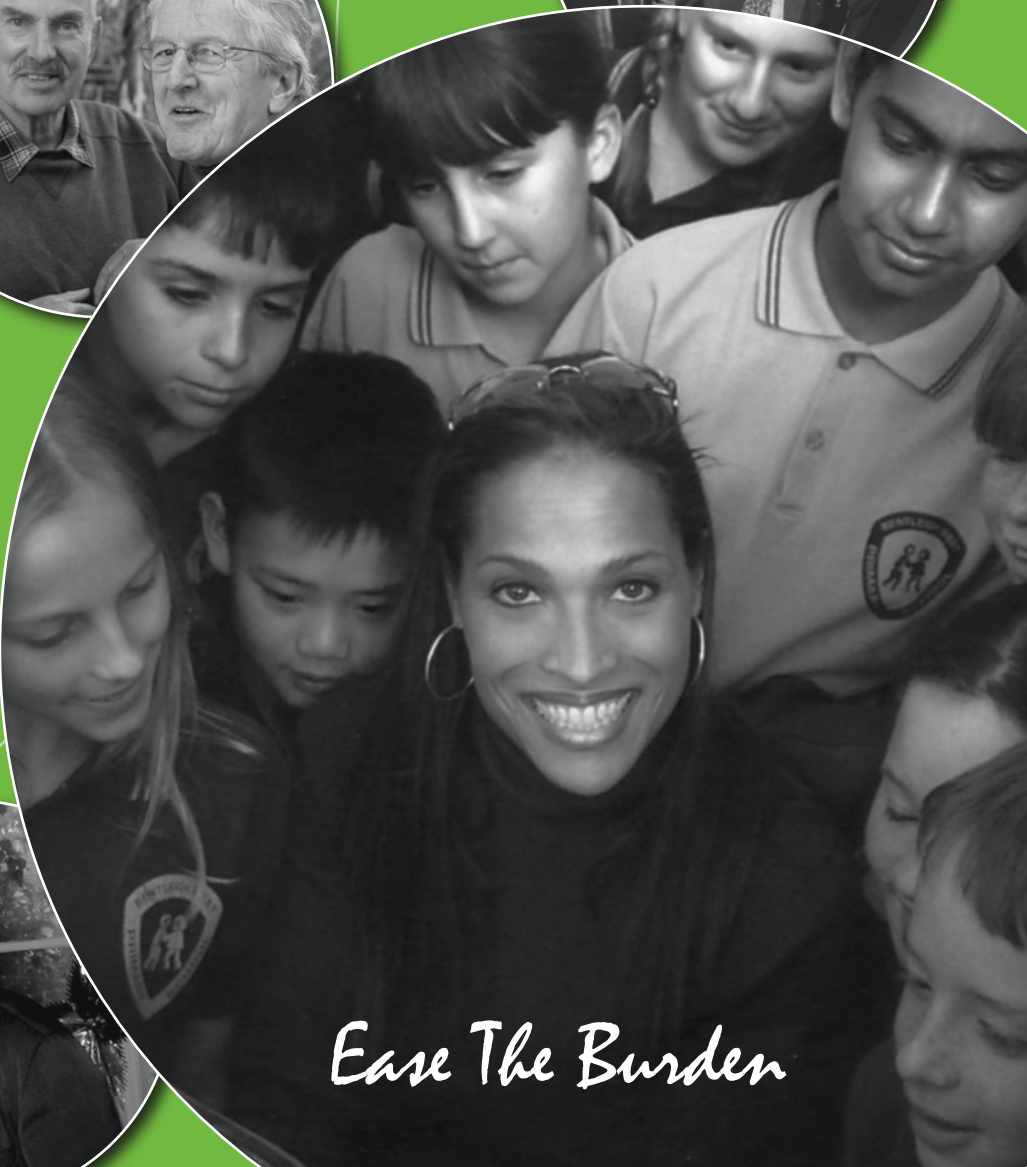




Parkinson's Victoria Inc

Annual Report
2004/2005



Ease The Burden

Vision

To **ENABLE** every person living with Parkinson's to be fully empowered
INSPIRE a community attitude change towards Parkinson's
BE the centre of excellence in reference to Parkinson's

