



The Parkinsonian

The Quarterly Magazine of Parkinsons New Zealand

Global Declaration on PD signed

The 8th World Parkinson's Day was celebrated around the world on 11 April 2004.

Part of the celebrations included the signing of the World Health Organisation's (WHO) Global Declaration on Parkinson's Disease.

In Canada key stakeholders from the Canadian Parkinson's community came together with government officials and representatives of the international Parkinson's alliance.

President of the European Parkinson's Disease Association and WHO representative, Mary Baker, presented the WHO's Global Declaration on Parkinson's Disease for signature by Canadian officials on behalf of the Americas.

Ms Baker said, "The Declaration is the culmination of a close partnership between healthcare professionals and patient organisations during the last three years, and highlights the importance of working together to try to effect attitudinal change in the everyday management of PD."

She spoke of the issues facing people with Parkinson's – and remarkably, how similar the experience is for the 6.3 million people with Parkinson's around the world. She encouraged everyone associated with Parkinson's to engage in honest dialogue about the needs of people with Parkinson's and their families, and to educate decision makers about the benefits of providing better supports and services.

The Global Declaration on Parkinson's Disease was launched last year at Mumbai, India.

The aim was to transfer the Charter for people with Parkinson's Disease into a Global Declaration was carried out by the Working Group on Parkinson's Disease, working in partnership with lay organisations within the WHO regions around the world.

It is anticipated that the declaration will be used as a campaign tool by non governmental organisations to encourage change in attitude and increase awareness of Parkinson's Disease.

The Global Declaration on Parkinson's Disease states that People with Parkinson's Disease have the right to:

- Be referred to a doctor with a special interest in Parkinson's disease
- Receive an accurate diagnosis
- Have access to support services
- Receive continuous care; and
- Take part in managing the illness

Over the next three years, the Global Declaration will travel around the world and be signed by representatives of the five other WHO regions: Europe, East Mediterranean, Africa, South East Asia, and Western Pacific. It is expected to be signed at the Asia Pacific Parkinson's Association conference in Melbourne, Australia in November 2005.

This conference will be co-hosted by



Muhammed Ali signs the Declaration with Dr Mark Stacy, Consultant Neurologist in the USA.

Parkinson's New Zealand.

Finally the Global Declaration will reside at the World Health Organisation's Headquarters in Geneva, Switzerland as a symbol of the international effort to ensure the best quality of care for the 6.3 million people with Parkinson's disease around the world.

Several issues have been raised by the Declaration - these include the possible worldwide decline in the (continued on page 2)

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A word from the National Director

On the 30th April/1 May council members and delegates from around the country gathered in Wellington for our AGM and associated workshops. It was wonderful that so many divisions attended and I greatly enjoyed the opportunity to meet with your representatives.

The Chair people attending gathered on the Friday afternoon to discuss issues affecting their divisions and share valuable information.

The Saturday had a very full itinerary that included Sonja Martell from the Lottery Grants Board explaining the new application process and its implications, Nick Dangerfield helped us all to better understand new Employment Laws and the Privacy Act and Jeanette Clark explained the new NZQA Field Officer qualification that Parkinsons NZ has been working on with other groups including MS, Epilepsy and the Brain Injury Trust for some time.

The AGM itself finished off the day with the election of the following members as the 2004/2005 National Management Committee: **Conrad Peterson (Chair), Bruce Cutfield (Vice-Chair), Bill Werry (Treasurer), Cilla Barkhuizen, Jeanette Clark, Mike Lynch, Nicole Maconaghie, Sue Milton, Noel Noonan, Dot Trail.** Additionally the council decided to make the position of President and Vice-President roles outside of the committee and duly elected **Nick Dangerfield-President and Andrew Dunn-Vice President.**

Our congratulations to them all for making this commitment to Parkinsons NZ and all our members, and our thanks to outgoing members Eleanor Mara, President; Morris Sands, Treasurer and Philippa Spackman.

With this issue you will find enclosed a request for

(continued from page 1)

number of practising neurologists and the growing reliance on carers to provide care in the home due to lack of available rest-home beds.

A media release from Canada states that as access to specialists becomes more limited, family physicians will experience an ever-increasing demand to become more knowledgeable about PD so that they are able to better diagnose and manage more aspects of their patients' care.

donations to Parkinsons New Zealand. Please do consider setting up an automatic payment or making a donation to help us continue our work. Don't forget that your friends and family may be happy to support us also so feel free to contact us for additional forms.

