



The Parkinsonian

The Quarterly Magazine of Parkinson's New Zealand

September 2008 ♣ Vol: 11, No. 3

POP LEGEND BECOMES PARKINSON'S AMBASSADOR

Parkinson's New Zealand is thrilled to announce that Kiwi pop music luminary Jordan Luck is now a special Ambassador for the Society.

Jordan, who was last year named as the first inductee into New Zealand music's Hall of Fame, developed a strong empathy for people affected by Parkinson's, following his late father Jamie Luck's diagnosis with Parkinson's at aged 60.

Jordan is best known as the singer of the hugely popular Exponents (formerly Dance Exponents). The Exponents produced many Kiwi pop anthems in the 1980s and 1990s including the classics *Who loves who the most?*, *Victoria* and *Why does love do this to me?*.

In 2001 *Victoria* was voted the eighth most popular New Zealand song of all time in a New Zealand top 100 chosen by music industry body the Australasian Performing Rights Association (APRA). *Why does love do this to me?* is now a well-known stadium anthem among rugby fans and it is the theme song for Air New Zealand's Super 14 television advertising campaign.

These days, fronting a band simply called The Jordan Luck Band, Jordan is known for his high energy performances and more than occasional stage antics. However, his serious side comes through when he talks about Parkinson's.

"Through my own family's experience I have an understanding of how Parkinson's can affect other New Zealand families. For my Dad, losing the ability to continue his usual active lifestyle was distressing. He loved his teaching job and was heartbroken when asked to resign after showing only early signs - a shaking hand at the chalkboard. My father also lost the ability to do so many other things he treasured like tramping, climbing, and green things like planting trees."

"I am really pleased to be able to become involved in supporting people living with Parkinson's. I hope that I can add to the brilliant work Parkinson's New Zealand does," he says.

National Director Deirdre O'Sullivan says the Society is really honoured and excited about Jordan taking on the Ambassador role.

"Having on board a Kiwi icon like Jordan, who's reputed for his passion and zest, and who has a real interest in, and caring for people affected by Parkinson's ... this is amazing for us."

Jordan's mother, Elizabeth, also commented on the challenges faced by the Luck family later on in Jamie's life.

"The hardest thing would have to be the decision to place [Jamie] in a residential home for about two months, when it was impossible to maintain the standard of care we wished to at our home; this especially involved the lifting as more than two people were required for showering and toileting," she said.

As the Society's second appointed Ambassador, Jordan joins Kiwi Olympian and former Society Patron, Dr Peter Snell.



Parkinson's Ambassador, Jordan Luck

PARKINSON'S AWARENESS WEEK

♣ 1-7 November 2008 ♣

Get in touch with your local division to find out what's happening in your area.

INSIDE THIS ISSUE:

- ♣ DBS Support Group formed
- ♣ Fact Sheet – Parkinson's and Tremor
- ♣ Parkinson's NZ Education Grant Awarded
- ♣ Election special continued....

NATIONAL DIRECTOR'S REPORT

Tena koutou e hoa ma

It's hard to believe that another Parkinson's Awareness Week (1-7 November) is only a couple of months off. While every day for us is about raising awareness, it is good to have a time of focus. We continue our theme of Get It On Time to draw the attention of Health Professionals to the importance of the right medication at the right time. As ever, I ask our members and supporters to do what they can during Awareness week to help – even just letting one person know about Parkinson's can make a real difference.

I am really very excited about our new Ambassador Jordan Luck. His music has been the soundtrack to many important parts of my life – especially university parties!! Having such a well known person, with such caring and goodwill for our Society and people living with Parkinson's, willing to publicly support our cause is fantastic and many of you will have seen some of the numerous newspaper articles already generated by our association in the last few weeks.

We were also very pleased to award our first education grant (see page 5) and look forward to giving you Dr Contractor's highlights in future editions.

We have received an invitation from our friends across the ditch (see below). Let me know if you are attending as it would be nice to meet up.

Kind regards



Deirdre

NEW INITIATIVE

DEEP BRAIN STIMULATION SUPPORT GROUP

A new initiative by Parkinson's New Zealand will provide further support for people who have undergone or are considering Deep Brain Stimulation (DBS) surgery.

A national support group has been set up and Otago Parkinson's Field Officer Paula Ryan has taken on the role of the National DBS Coordinator.

"The support group responds to feedback from people who have had the surgery asking for extra support and information," said National Director Deirdre O'Sullivan.