Values

To **BE** customer focussed
BE accountable to our members
BE sensitive to the needs of people living with Parkinson's
THINK nationally
BE fair and honest in all our dealings
DEMONSTRATE vitality, energy and enthusiasm

Patron: The Governor of Victoria John Landy AC, MBE

BOARD MEMBERS 2004/2005

Royce Pepin: *President* AM, MBE, KCSJ, Ph.C

Kate Brown: *Vice President*

*Sandra Eisner

*Fred Van Ross

Mary Jones

Professor Robert Iansek (resigned September 2005)

Peter Venosta

Peter Walker (appointed October 2005)

Stephen Duns (resigned February 2005)

Glenda Stahel (resigned August 2004)

* Representing People Living With Parkinson's Advisory Group



(L-R) Sandra Eisner, Kate Brown, Glenn Mahoney, Royce Pepin, Peter Walker, Peter Venosta and Fred Van Ross. (Missing from photo - Mary Jones)

STAFF MEMBERS AS AT 30 JUNE 2005

Glenn Mahoney: *CEO*

Hani Fernando: *Finance Officer*

Denise Perkins: *Administrative Assistant*

Sue Ryan: *Office Manager*

Amanda Spillare: *Client Services Officer*

Chris Stephens *Client Services Officer*

Vicky Wells: *Volunteer Coordinator*

Jenny Wright: *Manager Marketing and Media*

(Sarah Thomas left us in May, 2005)



Denise, Amanda, Sarah and Hani

Parkinson's Victoria Inc

ABN 68 038 728 034

20 Kingston Rd Cheltenham 3192

Tel 03 9551 1122 Fax 03 9551 1310 Toll Free 1800 644189

www.parkinsons-vic.org.au



Parkinsons fact: On average 19 people are diagnosed each week in Victoria

President's Report



I was pleased to be elected President of Parkinson's Victoria in March 2005. Reflecting on the 2004-2005 financial year, it has been a time of significant change and challenges that are not uncommon in not for profit organizations. We have seen increasing demand on services, unrealistically low levels of recurrent government funding, and an ever-increasing reliance on fundraising to offset a budget shortfall.

In the past financial year, our recurrent government funding for services was \$176,000 through the Victorian Government's Department of Human Services. While we are grateful for this support, it is inadequate. It represents approximately \$7.00 per person with Parkinson's in the state of Victoria, and must be addressed in light of the following:

Parkinson's is second only to Alzheimer's as the most common chronic neurological condition in Australia. In Victoria alone there are over 25,000 people with Parkinson's with a further 19 people being diagnosed each week of the year. The demand on services will increase, as numbers are likely to double over the next thirty years with the ageing of the population.

Twenty per cent of people diagnosed with Parkinson's are "young onset", between thirty and fifty. Thirty per cent are of working age.

In a 1996 burden of disease study undertaken by the Australian Institute of Health and Welfare, Parkinson's cost Australia approximately 26,000 "healthy life" years. This would have increased in the past decade. The economic cost of Parkinson's, both indirect costs to individuals and their families, and the costs to the health sector, is over four billion dollars annually nationally, and one billion dollars in Victoria. Again, this will increase. These statistics are compelling and we will continue to lobby governments for a more equitable deal. It is fair to say that people with Parkinson's feel disappointed with government support to date.

As can be seen from our financial statement, we have had a shortfall of over \$240,000 in our operating budget in the past financial year. This has been addressed by the Board through cost reduction and a balanced budget is forecast for

the coming financial year. We also reviewed the decision to re locate our Head Office to East Melbourne, deciding not to proceed, on the basis that it would necessitate significant borrowings for renovation and operation costs. This was not feasible in light of operating shortfalls. This decision was taken after considerable deliberation, consultation and budget forecasts.

Looking to the future, it is our intention to remain at the Kingston Centre. We have a sound existing partnership with Southern Health at the Kingston Centre, and we are working towards a relocation to purpose built premises on this site when a re development is undertaken over the coming years. Calvary Health Care Bethlehem, a specialist neurological service will be relocating to the Kingston Centre site, and there is already an excellent Movement Disorder Clinic located at Kingston. A neurological precinct will develop with the ability to maximise collective resources.