I do hope you enjoy this winter edition of The Parkinsonian which has been put together by our new Communications and Funding Officer, Ally Clelland, who I am sure you will join me in welcoming to the team. Please do contact us with any feedback you may have and remember that we love to hear news from your area.

Finally I would like to thank the JR McKenzie Trust whose generous support has made this publication possible.

Kind Regards
Deirdre



Parkinson's New Zealand delegates at the AGM in Wellington in May 2004.

Parkinson Society Canada has announced the development of the Medical Education and Support programme as a preliminary effort to enhance the knowledge of Parkinson's disease among family physicians.

"We expect to launch the programme later this year and now that it will immediately impact on the quality of care that people with Parkinson's experience today," said Barry Johnson, Chair of Parkinson Society Canada.

GUARDIAN HEALTHCARE



A New Name for the Same Great Service

In the past MASS[®] Healthcare provided important support for thousands of older New Zealanders providing them with their personal medical alarms and a range of life care products. From 1 April 2004 the company's name changed to:

Guardian Healthcare

This is an exciting development as it provides us with the opportunity to provide our clients with a more integrated range of services from support at home through to independent living units, rest home and hospital care.

Guardian Healthcare is part of the Guardian Healthcare Group (formerly Harbourside Group Holdings), New Zealand's largest operator of rest homes and hospitals. It is for this reason that we have changed our name: to provide our clients with an integrated support service for independent living.

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Please don't hesitate to call us if you have any queries on 0800 60 80 99 or visit our website at www.guardianhealthcare.co.nz.

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News and Research

Ritalin might ease effects of Parkinson's

PORTLAND -- A drug generally used to treat hyperactive children might help people deal with the effects of Parkinson's disease, according to researchers at Oregon Health & Science University.

A high dose of the drug Ritalin seemed to enhance the effects of levadopa (L-dopa), the main drug used to fight the tremors and movement problems of Parkinson's disease, researchers found.

Researchers gave 14 Parkinson's patients L-dopa every two hours, as is common, but occasionally added Ritalin. A dozen of the patients responded to the two-drug combination, but only five responded well to L-dopa alone. The Ritalin also lengthened the effects of the standard drug.

"You could probably give smaller doses (of levadopa) and have the effect last longer," said Dr John Nutt, the neurologist who led the research.

Dr Nutt cautioned that the study only suggests the benefit. He plans to study whether the benefit continues if patients take Ritalin several times every day.

At least a half-million U.S. residents have Parkinson's. The disease destroys brain cells that produce dopamine, a chemical that sends signals through the brain. The resulting loss of dopamine interferes with normal brain functions, especially those controlling movement.

(Source: Associated Press, May 2004)

First National Bank of stem cells

LONDON -- The world's first embryonic stem-cell bank opened in Britain in mid-May, breaking new ground in one of the most controversial areas of medical research.

The bank will store and supply stem cell lines -- strings of identical cells -- for research and possible treatment of conditions like Parkinson's, diabetes and cancer. Its store of cell lines is expected to number tens of thousands.

Stem cells are master cells in the body that have the capability to transform into new cells or tissue.

They can be taken from adults and discarded umbilical cords but those from embryos are considered especially powerful because each one has the potential to become any sort of cell or tissue in the body.

Researchers believe they offer a revolutionary way to repair diseased and damaged body tissue, although more research is needed to understand exactly how they work.

The bank puts Britain at odds with anti-abortion campaigners and with the United States, where President Bush issued an executive order in August 2001 limiting federal funds for embryonic stem-cell research.

The bank, in Hertfordshire, will be funded by the Medical Research Council and the Biotechnology and Biological Sciences Research Council.

"Stem cell research offers real promise for the treatment of currently incurable diseases," said Colin Blakemore, MRC's chief executive. "The bank will ensure that researchers can explore the enormous potential of this exciting science for the future benefit of patients."

(Source: Reuters, May 2004)

Special bottles may help with Parkinson's

GLASCOW -- A husband and wife team of Glasgow doctors has launched a unique study into Parkinson's disease, with the help of special pill bottles.

Dr Donald Grosset, a consultant neurologist at the Southern General, and his GP wife Catherine, want to find out why the symptoms of the disease come and go.

