

The Parkinsonian



The Quarterly Magazine of The Parkinsonism Society of New Zealand Incorporated
P.O. Box 10-392, The Terrace, Wellington

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The STEP Report

From the President

Parkinsons New Zealand – a brand name for easy identification – now has a website: www.parkinsons.org.nz. This is another important addition to the communication/education aspect of the Society's role. The site has been highly praised and well used already. On it is important information and news for our members.

Now is the time for the Society to seek the new government's support to strengthen the work and achievements of our volunteers and field officers. I'm seeking an appointment with the Minister of Health, Annette King, to brief her on the work we do. I suggest you all get to know your local MPs, so they too are aware of our work. We need their help to increase the availability of quality services, across the country, for all people with Parkinsons, their carers, families and friends.

The wonderful contribution of volunteers is a major part of our Society's success, and I would like to express my thanks to all those who do so many voluntary activities. They work in many areas to serve members: in committee work, supporting field officers, organising meetings, Awareness Week activity, fundraising, education activities and supporting those they know personally who have Parkinsons.

I encourage you to offer yourself in service in some way this year, or to encourage anyone else who might like to be a volunteer.

There are interesting challenges ahead with a new direction for health services, and I wish all of you well in your endeavours and activities in the coming year.

Kind regards
Andrew Dunn
President

PARKINSONS NEW ZEALAND

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Our new information officer



Eva Petro

Dear Readers

I'm very glad to be the new information officer for Parkinsons New Zealand. I've been in the job for several weeks now, and am gradually coming to grips with all the complexities of the position. So far I've met members of the National Committee, people from the Kapiti/Horowhenua Division and am looking forward to meeting many more of you throughout the country.

My interest in the organisation is a personal one, as my father has Parkinsons and my mother is doing a terrific job as his carer. Having a family connection certainly brings home the realities of living with the condition.

I have a 15 year old daughter and an 11 year old son, and a husband who has been very handy in setting up my work computer. I enjoy public speaking with Toastmasters, mountain running, swimming in the great outdoors, especially Lake Taupo, tramping and netball.

My background is in writing – I've produced publications for various government departments, including Inland Revenue, Justice and Social Welfare. I've also written some early reading books and poetry for children, had some short stories published and written articles for newspapers.

My aim as information officer is to help increase awareness of Parkinsons, assist people as well as I can, build on the excellent resources my predecessor Diana Jackson has established, and hopefully make a difference.

*Cover photo: Parkinsons field officer Gail Marshall with colourful children's posters for Awareness Week '99
Photo: Manawatu Evening Standard*

My other main task – and an exciting one – is to produce *The Parkinsonian*. In the next issue you will see some quite radical changes in its look.

As content is just as important as style, your feedback is invited. I want the magazine to be relevant to what you need, so please let me know what you would like to see in it: what the vital issues are for you, what is helpful – and what isn't.

Eva Petro, Information Officer

National Information Service shifts to Wellington

Our National Information Service is now based in Wellington, following its successful development in Christchurch.

Resources available to members include books, videos, audiocassettes and a comprehensive range of information on all aspects of Parkinsons.

Also don't forget our website – it's full of useful information and worldwide links to other organisations.

Eva Petro has joined our team as information officer. If you would like to use the information service, the best time to call us is in the mornings. Please leave a message if we are unavailable.

The freephone number has changed to:

0800 4 PD INFO (0800 473 4636)

and the e-mail address to:

parkinsonsnz@xtra.co.nz



Annette King – now Minister of Health – launches our website during Awareness Week 1999

Results of an international survey on Parkinsons

An international survey, the Global Parkinsons Disease Survey was recently completed. It was inspired by an original concept of the European Parkinsons Disease Association (EDPA). The survey investigated the factors believed to influence the quality of life for people with Parkinsons. It covered three continents and involved six countries: Canada, Italy, Japan, Spain, UK and USA. Two thousand randomly chosen patients, carers and specialist clinicians were personally interviewed by professionally trained medical interviewers.

The aim of the survey was to identify factors that have the most impact on quality of life: this knowledge will help to create a management framework for all those involved in caring for people with Parkinsons.

Summary of results of the Participation in Life Survey

The results show the extent of the problems faced by people with Parkinsons, because of the physical, emotional, psychological and treatment-related aspects of the condition.

Problem	Reported by
Tiredness in the day	92%
Medication three times daily	88%
Tremor	78%
Depressed or miserable	78%
Plan activities around medication	77%
Difficulty remembering	76%
Difficulty walking	76%
Difficulty staying asleep	73%
Poor balance	73%
Medication side effects	65%
Difficulty getting to sleep	64%
Medication wears off too soon	63%

These are the key results: in future issues we'll bring you more details of the results and the issues. If you would like more detailed information on the Survey results, please contact the National Information Service on **0800 4 PD INFO (0800 473 4636)**.