We will continue to develop statewide services, particularly in regional Victoria. This will be achieved through securing increased recurrent funding, and cultivating alliances and partnerships with existing service providers across Victoria.

We will advocate at the highest levels of public life to achieve the best for people with Parkinson's.

All aspects of our governance and accountability will continue to be reviewed to ensure that we are utilising all available resources, whether they are sourced from government, community, corporate or donor sectors.

We will provide further opportunities for volunteers to be involved across the organization.

We will continue to educate the community about Parkinson's.

The source of strength of any successful organization is its people- staff, community, volunteers, donors and the Board. We acknowledge and value the contribution you make to reduce the impact of Parkinson's on individuals, families and carers.

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

Chief Executive Officer's Report

I commenced with Parkinson's Victoria in May 2005 and have been impressed with the quality and breadth of services provided to people with Parkinson's. Our funding body, Department of Human Services, acknowledge the value of services we provide, yet so much more is possible if we were able to increase recurrent funding to a level People with Parkinson's deserve. I have worked in disability services for over 22 years, and the level of funding supporting the 25,000 Victorians with Parkinson's is inadequate in comparison to what is required, and in comparison with other disability support organisations. The bottom line is this:

In terms of prevalence, incidence, growth in numbers with the ageing of the population, economic cost, burden of disease, disability weighting, use of health resources, loss of productivity due to forced early retirement, Parkinson's is second only to Alzheimer's in chronic neurological conditions, yet we receive significantly less funding.

People with Parkinson's feel let down by their government via the lack of funding Parkinson's receives. Victoria pays a huge price as a result, in hospital bed occupancy, early retirement and pension costs, entering nursing homes earlier than necessary, increasing falls and fracture in the home and diminished quality of life.

Our approach is not to just say, "Look what they get so give us more". Our approach is this. Parkinson's costs Australia over 4 billion dollars per year in lost productivity, healthy life years lost, carers retiring early and direct health care costs. It is escalating. We are asking governments to invest 1.5 million dollars per annum in Parkinson's Victoria so we can do the following:

- Keep people at work longer
- Educate employees and employers about Parkinson's
- Raise awareness to enable people to be diagnosed earlier.
- Enable people to live in their own home longer
- Reduce fractures and hospital bed stays due to falls
- Employ clinical nurse educators to teach at acute hospitals, nursing homes and respite centres to educate staff about Parkinson's medical management. This will reduce bed nights and improve quality of care
- Have a service access worker in each DHS region, improving service pathways, linkages, networking, awareness and access to improved symptom management
- Provide direct cost benefits to the Victorian health sector by optimizing clients health, reducing risk, reducing hospital admissions.
- Revitalize information services
- Support research into the cause and cure for Parkinson's
- Save the Victorian economy money

Parkinson's Victoria will be celebrating 25 years of service in 2006. We want to improve the quality of life for all Victorians with Parkinson's and their families and reduce the health costs and indirect costs of Parkinson's in Victoria.

Services

"Thank you for your advice and prompt response...I've jumped online and checked out the link you provided which was extremely helpful and I have subsequently organised a get together with my siblings to work out a plan of attack. Thank you again for advice and help...you have made this transition period a lot easier for me and my family."

This is typical feedback endorsing the value of our information services for people who are newly diagnosed with Parkinson's. A diagnosis can be overwhelming for individuals and families, and many times we are the first point of contact.

We provide a range of support services for people living with Parkinson's experiencing a range of challenges. These are delivered via telephone, via the Internet, mail and face to face through our support group visits and education sessions. We provide linkage and referral advice to clients for relevant community and specialist services, as well as peer support services enabling people to talk with other's who have been diagnosed with Parkinson's.

Key outcomes achieved over the past year include:

- We responded to over 4,000 requests for information.
- We produced and broadcast a further three interactive satellite television programmes on Parkinson's, utilising the Education Department's satellite television network.
- Continuing broadcast of a half hour weekly Parkinson's programme on Channel 31 in Melbourne
- Enhanced our collection of resources for people from culturally and linguistically diverse backgrounds. Further CALD initiatives will form part of our services planning in 2006.

Through the services of volunteer Agata Rome supported by Swinburne University students we have developed a library database and catalogued library resource materials.