The doctors are using special pill bottles containing a computer chip which notes the time the bottle is opened and when the patient takes a pill. This helps them see if the patient is forgetting to take their medicine or taking it too often. That could help doctors round the world to work out whether this causes the return of unpredictable symptoms and help them develop new once-a-day treatments.

Dr Grosset said: "Forgetfulness is an issue with some people who have Parkinson's.

"It does not affect everyone...but it could be a factor in when they take their treatment."

The couple have already run a six-month pilot study on 100 patients aged 40 to 80 from the west of Scotland.

Dr Grosset said: "One of the aims of treatment is to smooth out the symptoms. Smoothing out the doses of drugs could be one way to help that."

Richard O'Grady, Manager of the Parkinson's Disease Society Scotland, said: "One of the difficulties with this illness is that people have to remember to take differing numbers of tablets up to six times a day.

"Anything that can help them to cope with their condition would be very, very useful."

(Source: Evening Times online, UK, May 2004)

Pergolide linked to cardio side effect

People with Parkinson's taking pergolide (Permax) may be aware that the drug has come under scrutiny recently for a previously unrecognised side effect.

However the study in the United States only involved around 200 patients so those in New Zealand taking pergolide should not stop taking the drug but should consult their doctor for advice.

Researchers from Texas presented evidence at the recent American Academy of Neurology 56th Annual Meeting in San Francisco, California that pergolide use may be associated with an increased risk of heart valve disease.

Wellington neurologist Edward Wong said, "Although recent reports have highlighted this issue, the frequency and the clinical importance of this complication is still to be determined. Most neurologists and physicians in New Zealand will be aware of this problem, and people concerned about this should discuss it with their doctor."

Tip - A great tip from one of Northland division's members – she found that using a telephonist's headphone while having long telephone conversations, and a music stand for reading books/newspapers, made life with a tremor easier.

Submissions due for Accessible Land Transport Inquiry

Submissions for Human Rights Commission's Inquiry into Accessible Public Land Transport for people with disabilities close on 31 August.

The Inquiry, which was announced in September, will consider the need for changes to legislation, regulations, policies and procedures and funding arrangements.

Chief Human Rights Commissioner Rosslyn Noonan said a lot of people take the ability to make use of a number of forms of transport for granted. "For many people with disabilities public land transport may be their only means of transport."

"The lack of an accessible public land transport system is often a major barrier for disabled people to access jobs, education or even recreation and other community activities," Ms Noonan said.

The Inquiry followed a number of complaints and enquiries, made to the Commission, suggesting some elements of the public transport system were not accessible to people with disabilities.

"Although we've been able to resolve some of these there are clearly issues that require a wider more systemic approach," she said.

The inquiry will look into:

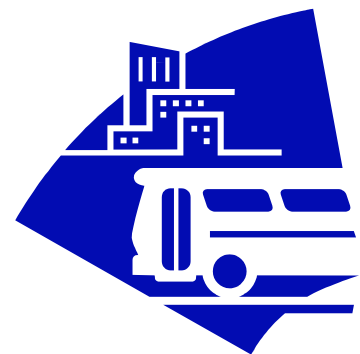
- the availability, accessibility and

affordability of public land transport for people with disabilities

- the quality and safety of public land transport services for users and service providers
- the economics of providing accessible public land transport for people with disabilities
- whether such services comply with human rights standards
- the adequacy of technical and engineering standards
- the particular needs of those people living in rural and provincial areas of NZ.

"It is important that all those with an interest in accessible land transport issues make a submission or attend a public hearing in July or August," Ms Noonan said.

Submissions made by members of the public are now being accepted and can be made in a variety of ways. Copies of the Inquiry Consultation Report can be found on the Commission's web site: www.hrc.co.nz/Inquiry or by phoning 0800 496 877 or via the TTY access number: 0800 150 111.



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STEP Report (Support Through Education Programme)

Living Alone with Parkinson's

Many people with Parkinson's live alone and manage very successfully. For some, living alone is a choice, bringing its own pleasures, even when they are diagnosed with Parkinson's. However, for others, the diagnosis can be shocking; with some people feeling that their single status will make their situation worse. However, a great deal of constructive advice and support is available, to help people living alone feel safer, more positive and less alone.

Practical issues

For many single people, the issue of retaining their independence and safety in their own homes is paramount, and causes the greatest worry.

