



# The Parkinsonian

The Quarterly Magazine of Parkinson's New Zealand

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## INTERVIEW WITH HON. TONY RYALL, MINISTER OF HEALTH

1-7 November 2008



Before the 2008 general election The Parkinsonian asked all major political parties for an overview on their policies that would benefit people with Parkinson's and their carers. Then health spokesperson for National, Tony Ryall discussed new community-based Integrated Family Health Centres and better access to respite care.

Now that the National-led government has had time to settle in, we decided it was time to speak to the new Minister for clarification on his election promises.

*In our last interview with you before the election, you talked about new community-based Integrated Family Health Centres which would provide more services than a GP can provide alone. Could you explain what these services would include and how they would be valuable to our members?*

To get this initiative underway, we have committed \$13 million to help DHBs devolve more services to primary care.

National believes that multi-disciplinary Integrated Family Health Centres bringing together a variety of health services in a convenient location will provide patients with a wider range of health services, faster. The services that are located in these centres will vary depending on the location, the community needs and the professional services available. It may include GPs, practice nurses, a nurse practitioner, a physio, and pharmacy for example.

And we recognise that not every general practice will want to become part of a large multi-practitioner health centre.

*You have mentioned that a National-led government would like to see more reasonable access to respite care. How do you plan to implement this?*

Part of National's Aged Care plan is to invest an additional \$5 million a year targeted at dedicated respite-care beds. This will mean an elderly person can stay in their own home for longer, and the wellbeing of their caregiver (usually a family member) will also be protected.

We will also be reviewing inconsistencies in the way DHBs contract for home-based aged-care services with a view to starting a stock-take of auditing processes, travel payments, remuneration, and training.

*Parkinson's and other neurological conditions currently affect hundreds of thousands of New Zealanders, and that number is set to increase dramatically. However these people are often overlooked when health priorities and strategies are being formed. How will a National-led government help to combat this?*

The government is committed to bolstering front line services to ensure we meet the health needs of New Zealanders, including individuals with Parkinson's disease.

The Ministry of Health is working with District Health Boards and health professionals on plans to better coordinate and manage long term conditions, such as Parkinson's disease.

### WORLD PARKINSON'S DAY



The 11th of April 2009 is World Parkinson's Day. The international day of recognition and celebration falls on this date as it is the birthdate of James Parkinson, the doctor who first described the condition.

## NATIONAL DIRECTOR'S REPORT

### Tena koutou e hoa ma

Welcome to the first edition of The Parkinsonian for 2009. I hope you and your family have had a restful and enjoyable start to the year. I look forward to meeting with many of you during the year.

This edition of the magazine has been put together by our new Communications Officer Nicole Skews. Nicole joined the Parkinson's team in early January and we are delighted to have her on board. She would love to hear from readers, any comments or requests they may have regarding The Parkinsonian, so please feel free to contact her on 0800 473 463 or [nicole@parkinsons.org.nz](mailto:nicole@parkinsons.org.nz). Our generous designers at Gibson Rusden are continuing to design the magazine for us this year.

Like many in the not for profit sector we are feeling the effects of the economic recession. You may notice the magazine has fewer paid advertisements and our thank you section is somewhat diminished. We remain extremely thankful to those who are able to continue their support for us. In addition to the usual support you show the Society any contacts or ideas you have that could help with raising funds would be gratefully received.

The next month or so will be busy ones for UPBEAT members so we wish all those with early onset Parkinson's who are attending the national weekend in Christchurch and/or Outward Bound enjoyable and informative times.

Kind regards,

Deirdre and the Parkinson's NZ team.

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## 2009 ANNUAL GENERAL MEETING

The Parkinson's New Zealand 2009 AGM and workshops will be held on Friday 17 April and Saturday 18 April at St John's Conference Centre, Dixon Street, Wellington.

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## BOOK REVIEW

### I HAVE PARKINSON'S BUT PARKINSON'S DOES NOT HAVE ME by Leif Ogard

*Reviewed by Fran Allcock, a Parkinson's NZ and UPBEAT member*



When I got this little book [165 pages] someone visiting my home picked it up, speed-read it cover to cover, and provided me with a precise on it – in an hour! Hmm, I thought! It shouldn't take me too long to read it and review it. But, you see, that person didn't have Parkinson's.

I read the book but I didn't read it well enough, so I read it again and again. This 'little' book is actually huge!

