



ROUND THE BAYS
659
10km Fun Run and Walk



ANNUAL REVIEW

2012

OUR MISSION

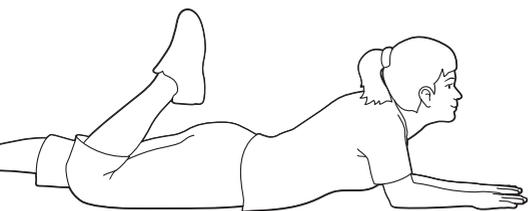
To provide support, education and information for people with Parkinson's and Parkinsonism conditions, their families, carers and health professionals.

OUR STRATEGIC OBJECTIVES ARE

-  To ensure Parkinson's New Zealand is a reflective and well-managed organisation which works efficiently and effectively.
-  To provide accessible and authoritative information, education and support services for people living with, affected by and treating Parkinsonism conditions.
-  To raise awareness of Parkinsonism conditions and of Parkinson's New Zealand.
-  To ensure that Parkinson's New Zealand is the leading, credible and expert voice in New Zealand on Parkinsonism conditions and the experiences of those affected by them.
-  To initiate and support medical and social research.



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THEME FOR 2012

 KEEP MOVING



The cover of the *Keep moving* publication

The theme for Parkinson's Awareness Week 2012 was the importance of exercise for people with Parkinson's. As part of this, a new resource was created intended to encourage people with Parkinson's to increase their activity levels. *Keep moving: an introduction to Parkinson's and exercise* provides information about the importance of exercise for people with Parkinson's and a poster of simple exercises they can follow at home.

We were fortunate to have the endorsement of Sir Peter Snell when publicising this booklet. Sir Peter said "Exercise is extremely important for people with Parkinson's. If you have Parkinson's ask for a copy of *Keep moving*. If you know someone with Parkinson's you can help them by joining them when they exercise."

Keep moving was officially launched at an event at Parliament in The Banquet Hall by Dr Jackie Blue, MP. Dr Blue is the Deputy-Chairperson of the Health Select Committee. Posters were circulated by the divisions and displayed in libraries, doctors' surgeries, at shopping malls and other places where they would be seen by people with Parkinson's. A number of bus companies displayed over 1000 posters in buses around the country. Local papers were contacted and stories placed about the importance of exercise for people with Parkinson's. The result of this publicity is that over 4,000 booklets have been sent out to date.

The theme of exercise has also been carried through to *The Parkinsonian* where a different exercise is featured in each edition. Parkinson's New Zealand is extremely grateful to Jessie Snowdon who wrote the booklet. Jessie is the physiotherapist for the MS and Parkinson's Society Canterbury.

CHAIRPERSON'S

REPORT

After the 2012 AGM, Marg Adamson was elected Chair of the Board. Unfortunately due to ill health she stepped down in November. It was at that time that I took on the role of acting Chair after being co-opted to the Board in September.

During 2012 Parkinson's New Zealand continued to embed the role of the clinical lead within the organisation. The clinical lead's role is not just to support field officers, but also to ensure we are legally compliant. The employment of the clinical lead has been a big investment for the organisation, but one which we needed to make. The board at the time was aware that this investment could lead to deficits in the coming years but were confident that these could be covered by money the organisation had been building up in reserves in preparation for this.

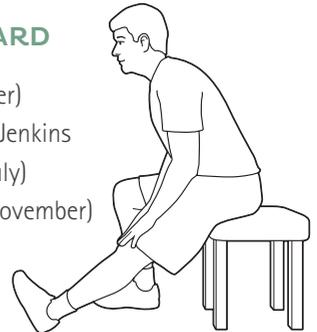
2012 has been a challenging time for the organisation. There have been a number of changes to legislation we have had to be aware of. The Gambling Harm Reduction Amendment Bill went before the select committee during the year. The outcome of this could impact on both our local divisions and National Office who are all reliant on the existing local trusts for funding to enable them to provide services. The Board signed off on a submission which was also presented orally to the select committee for this Bill by our Chief Executive Deirdre O'Sullivan. Our concerns were mirrored by many other well respected organisations in the community who also felt that this Bill required more work around how the funds are distributed to ensure we were not disadvantaged.