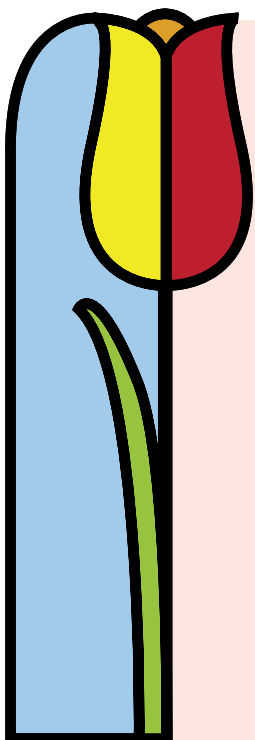
A growing number of New Zealanders with Parkinson's have had the surgery in recent years.

Paula's role as National Coordinator is to help ensure that support and information needs are met for Parkinson's New Zealand members who have had DBS or are contemplating surgery. She will also be liaising with the health professionals involved.

The National Deep Brain Stimulation Support Group is a special interest group of Parkinson's New Zealand.

"I am very keen to hear from anyone who has suggestions that would improve understanding and knowledge or provide support," said Paula.

Paula can be contacted on 03 455 9435 or email paularyan@xtra.co.nz.



INVITATION FROM PARKINSON'S AUSTRALIA

I am very pleased to invite everyone in New Zealand to join us for Parkinson's Australia's 2008 National Conference at Sydney, Olympic Park, Sydney in October. This will be the only event in 2008 which will bring together Australians and New Zealanders living with Parkinson's, along with their families, carers, health providers and researchers to learn more about the search for a cure and recent developments in managing this illness.

The conference will enable participants to learn more about living with this illness and to compare notes, researchers can brief medical practitioners on progress and delegates can share insights on living their lives to the fullest potential.

I encourage you to take part in Parkinson's Australia's 2008 National Conference – it could make a difference.

Kind regards

Norman Marshall, CEO

**Parkinson's Australia National Conference, Reaching for our goals,
Thursday 16th – Friday 17th October.
See www.parkinsonsnsw.org.au for programme
and registration details**



PARKINSON'S FIELD OFFICER TRAINING CONFERENCE

Key to the delivery of the Society's services and support is the Field Officer. There are 36 Field Officers operating through 20 Divisions covering all of New Zealand.

To help ensure that our Field Officers continue to be well trained, have up to date information and are aware of developments, our annual, two-day training conference was held 24-25 July in Wellington.

Mr Ron Dick, Clinical Neuropsychologist at Health Waikato spoke about intimacy and sexuality; Dr Eleni Nikolau, Consultation Liaison Psychiatrist, Waikato Hospital discussed non-motor symptoms; Geoffrey Coe, Clinical Educator, School of Physiotherapy, University of Otago presented physiotherapy developments; Dr Daphne Manderson, Graduate Studies Coordinator, School of Nursing, CPIT spoke about Parkinson's care as both art and science – focusing on the art and Professor Tim Anderson, Van der Veer Clinic, Christchurch presented The Medical Management of Parkinson's. Group work and a review of major issues were also included in the programme.

INAUGURAL PARKINSON'S COORDINATORS TRAINING CONFERENCE

The Society was delighted to offer specifically created training to its Coordinators for the first time in Wellington on 21-22 August.

The number of Coordinators employed by divisions has grown to 15. Coordinators now play a vital role in many of our divisions and without their support and input much of the Society's work would not be done. Topics ranged from the privacy act and finances to fundraising and newsletters



PARKINSON'S NEW ZEALAND WOULD LIKE TO THANK THE GENEROUS SPONSORS AND SUPPORTERS OF OUR FIELD OFFICER AND COORDINATOR CONFERENCES.

PLEASE SEE PAGE 11 FOR FULL DETAILS.

🔥 Prolonged release Ropinirole launch in UK

GlaxoSmithKline has announced the UK launch of ReQuip XL (ropinirole prolonged-release tablets), which is the prolonged release version of ReQuip.

Ropinirole prolonged release is approved in the UK for the treatment of idiopathic Parkinson's disease in people already taking ropinirole immediate release tablets and in whom adequate symptomatic control has been established. Clinical trials demonstrated that ropinirole prolonged-release is effective and generally well-tolerated in the treatment of early and advanced Parkinson's. The new tablets produced a significant reduction in awake time spent "off" with no increase in troublesome dyskinesias during "on" time compared to placebo when used as an adjunct to L-dopa.

Source: Viartis.net

🔥 Scientists say a valuable discovery for Parkinson's Disease might be right under their noses...

Researchers from Griffith University have published a study in the journal *Stem Cells* that has found adult stem-cells harvested from the noses of Parkinson's patients developed into dopamine-producing brain cells upon being transplanted into the brain of a laboratory rat.