Leif Ogard starts our journey with him by taking us back some 20 years to his day of diagnosis. He was given confirmation that he had Parkinson's disease, along with the prognosis that he would deteriorate rapidly and should expect to be 'confined to a wheelchair' within five years.

At the time Leif was in his mid-forties, he had a successful life with his wife and teenage daughters. He also had what he refers to as 'a powerful dose of trust in authority' and that included 'the medicine man in the white coat'.

He explains how it was therefore natural to expect the prescribed wheelchair, and how his brain – unconsciously primed with

the mental image supplied by his specialist – unquestioningly steered in the direction of the 'goal-picture'; and into despair and deterioration just as his specialist had told him to.

Fortunately for Leif (and his readers!) he read a scientific report by researchers of Parkinson's patients that challenged this thinking. It presented proven evidence that a person's attitude and mind-set could positively influence their medical and life situations.

From this turning point, Leif recounts his journey in a new direction away from conventional thinking. It becomes a journey of recovery and struggle against the ever-present 'Mr Parkinson'; a journey of self-discovery and personal development; a journey of success.

Leif gives us a frank and open look into his life with Parkinson's: the good, the bad and the worst. Most importantly he discusses his amazing turn-around, how he achieved it and how you can use these same skills to change your outlook as well.

With enthusiastic conviction born of his own experience of victory-over-struggle, he encourages and teaches the reader to take a closer look at the power of the mind; how to think wellness; how to regain (or start taking) control and responsibility for one's health and one's life. Perhaps I could best say it like this: how to get off autopilot. How to grab back the steering wheel and the gear stick of your own car, draw a map of where you want to go, and drive in the direction of your goal.

This 'little' book is full of inspirations, advice, and the personal experiences of the author from mistakes to mastery. Every chapter is concluded with a summary entitled 'Advice for a better life', giving a guidance-style check-list to help the personal development trainee (i.e. you the reader) put in to practice the life-altering concepts and reinforce the learning in that chapter.

We are also given 'Basic Information' on Parkinson's, an interesting factual section with some positive surprises that left me thinking 'Wow! I never thought of it that way before!'. Medications are discussed, their effects, side effects, and dietary effects. And as I've come to expect from this 'little' book, no subject is alluded to then left unexplained – so there's a detailed example of Leif's average day: food, medications, activities etc.

Whether you're new to the concept of the power of the mind, and the power of thought, or you're familiar with its endless possibilities – this 'little' book could challenge your current thinking, and might even change your life.

Oh, by the way, did I mention? ... I have Parkinson's.

### **I have Parkinson's but Parkinson's does not have me**

is available for loan from the  
Parkinson's NZ library.

Call 0800 473 4636 or email  
[info@parkinsons.org.nz](mailto:info@parkinsons.org.nz)  
to apply to borrow.

## 🔥 Alzheimer's and Parkinson's Medicines Guidelines

The European Medicines Agency (EMA) has released two guidelines for companies developing medicines for the treatment of Alzheimer's, other dementias and Parkinson's. This development stems from recent scientific progress in the understanding of these conditions.

Advances in clinical science, physiopathology and molecular biology have stimulated new interest in the development of more effective symptomatic or disease modifying treatments. This includes early treatments that may prevent the emergence or slow down the progression of the disease.

The guidelines were developed in response to the need of companies developing these new types of medicines for guidance on appropriate clinical-trial designs.

The Parkinson's guidelines can be viewed at <http://www.ema.europa.eu/pdfs/human/ewp/056395en.pdf>

Source: <http://www.ema.europa.eu>

## 🔥 Immune Cells Implicated in Parkinson's Disease

Scientist Vanessa Brochard of the Université Pierre et Marie Curie in Paris, along with colleagues in the US, have discovered that a type of immune system cell may facilitate the development of Parkinson's. They have also found that targeting part of the immune system with drugs could be a new way to treat the disease.

The study has shed doubt on previous assumptions that changes in immune system cells leading to Parkinson's were results of injuries to the cells not primary events. It is now believed that changes in the cells make a significant contribution

to neurodegeneration. Even if they are not the primary cause of Parkinson's, at the very least they worsen the inflammatory process and aid extensive damage to develop from a small population of stressed dopamine cells.

The study gives further evidence that immune cells can both protect and attack the brain.

Source: Medical News Today

## 🔥 A Good Night's Sleep

The Parkinson's Disease Society of the United Kingdom (PDS) has been awarded over £400,000 of lottery funding for research into sleep disorders and Parkinson's.