I would like to take this opportunity to thank all the volunteers who make our organisation great. From the people who work on a local level as committee members, fundraisers or who help with support group meetings and social activities, to Parkinsons' New Zealand's Board. We greatly appreciate all that you do.

Judi Weir (acting chair)

PARKINSON'S NEW ZEALAND BOARD

- 👤 Marg Adamson, Chair (resigned November)
- 👤 Dr Gary Cheung 👤 Nick Dangerfield 👤 Kathy Jenkins
- 👤 Florence Leota 👤 Mike Lynch (co-opted July)
- 👤 Fiona Mathieson 👤 Michael Sinclair (co-opted November)
- 👤 Judi Weir (co-opted September)



CHIEF EXECUTIVE

REPORT

During 2012 Parkinson's New Zealand continued to focus on being at the forefront of our field and improving our services to members. Some of these new and innovative initiatives are outlined in the following pages.

Parkinson's New Zealand was one of the first organisations to employ a clinical lead in 2011. The next big part of this programme is to develop a national database to hold both client records for the field officers and membership records for the administrators.

Parkinson's New Zealand continues to be a leading voice in the Parkinson's world. In 2011 I was invited to sit on the Communications Committee for the World Parkinson Congress to be held in Montreal in 2013. I also sit on the organising committee for the 9th Asia Pacific Parkinson's Association meeting which will be held in Sydney in June 2013.

Parkinson's New Zealand's presence at Parkinson's Australia's conference in Brisbane, July 2012 was well received. This included two of our field officers giving presentations.

Like many of our divisions, National Office also finds raising sufficient funds a challenge. During this first full year of our appeal programme I am pleased to see that this is showing good potential. The next step is to offer this to all of our divisions.

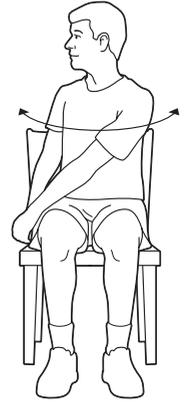
At the 2012 AGM the PSNZ Council passed a remit moving Auckland services from a division structure to a branch structure. Prior to the AGM 10 meetings were held where Auckland members were invited to meet with National Office staff to discuss the proposed changes. The proposal was responded to positively by members. My thanks to the staff in Auckland and National Office who have all worked to ensure the changes had minimal impact on services.

I spent much of 2012 on parental leave and I would like to thank the wonderful staff who worked so hard during this time.

Finally, I would like to thank those individuals, trusts, foundations and businesses who have continued to support us throughout the year. Of special note are our volunteers around the country; without your help we simply couldn't continue to provide the quality service we do.

Deirdre O'Sullivan

PROVIDING INFORMATION



Parkinson's New Zealand provides a wide range of information for people living with Parkinson's including: our regular publications *The Parkinsonian* and UPBEAT the newsletter for people with early onset Parkinson's; booklets, factsheets and leaflets that give information on Parkinson's, detailed guides to aspects of the condition; daily living advice; and information about how Parkinson's New Zealand can help.

A focus for Parkinson's New Zealand this year was making our new and existing publications more accessible. In this digital age we have the opportunity to make it easier for people to use the information we provide. We have done this in a number of ways.

INTERACTIVE PDFS – these PDFs have live web links embedded in them. This enables readers to click a link in the document to find out further information.

DOWNLOADABLE E-BOOKS – with the increased use of e-book readers and tablets, e-books are a new way for people to access our information. Once an e-book file has been downloaded onto a compatible device it can be read at a time and place that suits the reader. This is not only a new initiative for Parkinson's New Zealand, it is a largely unused format for organisations like ours. Our first e-book publication was December's edition of *The Parkinsonian* and in the coming year we intend to convert many of our older publications to e-books.

SOCIAL NETWORKS – Parkinson's New Zealand has had a presence on Facebook and Twitter for a number of years.

In 2012 Parkinson's New Zealand was one of the first New Zealand charities to sign up to HealthUnlocked. Our members had wanted an online space where they could meet, ask questions, share experiences, support one another and learn from each other. HealthUnlocked offered this space and our members are actively supporting each other and finding comfort in talking to others in a similar situation.