In terms of basic home safety, a great deal can be done. A common concern is a fear of falling but a lot can be done to make the home less hazardous, including:

- Rearranging furniture and rugs to make rooms safer and eliminating trailing electric leads and fixing loose carpets.
- Adding grab rails around the house (stairs, bath or shower, toilet etc).
- Brighter lighting.
- Buy things in plastic containers rather than glass.
- Change from using glass tumblers and crockery to plastic drinking cups and plates to minimise breakages.

Home help

If you find coping at home difficult, you may be entitled to certain services, such as home help, Meals on Wheels, child care, or personal care. If you think you need assistance, contact your local

Parkinson's Field Officer, who will arrange for your needs to be assessed or make the necessary referrals. This involves someone from a needs assessment agency visiting you at home to find out what you need and what you are entitled to.

Financially

Living alone with Parkinson's can also be extremely difficult financially. Make sure you are receiving all the benefits and help to which you are entitled. This is also important if you are recently single because you have been widowed, separated or divorced.

For further help contact your local Work & Income (formerly WINZ) office.

Safety issues

When you have Parkinson's, having a phone that you can easily reach can be essential. A cordless phone kept within easy reach may be an option to consider. A mobile phone may be offer you greater flexibility as you can carry it around with you at home and take it with you when you go out.

Another option worth considering is a personal alarm. These allow you to call for help in an emergency, either by hitting a special button on your phone, or pressing the alarm on a special device worn around your neck or wrist.

Medical alarms may be funded by Work & Income through the disability allowance.

Sleeping

Getting yourself out of bed can be a problem. An aid like a bed pull which lies on top of the covers (check to make sure it is safe with an Occupational Therapist) or a bed rail

might be helpful.

If your main difficulty is getting into a sitting position, you could consider an electrically operated bed, mattress or part mattress.

Many people find satin or silky type slippery sheets a great advantage, particularly to make turning over in bed easier.

A duvet, rather than sheets and blankets, can be lighter to move under and easier to handle.

Dressing

- Sit down to put on trousers, socks etc.
- Replace any fiddly dressing devices that you can, i.e. buy trousers or skirts with elastic waists, change from buttons and shoe laces to Velcro fastenings, slip on shoes, or elastic shoelaces.

Bathing

- A bath or shower seat and a non-slip mat to avoid a fall.
- Install grab rails – towel rails are not a strong enough support.
- Use a toweling wash mitt instead of a flannel.
- Have a raised toilet seat installed, along with arm rails for leverage.
- Keep a night light in the bathroom to reduce the risk of falling.

In the kitchen

- Prepare food while seated; make large quantities during 'on' times; freeze extra food for those times when you don't feel up to cooking.
- Put a Lazy Susan in the centre of the kitchen table or counter to hold frequently used items so you won't need to collect them before every meal.
- Try drinking through a flexible straw if you have a tremor.

- Use cutlery with built-up handles, or add tubular foam padding to regular utensils.

Emotional and psychological considerations

Physical issues are more visible, and sometimes easier to come to terms with than emotional ones. For some people living alone, isolation, loneliness and depression can prove more difficult to deal with.

Depression is very common, affecting up to 40-50% of people with Parkinson's. Those who live alone may be particularly prone to reactive depression and these

feelings can sometimes be overwhelming. Discuss these feelings with your doctor or Parkinson's Field Officer.

Transport

In the early stages of Parkinson's it will often be possible to drive effectively but inevitably at some stage there will be a time when driving is no longer safe.

You may need to get your driving ability assessed.

For more information on where to find the closest assessment centre, contact Enable New Zealand (freephone 0800 171 981).

Facing the future

The future remains a big worry for many single people, who fear that they may not be able to cope. There are however, many options available in terms of care; but planning is paramount. The earlier you start to plan for the future, the more control and choice you may have.

(Source: PDS UK)

Advice from a PwP who is living alone

Kindly supplied by Lynn Pollock

1. Main issues

- Ensuring that the physical environment is user friendly.
- Setting up and maintaining a support network.
- Monitoring your own health.
- Living life to the full.