Staff made 68 visits to Support Groups throughout Victoria. Presentations were made on topics such as sleep and Parkinson's, stress management, research, movement disorder strategies and diet. These visits are an opportunity for people to receive individualised help and advice. During 2005, a Support Group needs assessment was undertaken, with the outcomes to form part of our service plan for 2006.

Partnership and alliance development is core to our service model. We ran a number of programs in collaboration with Carers Victoria, Carers links West, Brain Foundation, Strathdon Therapy Group and the Elgin St Centre.



The popular “Recently Diagnosed Seminar” was attended by over 150 people at the Ivanhoe Centre in 2005.

Additionally, we participated in a number of group seminars including a neurological seminar in Woodend, the Progressive Supranuclear Palsy Conference at Kingston and the Adult Day Therapists Conference.

Our commitment to providing education and improving community awareness continued, with over 100 education sessions delivered to community groups and community health service providers.

We continued to support access to specialist services via videoconference technology, with over 50 regional Victorian clients linking with Parkinson’s specialists via Telehealth services.

Volunteers

Volunteers are integral to our ability to meet the growing demands on services throughout Victoria. Over the past year, volunteers have given over 6,900 hours of service, conservatively valued at \$110,000.00 (ABS). The value of volunteers is not solely in the task undertaken, but in the friendship, fellowship and support they give to others, which is priceless. Highlights of the year include:

The launch of the Ambassador program, improving community understanding of Parkinson’s across Victoria.

The volunteers coordinating the 42 Support Groups across Victoria, providing peer support, community awareness, lobbying, information and companionship.

Event volunteers assisting with the Unity Walk, the Recently Diagnosed Seminar and the ‘Parky for Parkinson’s’ Business Breakfast.

Volunteers on the Asian Pacific Parkinson’s Disease Conference Committee under the chairmanship of Ron Eisner.

Administrative Support to our Head Office including reception, mail outs, newsletter collation and distribution, membership renewals and the Christmas Card fundraising project.

We thank each and every one of you for your valued contribution.

Fundraising and Events

We rely heavily on fundraising to offset the shortfall in our operating costs. We also undertake events and activities to improve Parkinson’s community awareness, which is a high priority for people with Parkinson’s. Highlights of the past year include the following:

Awareness Week—(September 5 – 11 2004)

Maggie and Martin’s Wedding to launch the week

TV and radio advertisements promoting Parkinson’s Awareness Week.

The ‘Parky on Parkinson’s’ breakfast at the Hilton on the Park, with guest speaker David Parkin.

Broadcast the satellite television program “Understanding Parkinson’s – The Panel”

Conducted the **Recently Diagnosed Seminar** attended by over 150 people

Christmas Cards – 2004. Sold through Members and through Charity Christmas Card shops

Parkinson’s Business Luncheon in Warrnambool – March 4th, 2005. Hosted by Warrnambool Support Group and supported by Parkinson’s Victoria.

‘Bid for a Bimbo’ – March 18, 2005. ‘Bimbo Deluxe’ owners hosted a unique event as part of L’Oreal Melbourne Fashion Week with \$5,000 from the auction supporting Parkinson’s Victoria

Knockout Parkinson’s Unity Walk – April 10, 2005. In line with international Unity Walks, this walk around Caulfield Park is held the day before International Parkinson’s Day and raised \$9000.00 and significant awareness.

City Loop Tin Rattle – Monday April 11, 2005. To celebrate and highlight International Parkinson’s Day a tin rattle is held at City Loop train stations and raised profile among commuters and \$1754.00 in two hours!

PARKINSON'S VICTORIA INC.

