

## GENE THERAPY DEVELOPMENTS WITH DR MATTHEW DURING

*Using gene therapy to treat Parkinson's has come a step closer with the recent publication of the stage II clinical trial results showing the NLX-P101 treatment is effective. The results showed that 50% of people in the trial who received the gene therapy showed moderate to large improvements in their symptoms, compared to 14% of those in the sham surgery group.*

The therapy is given under local anaesthetic and involves drilling a hole in the skull. A hollow needle and catheter are used to insert a harmless virus carrying the genes into the sub-thalamic nucleus of the brain. This is the area of the brain that is extremely overactive in people with Parkinson's. Once the gene, called GAD, is in the brain it makes the brain cells produce more of a neurotransmitter substance called GABA which calms the over activity of this area of the brain, improving motor symptoms of people with Parkinson's.

The stage 2 trial involved 45 people with advanced Parkinson's where 22 people received the new treatment. The other 23 people made up a control group who were given a sham surgery which replicated the gene therapy surgery, but didn't involve injecting the neurotransmitter substance into the brain. None of the people taking part in the trial knew if they had received the treatment or not.

The treatment, which holds a lot of hope for people with Parkinson's, has been developed by Neurologix, an American company co-founded by Dr Matthew During. Dr During is one of us. He was born and started school in Eastbourne, Wellington, before moving to Hamilton around the age of 7. He attended Hamilton Boys High School and studied for his medical degree at the University of Auckland. The Parkinsonian caught up with Dr During and asked him a few questions about himself and his research.

### What got you interested in Parkinson's research?

I have always had an interest in the brain, including neurodegenerative disease and how the brain integrates with the rest of the body. I chose Parkinson's as one primary area of research because I felt that we had well characterized models, and it was a condition that could potentially respond to targeted molecular (cell and gene) therapies.



### When did you start researching gene therapy as a treatment for Parkinson's?

The research started in the early 1990s and our first papers on gene therapy were published in medical journals in 1994. It has taken a long time, around 17 years, to get to where we are today.

### The results of your recent NLX-P101 study have been well received by the medical community. What is this study?

NLX-P101 is the name that Neurologix, a biotechnology company that I co-founded gives to the AAV-GAD gene therapy product. It is a defective viral particle based on the adeno-associated virus (AAV) that encapsulates a short strand of DNA that consists of regulatory elements (control elements) and the sequence for GAD (glutamic acid decarboxylase), the enzyme

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## A WORD FROM THE CHIEF EXECUTIVE

### KIA ORA KOUTOU E HOA MA

This edition of *The Parkinsonian* has a great deal of news about research into treatments for Parkinson's. I am pleased by the latest results of Dr Matt During's gene therapy work and will be watching for the results of the stage III clinical trials with great interest. Dr During was kind enough to grant an interview to *The Parkinsonian* (cover and page 3) about this work which he started almost 20 years ago.

I was recently asked by a member how the work of National Office differs from the work of the local divisions. Local divisions provide the day to day services required for people living with Parkinson's. This includes providing the field officer service for their region, running support groups, organising social occasions and providing information on local services that may benefit members. Local divisions are funded by grants from trusts, membership fees, fundraising events and general donations.

Some of the areas that National Office cover include training for field officers and we have recently employed a Clinical Lead to provide clinical management for the field officer service. This will ensure a consistently high level of care is provided to people with Parkinson's around the country, improve professional support for field officers and better identify and meet training needs to ensure our field officers provide a first class service.

Advocacy is a very important part of the work of National Office which acts as a national voice to legislators and government. With the upcoming election we will be closely scrutinising each party's position and promises around health care. I also belong to a number of groups which aim to improve the quality of life for people with chronic conditions. These include the Access to Medicines Coalition, the Neurological Alliance, the Carers Alliance and the Disability Sector CEO group.

Providing information is another important part of National Office's role. We provide leaflets on a wide range of topics including information for the newly diagnosed, factsheets on living with the symptoms of Parkinson's and information on different types of Parkinsonianism conditions. We also produce this magazine *The Parkinsonian* which keeps members up to date with the latest research and treatments for Parkinson's, contains information for carers and useful advice on living with Parkinson's. Making sure people can rely on the information we provide is vital and all of the medical and research content of our publications are checked by our Medical Advisory Panel before publication. National Office is funded by grants from Trusts, bequests and donations from the public.

Many of our divisions celebrate midwinter Christmas with lunches or dinners at this time of the year and I have enjoyed the opportunity to attend a number recently and meet with many of our members. Thank you for the feedback you have given us on our services both locally and nationally.

While those of us who enjoy rugby will be gearing up for the World Cup, it is good to not let it overshadow the importance of our upcoming election. We look forward to bringing you comments in the next *Parkinsonian* from a range of political parties regarding their policies going into the 2011 election.