The project involves a partnership with several UK research centres including The Cambridge Centre for Brain Repair, The Papworth NHS Trust's Respiratory Support and Sleep Centre and Oxford University's Department of Psychiatry.

Researchers will study sleep problems that seriously affect the quality of life of many people who have Parkinson's and place additional stress on their families.

Dr Kieran Breen, PDS Director of Research said 'A lot of people with Parkinson's disease find it difficult to sleep, or they keep waking up, then fall asleep during the day. We don't really know why this is – it is not caused by tremors, because when people with Parkinson's sleep, the tremors stop.'

Research methods will include questionnaires, visiting newly diagnosed people, monitoring sleep behaviour in sleep laboratories, and looking at alterations in people's 24 hour 'body clocks' using donated brain tissue by deceased people affected by Parkinson's.

Dr Roger Barker of the Cambridge University's Centre for Brain Repair said 'Sleep difficulties may occur for many years before a diagnosis

of Parkinson's is finally made, and finding out what is happening in the brain will provide clues as the disease progresses.'

Dr Breen said 'If we know what the problem is, it is quite possible there are existing drugs out there which may be able to improve people's sleep patterns and their ability to carry out everyday tasks.'

Source: European Parkinson's Nurses Network Journal

## 🔥 Study to Test Smell as Signal

Many individuals with Parkinson's are able to recall losing their sense of smell well before the onset of more commonly recognized symptoms such as tremors, impaired dexterity etc. To determine if a fading sense of smell may signal Parkinson's, researchers at Northwestern Memorial Hospital and Northwestern University's Feinberg School of Medicine (US) are participating in a national study. The study will examine the correlation between loss of smell and Parkinson's, and ascertain whether smell loss presents a tool for early detection of the disease.

Director of Northwestern's Parkinson's Disease and Movement Disorders Center, Tania Simuni says 'By utilizing smell testing in conjunction with other tests, we hope to develop a system that identifies the presence of Parkinson's before it develops into problematic symptoms.'

Northwestern is one of 15 sites in the US to participate in the Parkinson's Associated Risk Study (PARS), the largest long-term study in the US for relatives of individuals with Parkinson's. Evaluating 7,500 relatives for 3-5 years the study draws on research demonstrating that first-degree relatives have a slight increase in their risk of developing the disease.

As age has been recognized as the single proven risk factor for the onset of Parkinson's symptoms, the study will monitor relatives 50 years or older.

PARS study participants will be sent a scratch-and-sniff test accompanied by a questionnaire, with possible follow up through a neurological evaluation and more extensive testing.

'This study presents an enormous opportunity to not only better understand the initial stages of Parkinson's, but also to help future generations,' says Simuni. 'In future, early detection combined with neuroprotective therapy may pave the way for interventions that slow the progression or even prevent the onset of Parkinson's.'

Source: [physorg.com](http://physorg.com)

## 🔥 Study Links Genetic and Environmental Causes of Parkinson's

Scientists at the Whitehead Institute for Biomedical Research (U.S) have demonstrated one of the first links between genetic and environmental causes of Parkinson's disease.

Researchers have long known that Parkinson's can be caused by faulty genes or environmental factors. But a new study by Whitehead scientists found that a single gene, known as PARK9, protects cells from manganese toxicity and rescues neurons from over-expression (replication) of the protein alpha-synuclein. Misfolded alpha-synuclein is the hallmark of Parkinson's.

'This is one of the first connections between Parkinson's disease genetics and the environment,' says Aaron Gitler, one of the co-authors of a paper published online in the Feb. 1 edition of Nature Gen-etics.

In the neural cells of Parkinson's patients' brains, researchers have noted Lewy bodies – abnormal spheres composed of the protein alpha-synuclein. The specific causes of the disease remain unknown. Growing evidence in the research and medical communities implicates baffling and disconnected genetic and environmental factors. One genetic factor seems to be alpha-synuclein overexpression, which can be caused by too many copies of its gene. Another is mutations in a gene of previously unknown function, PARK9, and an overexposure to the metal manganese can lead to a Parkinson's disease-like syndrome. Now researchers in the laboratory of Whitehead and MIT Professor of Biology Susan Lindquist have associated these three factors.

'One of the reasons PARK9 is so interesting is when it's mutated, it leads to early onset Parkinsonism,' says Melissa Geddie, a postdoctoral researcher and co-author of the paper.