ABRIDGED FINANCIAL STATEMENTS 2004-2005

FOR THE YEAR ENDED 30TH JUNE, 2005

Full audited accounts are available to members upon request

STATEMENT OF INCOME & EXPENSES

2005	\$	EXPENDITURE (CONT'D...)	\$
		Carried Forward Balance	<u>\$162,967</u>
INCOME		Administration	2,375
Grants	70,000	Bookkeeping	34,610
Grants - Other	176,341	Database Management	281
Interest	38,936	Discounts Received	(154)
Products Sales	46,431	Entertainment	313
Membership Subscriptions	29,102	Expos & Trade Fairs	1894
Donations & Bequests	186,494	Fundraising exp.	12,945
Education	8,650	General	160
Other	-	Legal Fees	-
TOTAL INCOME	<u>555,954</u>	Motor Vehicle	-
COGS	<u>32,259</u>	New Premises	-
		Office Expenses	10,111
EXPENDITURE		Photocopier Maintenance	2,104
Advertising	8,305	Postage & Courier	17,828
Annual Leave Entitlements	7,937	Printing and Stationery	14,846
Audit Fees	850	Product Purchases	-
Bank Fees	2,259	Net of Stock on Hand	-
Computer Consumables	14,512	Rent	8,455
Conference Costs	-	Repairs and Maintenance	-
Co-Ordinators Expense	-	Research	63,068
Depreciation	11,921	Salaries and Wages	307,824
Functions & Public Relations	-	Payroll	518
General Expenses	-	Satellite Program	18,867
Insurance	5,251	Service Development	-
Internet Services	1,603	Staff Amenities	1,966
Consultancies	55,207	Subscriptions	841
Education Expenses	5,949	Superannuation	18,399
Interest	29,323	Telemedicine Program	-
Computer Maintenance	4,904	Telephone & Facsimile	16,087
PSP Expenses	4,603	Temporary Staff	-
Planning & Governance	3,800	Training	8,785
Equipment	4,058	Travelling & Accommodation	9,238
Rates	2,485	Volunteer Costs	7,254
Cost of Christmas Cards	11,384	Workcare	11,762
Membership Expenses	726	YPH Expenses	10,000
Newsletter Expenses	9,637	EXPENSES	<u>765,091</u>
CARRY FORWARD		TOTAL EXPENSE	
EXPENSES	<u>162,967</u>	(inc COGS)	<u>797,350</u>
		NET SURPLUS/DEFICIT	<u>(241,396)</u>

STATEMENT OF FINANCIAL POSITION

2005	\$
CURRENT ASSETS	
Cash	236,858
Term Deposit	436,128
Receivables	-
Stock	3,894
Prepayments	15,378
TOTAL CURRENT ASSETS	<u>692,258</u>
NON-CURRENT ASSETS	
Land & Buildings	1,148,463
Plant & Equipment	63,250
TOTAL NON-CURRENT ASSETS	<u>1,211,713</u>
TOTAL ASSETS	<u>1,903,971</u>
CURRENT LIABILITIES	
Provisions	5,167
Creditors	<u>820,967</u>
TOTAL CURRENT LIABILITIES	<u>826,134</u>
NON-CURRENT LIABILITIES	
Provisions	-
TOTAL NON-CURRENT LIABILITIES	<u>-</u>
TOTAL LIABILITIES	<u>826,134</u>
NET ASSETS	<u>1,077,837</u>
EQUITY	
Members Funds	972,892
Research Funds	66,188
YPH Funds	<u>38,757</u>
TOTAL EQUITY	<u>1,077,837</u>

STATEMENT OF FINANCIAL PERFORMANCE - YPH ACCOUNT

2005	\$
INCOME	
Interest	4,698
TOTAL INCOME	<u>4,698</u>
EXPENDITURE	
YPH Expenses	10,000
TOTAL EXPENSES	<u>10,000</u>
SURPLUS (DEFICIT) FOR THE YEAR	<u>(5,302)</u>

STATEMENT OF FINANCIAL PERFORMANCE RESEARCH ACCOUNT

2005	\$
INCOME	
Donations	3,126
Interest	4,378
TOTAL INCOME	<u>7,504</u>
EXPENDITURE	
Bank Fees	-
Research Projects	63,068
TOTAL EXPENDITURE	<u>63,068</u>
SURPLUS/(DEFICIT) FOR THE YEAR	<u>(55,564)</u>

How you can help

Parkinson's Victoria relies on funding from various sources to be able to provide services. Funds that keep our organization operating come from fundraising events, bequests, gifts, donations, sponsorships and through the Department of Human Services. Community support is vital to ensure that we have the funds necessary to be able to continue to provide existing services and create new ones to respond to increasing demand. Many people who support our organization receive services, or have a family member, a close friend or a work colleague who benefits from our services.