Professor Alan Mackay-Sim said researchers simulated Parkinson's symptoms in rats by creating lesions on one side of the rat's brain to imitate the damage Parkinson's disease wreaks on the human brain.

According to Mackay-Sim, the evidence showed the injected stem-cells had differentiated into "dopamine-producing neurons influenced by being in the environment of the brain." Mackay-Sim explained that, like all stem-cells, these adult stem-cells from

the olfactory nerve in the nose are "naïve," since they have not yet differentiated into any particular type of cell.

"They can still be influenced by the environment they are put into. In this case we transplanted them into the brain, where they were directed to give rise to dopamine-producing brain cells," he added.

"Significantly, none of the transplants led to formation of tumours or teratomas in the host rats as has occurred after embryonic stem-cell transplantation in a similar animal model."

Mackay-Sim's latest discovery in the little-recognised field of adult stem-cell research is the work of the National Centre for Adult Stem Cell Research, part of Griffith University's Eskitis Institute for Cell and Molecular Therapies

Source: ScienceDaily, July 2008

🔥 Blood related genetic mechanisms found important in Parkinson's

What does the genetics of blood cells have to do with brain cells related to Parkinson's disease? From an unusual collaboration of neurologists and a pharmacologist comes the surprising answer: genetic mechanisms at play in blood cells also control a gene and protein that cause Parkinson's disease.

The study is published in the *Proceedings of the National Academy of Sciences Online Early Edition* the week of 21-25 July 2008.

People with Parkinson's disease (PD) have elevated levels of the protein called alpha-synuclein in their brains. As the protein clumps, or aggregates, the resulting toxicity causes the death of neurons that produce the brain chemical dopamine. Consequently, nerves and muscles that control movement and coordination are destroyed.

The researchers discovered that the activity of three genes that control the synthesis of heme, the major component of hemoglobin that allows red blood cells to carry

oxygen, precisely matched the activity of the alpha-synuclein gene, suggesting a common switch controlling both.

The scientists then found that a protein called GATA-1, which turns on the blood-related genes, was also a major switch for alpha-synuclein expression, and that it induced a significant increase in alpha-synuclein protein. Finally, they demonstrated that a related protein -- GATA-2 -- was expressed in PD-vulnerable brain cells and directly controlled alpha-synuclein production.

Source: University of Wisconsin, USA

🔥 Chair in Neurology appointment

The Neurological Foundation has appointed Dr Alan Barber as its first Chair of Clinical Neurology at The University of Auckland.



Dr Barber is currently a clinical neurologist and director of the Auckland City Hospital Stroke Service. He also provides leadership in stroke treatment and management at the three Auckland regional hospitals and teaches at the Faculty of Health and Medical Sciences.

Although Auckland based, Dr Barber's research involves collaboration with neuroscientists and neurologists throughout New Zealand.

"Dr Barber is an excellent choice for the role. He is committed to combining and building the unique strengths provided by the world-class neuroscience research carried out by The University

of Auckland and the extensive clinical and research expertise of Auckland City Hospital Neurology Department," says Foundation Chairman Ian Robertson.

🔥 Changes to the Unified Parkinson's Disease Rating Scale

The Unified Parkinson's Disease Rating Scale, or UPDRS, is currently the most widely used clinical assessment tool for Parkinson's in the world.

Dr Christopher Goetz from Rush University Medical Centre in Chicago recently announced a 're-launch' in June at the 12th International Congress on Parkinson's Disease and Movement Disorders held in Chicago.

Dr Tim Anderson, Neurologist and Cas van der Veer, Chair in Parkinson's Disease and Movement Disorders, Department of Medicine, Christchurch School of Medicine says "The new UPDRS will be welcomed by clinicians and researchers. It much better reflects the true spectrum of symptoms that are experienced by people with Parkinson's. In particular it places better emphasis on the so-called non-motor symptoms and the degree to which they may affect daily life.

"The traditional UPDRS has been very good at measuring the degree of stiffness (rigidity), slowness (bradykinesia) and shaking (tremor) in Parkinson's but the new version is much better at measuring symptoms such as urinary and bowel problems, pain, sleep problems and dizziness, as well as difficulties with fine or small movements. In addition, the new UPDRS will be much better at measuring and following changes in symptoms occurring early in

the course of Parkinson's. This is important since most trials of new medications for Parkinson's use the UPDRS as the key measure for detecting improvement or worsening after administration of the novel (trial) drug, and the traditional UPDRS was not particularly good at detecting this in early or mild Parkinson's."

🔥 Dyskinesia is related to weight

Levodopa dose per kilogram body weight is reported to be a significant factor for dyskinesia in Parkinson's disease. This hypothesis has been investigated in data from the studies comparing ropinirole versus levodopa as the initial therapy.