2. How I cope with these issues.

(a) Physical environment. I moved house from one with forty steps to one on the flat close to shops and bus route. There are enough bedrooms so that if necessary I can have someone living in. To make the house more user friendly the bathroom was moved closer to the bedroom and a wet shower put in replacing a shower over the bath. I'm still trying to keep the floor free of obstacles. I introduced the architect to Project Enable for barrier free documents. As I'm not a keen gardener I'm considering how much of the area to have paved and whether to employ a gardener or to rely on family and the local youth group.

(b) Support network. I have been accustomed to letting friends and neighbours know when I'm going away for Christmas. However I've had several incidents lately when I've been absent from a regular activity and worrying friends. It is now a case of "asking to be excused". My house security system has the capacity to include a medical alert. I try to know my neighbours, which is not easy as many are students. Keeping in touch

with family means an email or a toll call. I have organised a local friend to have Power of Attorney. The field officer is an important link in the network, as are the local Parkinsons group and Upbeat. Also, of great value is knowing that others are praying and caring for me.

(c) Monitoring my health. Most days I manage to record my medication, food intake, what I've been able to do, and any thoughts or feelings. Before going to the Doctor I make a list of observations and questions. I have had to put my pills into daily containers to ensure I take the correct amounts. I try to understand what each pill is designed to achieve. My knowledge of new drugs and techniques is mostly limited to articles in The Parkinsonian. Decision-making alone can be very tiring, so that knowing when to ask for help, is most important. Tears come easily and they can be cathartic.

(d) Living life to the full. Counting your blessings is not always easy, but it is a helpful way to be positive. I was able to continue working longer than expected as I'm left-handed and it was my right side that was most affected. My softest fall was on to cushions. I refuse to let my tremor stop me from taking photos – a faster film and a tripod usually works. Since retiring I've joined several organisations which provide new contacts and opportunities. I accept challenges that can be achieved in a short period of time. I'm learning to prioritise and that may mean saying "no" in some situations.

Tips for PwPs living alone.

- Active.** Do physical and mental activities you enjoy.
- Be Positive.**
- Concentrate** (Advice from my swimming coach).

Parkinson's research boosted by Van der Veer Institute

By Professor Tim Anderson

In 2002 The University of Otago established The Van der Veer Chair in Parkinson's Disease. This new position is funded by the Canterbury Medical Research Foundation (CMRF) from a generous endowment from the trustees for the estate of the late Casper Van der Veer. The CMRF funding was sufficient for five years professorial salary, but the University have undertaken to continue the position indefinitely for the appointee.

I was appointed to the Van der Veer Chair and assumed this position in February this year.

The position incorporates specialty out-patient clinics as well as research, public education, and teaching commitments.

Each week I undertake two clinics devoted to Parkinson's and other movement disorders. These clinics have already got partly underway at the Christchurch Hospital but in July will move to a dedicated building - The Van der Veer Institute for Parkinson's and Brain Research in St Asaph Street, very near Christchurch Hospital.

A full time Parkinson's and movement disorders nurse is currently being appointed and will be a vital part of the new service and an important link with patients, their families and general practitioners. In particular, the nurse will provide a pivotal liaison with the Canterbury Parkinson's Society resource nurse, Janet Wells.

A unique initiative involving a partnership between the specialised clinics and the Society will involve people with Parkinson's, who are Society members and are attending the clinic, being visited by Janet before and after their clinic appointment. This project, involving the sharing of information should facilitate a more thorough and complete evaluation of patients' needs and medication requirements.

In the medium term the Clinic Nurse and I plan to be able to provide a day stay observation clinic for patients with difficult or troublesome motor fluctuations. These patients will attend for a full half day and the status of their Parkinson's will be monitored closely over several hours to gauge just what is happening after taking medication. It is hoped that this will improve control and may even obviate hospital admission. The clinics will

also be attended by registrars in training as well as Health Care of the Elderly physicians. Referral will be via the Neurology Department by specialists or general practitioners.

I will be undertaking trials of new medications for Parkinson's and hope that the establishment of the new Institute will attract a greater number of such trials in the future.

A significant aspect of my role will be to foster and engage in more research into Parkinson's. This research is being undertaken in the Van der Veer Institute and patients attending the clinics will have the opportunity of participating in the various research projects. Current research includes improving off-road driving assessment for people with Parkinson's and other neurological disorders, investigation of swallowing disorders in those with stroke and Parkinson's Disease, the investigation of depression, memory and other cognitive changes that may be present in people with Parkinson's, the recording of subtle changes in eye movements in Parkinson's, and the testing of virtual reality techniques for improving movement speed and size.