Your donation would be most appreciated. Alternatively you might consider leaving a bequest to Parkinson's Victoria in your will. Even a small bequest can make a real difference.

You can support Parkinson's Victoria in the following ways:

- Become a member
- Make a donation for a specific purpose
- Make a donation in memory of a loved one
- Sponsor a research project
- Support our fundraising events
- Sponsor an event
- Leave a bequest to Parkinson's Victoria in your Will
- Purchase our merchandise
- Volunteer across a range of services programmes and activities

All donations over two dollars are tax deductible.

For information on making a donation please contact us on 9551 1122



Parkinsons fact: Parkinson's costs Australia over four billion dollars a year.

My first 12 months with Parkinson's



I am quickly approaching the first anniversary (December 20th) of knowing that I have Parkinson's.

After nearly 3 months off work with what was thought to be the impact of a very severe and sustained bout of arthritis, I fronted up to a specialist physician who was consulting me for the first time with a degree of cynicism. Within 5 minutes I had been informed that I had Parkinson's. My life and my family's lives were subsequently turned upside down.

I was 52 at the time, and had been employed as Chief Executive of Kyneton District Health Service (I resigned shortly after diagnosis).

Within days of diagnosis, I became very well informed about Parkinson's, mainly by virtue of the internet. I quickly learned that Parkinson's was far more than having a blank face and tremors – potential symptoms are many and varied – the disease profile varies from day-to-day and from person-to-person.

My initial contact with Parkinson's Victoria was very informative and productive, courtesy of a knowledgeable and caring client services officer, Amanda Spillare. It was suggested by her that I seek services through the Movement Disorder Program at Peter James Centre in East Burwood. The services of this valuable program have been paramount to me dealing with issues of Parkinson's. After 10 weeks of weekly visits, I wondered - why don't we have these services available in western metropolitan and rural areas? I have since learnt that many others share this view.

In hindsight I was fortunate to obtain a quick and accurate diagnosis from my medical team. I have since found that diagnosis can take a long time due to lack of awareness about Parkinson's.

The personal impact of Parkinson's has been significant:

- Simple personal tasks such as eating, dressing and bathing were affected; I have learnt what frustration is – basic skills that are “here-today gone- tomorrow”.
- I have not been unable to continue to work due to the symptoms (my mental alertness,

literacy and numeracy dexterity have all deteriorated greatly);

- I didn't realise how crucial balance was;
- I have lost some personal independence;
- I must plan more – where I am going and what I am likely to be encounter;
- There is an array of financial issues – obviously my financial situation has been impacted upon significantly. Superannuation laws and eligibility to social entitlements are built around a minimum retiring age of 55
- I have learnt that Parkinson's impact is not merely the physical symptoms but the mental and psychological;

Early-onset Parkinson's causes huge stresses to those who consider themselves not yet ready for retirement. The diagnosis itself is a big enough factor in its own right, but on top of this I had to deal with leaving work, changing personal relationships, and the frustration of dealing with a myriad of financial issues.

Parkinson's has dominated my family's life for long enough. I believe that a big part of dealing with Parkinson's is trying to keep your mental and physical fitness at their highest levels - keeping active and maintaining a reasonably strenuous exercise regime. I have achieved this in the form of bike-riding and walking.

The challenge is to think in terms of what you can do or continue to do rather than what you can't do.

My wife and family have been wonderful and strong for me, and we having regular chats of how “we” live with Parkinson's.

Looking back over the last 12 months I now see that I have merely commenced the journey of dealing with Parkinson's. Looking forward is often difficult. However, I have adopted an attitude that Parkinson's is not going to keep on putting a “steady squeeze” on me – I will continue to confront the challenges head-on; although some days I would like a rest from the many rituals that have become necessary as part of living with Parkinson's.