Data from the ropinirole versus levodopa studies O56 and REAL-PET in early Parkinson's disease were pooled and manipulated to calculate levodopa dose per kilogram body weight. Statistical analysis was performed to investigate significant variables for the development of dyskinesia. Only the patients on levodopa monotherapy or with ropinirole were analysed.

Analysis of levodopa therapy patients revealed that dyskinetic patients had received significantly higher absolute levodopa dose and levodopa dose per kilogram body weight. Variables of gender, absolute levodopa dose, weight, disease duration and initial motor Unified Parkinson's Disease Rating score were not significant.

This means that lighter people appear to be slightly more likely to develop dyskinesia on a certain dose of levodopa per day than heavier people. This relationship should be considered in treatment of Parkinson's disease patients aiming to prevent and manage dyskinesia.

It should be noted that the size of the effect of weight on development of dyskinesia, although significant amongst findings by investigators, was not large.

Source: European Journal of Neurology 2008; 15 (5); 493-496

🔥 Parkinson's New Zealand Education Grant

Congratulations to Dr Nisar Contractor who is the recipient of the Society's education grant of \$6,000 towards attendance at the 6th International Congress on Mental Dysfunctions & Other Non-Motor Features in Parkinson's Disease, Dresden, Germany, 16-19 October 2008.

The Society decided to make this grant as a sign of its commitment to the education of Health Professionals throughout New Zealand.

Support for attendance at this particular conference is an opportunity for the Society to encourage the study into, and treatment of, the non-motor symptoms experienced by those affected by Parkinson's.

Dr Contractor, MBBS; MD (General Medicine); FRANZCP; Cert Psychiatry of Old Age; is a Consultant Psychiatrist working at both Wellington and Kenepuru hospitals and in the community.

Dr Contractor will share what he learns when he returns, through the Field Officer conference and various written materials.

The Society is delighted to be able to provide this support and looks forward to supporting further Health Professional education in the future.

Please do not interpret anything in this magazine as medical advice always check with your Doctor. The appearance of any article or other material in this publication does not imply the agreement of Parkinson's New Zealand with the opinions expressed therein.

PARKINSON'S AND TREMOR

About 70% of people with Parkinson's have a tremor and it is the most common visible sign of Parkinson's.

Tremor is a form of involuntary movement (a movement that is not under conscious control). Many conditions can cause tremor; however, Parkinsonian tremor has some distinct characteristics. It is commonly called 'pill rolling' as people seem to be rolling a small sphere between their thumb and index finger. Often referred to as a resting tremor it most often occurs when the muscles of the hands or feet are relaxed, when they're at rest; hence the name. Usually, the tremor decreases or disappears when the muscles of the hands or feet contract during movement and often during deep sleep. Sometimes the tremor can occur on action, perhaps while trying to hold a magazine steady (postural tremor), or during a movement like writing (kinetic tremor).

Tremors usually start in the fingers of one hand and in time can spread up the arm and even extend to other parts of the body as the condition progresses. Occasionally, Parkinson's tremor might start elsewhere, like the foot, then spread up the leg into an arm.

After several years the tremor usually spreads to affect the other side of the body. However the tremor is often less severe than on the side first affected and this asymmetry normally persists. In some cases a tremor can also spread to include the jaw, lips, tongue and trunk.

Some people with Parkinson's can experience an 'internal tremor', a feeling of tremor that is not obvious to others.

Factors that may worsen tremor

Emotions such as stress, anxiety, anger or fear can cause tremor (physiologic tremors) in all people and can worsen a Parkinson's tremor. However, this is temporary and will settle down as the heightened emotion subsides.

Tremors can also be caused or worsened by some medications including some mental health medications and anti-nausea and anti-dizziness medications. There are also some anti-asthma drugs, lithium and the anti-epileptic sodium valproate which can heighten tremor. It is always good to discuss new medications with your doctor to see if that particular medicine can cause or worsen tremor. Never stop taking medication without consulting your doctor.

Acknowledgements:

Rodger J Elble MD, PhD. Department of Neurology, Southern Illinois University School of Medicine
'Parkinson's at your fingertips'. Dr Marie Oxtoby and Professor Adrian Williams
'About Parkinson Disease'. Abraham Lieberman, MD, with Marcia McCall
Parkinson's Disease Society, United Kingdom

There is help for tremor

Some people with a mild tremor find that squeezing or rolling a ball, pen or similar object can help suppress the tremor.

