses, and to announce the launch of **Parkinson's Passion** – an entirely new rose variety named for Parkinson's Australia and all those affected by Parkinson's.

The name was suggested as part of a competition and we believe it's a perfect fit for the vibrant blooms: The orange rose is known to symbolise "passion" and passion is associated with enthusiasm, desire, strong emotions and feeling.

Passionate could also sum up James Parkinson, whose name was given to the condition he first described in 1817. Dr Parkinson was passionate in his work and diverse interests, as well as his commitment to improving the world and the lives of those around him. As an organisation, we are passionate about finding a cure and securing improved services and support for people living with Parkinson's.



As part of the National Australia Bank's Corporate Social Responsibility Program, staff volunteered to assist with our 2007 Christmas card fundraiser by packing cards.

The rose will not only raise awareness, but 10 percent of sales will be donated to Parkinson's Australia to aid the delivery of support and information, as well as research initiatives.

We would like to thank Treloar Roses for their support and also Nola Matuschka, leader of the Portland Support Group, who helped coordinate the partnership between Treloar Roses and Parkinson's Victoria.

Nerissa Mapes was diagnosed with Parkinson's in 2006 at the age of 28.



From left: Parkinson's Victoria CEO Glenn Mahoney holding a cheque for \$4000 from Nerissa Mapes, POP Founder, and Director of the Florey Neuroscience Institutes, Fred Mendelsohn.

Determined to "find a cure in her lifetime", Nerissa founded POP – Perspectives on Parkinson's to raise funds to support research and to provide vital services and information to the Parkinson's community.

We are proud to be one of the official recipients of POP funds and in 2007, on behalf of the organization, CEO

Glenn Mahoney presented Nerissa with a Certificate of Appreciation for her contribution to our work in the community.



City of Kingston Mayor, Bill Nixon, Spring Valley Golf Club President, John Philp, Charity Golf Day committee member, Sue Semmons and Parkinson's Victoria Board Member and Ambassador Coordinator, Peter Raymond during the Spring Valley Charity Golf Day for Parkinson's Victoria.

Earlier this year, we were contacted by Spring Valley Golf Club and informed that we had been nominated as the charity of choice for their annual charity golf day.

This was an unexpected and wonderful opportunity to enhance our fundraising and awareness activities.

We gratefully acknowledge the generous support of the Spring Valley Golf Club for their tremendous support. We would also like to thank the Kingston Charitable Trust, and all our sponsors who contributed to the event's success by donating prizes for the day.



CEO Glenn Mahoney speaking at the Kingston Charitable Trust presentation dinner, where Spring Valley Golf Club presented a cheque to the organization for \$8250. Also pictured are City of Kingston Councilor Topsy Petchey and Spring Valley Golf Club President, John Philp, who has Parkinson's.

"The first time I went to a Parkinson's Victoria meeting, I was newly diagnosed with Parkinson's and very apprehensive. The meeting was held at the organisation's office, then in Springvale Road, Springvale, and the number of staff at that time was two.

I was greeted with friendliness, there was lots of conversation, and when I left, I felt much better about things.

That friendliness has remained through almost two decades of contact, through changes in me and changes in the Parkinson's Victoria team.

From the first contact, I found I was encouraged to live with intelligence and confidence. Acceptance of the diagnosis didn't mean resignation; rather it marked the beginning of new learning. I have learnt about myself, complementary therapies, medicine, and the list goes on. Knowledge leads to confidence, confidence reduces fear, reduced fear reduces muscle tension, reduced muscle tension frees up the body for moving, and exercise improves muscle tone, digestion, and outlook. A nice upward spiral! There is always more to explore.

The information, encouragement and support from the staff and other members have all made a positive difference to my quality of life. Life is better when I allow myself to ask for, and receive help.

At Parkinson's Victoria there are leads to many helpful resources. Talking with members of the team helps in sorting out what assistance is needed and the appropriate steps to take to get it. This is valuable to me now, and may become indispensable in the future.

I enjoy being a regular volunteer at Parkinson's Victoria. I observe that each caller and visitor is greeted with the same genuine friendliness that has made such a difference to me. Even if I don't have frequent contact or many questions to ask, it is reassuring to know these capable people are there."