FIELD OFFICER SERVICE



In its National Review (2009 – 2010) Parkinson's New Zealand recognised that to remain a lead player in providing support services to people with Parkinson's the Field Officer Service needed to be further developed.

During 2012 the Clinical Lead worked on developing quality initiatives such as standardised processes and procedures. This is to ensure people living with Parkinson's receive the same high quality information, help and support regardless of where they live in New Zealand.

Professional development planning for each field officer was undertaken to ensure they reached the requirements of Parkinson's New Zealand's competency framework. Field officers who are registered nurses but do not hold a current Annual Practising Certificate (APC) were supported to attend courses to enable them to regain their APC. This work is not only to support our field officers, but also to ensure we are legally compliant.

Division committees are also assisted by the clinical lead. The clinical lead reviews all applicants for field officer roles being advertised and assists the local committee to shortlist candidates. The clinical lead attends the interviews and works with the committee to ensure the best possible candidate is employed. All field officers newly employed must now hold a relevant qualification.

FIELD OFFICER CONFERENCE

Twenty five field officers attended the 2012 Field Officer Conference held in Wellington in September. This two day meeting provides training and an opportunity for field officers to network with their colleagues from around the country.

Speakers at the conference included: Lorraine Macdonald who presented on Parkinson's medications and the criteria for DBS; Sara Lo from the Privacy Commission; Psychologist Lizzie Kent who spoke about intimacy and sexuality; Tara Martin, Physiotherapist and LSVT-BIG instructor; Garth Wyatt from the Health and Disability Commission; and Katherine Reweti-Russell who presented on Tikanga Maori.

Workshops were also held introducing the field officers to the new forms that had been produced to improve service quality, and on developing nursing portfolios.

UPBEAT



UPBEAT is the programme for people with early onset Parkinson's. These are people diagnosed with Parkinson's before the age of 60. There were two highlights this year for UPBEAT members.

UPBEAT CONFERENCE

Held at Auckland's Waipuna Lodge in March, the UPBEAT National Weekend was well attended by 44 people with early onset Parkinson's and 26 carers. These weekends provide important information, education and fellowship for the attendees. Many friendships are formed at these weekends and it is an opportunity for newly diagnosed people and their partners or carers to talk to others who have experienced what they are going through. Feedback after the weekend from attendees was overwhelmingly positive.

We were fortunate to have a number of excellent speakers at the conference. Physiotherapist Tara Martin talked about the new physiotherapy programme for people with Parkinson's based on the Lee Silverman Voice Treatment (LSVT) called LSVT-BIG. Neurologist Barry Snow's keynote address covered the Parkinson's therapies available today and those under development for the future. Dr John Parsons from the School of Nursing at the University of Auckland presented on Goal Setting and spoke about how a person's goals will often need to change once they have been diagnosed with a condition like Parkinson's.

UPBEAT OUTWARD BOUND

Nine UPBEAT members, three of their partners and two Parkinson's NZ field officers attended the 2012 Outward Bound course. Over six days they pushed their physical and mental limits, challenging themselves to do things they never thought they would attempt.

Dorothy Wallace from Hamilton said "I was challenged every day and, looking back, feel proud of my achievements and have the confidence to try new things and not let fear of failing rob me of new experiences."

Parkinson's New Zealand would like to thank Douglas Pharmaceuticals whose ongoing support makes this course possible.



RAISING AWARENESS



Throughout the year, Parkinson's New Zealand raises awareness in many ways. In advance of 2012's Awareness Week 2000 posters were circulated around the country. Local media carried stories, many with a person's first hand experience of Parkinson's and local divisions were provided with materials to display on awareness stands at libraries, shopping malls and other public places.

Finding new and innovative ways to increase awareness of Parkinson's is often a challenge. Coffee cup lids have a lovely bit of advertising space on them. So this year, as part of Awareness Week, we produced 10,000 coffee cup lids (the same number as the estimated number of people in NZ with Parkinson's) with a message about Parkinson's on them. These lids were provided to the divisions to circulate in their area.

Research has shown that the average time a person spends holding a takeaway coffee is 37 minutes and they will view a message on the lid at least 20 times. So this was seen as an excellent way to improve awareness of Parkinson's and drive people to our website.