Hints and Tips

My husband George and I found it difficult to sleep with the light on, but if we didn't he would often end up in the wardrobe on his way to the bathroom! Recently we have used 'glowing stars' purchased from a toy shop, placed on the floor and now he has his own runway light to the loo and I can sleep too!

Mrs Reason, Leicestershire

I, among many other people with Parkinson's, suffer from constipation. It can be a real problem, and a subject people are reluctant to talk about. I have recently found a secret weapon and it has changed the focus of my day, improved the benefits I get from my medication and has put the smile back on my face. What is this wonder of wonders? Kiwifruit. I started with a whole kiwifruit sliced with my breakfast cereal, but now I find that half is enough most of the time. Why not try it if you have problems.

J Sanders, Somerset

(Source: PDS UK)

Wear clothing with pockets large enough to drop change into, rather than fumbling to separate paper bills and coins when you are handed change.

(Source: Braintalk Communities)

Parkinsons Annual Field Officer Conference

Field Officers from around the country attended the Annual Field Officers Conference hosted by Auckland division in March 2004.

The national conference was scheduled to coincide with a seminar for health professionals giving an ideal opportunity for all the Field Officers in New Zealand to learn from three of Auckland's leading specialists.

The half-day seminar programme attempted to cover the progress and pitfalls in the life of a person with Parkinsons (PWP) from early diagnosis and treatment options presented by Dr Barry Snow to late stage symptoms and treatment options including surgery presented by Dr David McAuley. The intervening years, looking at problems with sleep, pain, depression and cognitive changes were presented by Dr Greg Finucane. The

information was presented as case studies of real (anonymous) people and stimulated the audience to ask numerous useful questions.

After the health professionals departed at lunchtime the Field Officers used workshops to discuss the information and learn from each other ways of assisting PwP's and their families.

It became clear that the resources available to rural PwP's and Field Officers differ from those available in the urban areas. The exchange of ideas was stimulating and helped Field Officers develop their professional boundaries.

On the second day the presenters included Emma Holmes, a clinical psychologist whose session focused specifically on four possible challenges of Parkinson's – hallucinations, depression, anxiety

and frustration. She provided a greater understanding of these issues and some helpful coping strategies for PwP and their families.

The last session was stimulating and interactive by Debbie Hager, on group facilitation. Everyone participated in interactive learning, examining their own attitudes and comparing themselves to others in the group. Ideas that could be incorporated into in-service (hospital, resthome etc.) training, group meetings and family meetings were demonstrated.

National Office would like to thank Auckland division for hosting this excellent conference which provided an invaluable two days of training and education for our Field Officers. Thanks also to the speakers, sponsors and funders without whom none of this could have happened.

New website on disability equipment funding

Finding out if you are eligible for funding for disabled equipment or housing modifications has suddenly become a lot easier.

A new website www.disabilityfunding.co.nz which provides comprehensive information on Ministry of Health funding for equipment, housing modifications and vehicles has been launched by Enable New Zealand.

The Ministry of Health asked Enable New Zealand to develop the website after realising that accessible and up-to-date information on funding for environmental support services was not readily available on the internet.

The site includes sections on

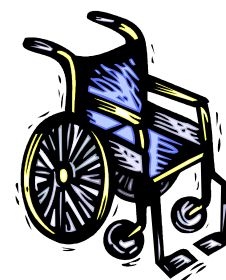
eligibility, how to apply, what is and what is not funded, and how the funding process works. There is also a 'frequently asked questions' section. If you cannot find the information you are looking for you can ask a question online.

You should be aware that due to the increase in demand for these services in the last year, the Ministry of Health has advised that spending for the remainder of the financial year is to be carefully managed in order to remain within the 2003-04 budget limits.

This means that most current and future applications will be put on hold until 1 July 2004. There are some exceptions such as urgent

equipment items or housing modifications essential to client safety and mobility where there is no other option to meet the need, common list equipment or where a refurbished item is available from Enable New Zealand or *accessible* Stores to meet a client's essential disability related needs.

Further information about the exceptions is available on the disability funding website.



News, Fundraising and Events from around the country

Taranaki

Having a meal out is not something disabled people often feel comfortable about. But thanks to the initiative of several health groups in the Taranaki region disabled people are welcomed at a special day called Memory Café Day - a joint initiative by ADARDS, the Stroke Foundation and Parkinson's Society.