Liz

# Changing lives

### How you can provide help for today, and hope for tomorrow

Our supporters make a vital contribution to our work in the community. In light of the increasing demand for services, due to the increasing prevalence of Parkinson's, and limited government funding, the support we receive is integral as we strive to respond to this demand, and provide and develop services.

Your support will enhance our efforts to continue to provide education, support and information to individuals, families, the community and health professionals. It will directly improve our ability to fund research into the cause of Parkinson's and improved quality of life strategies. Your support will also enable us to lobby government for improved services and assistance for those affected by Parkinson's.



Brendan McCormick (left) presents CEO Glenn Mahoney with a cheque for \$1500, the result of Brendan's "Fat Quaddies" winnings.

### How you can contribute

There are several ways you can play a valuable part in our work and make a personal contribution to support those affected by Parkinson's:

• **Giving today:** Direct financial support for Parkinson's Victoria to apply wherever the need is greatest. We gratefully receive donations throughout the year and in response to our two annual appeals.

Many choose to mark special occasions in their lives and to remember and honour loved ones with a donation.

- The gift that keeps on giving: We have established an Endowment Fund which allows you to provide a tax deductible gift that "keeps on giving." Donated funds form a capital base and are invested for the purposes of capital appreciation and to produce income to support the mission of the organization. Endowment donors and named endowments are acknowledged in the Annual Report of Parkinson's Victoria.
- Leave a bequest: Making a will is an important part of planning for the future. After you have provided for loved ones, you may like to consider including Parkinson's Victoria

as a beneficiary. This is often a way for those who cannot give *today* – to give *"in the future"*.

- Giving time: There are many ways that Corporate Victoria can help make a difference. Engage your staff in workplace giving and volunteering. Support the community values of your staff with gift matching, sponsorships or gifts in kind – helping with materials and resources we would otherwise have to purchase.
- Stay connected:
   Subscribe to our newsletter and stay up to date with the latest news and initiatives of Parkinson's Victoria.



Team Parkinson's Challenge participant Jenny Young (left) with Liz Bisset. Jenny is a member of Liz's Felting Group, a group of women who meet to socialize and create stunning craft using felt. Liz organized an exhibition of the group's handiwork to help Jenny reach her Challenge fundraising goal.

• Help spread the message:

Request a Parkinson's Victoria Ambassador to speak at your next social or corporate function.

We encourage you to conduct your own fundraising event or awareness raising campaign in your work or personal environment. Parkinson's Victoria welcomes requests for information materials to support these ventures and encourages all those wanting to make a difference to contact us to talk about your ideas.



Volunteers from our 2007 National Parkinson's Awareness Week and World Parkinson's Day tin rattles at Melbourne Connex city loop train stations. Donations from morning commuters for the 2 days raised almost \$7,000 in just 4 hours!

### **Our Supporters**

#### **Our supporters**

Parkinson's Victoria acknowledges, with thanks, the generosity of individuals, community groups, businesses, trusts and foundations for their support\*.

Unfortunately, due to the number of supporters we are unable to list them all here, however we remain grateful for their continued support.

#### Private donors \$500+

Adams D Atkinson P Bowles J Buckle R Gibson L Hannan P Height BJ Laidlaw J & B Madhaven A Morrison D & J Robinson A Timewell P Williams K & M

### \$1000+

Collier D O'Conner S Tedesco J

### \$2000+

Alach D [ Delaney P Moffatt G (A.M., K.S.J.)

#### Foundations, Grants, Trusts

AUDA Foundation Gates Family Trust Handelsman Charitable Trust Lord Mayor's Charitable Fund NAB Employee Volunteer Grant Program The Churchill Trust The William Angliss Charitable Fund The Ruth Fagg Foundation (Victorian Community Foundation)

#### **Bequests**

Estate of Suzan Johnston Estate of Caroline Marston The Joe White Bequest Estate of Harriot Amies

### **Endowment fund**

Moffatt G (A.M., K.S.J.)