The campaign was linked to the recently published research that suggested that coffee may one day be used to treat Parkinson's. An image of the coffee cup lid sticker on the front page of our website directed people to the research article and raised awareness of Parkinson's New Zealand.

We are not aware of any other charities in New Zealand who have used coffee cup lids in this way. This awareness campaign was very well received by both the divisions and the general public.

AROUND THE COUNTRY

PROMOTING EXERCISE

Exercise is extremely important for people with Parkinson's. People with Parkinson's often experience physical changes to their body which, over time can lead to a forward bending posture and stiffness throughout the body in joints and muscles. These changes occur slowly and with the right sort of regular exercise the onset of these changes can be significantly delayed. Because of this, most divisions run general exercise groups for people with Parkinson's in their area. These groups are designed to provide exercise regardless of the participants' ability.

There are some activities that are considered to be particularly beneficial to people with Parkinson's. Many of the divisions also offer these activities to their members. These activities include: Yoga, Tai Chi, Nordic Walking and Pilates.

SINGING FOR PARKINSON'S

Singing can help improve the speech of people with Parkinson's. It can also lift people's moods and is a good social activity. To promote this some of our larger divisions have set up singing groups, or joined forces with other organisations to create choirs for members to sing with. These choirs often perform concerts for other groups in the community or at their division's Christmas function.

FUNDRAISING

Our divisions couldn't operate without raising the funds they need to cover their expenses and employ their field officers and administration staff. There are always the tried and tested fundraisers like sausage sizzles, raffles, garage sales and street collections. However we wanted to highlight some of the more interesting or unusual fundraising initiatives undertaken during 2012 which include: a local division member who raises money for the division acting as Santa at Christmas parties; two divisions produced items to sell at Christmas, one a calendar, the other a cookbook; a number of division have held theatre nights; one division teamed up with a pizza shop who donated \$1 from each pizza sold on a charity night to the division; and one division was fortunate to have the original Chitty Chitty Bang Bang car giving rides at a local show with all proceeds going to the division.

FINANCIAL REPORTING

THE PARKINSONISM SOCIETY OF NZ INCORPORATED NATIONAL OFFICE OPERATIONS 2012 FINANCIAL SUMMARY

In 2011 Parkinson's New Zealand expanded its fundraising efforts to include donor appeals. This was to provide a more sustainable stream of income to the organisation and decrease our reliance on income from the sources we have traditionally gone to. In 2012 the Society received more support from the community than ever before and donations from individuals raised \$73,197 for Parkinson's New Zealand, which was up from \$32,347 in 2011. We are looking to expand this fundraising in 2013 which will also assist our divisions in improving their income levels.

Unfortunately, these gains were negated by a decrease in income from bequests and grants. In addition the timing of Lottery distribution was altered which resulted in an unfunded period of almost three months. This led to a reduction in total operating income from 2011's \$565,686 to \$498,385 in 2012. This resulted in a deficit of \$81,098 in 2012 (2011 deficit was \$66,410).

Care was taken during 2012 to keep expenses as low as possible without reducing services provided to our members. Regular reviews of the operating expenses led to a reduction from 2011's \$686,724 to 2012's \$669,288. During this period we also expanded the Field Officer Service with the employment of the clinical lead, and held a heavily subsidised UPBEAT weekend for people with early onset Parkinson's. These two activities resulted in an increase in spending of \$51,805 in these two areas.

AUDITED FINANCIAL STATEMENTS

This Financial Summary of National Office Operations for 2012 has been extracted from the audited Financial Statements of the Parkinsonism Society of NZ Inc. The 2012 Financial Statements for National Office have been audited and an unqualified audit opinion was received. These audited Financial Statements are available on request from:

The Parkinsonism Society of NZ Inc.