The idea is to have the third Monday of the month set aside at a café so that members in the community with any disability can feel welcomed and enjoy a meal out. While eating out is a part of everyday life, some people feel unable to go to a café or restaurant because of their disability. Memory Café Day provides a special day encouraging people with any disability to get out and have a good time. The café is also open to the public on Memory Café Day.

Memory Café Day has been operating successfully at the Gables in South Taranaki for a year now and there are plans for a special celebration to mark the occasion. The idea has now spread and was recently started at the Pukekura Kiosk in New Plymouth.

Tauranga

Tauranga division will be holding their July mid winter luncheon and support meeting at the Kwanchou Chinese restaurant in Mt Maunganui on Tuesday 6 July from 11.45am. If you wish to come please contact Dawn on 07 548 1560.

Hawkes Bay

Around 150 people attended a special function to celebrate World Parkinson's Day, in Napier on 1 April. People with Parkinson's, health professionals and residential home staff from Wairoa to Waipukurau came to hear Dr Trish Lawlor, who works with Matt During, speak about the gene therapy work currently being conducted at Auckland University.

Manawatu

Professor Tim Anderson will speak at Palmerston North Convention Centre at 1.00pm on Tuesday 10 August. Professor Tim Anderson is the Van der Veer Chair at Christchurch School of Medicine and Health Sciences, Otago University (see article page 8).

Contact Raymond Jackson, phone 06 359 6338

National Raffle

Thank you to everyone who has taken part in the national raffle. Good luck for the draw.

From Auckland to Lisbon

Auckland Division's Field Officer Team Manager Cilla Barkhuizen attended the 5th European Parkinson's Disease Associations (EPDA) multi disciplinary conference 'Working in Harmony-The Team Approach' in Lisbon during May.

The aim of the conference was to 'Develop a dialogue between science and society'.

Keep an eye out for Cilla's report on the conference in the next issue of The Parkinsonian.

Kapiti/Horowhenua

Call 04 904 4240 if you are interested in attending Kapiti's seminar on access to disability services for physically impaired people on Thursday 15 July in Paraparaumu.

Farewell to Geoff – Chairperson Gisborne Division

Geoff Keenan Musgrave, 1931- May 2004

Geoff will be remembered by his friends as being cheerful, positive, forthright and committed to fair outcomes.

He had a long involvement in the transport industry – first with his father's business, Ward's Transport, as a council member of the NZ Road Transport Association and chairman of its industrial committee.

Additionally he had an extensive record of public service and activity in the commercial life of Gisborne. His community involvements include: Kaiti School Committee for 15 years, member of the East Coast Regional Development Council for 16 years, member of Gisborne District Council for 6 years and as a life member and patron of Wainui Lifesaving Club.

Geoff was Chairman of the Gisborne Division of Parkinsons New Zealand from 2003 to 2004.

Our sympathies to his family and friends.

Air NZ bans lifting

Air New Zealand has recently introduced a policy that would mean disabled people who need transfer assistance to and from aircraft seats either don't use the airline or pay for a travelling companion to help.

Citing the new lifting regulations, the airline claims it is a safety issue. However, while the airline is keen to protect its staff, it is quite happy for farepaying passengers to be exposed to the perceived risks. Disabled Persons Assembly is investigating the options to make Air NZ reverse its discriminatory policy.



UPBEAT is a special interest group for people with early onset Parkinson's and their carers.

The group provides support and information via regular newsletters, email and weekend meetings around

the country.

A meeting for those in the far north will be held in July.

The Upbeat AGM will be held in Taupo in September/October.

An Outward Bound course is also planned for November this year.

For further information contact Bruce Cutfield, phone 06 307 8853 or email parkinsonsnz@xtra.co.nz

Tips

If you take the drug apomorphine, and any is spilt, it can stain. However, fresh lemon juice, applied directly, can really help.

Mrs Lupo, Pembrokeshire

Try peppermint oil or peppermint tea to relieve flatulence.

Parkinson's Disease Nurse Specialist

Books for sale available

National Office has a number of books available for sale about Parkinson's. If you would like to purchase any books please either telephone (04) 472 2796, fax (04) 472 2162, email parkinsonsnz@xtra.co.nz or write to P O Box 10 392, Wellington.