Tremor can sometimes be suppressed effectively by medication. Levodopa (Madopar, Sinemet) can reduce or stop tremor quite effectively in some people. However, not everyone's tremor responds effectively to levodopa even if in the same person the other 'cardinal features' like rigidity and slowness of movement, respond well to the drug. Current thinking is that this may be because tremor, unlike rigidity and slowness of movement, is not a direct effect of the dopaminergic deficiency present in Parkinson's.

Dopamine agonist medications like ropinirole and pergolide also have anti-tremor effects when used alone or in combination with levodopa.

There are also some anti-muscarinic medications that can have a role to play in tremor management, for those who are intolerant of dopaminergic drugs.

In some cases Beta-blocking drugs can reduce tremor. Some people use them in small doses as required before, say, a big meeting or social occasion.

As with all medications and other treatments, advice should always be sought from your Doctor or Specialist to ensure that you are taking what will work best for you. No two people with Parkinson's are the same and no two treatments will be exactly the same.

Surgery and tremors

In the past surgery on the thalamus was used for some people with Parkinson's. More recently the technique known as Deep Brain Stimulation (DBS) has emerged as a treatment for tremor.

DBS involves implanting small electrodes within the brain into the subthalamic nucleus (STN) and then passing small electric currents through them. DBS of the STN improves tremor, rigidity, slowness of movement and drug-induced dyskinesia (potentially allowing a reduction in medication).

It is very important to note however that this surgery is not suitable for everybody and recipients of the operation must be carefully selected to minimise risk factors.

Treatments for tremor, including medication and especially surgical interventions, can carry problems of their own and always need to be used thoughtfully.

Essential Tremor

Some Parkinson's New Zealand members have Essential Tremor (ET). ET is the most common form of tremor and is often referred to as familial tremor or benign essential tremor.

Onset of ET is most common after age 40, although symptoms can appear at any age. Usually, ET has been present, even in milder form, for many years and there is often a family history of essential tremor. Children of a parent with essential tremor have a 50% chance of inheriting the condition. By contrast, finding another family member with Parkinson's is rare.

Although the tremor may be mild and non-progressive in some people, in others the tremor is slowly progressive. Tremor frequency may decrease as the person ages, but the severity may increase.

ET is a hyper-kinetic disorder and is 10-20 times more common than Parkinson's tremor. ET primarily affects the hands, less often the head and rarely the feet, although voice, tongue, legs and trunk may be affected too. Head tremor may be seen as a "yes-yes" or "no-no" motion. Unlike Parkinson's tremor, ET appears when the hands are moving and it can be disabling, affecting fine motor skills such as shaving, buttoning clothes and feeding oneself. However, in many people the tremor is not sufficiently bothersome to require treatment.

Essential tremor is at its worst when the arms are outstretched or when holding a drink or writing, whereas a Parkinson's tremor is usually most obvious when the arm is doing nothing and at rest (this is why it is often described as a resting tremor). Heightened emotion, stress, physical exhaustion, or low blood sugar may trigger tremors and/or increase their severity.

There are other clear differences between Parkinson's tremor and ET; for instance handwriting. With Parkinson's writing can become small and cramped, with ET it becomes shaky. An occasional alcoholic drink may help ET but appears less beneficial for Parkinson's. Quite why alcohol helps with essential tremor is not well understood and overuse of alcohol could of course lead to dependence and is not recommended.



CLARIDGES ORGANIC



BLACKCURRANT ANTIOXIDANTS

New Zealand Blackcurrants are classed as a "SUPER FRUIT"

because they are naturally loaded with high amounts of antioxidants.

Antioxidants are beneficial in maintaining good health. Traditionally, antioxidants are obtained through eating a well balanced diet of fruit and vegetables

Research clearly shows that the antioxidant activity of blackcurrants is significantly higher than other fruits or vegetables.

"Claridges Organic Ltd advises that there is no scientific research to support claims that those with Parkinson's will benefit from taking Blackcurrant Antioxidants. We advertise in this magazine in response to many enquiries from those with Parkinson's, their families and friends who have gone to great lengths to find a supply of Blackcurrant Antioxidant capsules, after hearing that others have benefited from taking them"

Lawrence Heath, Owner Claridges Organic Ltd

Blackcurrant Antioxidant capsules come in 60 x 500mg capsules per bottle. Order 4 bottles and receive them freight free

To purchase Claridges New Zealand grown Blackcurrant Antioxidant capsules or to receive further information, please phone, fax or e-mail us

Claridges Organic Ltd

P.O. Box 39068, Christchurch 8545
2 Ivan Jamieson Place, Christchurch

Phone 03 3583155 • Fax 03 3583156
info@claridges.co.nz • www.claridges.co.nz

RIGHT MEDICATION, RIGHT TIME

The "Get It On Time" Parkinson's medication message came through loud and clear when Wellington division member Barbara Ruffles spoke to health professionals at an Understanding Parkinson's seminar at Lower Hutt Hospital recently.