First, Aaron Gitler found that wild-type (no mutations) PARK9 suppresses alpha-synuclein toxicity in a yeast model of Parkinson's disease. A yeast model was chosen as it exploits the biological similarities between yeast cells and human cells.

Gitler, Geddie and colleagues then examined the function of the yeast version of the gene, called yeast PARK9 (YPK9). When yeast cells possessing a normal YPK9 gene were exposed to various metals they were more resistant to manganese than cells lacking the YPK9 gene. Mutations engineered to mimic those associated with early onset PD in humans failed to provide protection.

'These results suggest that one of the gene's functions is to protect cells from manganese,' says Gitler.

The relationship between PARK9 and alpha-synuclein in yeast were later confirmed in additional Parkinson's models, including those in rat neurons, in collaboration with investigators at the University of Alabama and Purdue University.

Lindquist says that the yeast model is particularly well-suited to enhancing our knowledge of what actually happens in cells affected by Parkinson's.

'Using yeast to study Parkinson's means that we will be able to start understanding the underlying pathobiology of the disease and eventually design rational therapeutic strategies based on what's causing the disease rather than what's the outcome,' says Lindquist, who is also a Howard Hughes Medical Institute investigator. 'In other words, treating the root cause rather than the symptoms.'

Source: [Massachusetts Institute of Technology News](http://Massachusetts Institute of Technology News)

## 🔥 Parkinson's NZ Passes on Bequest to Fund Research

PSNZ was pleased to pass on a bequest of over \$54,000 from Wairarapa division member Nellie Ward to Professor Richard Faull to use at the University of Auckland's Brain Bank. The generous bequest will be used to help fund new -80°C freezers for storage of Parkinson's brains, which are a costly \$25-30,000. The remainder of the money will be used to help fund research investigating how the human brain can be stimulated to repair itself by making new replacement cells. Professor Faull says the team are 'very humbled and so appreciative of this very special support for our research.'

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.

## HALLUCINATIONS



### What are hallucinations?

A hallucination is defined as a perception of something in the environment which is not there. While some people with Parkinson's experience hallucinations, most do not. Hallucinations can involve all of the senses; however people with Parkinson's are more likely to experience smell, auditory or visual hallucinations, with the latter being the most common.

Hallucinations often begin in a mild form – you may begin to see spots, dots, lines or small shapes in your peripheral vision. You may also have persistent feelings that someone else is in the room when you are alone. These are called delusions of presence and share many similarities with hallucinations.

Hallucinations can last for seconds, minutes or hours, and are commonly reported as involving animals, bugs, children or people. These visions do not usually respond when engaged or spoken to.

Hallucinations experienced by people with Parkinson's are usually not disturbing, and people are often able to recognise what is happening. That said, they can

still be frightening and difficult to deal with for you and your family. It helps to know more about them.

### Why do people with Parkinson's experience hallucinations?

There are two factors that can contribute to hallucinations in Parkinson's. Firstly, many of the drugs used to treat Parkinson's may contribute to hallucinations. It is important to remember that this doesn't happen with most people, but the possibility of hallucinations occurring grows with higher doses and greater numbers of medications taken.

Anticholinergics, direct acting dopamine agonists and Levodopa can all contribute to hallucinations. However we know that Parkinson's drugs are not the only cause of hallucinations, and some people with Parkinson's may have hallucinations even if they are not taking these medicines.

The second factor in hallucinations is the brain itself. Brain perception circuits can be affected by the development of Parkinson's, and areas that interpret visual images may have some inherent instability.

This is presumably due to the same neuro-degenerative process that causes the tremor and motor symptoms of Parkinson's.

## Do some people have a higher risk of experiencing hallucinations?

Hallucinations are more common in older people who have had Parkinson's for a long time, and are on several medications. Memory loss associated with Parkinsonism is also one of the most notable risk factors.

Hallucinations can be due to other illnesses such as infections, kidney/liver failure or pneumonia, and if you have a severe sleep disorder or insomnia you may also experience hallucinations.

It is worth noting that hallucinations are rare early on in Parkinson's or in younger people with Parkinson's.

## What can be done?

It is important to remember that if you are beginning to experience hallucinations it does not necessarily mean your Parkinson's has taken a turn for the worse. They are nothing to be ashamed of, but the symptom should be reported to your doctor.

If you are experiencing hallucinations severely and regularly it is important to stop any activities such as driving or operating machinery until medical advice has been sought, and the hallucinations have been controlled.