#### In memoriam 500+

Pisani M Barr P Bourke P Bower B Burge R Edwards J Gandolfo G Hirt D Jones H Matthews M O'Leary V Robbins K Ward R

ANZ Atkin D Austin | Bradfield M Furnell P Grinlington D Hedstrom | Heisler GÁ Lewis R & M McCoskey D Pitfield G Robinson | Williams B Cumming S Todd B Delahuntly P Kentish M Ward |

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Brear |

Cabassi |

Evans M

Hardley DJ

Horsburgh N

Von Strokirch K

Marston B A

Molinaro A

Perrone A

Wills HI

Bowditch I

Alias Wines All Souls Opportunity Shops Alzheimer's Australia Australian Charity Greeting Cards Ballarat Combined Charities Card Shop Bass Coast Community Health Service Bayside Bentleigh Community Health Service Bayule Support & Information Centre Bellarine Peninsula Health Betts Williams Group Beyond Blue Brainlink Bridging the Gaps project advisory group, The Camberwell Parkinson's Support Group Camcare Canon Central Gippsland Health Service Charity Greeting Cards City of Casey Cobaw Community Health Service Cobram Community Health Service Colac Area Health Community Rehabilitation, Wangaratta Connex Dandenong Magistrates Court Delatite Community Health Service Donation Home Loans Doran Printing East Wimmera Health Service Easywear Australia Elsternwick Private EsiT Pty Ltd European Parkinson's Disease Association (EPDA) Francis Maurice Designs Frankston Combined Charities Christmas Card Shop/Lions Club of Karingal Fred Hosking Gannawarra Neighbourhood House GIO Insurance Gippsland Lakes Community Health Service Goldman Sachs IB Were Hamilton and Alexandra College, The Imagine Just Wright Productions Kingston Centre Kwik Kopy La Trobe Community Health Service Leader Newspapers Leongatha Hospital Lions Club of Moe Maidstone Tennis Club Memorable Challenges Mitchell Community Health Service Moe Parkinson's Support Group Monashlink Community Health Service Mornington Community Information and Support Centre NÁB National IT Solutions Network Ten Nillumbik Community Health Service Novartis OfficeMax Orbost Regional Health Ovens and King Community Health Service Parkinson's Disease Association (UK) Parkinson's Foundation (USA) Parkinson Society Canada Perspectives on Parkinson's (POP) Plenty Valley Community Health Service Portland District Health Service Prime TV PSP Support Group Ritchies IGA

Rosebud Parkinson's Support Group

**Organisation and corporate** 

sponsors and supporters++

AGE,The

Russell Investment Group Pty Ltd Satin Collections SBS Television Seven Network Shepparton Parkinson's Support Group Shire of Campaspe Southaven Day Centre Spring Valley Golf Club St Andrew Opportunity Shop St Paul's Charity Christmas Card Shop St Peter's Anglican Opportunity Shop Suncorp-Metway limited Supply & Demand Company Swan Hill Carer Support Services Tabcorp Wagering Division Terry Hammond Cycles Treloar Roses Trust Company Ltd, The University of Melbourne LIVE Unit (Leadership, Involvement & Volunteer Experience) VCOSS Combined Charities Christmas Shop Vision Australia Radio Volunteering Victoria Wantirna Health Movement Disorder Clinic Warrnambool Parkinson's Support Group Watsons Pty Ltd Webfuture Western Health District Westpac Banking Corporation (community Involvement) Wild about Flowers Wodonga Regional Health Service World Expeditions Yarra Valley Health Care Centre Yarrawonga District Health Service Zouki

### Team Parkinson's Challenge participants

Fred and Christine Van Ross Kim Nicholson Nicholas Taylor Edward Beesley Catherine Watons Leanne Barnes Max Bradfiled Karyn Spilberg Kim Harris Suzanne Dutton David Gibson Brendan Lourey Jenny Young David and Noela Wilson Clare Eizenberg Nahid Jones

### Legal and financial support

Bentleys Freehills Maurice Blackburn Cashman Orr, Martin and Waters

#### Government

Victorian Department of Human Services

#### **Research partners**

Deakin University Florey Neuroscience Institutes La Trobe University Melbourne University Swinburne University 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 the families who lost loved ones.

\* Covers the period 1 July 2007 to 30 June 2008 ++ Donations in kind and financial support of \$500+

# **Guess which one has PARKINSON'S DISEASE?**

# ... They all do!

In Australia today, there are 80,000 people living with Parkinson's disease. 25 more people are diagnosed every day. Parkinson's disease affects adults of all ages. To date there is no cure. Parkinson's Victoria needs your support to provide help for today, and to give hope for tomorrow.

Help make a difference. Donate today. www.parkinsonsvic.org.au. For more information and support call: 1800 644 189