PUBLICATIONS AVAILABLE

(All prices include GST and postage and packing)

	Price
MOVING AHEAD WITH PARKINSON'S Meg Morris, Robert Iansek, Beth Kirkwood A Guide to Improving Mobility in People with Parkinson's	\$46.00
THE PARKINSON'S HANDBOOK A great read for those who want a little more information. Written by Dwight C McGoon, M.D. An inspiring, practical guide for patients and their families by a Mayo Clinic surgeon with Parkinson's Disease.	\$30.00
SHAKING UP PARKINSON DISEASE – Fighting like a Tiger, Thinking like a Fox Written by Dr. Abraham Lieberman, M.D. (2002) A book for the Puzzled, the Hopeful, the Willing and the Prepared. (Stocks on order – currently being reprinted)	\$45.00
100 QUESTIONS & ANSWERS About Parkinson Disease Written by Dr. Abraham Lieberman, M.D.	\$45.00
PARKINSON'S AT YOUR FINGERTIPS – new edition Written by Marie Oxtoby BSC(Soc), PhD and Adrian Williams MD, FRCP The Comprehensive and Medically Accurate Manual on Living with Parkinson's Disease.	\$48.00
EAT WELL, STAY WELL with PARKINSON'S DISEASE A nutrition handbook for people with Parkinsons by Kathrynne Holden, MS, RD	\$28.00
RIDING THE STORM By Lois Tonkin A Book about Loss and Grief for Older People	\$ 8.00
MY SPIRIT STILL SINGS (Video and Book) The Challenges of Accommodation and Care for people living with Young Onset Parkinson's. 2001 Young Parkinson's Housing Inc	\$36.00

Field officer contacts		
<p>Northland Division Jeanette Caldwell phone 09 432 2868 Megan Scott phone 09 402 7485</p> <p>Auckland Division Cilla Barkhuizen phone 09 278 6918 (Field Officer team manager) Annette MacNevin phone 09 267 8960 Kay McGarry phone 09 846 6602 Sally Anderson phone 09 534 0200 Sally Johnson (Rodney area) phone 09 413 9449 Trudi Clements (North Shore area) phone 09 480 0224</p> <p>Waikato Division Gwen Nichol phone 07 849 5281 Johanna Macdonald (City and West) phone 07 827 8793 Sue Green (Thames/Coromandel) phone 07 868 7007</p>	<p>Bev Turner (Kaimai area) phone 07 888 5601</p> <p>Bay of Plenty Division Joelene Morris phone 07 574 8120 Lynette Richardson phone 07 312 9397</p> <p>Central Plateau Division Pauline Hikairo phone 07 345 3951</p> <p>Gisborne Division Kay Beck phone 06 867 7061</p> <p>Hawkes Bay Division Morag Murray phone 06 878 8954</p> <p>Taranaki Division Susan Allemann phone 06 751 2903 Margaret Mullin phone 06 761 7294</p> <p>Wanganui Division Sue Wilson phone 06 345 0847</p> <p>Manawatu Division Dianne Ackerman phone 06 325 8058</p> <p>Kapiti/Horowhenua Division Pauleen Kaimoana phone 04 904 4240</p>	<p>Wairarapa Division Bev Nation phone 06 377 1766</p> <p>Wellington Division Diane Stevens phone 04 389 9002 Marilyn Berry phone 04 562 7952</p> <p>Marlborough MS Society Beverley Jones phone 03 578 4058</p> <p>Nelson MS Society Pam Grey phone 03 544 6386</p> <p>West Coast MS Society Lyn Hahn phone 03 732 3827</p> <p>Canterbury Division Janet Wills phone 03 366 2857</p> <p>South Canterbury Division Margaret Bates phone 03 688 8770</p> <p>Otago Division Paula Ryan phone 03 455 9435</p> <p>Southland Division Doreen Dickey phone 03 208 4068 Julie Jones phone 03 218 3975</p>

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Thank you for your support

Parkinsons NZ relies on grants and donations to continue its work. Call 0900 FOR PD (0900 367 73) to make a \$20 donation through your phone bill. Or call National Office to discuss other ways of supporting us including volunteering, donating services, regular driving, bequests and sales.

Our thanks to J. R. McKenzie Trust, Telecom, The Southern Trust and The New Zealand Community Trust for their recent support.