The first course of action should be to speak to your GP or specialist and consider the following questions:

Are all of the medications you are on necessary?

How much is each drug helping?

Are you taking drugs for other purposes that could also be a factor in hallucinating?

Did the hallucinations start within a few weeks of beginning a certain medication or increasing a dose of an established medicine?

If the hallucinations are associated with Parkinson's but are not troublesome, the doctor may suggest that the situation is simply monitored. However if hallucinations are becoming a problem, the medication

used to control Parkinson's will often be adjusted. Such measures can often eliminate or reduce the hallucinations, and improvement is usually noticed within a few weeks.

However, because hallucinations are not just a side-effect of Parkinson's medications, making adjustments to the drugs does not always eliminate them. In these cases, the doctor will usually try to achieve a balance by reducing the hallucinations to an acceptable level, but also maintain a good amount of control over the Parkinson's symptoms.

If a satisfactory balance cannot be achieved, the doctor may consider prescribing an antipsychotic drug to treat the hallucinations. This is not the preferred option, as some of these drugs may worsen the movement symptoms of the Parkinson's. The potential risk of drug treatments will need to be balanced against any difficulties that may ensue if nothing is done.

## What can I do if someone I care about is experiencing hallucinations?

It can be difficult to care for someone who is experiencing hallucinations, as it is not always easy to know how to react and what to say.

If the person with Parkinson's lacks insight into the nature of the things they are experiencing, it can often take a while for them and their families to ascertain that they are hallucinating.

It is important to stay calm. Don't pretend that there is something there when there is not, but try not to let an argument develop. Instead, offer reassurance, particularly if the person is distressed by their hallucinations. It is sometimes useful to explain that you can not see or hear what they are experiencing, but that you understand that it is very real to them. Distracting the person can often be effective. The experience will eventually pass and any loss of insight may be restored.

If you are worried about yourself or someone you care about do not hesitate to speak to your GP or specialist as it is likely that something can be done to help.

**Sources:** [The Parkinson's Disease Treatment Book](#), [PDS UK Fact Sheet FS11](#), [American Parkinson's Disease Association journal](#), & [Parkinson's at Your Fingertips 2nd Ed.](#)

## CARING FOR THE CARER

Carers play an extremely important role in the lives of many people with Parkinson's, by providing much needed practical and emotional support. Caring for someone can be very rewarding; however it can also be extremely hard, especially when the carer feels isolated. The needs of the carer are as important as those of the people they are caring for, yet they often get overlooked because attention tends to focus on the person with Parkinson's. It is vital that carers maintain their own health and wellbeing while caring in order to cope with the challenges they can be presented with. Below is a checklist for carers to consider.

**1 GETTING INFORMATION** Make sure you have all the information you need to care for the person you are supporting. Parkinson's NZ and Carers NZ can be important sources of information as can the health professionals you are in contact with.

**2 KEEPING RECORDS** Keep a diary of the symptoms and difficulties the person you are caring for has and the details of your caring role. This can help you keep track of how living with a disability affects you, and can assist you when communicating with health professionals.

**3 FINANCIAL HELP** Check what financial benefits you could be entitled to, ask a Parkinson's Field Officer or WINZ to advise you on this.

**4 DEALING WITH EMOTIONS** Don't be surprised if you have complex, conflicting and fluctuating emotions about caring. Talking about your feelings and what you are doing is important. Some people prefer to talk to the person they are caring for, or friends and whanau. Others find it helps to talk to someone who is not so closely involved in their lives such as a counselor or support group.

**5 NETWORKING AND SUPPORT** Try to have contact with other carers. Many carers find contact with other people who are in a similar position is the key to providing invaluable mutual support, information, ideas and friendship. The internet can be a great place to start with this.

**6 ENCOURAGING INDEPENDENCE** Wherever possible, promote independence on the part of the person you are caring for, even if

this means activities take longer. This can help to improve their self esteem and can ease some of your responsibilities.

**7 ASKING FOR HELP** Make it clear what you are willing to do. Set priorities and don't be afraid to ask for help when you need it. Sometimes breaking down large difficulties into smaller, more manageable pieces can help. Remember you don't have to do everything single handedly, and talk to health professionals or support groups for advice on solutions.

**8 MAINTAINING A LIGHTER PERSPECTIVE** Try to keep your sense of humour. Many carers say that seeing the funny side of things has helped them and the person they are caring for enormously.