The Society has been running an ongoing Get It On Time campaign and the theme will be central to Parkinson's Awareness Week 2008, from 1 November until 7 November. Raising awareness and understanding among health professionals of the importance of the right medication at the right time is essential.

Barbara, whose husband Monty was diagnosed with Parkinson's 23 years ago, talked about her struggle trying to ensure Monty received the right medication at the right time while in care and rehabilitation.

"One time, he went into a rest home and his entacapone was stopped within seven days He developed leg cramps and his whole body shook for several days because he was taken off this medicine.

"For nearly three months Monty unnecessarily suffered a severe stiffening of his body. His voice became faint; he was unable to feed himself and he was very apprehensive about the future. The rest home staff did not realise it was the Parkinson's that was causing this and not the stroke.

"I really battled to have my views heard and my medical evidence listened to and understood. I even ended up leaving cards I'd written on next to his trolley to try to ensure that he was given the right help in my absence."

Having been told that only a neurologist could re-prescribe the course of essential drugs cancelled by the rest home doctor, Barbara booked an appointment for a neurologist as soon as she could: they still had to wait for two months.

"Once the neurologist saw Monty he immediately understood what was happening to him and within 24 hours of his being back on his original drugs, there were visible improvements. He could speak more clearly and could even feed himself again."

Barbara says Monty has now been in a rest home for 17 months and trying to get medication at the right time as specified by the neurologist continues to be a challenge, because medications are often given at times to suit staff and their routines, rather than geared to the needs of the patients.

However, giving medication too early or too late makes an instant impact, she says, as the body either has too much or too little medication at any one time, not the steady flow required for the best results.

As Monty's wife and carer, Barbara has to wear many hats, including advocating for her husband. She's had to work hard to get across the vital yet easily over-looked 'Get It On Time' message to people who play an important role in the well-being of people with Parkinson's.



BOOK REVIEW

The Complete Carer's Guide



The Complete Carer's Guide by Bridget McCall Published Sheldon Press 2007

The chapters are well titled, there is a wealth of information available and it is easily read but unfortunately it is written with the United Kingdom reader in mind. The personal stories are relevant the world over and there are some pointers that could help a carer of any age at any stage. It would be good to have the equivalent written for New Zealand readers to know where help is available both in the medical field and local community support groups. There are numerous references to web sites, mostly in the UK; I did not follow these up. Perhaps a book to have available in a general library as a reference book, but not one that many would give pride of place to on the home bookshelf.

Reviewed by Jean Adams

Continuing from the June Parkinsonian, we asked political parties to tell us about their policies that may affect people with Parkinson's and we also put to them a question, submitted by Sandra Stacey, a Parkinsonian reader, regarding the fairness and suitability of people with Parkinson's being placed in residential care and/or dementia units regardless of age and ability.

Q. Do you believe it is morally correct and fair to tuck-away people with advanced Parkinson's into rest homes that have been given hospital status, when all the programmes at these homes are geared up for geriatric/dementia care and where most of the staff have no understanding of the intricacies of the disease. Some of the conditions of Parkinson's are seen as dementia to a caregiver who has little medical experience, when in fact the patient is mentally fully aware of what is going on around him, but he is treated as a geriatric.



Unfortunately New Zealand is not at the forefront of countries with regard to medicines. Lack of access to new, quality treatments is compounded by a shortage of neurology specialists. PHARMAC has a brief to keep costs down and does so ruthlessly. I have no problem with cost efficiency but the brief is too narrow, as it looks at drug costs alone and ignores wider costs. A medication that allows someone to function independently is a valuable drug as rest home care starts at about \$600 per week. But that saving is never included in calculations. ACT would broaden their brief to look at all health costs including patient costs.

A. It is correctly stated that most caregivers receive little medical training and are largely unaware that the Parkinson's patient is of sound mind and fully aware of their surroundings. "Hospital level care" is not the same as hospital care. Few of

the nurses are registered and there are no resident doctors on hand. Mixing patients with different diagnoses will always be necessary to an extent but patients who are accepting treatment voluntarily shouldn't be subjected to the constraints imposed on those who require a secure facility. The biggest problem facing the health system is maintaining our workforce. Economic policies that will make us more prosperous as a nation are the real answer – that will allow the vulnerable in society to be treated much more generously.



New Zealand in many respects has a comprehensive public health system. We believe that, to deliver the 'fair go for all' this should be funded at levels which make it accessible to all citizens on the basis of need. That said, no-one has been able to invent a system, public or private, to deliver all of the treatment that people need and want as soon as they want it. The demands on such a system are potentially infinite, and treatments have always had to be prioritized.