I hope you and your family/whanau keep well during these colder months.

Kind regards



Deirdre O'Sullivan

## EARLY ONSET PARKINSON'S ARE YOU ON OUR MAILING LIST FOR UPBEAT?



2011 UPBEAT Outward Bound group

UPBEAT is the special interest group for people with early-onset Parkinson's. Anyone diagnosed before the age of 60 is considered to have early-onset Parkinson's.

Parkinson's NZ produces four UPBEAT newsletters a year, runs an annual Outward Bound course and a biennial weekend away. If you didn't get our latest UPBEAT newsletter, which was sent out in June, you aren't on our list. Please email us at [info@parkinsons.org.nz](mailto:info@parkinsons.org.nz) or phone 0800 473 463 to be added to our list.



## INTERVIEW WITH MATT DURING, PARKINSON'S RESEARCHER

STORY CONTINUED FROM PAGE 1

responsible for the generation of GABA, the brain's primary inhibitory neurotransmitter. In Parkinson's, as a result of the deficient dopamine signaling, there is an imbalance downstream between excitation (mediated by glutamate) and inhibition (mediated by GABA) in key regions of the network that regulates movement. In the subthalamic nucleus (STN) and downstream in the basal ganglia, i.e. the GPi (globus pallidus internal segment), there is too much glutamate and not enough GABA signaling, our AAV-GAD restores the neurochemical balance, and thereby improves motor symptoms.

**We have read that the Stage 2 trial has shown very good results. What does this mean for people with Parkinson's?**

We believe that for the first time we have met a key threshold (a successful sham control blinded Phase 2 study), and can now move to a larger Phase 3 study. If our Phase 2 results are confirmed, Neurologix will obtain a BLA (approval to market a biological product, NLX-P101), and we will have an approved product that we believe will be a significant advance over DBS, equally effective, but without the side effects, and a much simpler and safer operation.

**What are the next steps in this research?**

We are now in the process of treating those individuals who were randomized to the sham surgical arm of the Phase 2 study (i.e. they only had a partial thickness burr hole). Those subjects (approx. 20) will now get the real treatment. We will then start the Phase 3 study - likely starting sometime in 2012, and follow those individuals for a year, at that time, we will submit a request to the US FDA to enable AAV-GAD (NLX-P101) as an approved therapy.

**Who will most benefit from this treatment?**

It is most unlikely that any surgical treatment will be offered to individuals early in their disease when they have excellent responses to oral agents. Our studies suggest that both individuals with moderate disease and more severe disease are likely to benefit. The surgery is carried out under local anesthesia, and so we can operate on the elderly as well as younger people. Hence, anyone whose disease has advanced to the stage where they are getting significant fluctuations, and have major limitations in the "off" state would be a candidate, so long as they don't have any contraindications (i.e. cannot undergo surgery, have lesions in the brain, have severe cognitive impairment or major depression). In time, we may be able to broaden the indication, but initially we would be treating the same sort of patients who would otherwise be considering DBS.

**How long will the treatment last once a patient has had it?**

We can't really say as we don't have long-term evidence of people who have undergone the treatment, except for a year follow up during which the benefit was maintained. In the phase 2 study, none of the people who received the treatment had any worsening in their condition over this time period, however 35% of the control group (who received the sham treatment) had worsening of their Parkinson's. The data suggests that the treatment benefits will be maintained and will modify the natural history of the disorder, but as yet we can't prove this.

**Where are you based nowadays?**

I am largely US based. I did come back in 1996 and spent two years full time in New Zealand, I love NZ and have family there, the greatest difficulty is that the environment (research/funding) is not very supportive for translational research, i.e. bringing new (often risky) therapies to the clinic. In the U.S. they are far less risk averse, and willing to try new things. There is a lot more interest in clinical research, with large academic centres where doctors spend more time doing research than straight clinical care.

*The Parkinsonian is extremely grateful to Dr During for spending time with us to discuss his exciting work.*

**"I've stopped falling!"**  
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## 🔥 Research Grants

The Neurological Foundation has recently awarded two Miller Scholarships to students undertaking PhD research into Parkinson's.

Hayley MacDonald was awarded \$100,224, funded by the Douglas Charitable Trust. Her research aims to develop a simple method for clinicians to measure response control for early identification and monitoring of patients who might benefit from drug therapies to slow Parkinson's progression.

Jerusha Naidoo was awarded \$100,224 to see if an existing gene regulation system, that senses cell stress and switches on to express a therapeutic gene only to cells at risk, can be used to control the expression of Parkin\*. This system, if it is found to be effective, could limit the side effects typically seen with traditional Parkinson's pharmacotherapies.