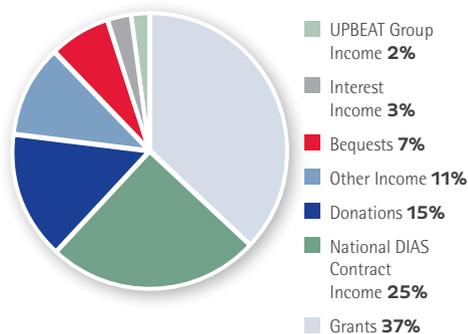
PO Box 11 067
Manners Street
Wellington 6142
info@parkinsons.org.nz

THE PARKINSONISM SOCIETY OF NEW ZEALAND INCORPORATED
NATIONAL OFFICE ONLY

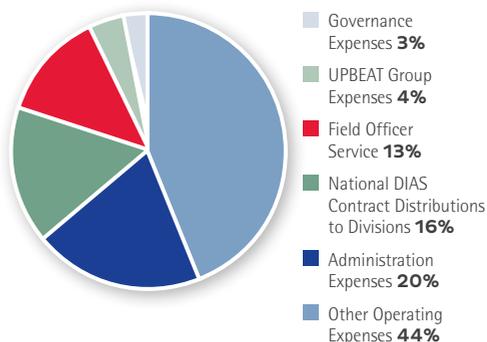
STATEMENT OF FINANCIAL PERFORMANCE
FOR THE YEAR ENDED 31 DECEMBER 2012

	2012 (\$)	2011 (\$)
OPERATING INCOME		
Donations	73,197	32,347
Bequests	33,624	55,320
Grants	183,471	276,905
National DIAS Contract Income	126,645	124,608
UPBEAT Group Income	11,345	3,260
Interest Income	12,875	18,537
Other Income	57,228	64,709
TOTAL OPERATING INCOME	498,385	575,686
LESS OPERATING EXPENDITURE		
National DIAS Contract Distributions to Divisions	109,627	109,627
Field Officer Service	85,047	54,926
UPBEAT Group Expenses	24,711	3,027
Other Operating Expenses	296,655	325,446
Administration Expenses	130,692	167,947
Governance Expenses	22,556	25,751
TOTAL OPERATING EXPENDITURE	669,288	686,724
NET OPERATING SURPLUS / (DEFICIT)	(170,903)	(111,038)
PLUS RESTRICTED SPECIAL PURPOSE INCOME	89,805	44,628
NET SURPLUS / (DEFICIT)	(81,098)	(66,410)

2012 OPERATING INCOME



2012 OPERATING EXPENSES



THANK YOU



IRIS & ERIC NANKIVELL CHARITABLE TRUST

DAVID LEVENE FOUNDATION

THE JAMES LEWIS RUSSELL TRUST

THE ALEXANDER HAROLD WATSON CHARITABLE TRUST

WALTER & RITA NORWOOD TRUST



MEDICAL ADVISORY

PANEL

Parkinson's New Zealand is fortunate to work with a panel of health professionals working in a range of fields. The Society consults the panel on new publications, updates to existing publications and relevant sections of *The Parkinsonian* and the *UPBEAT* newsletter.

PROFESSOR TIM ANDERSON

Professor Anderson is a neurologist at the Christchurch School of Medicine, Christchurch Hospital and the New Zealand Brain Research Institute.

DR STEPHEN CHALCROFT

Dr Chalcraft is a Geriatrician now (since 2009) with the Southern District Health Board and an Honorary Lecturer in the School of Medicine at the University of Otago.

DR ALISON CHARLESTON

Dr Charleston is an Auckland Med School graduate practicing in Geriatric Medicine and Neurology, primarily at Auckland Hospital and in private practice.

DR NISAR CONTRACTOR

Dr Contractor is Psychiatrist - Adult, Specialist Old Age and ECT Psychiatrist - and works at the Capital and Coast District Health Board in Wellington.

DR MATTHEW CROUCHER

Dr Croucher is an Old Age Psychiatrist working for the Canterbury District Health Board with special interest in Parkinson's and in the dementias.

PENNEY KEMP

Education Programme Manager, Nursing & Education Team, Nurse Maude

LORRAINE MACDONALD

Movement Disorders Nurse Specialist, Neurology Department, Auckland City Hospital

DR GAIL RICCITELLI

Dr Riccitelli is a Psychiatrist working with the elderly at Taranaki District Health Board.

DR JONATHAN SIMCOCK

Dr Simcock is a retired Neurologist.





PARKINSON'S NEW ZEALAND | PO Box 11-067, Manners St, Wellington 6142
Phone 04 472 2796 | Freephone 0800 473 4636 (0800 4PD INFO) | Fax 04 472 2162
Email info@parkinsons.org.nz | Web www.parkinsons.org.nz

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