We have been instrumental through the coalitions with Labour in which we have taken part, in ensuring that public resources for public health have been increased to the degree that this now accounts for 16-20% of all public expenditure and is the single largest item of government expenditure. As a result there have been many improvements such as the employment of over 5,000 more medical professionals within the public system than there were nine years ago.

A. Parkinson's is a priority which needs to have the best available support services within the homes of those who have the condition if this is at all possible, and it is clearly inappropriate for sufferers from the condition to be cared for in geriatric hospitals because these are two quite different conditions requiring different therapies and support strategies.



We are keen to ensure that all our policy for this sector reflects our willingness to 'listen before speaking'. Readers can visit www.unitedfuture.org.nz to download a copy of our disability discussion document and return it with any comments they may have.

For most people services are pre-determined rather than self-determined. This means that money is wasted. There is a serious lack of appropriate respite providers and a desperate need to better support family carers/supporters. We welcome the recent 'Carers Strategy' and the five year action plan. The need to support and value family carers is important. We also need to future-proof by improving the way we plan for, train and pay our caregiver workforce.

We also would like to see improved access to advocacy support for both clients and their family to ensure that they are receiving all that they are entitled to in a timely way.

A. The scenario outlined is a clear example of what happens when impairment is treated as a medical need not a social need. The Social Services Select Committee is currently completing an inquiry into Disability Services in New Zealand and a number of submitters told us similar stories. It seems that geriatric care facilities are often used for both respite and longer-term care of younger people in a way that is totally inappropriate. The problem of course is that there is a wide-spread shortage of respite opportunities, particularly for those with high and complex needs. You are right to ask about the moral obligation government has to ensure people are supported by those who are well trained and appropriate in the support they provide. Any issue that deals with issues of personal dignity are indeed moral issues.

🔥 Kapiti/Horowhenua

On Sunday 22 June three brave division members took part in the annual mid-winter Polar Swim which took place at Waikenae Beach.

Taking to the freezing water dressed as seals they raised funds and awareness.

🔥 Tauranga

Tauranga members enjoyed the opportunity of hearing Professor Richard Faull, Director of the New Zealand Human Brain Bank, deliver the Rutherford Lecture at the Armitage Hotel, Tauranga on 11 June.

Prof Faull's lecture, as always, was delivered with infectious enthusiasm.

🔥 25th Anniversary celebrations continue around the country

Over the last few months there have been a number of special lunches with Recognition Award presentations. Most recently events have taken place in Southland, Otago, West Coast, South Canterbury, Wellington, Kapiti, Hawke's Bay, Bay of Plenty and Northland.



Northland Division 25th Anniversary Award recipients with National Director Deirdre O'Sullivan

🔥 Wellington

Understanding2Care - Parkinson's was the theme for an interactive seminar held 22 July at Hutt Hospital and supported by the Wellington Division and Hutt Valley DHB. The full house of more than 100 carers and health professionals heard a family care giver explain the importance of the right medications always being given on time (see page 8), a session titled 'What people with Parkinson's would like you to know', hints and tips from Physiotherapists, and a Speech and Language Therapist and finally Dr Lord, a Geriatrician also spoke. It was a great opportunity to highlight Parkinson's and how best to serve those who have it or care for those who do.

🔥 Poetry for Parkinson's

The Wellington division and National Office joined forces to organise Poetry for Parkinson's in Wellington on 11 June. Attendees were given a rare opportunity to listen to some of New Zealand's best known and talented poets read from their own works. Wine and nibbles were also enjoyed. Our thanks to the poets and MC for their generous support.



Brian Turner, Harry Ricketts, Jane Westaway (MC), Michael Harlow, Jenny Bornholdt, Vincent O'Sullivan and Anne French.

🔥 Thanks to the Freemasons

Master of The Empire Fergusson Lodge, No. 225, Clive Lloyd, recently presented Parkinson's New Zealand with a cheque for \$4,000. The Lodge learned of the work that the Society does and was pleased to provide the generous donation as part of its commitment to charitable giving. Traditionally, Freemasons are known for helping the community, for instance involvement in the provision of retirement villages throughout New Zealand, helping to set and maintain standards for the care of our older citizens.

The donation will be used to support the Society's library and resources.



Master of the Lodge Clive Lloyd and PSNZ National Director Deirdre O'Sullivan

🔥 Parkinson's Disease Foundation Webcasts

If you have broadband computer access you can watch webcasts of Parkinson's educational symposia on The Parkinson's Disease Foundation's (PDF) (United States of America) website.