**9 TAKING TIME OFF** Where possible, try not to make Parkinson's the sole focus of your life. Make sure that you and the person you are caring for have things that you like to do together that are not related to Parkinson's or health. Having time away from each other to pursue individual interests is also important.

**10 LOOKING AFTER YOURSELF** Make sure you maintain your own health and wellbeing. Try to eat well, exercise regularly and consider learning relaxation techniques. Take advantage of any respite care facilities that are available to you and the person you care for. If you find your responsibilities overwhelming you or you are feeling depressed or exhausted, make talking to your doctor your top priority.

**A fitness routine involving an exercise band could help strengthen the muscles used for common caring tasks such as lifting, transferring and handling equipment.**

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## A New Way of Taking Levodopa

*A personal account of taking part in a research trial by Andrew Young*

As some of you will know only too well Levodopa + Carbidopa (Sinemet, Madopar) may not work so well over a long period of time, and severe side effects can occur with high doses e.g. dyskinesia (involuntary twisting and turning movements). I have had Parkinson's disease (Pd) for over twenty years, and for some years have had bouts of dyskinesia and pain in my limbs. If I reduced my Sinemet I froze several times a day.

Amantidine was marvellous but wore off in 4 months. I ended up taking 15 or more tablets a day plus two other medications and just put up with the continual involuntary movements. Pain and freezing were relieved by injections of apomorphine but these wore off in 15-25 minutes.

A European drug company (Solvay Pharmaceuticals) has developed a new way of giving Levodopa which is proving effective in several countries in Europe. But to be able to market it more widely, they have to find out how well their system works as treatment for advanced Pd. They are carrying out an international safety and efficacy study of Duodopa Intestinal Gel given by a pump to people in late stage Pd with severe motor fluctuations. The pump inserts the gel through a PEG tube directly into the small bowel where Levodopa is absorbed. Christchurch, Wellington and Hamilton are taking part in the research and I am the first NZ guinea pig.

I was screened in mid October to check that I met the admission criteria. Detailed information was provided and Prof Tim Anderson went over it with my wife and I before we signed informed consent. All Pd medicines except Sinemet were stopped immediately. I expected this to be difficult but in fact it was uneventful even though I had been on Pergolide since diagnosis and Tolcapone for years. For three days before admission I had to keep a detailed diary, every half hour, recording my Parkinson's symptoms and any medication changes.

On 28 October I was admitted to Christchurch Public Hospital and next day had a tube passed via my nose into my stomach and on into the small bowel. This was done by a radiologist under x-ray control. The procedure was uneventful – the nostril and throat were numbed by an anaesthetic spray – and also fasting for 6 hours had made me freeze so I didn't move an inch.

Then I started getting the gel through the tube. This test

period showed whether I could tolerate the medicine and benefit from it: I could and did. Viki Robinson the specialist nurse from the Van der Veer Institute and Katarina, a Swedish nurse from Solvay, were constantly available. My wife and I were taught how to use the pump and I went home two days later with a bumbag and holster to carry the pump in.

On 5 November I was readmitted and next day had a PEG tube inserted under heavy sedation through a small cut in the upper abdomen. I didn't feel pain nor do I remember anything about it – just as well because I am told I struggled vigorously making life very difficult for the team. It was great to lose the nasogastric tube after 10 days, though it really wasn't too uncomfortable. Following this, two nurses from Wellington joined the team as part of their preparation for the next candidate. I was discharged home on 8 November and the nurse visited us at home to check the wound and advised on caring for it. It takes about 6 weeks for the incision site to heal fully.

The pump runs for 16 hours per day from 6 am to 9 pm. It is disconnected at night and the wound cleaned. My wife gets up at 6 am each morning to hook me up to the pump. I am usually fully mobile in 10-15 minutes and I clean the wound in the shower. The dose has been adjusted and now I receive a settled morning dose and a steady flow rate throughout the day, but if necessary I can give myself an extra dose. Lois and I will attend follow up clinics for a year and complete a diary for three days prior to each meeting. Prof Anderson and Viki are also available at any time by phone.

The results so far have been very good and many friends have commented that I am a new man. It has revitalised me. For example in late November we spent four nights in Kaikoura, eating out on two evenings, something we couldn't do from home as I was usually 'off' by 6-7 pm. I am also sleeping much better. On 2 December I went into town by bus on my own using my senior gold card. The joy of being so independent was enormous. On 3 January we went to Blenheim and on the 6th drove through Molesworth Station to Hanmer Springs.