*\* Parkin - Parkin is a protein that in humans is encoded by the Park2 gene. The precise function of this protein is unknown however it appears to be part of the cell's defence against environmental factors that may damage it. Mutations in the Park2 gene are believed to cause some forms of Parkinson's.*

## 🔥 Safinamide reduces motor fluctuations in Parkinson's

Encouraging results have been returned from a phase 3 clinical trial assessing the efficacy and safety of a new add-on drug safinamide. Results of the trial, which was conducted over a 2 year period, and included trials in New Zealand, suggest that

taking safinamide in addition to levodopa and other dopamine treatments could help patients who continue to experience tremors and dyskinesia. The trial showed that safinamide improved 'on' time and improved depressive symptoms and the quality of life of participants without worsening dyskinesia. During the course of the trial no new safety concerns emerged.

Safinamide reportedly blocks dopamine reuptake and glutamate release. It may also inhibit sodium and calcium channels. The drug may now be submitted to regulators in the USA as early as next year.

## 🔥 USD\$40m study launched to find biomarkers

Promising progress has recently been made in the search for biomarkers for Parkinson's prompting a \$40m 5 year study funded by the Michael J Fox Foundation to find them. A biomarker is a substance or characteristic in our bodies that is associated with the presence of a disease or that changes over time in a way that can be linked to the progression of a disease. Biomarkers exist for other neurodegenerative disorders, such as Alzheimer's, but to date few have been identified for Parkinson's. The study to search for these biomarkers will use a combination of imaging techniques, collection of blood, urine and spinal fluid, and clinical tests.

Biomarkers are difficult to find for Parkinson's because the changes in the brain are less widely distributed than in other conditions like Alzheimer's. This new study will compare 400 newly diagnosed people

with Parkinson's to 200 healthy age-matched control participants.

The current lack of biomarkers means that, although an experienced neurologist can make an accurate diagnosis for most people with Parkinson's, for those who have unusual, mild or ambiguous symptoms, biomarkers could help improve the accuracy of their diagnosis.

The treatment of Parkinson's would also benefit from the identification of biomarkers as they can provide a valuable way of measuring how a drug is influencing the brain.

They could also be used to measure the progression of Parkinson's in a person and how genetic and environmental risk factors affect the brain.

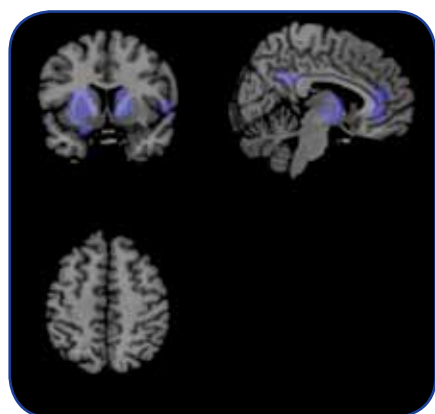
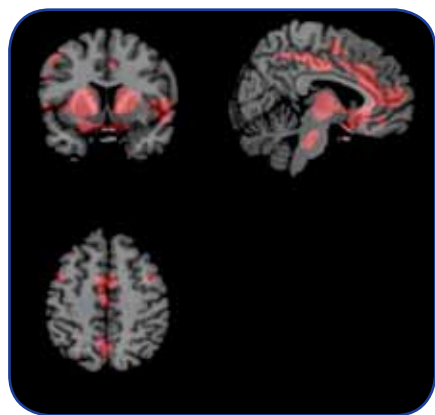
## 🔥 Brain imaging provides new hope for understanding Parkinson's

The University of Michigan has developed a non-invasive brain imaging technique which will help find new and improved treatment plans and can be used to track the progression of Parkinson's. An MRI scan measures brain activity oscillations which were previously only available for study during brain surgery or in animal models. Neural oscillations in the part of the brain affected by Parkinson's, the basal ganglia, go haywire and spill into other parts of the brain causing cognition, movement, memory and other problems. The effect has been likened to the ripples in a pond spreading and disturbing the entire surface of the pond.

In a recent study by the University's School of Kinesiology and Department of Psychology,

people with Parkinson's came in twice for testing and either received an L-DOPA tablet or a placebo prior to undergoing an MRI scan. These scans showed that the increased oscillations were reduced with L-DOPA. This change in brain activity also correlated with the improvements in symptoms shown by the patients.

In some cases, the MRI imaging found that the L-DOPA dose was too high, causing the oscillations to be slowed too much, thus 'freezing the pond'. Researchers believe the imaging could be used to ensure the dosage for a patient is correct.



The top image is the MRI of an unmedicated person with Parkinson's showing more coloured areas which indicate the spillover of the disruptive brain oscillations. The image below is of a person with Parkinson's who has been medicated with L-DOPA showing fewer areas of spillover.

The data from this study may now be used to analyse the size of the oscillations and how this relates to cognitive and motor performance in newly diagnosed people.