Watching a webcast is like watching TV on your computer. You can watch a broadcast live and even submit your own questions if you join in advance through the computer. Alternatively you can also watch archived webcasts for up to 12 months after they have been filmed.

The most recent webcast is from 18 July titled Mind, Mood and Body: Understanding Non-motor Symptoms of Parkinson's Disease.

The next live webcast will be on 11 October and is titled Surgical Advances, DBS and Parkinson's disease.

Visit www.pdf.org/webcast/ to find our more. For webcast specific questions, please email: webcast@pdf.org.

🔥 Family Care Radio

Carers NZ have launched a one hour internet radio show for families with health and disability needs.

The magazine style show is hosted by Pip Fowler, Margie Wheeler and broadcaster Todd Niall.

You can listen to the whole programme each month at <http://familycareradio.net.nz> or just the segments that interest you.

The September programme features an interview with entertainer Tina Cross, a special report about the Carers Strategy including an interview with the Minister of Social Development and also information from ACC about how to prevent injuries and stay well.

PARKINSON'S NEW ZEALAND
WOULD LIKE TO THANK THE GENEROUS
SPONSORS AND SUPPORTERS
OF OUR FIELD OFFICER
AND COORDINATOR CONFERENCES.



Baches & Holiday Homes to Rent
Bloomsberry & Co. Limited • Cotterill & Rouse
Giustis NZ Limited – Spoon Biscookie • Novartis
Office for the Community and Voluntary Sector
Onya Bags – Canterbury Cathedral
Square Market – ph: 03 377 5443

THANK YOU



supported by

Absolutely

POSITIVELY

ME HEKE KI PŌNEKE
WELLINGTON CITY COUNCIL

Wellington



Parkinson's New Zealand

PO Box 11-067
Manners St
Wellington 6142
Phone: 04 472 2796
Fax: 04 472 2162

Email: info@parkinsons.org.nz
Website: www.parkinsons.org.nz

Freephone: 0800 473 4636 or
0800 4PD INFO

National Director:
Deirdre O'Sullivan

Office Manager:
Patricia Hastings

Communications Officer:
Norman Denham

Project Coordinator:
Jennifer Rainville

Financial Administrator:
David Bailey

Proudly designed by:



Gibson Rusden Design Group

www.gibsonrusden.com

CONTROL YOUR SYMPTOMS LONGER

Comtan is taken together with levodopa and increases the time Parkinson's symptoms are effectively controlled.¹⁻⁴

Ask your doctor if Comtan is right for you.

If you would like to receive a free patient booklet entitled "10 Key Points you need to know about levodopa therapy", please call our free phone number on 0800 838 909. This leaflet focuses on how to get the most out of levodopa therapy in the long-term.

www.comtan.co.nz

COMTAN[®]
(entacapone)

Comtan[®] is a prescription medicine for the treatment of symptoms of Parkinson's Disease in people already taking a medicine called levodopa. The tablet contains 200mg of entacapone. Check with your doctor if Comtan is right for you. Comtan is funded under special criteria and doctor's charges will apply. Do not take Comtan if you are pregnant, breastfeeding, have liver disease, a tumour on the adrenal gland (phaeochromocytoma), severe muscle weakness or a serious condition called neuroleptic malignant syndrome. Tell your doctor if you have severe kidney disease or are on dialysis or you are on certain medicines for depression like MAO inhibitors, warfarin or iron. Common side

effects are nausea or vomiting, diarrhoea, constipation, pain in the stomach, dry mouth, dizziness, vertigo, shakiness, headache, increased sweating, difficulty sleeping, unusual dreams, feeling depressed, reddish-brown urine. Rarely sudden onset sleepiness. If symptoms persist or you have side effects see your doctor. Always read the label and use strictly as directed. Comtan is the registered trademark of Novartis AG. Novartis New Zealand Limited, Auckland. For further information check the Consumer Medicine Information [CMI] at www.medsafe.govt.nz

NOVARTIS

References: **1.** Rinne UK et al. for the Nomecomt Study Group. Entacapone enhances the response to levodopa in parkinsonian patients with motor fluctuations. *Neurology* 1998;51:1309-1314. **2.** Kieburtz K et al. for the Parkinson Study Group. Entacapone improves motor fluctuations in levodopa treated Parkinson's disease patients. *Ann Neurol* 1997;42:747-755. **3.** Larsen JP et al. for the NOMESAFE study group. The tolerability and efficacy of entacapone over 3 years in patients with Parkinson's Disease. *Eur Neur* 2003;10:137-146. **4.** COMTAN[®] Datasheet, Novartis New Zealand Limited. COM 0508-181-0510 TAPS NA 2955