We are still fine tuning the dosage settings but overall I now receive much less Levodopa/Carbidopa per day. I feel very fortunate and grateful for the chance to benefit from this new method, which I believe would cost an estimated NZ\$50,000 to buy.

The success of this initiative is due mainly to the support and hard work of Tim Anderson, Viki Robinson, Katerina, all the staff on ward 28, and not least my wife Lois. Thanks also to Andrew Laing [radiologist], Steven Ding [gastroenterologist] and Thysje Waghorn [clinical nurse specialist] for their vital input.

## Professor Tim Anderson from the Van der Veer Institute Comments on the Duodopa Trial

Enteral delivery of Levodopa (i.e. direct delivery of Levodopa into the upper small bowel) is a relatively new form of treatment for advanced Parkinson's disease. The Levodopa is in a special gel form and is introduced directly into the jejunum (near the top of the small bowel) by a feeding tube that has been inserted through the abdomen. This allows continuous dribbling in of Levodopa which then permits fairly stable levels of Levodopa in the blood and subsequently Levodopa levels in the brain. The intent is to reduce fluctuations (i.e. people switching on and off during the day) and therefore make life more comfortable for people with advanced Parkinson's disease who have had a fluctuating response to their Levodopa. Sites in New Zealand are participating in a multi-national open label trial of this type of Levodopa, trademarked

as Duodopa. This type of treatment is really one of three forms of advanced therapeutic options available for persons with more advanced Parkinson's disease, the other two being Apomorphine, a subcutaneous infusion via a pump and a needle sited under the skin, and deep brain stimulation. It needs to be remembered that for all three of these advanced therapies, the best response is no better than the best response with Levodopa tablets (Madopar or Sinemet). However, these three different methods generally allow a more predictable and smoother response with generally less dyskinesia and more on time. It remains to be seen just where Duodopa therapy will sit in relation to deep brain stimulation and Apomorphine infusion treatment. Nevertheless, this represents a welcome new, albeit potentially expensive, therapy.

## Disabled Sailing Trust NZ

Disabled Sailing Trust NZ is embarking on an exciting sea going venture for the disabled community of New Zealand.

The Trust is committed to making a significant difference to the quality of life of families and individuals affected by disability and serious long term medical conditions. It aims to do this by promoting social, emotional and physical wellbeing through active participation in sailing and related activities.

The primary objective of the Trust is to fund-raise, build and operate a purpose built and fully adapted 16 metre catamaran that can be sailed by disabled people. Other activities will include fishing, swimming, kayaking, snorkeling or just sitting and enjoying a sail.

Features of the catamaran will include: A one-level deck around the yacht, electric lifts into the hulls allowing wheelchair access throughout the vessel, and a platform that can be raised to deck level for wheelchair access and then lowered into the water for swimming or kayaking. Preliminary boat plans have been completed by Roger Hill Yacht Design and early in 2009 we expect to be in a position to obtain quotes.

The yacht will be based in Auckland, probably in the Viaduct Basin but possibly operating out of other harbours for two or three months of the year.

The Trust is extremely pleased and encouraged by the support they have already received. They now plan to document this support to help in their approach to major funding organisations.

Their most urgent needs are (a) support from the

community generally but particularly the disabled community. (If you or your organization are able to support the project in any way, even if only in principle, then please consider the Expression of Interest on the You Can Help page on the Trust's website.) (b) assistance in getting the project known around the country. (Please contact the Trust if you would like to help.) Estimated costs are (a) the yacht: \$2,000,000 (in the water cost excluding GST) (b) annual operating expenses: \$200,000 (excluding GST).

Any financial contributions should be sent to Disabled Sailing Trust NZ, PO Box 32 057, Devonport, North Shore City, 0744.

For further information:

Email: [trustees@disabledsailingtrust.org.nz](mailto:trustees@disabledsailingtrust.org.nz)

Website: [www.disabledsailingtrust.org.nz](http://www.disabledsailingtrust.org.nz)



*'Impossible Dream' - a UK based, purpose-built catamaran for disabled*

# HOW CAN YOU HELP?

Dear Friend,

Like everyone, Parkinson's New Zealand wants to ensure a sound financial future for our organisation, guaranteeing we'll always be here to provide information, education and support to people with Parkinson's, their carers and families and health professionals. In order to make sure that we can continue to provide our invaluable services to people well into the future, we must ask for your assistance, even during difficult financial times.