Brendan Lourey

Sponsors, Supporters and Partners

AAMI
ABC Radio
3MMM Radio
A & M Buxton Foundation
Andersen K
Andrew Wiseman
ANZ Bank
Ararat North Primary School
Australian Pops Orchestra
Avondale Primary School, Essendon
Bafam P/L
Bayside Community Health Services
Bairnsdale Primary School
Bendigo Advertiser
Bentleigh West Primary School
Bellarine Penninsula Health
Bimbo Deluxe
Bolton M
Bunnings Hardware
Bunyip Community Health Centre
Camberwell Primary School
Caravan Industry Australia
Carrum Bowling Club
Channel 31
Chris Robie, Valuer
City of Kingston
City of Stonnington
Close Family
Cobram Community Health Service
Colac Area Health
Comet Hill Primary School, Bendigo
Community Rehabilitation, Wangaratta
Connex
Cranbourne Primary School
David Kestel
Delatite Community Health Service
Department of Human Services
Donation Home Loans
Edgerton, J & G
Eltham North Primary School
Essendon Support Group
Fairfax newspapers
Fernstar P/L

FHB Holdings
Fiona Lourey
Frankston Support Group
Gala Spectacular Committee
Gippsland Community Health Services
Glen Iris Primary School
Glen Waverley Secondary College
Golf Retreats
Harvey Norman P/L
Herald Sun Newspaper
H M Amies
Horsham High School
Jean Austin
Jill Morrison
JLC Valuers
Kingston Centre
Kingston Heath Golf Club
Kyabram Secondary College
LaTrobe Community Health Services
Leader Newspapers
Leonard Joel Auctions
Leongatha Secondary College
Longwarry Primary School, Bunyip
Lorraine McKenzie Memorial Fund
Lord Mayors Charitable Trust
Macedon Ranges Shire Council
Mentone Park Primary School
Miles family
Mildura Secondary College
Mitchell Community Health Services
Monashlink Community Health Services
Mrs McCreary
National Australia Bank
National Nine Network
Network Ten
Newspix
Olympic Fitness
Paul Atkinson
Paul Newman Charitable Fund
Peranbin Primary School, Benalla
Pericles Films
Pleasant Street Primary School, Ballarat
Plenty Valley Community Health Services
Portland Betta Electrical
Portland District Health Services

Powercorp Australia P/L
Prime TV
Retravisision, Rosebud
Rosebud Primary School
Rosebud Support Group
Roy Johns
San Remo Community Health Services
Seven Network
SBS Television
Sensis P/L
Schools Television, Education Department
Seymour East Primary School
Shepparton High School
Shepparton Support Group
State Trustees
Stawell Secondary College
Stevensville Primary School, St Albans
SouthEast News, Cranbourne
Southern Cross Ten
Southern Health
South Gippsland Support Group
St Andrews Anglican Church, Brighton
Tate Street Primary School, Geelong
The Estate of Muriel Ellen Agnes Bolton
The Estate of Anastasia Coleman
The Estate of Sophie Gerstmann
The Estate of Juergen Ricke
The Estate of Edward Eric Rodda
The Estate of Joe White
Tim's Bookshop, Canterbury
Tom Atkin
Unity Walk Committee
Wangaratta West Primary School
Warracknabeal Secondary College
Warrnambool East Primary School
Warrnambool Support Group
Werribee Primary School
William Angliss (Vic) Charitable Fund
WIN TV
Woodend Primary School
Working Dog Productions
Wynne H
Yarra Junction Community Health Services
Yarrowonga Primary School

Government

Australia Department of Family and Community Services
Department of Human Services, Victoria
Department of Justice, Victoria

Legal, Financial and Administrative Services

Clayton Utz – Solicitors
Orr, Martin and Walsh – Auditors
Deloitte Touch Tohmatsu – Solicitors
Rose Lawyers

Research

Swinburne University
Monash University
Brain Foundation
Deakin University
Howard Florey Institute
Michael J Fox Foundation

Sponsors and Participants in

'Parky for Parkinson's' Breakfast

Darling Park
Kingston Heath Golf Club
Golf Retreats
Menz Club
IT Solutions
Ryder Communications

Sponsors and Participants in the Unity Walk

Meditext
Wimmera Support Group
Joe Boyar
Smorgon Steel
Gott Family Trust
DFP Recruiting



Have you considered leaving a bequest in your Will to Parkinson's Victoria?

Your bequest will assist in the provision of services, education, support and information to all people living with Parkinson's and research to help find a cure for this chronic debilitating condition



Parkinson's Victoria thanks every-one for their generous support during 2004/2005