We understand that everyone must make difficult decisions about their finances when the economy is tightening. But there are some ways that you can contribute to Parkinson's New Zealand without significantly affecting your budget. Additionally, you can receive some great tax benefits because there are no longer tax deduction thresholds for donations to charities.

## Payroll Giving

Speak to your employer about signing up to make donations to Parkinson's New Zealand through their payroll giving programme. You can ask your employer to deduct a regular set amount out of your wages and receive an immediate PAYE credit if your employer files returns electronically with Inland Revenue. Some employers will even match your contributions.

## Bequests

Bequests are a wonderful way for people to contribute to the long-term future of our Society, ensuring that we can continue our services, even during difficult financial times.

## Get Going for Parkinson's

Join Team Parkinson's and raise funds for Parkinson's New Zealand by walking, cycling, swimming or any other activity and you'll receive a fantastic event pack or encourage family and friends to join.

Contact us on [getgoing@parkinsons.org.nz](mailto:getgoing@parkinsons.org.nz) or go to our website at [www.parkinsons.org.nz](http://www.parkinsons.org.nz) for more information.

## Automatic Payments

Consider setting up automatic payments to make donations to Parkinson's New Zealand. This is a great way to provide assistance for our work, and enables you to plan regular weekly, fortnightly or monthly donations into your budget.

## Donations

Alternatively, you can help us by making a one-time donation. Please complete the form below and post it with your cheque made out to Parkinson's New Zealand to the address below.

If you choose to make regular automatic payments or make a one-time donation, we will send you a receipt that will enable you to make a Personal Tax Rebate (IR 526).

Thank you. Your generosity makes a very real difference to our society.

*Deirdre*

Best wishes

Deirdre O'Sullivan, National Director

Name \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Town/City \_\_\_\_\_

Post Code \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_  
\_\_\_\_\_

I would like to make a donation of

\$20     \$50

\$100     Other \$ \_\_\_\_\_

Please find my cheque enclosed.

*We will send you a receipt  
that will enable you to make  
a Personal Tax Rebate.*

I would like to be contacted  
in regards to:

Payroll Giving

Bequests

Get Going for  
Parkinson's

Automatic Payments

Volunteering



Please return this form to  
Parkinson's New Zealand  
PO Box 11 067  
Manners Street  
Wellington 6142

# NEWS FROM AROUND THE COUNTRY

## 🌸 Tauranga

A Golf Day was held on 11 December to celebrate the end of the year and raise money for the division. The event was supported by two local businesses, AnnanLaw and SBS Bank and was great fun. It raised over \$780.



Field Officer Joelene Morris, Philip Annan of AnnanLaw, Division Co-ordinator Mary Reid and Terri Gregory of SBS with the money they raised.

## 🌸 South Canterbury

Peter Dawkins launched his book 'The Icecream Boy' in his home town of Timaru to a crowd of about 75, where many people present remembered him winning a twisting competition in a shop window when he was younger. A Christmas party was also held at the RSA where the Waimataitai School choir entertained guests.

## 🌸 Northland

Northland held two Christmas parties, one in Kerikeri and one in Kaitiāia which were attended by members, carers and friends of the division.



Attendees enjoy the Christmas dinner in Kerikeri

## 🌸 West Coast

The society held a raffle day in each of the three main centres Greymouth Westport and Hokitika during Awareness Week (1–7 November). They were generously supported by the general public and gained excellent exposure with articles in the local papers.

## 🌸 Hawke's Bay

The Hawke's Bay division took part in a 'Seniors Expo', which was organised by Work and Income New Zealand and Age Concern. The expo brought together a range of community and government agencies to raise awareness and provide up to date information on the services available to the elderly. In December they held a Christmas lunch where division members, carers and friends were treated to Christmas carols and action songs by pupils from the local Greenmeadows School. The division has also recently moved shop and we look forward to seeing photos once it is refurbished.



The Hawke's Bay's display at the Seniors Expo with Field Officer Morag Murray, Treasurer Judy Sharman, and Committee Member Pat Prichard.

## 🌸 Taranaki

The Taranaki Parkinson's Society were invited to a kiwi release by the Taranaki Kiwi Trust on Friday, 28 November in Midhirst. The kiwi was blessed and then they had the opportunity to see and touch it before it was released into its new habitat on the mountain. There was a little talk about where they came from and how the chicks were hatched at Rotorua as part of Operation Nest Egg. This was a great opportunity to see first hand the reintroduction of our endangered icon back into its natural habitat.



## Parkinson's New Zealand

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