## 🔥 Orphan drug may halt Parkinson's progression

A drug that could halt the progression of Parkinson's is currently being evaluated in human patients. The drug, phenylbutyrate, is already on the market as an orphan drug\* for a rare genetic disorder. University of Colorado researchers have shown that the drug turns on a gene that can protect dopamine neurons. The gene targeted is called DJ-1 and is crucial in keeping brain cells healthy and functioning.

DJ-1 was discovered in 2003 and since then researchers have been searching for a substance to switch the gene on. They identified that when phenylbutyrate was put in the drinking water of mice who had been genetically programmed to develop Parkinson's as they aged, the mice showed no decline in physical or mental function. Their brains also showed no evidence of Parkinson's.

The medication is now undergoing safety tests.

*\* Orphan Drugs – An orphan drug is a drug specifically developed to treat a rare disease that has been classified as an 'orphan disease'. The designation of orphan status to a disease or medication is a matter of public policy in the USA, EU and other countries. This status is given where, because the disease is so rare, the economics or practicality of testing the drug would prevent the treatment being developed, eg there may not be 1,000 people with the condition required to test in a phase III clinical trial.*

## 🔥 Eli Lilly and Medtronic collaborate to develop new treatment

Medtronic and Eli Lilly have announced they will collaborate to research and develop a new approach to treating Parkinson's. The collaboration involves using an implantable drug delivery system to administer a new medicine to targeted areas of the brain.

Eli Lilly, using its expertise in biotechnology, has designed its modified form of glial cell derived neurotrophic factor (GDNF) with the intent to achieve increased distribution in the brain. GDNF is a small protein that potently promotes the survival of many types of neurons. It has been shown to promote the survival of dopaminergic neurons in cultures.

Medtronic have developed a drug pump and specially designed catheter to enable the precise delivery of the drug to the areas of the brain it is needed. The combination of the optimised delivery system and the new drug GDNF has the potential to impact the neurodegeneration that leads to worsening symptoms and progression of Parkinson's.

The companies are hopeful that early testing of GDNF with Medtronic's device will provide the necessary data to safely advance the treatment system into human studies.

## 🔥 Drug fares well in study

A phase III study of IPX066, an extended release version of carbidopa-levodopa has shown good results in decreasing "off times" in people with Parkinson's.



The phase III trial programme for IPX066 consists of three studies. The first of these studies reported positive results in people with early Parkinson's last November. The most recent study has showed IPX066 reduces "off time" by 37%. It is expected a new drug application will be filed in the US for IPX066 in late 2011.

## 🔥 Test for cognitive decline in Parkinson's patients

University of Pennsylvania researcher are investigating a blood test that may shed some light on the chance that a person with Parkinson's disease will go on to develop significant cognitive impairment.

The test, the first of its kind, uses blood based biomarkers to examine the level of epidermal growth factor (EGF) found in patients. Scientists determined that people with the lowest levels of EGF and normal cognition were eight times more likely to subsequently develop serious cognitive impairments during the 21 month median follow up period.

A second group of patients are now being studied to see if this pattern continues and this data will be available in 2011.

The most efficient and cost effective way to test a drug to preserve cognitive function in Parkinson's is to identify the most at risk group to be involved in a clinical trial and evaluate the effect of the drug in a short timeframe. This test could also be used to

assist people with Parkinson's in planning their futures.

## 🔥 Retinal stem cells fail to treat Parkinson's

As human retinal pigment epithelial (RPE) cells in the eyes also produce L-dopa, researchers have been investigating the safety and efficacy of transplanting these cells into the brain of people with advanced Parkinson's. The study involved injecting around 650,000 cells into the brain of each patient and assessing their symptoms after a year.

Researchers found that the treatment made no difference to the person's symptoms of Parkinson's and that some adverse effects, mostly neurological or psychiatric, were reported. A previous study had concluded that the transplanted retinal cells simply failed to survive.

## 🔥 UK study to investigate dance for people with Parkinson's

The University of Hertfordshire is beginning a new study looking into how different types of dance affect people with Parkinson's. The study will investigate how dance affects both physical and psychological symptoms in people with Parkinson's. It will also look at what kinds of dance classes produce the best benefits.

There have been a number of recent studies that have highlighted the benefits of dance. In one study, it found that after just one month of attending weekly tango dance

sessions, people with Parkinson's had better posture and mobility as well as improvements in their mood and self esteem.

## 🔥 PHARMAC funding of Pramipexole

From 1 September 2011, PHARMAC will fund without restriction Dr Reddy's Pramipexole. Pramipexole is a treatment for Parkinson's and restless legs syndrome.

Sources:

- *Parkinson's UK*
- *viartis.net*
- *University of Pennsylvania*
- *GlaxoSmithKline*
- *PR Newswire*
- *Massdevice.com*
- *University of Michigan*
- *Headlines Autumn 2011*
- *Medscape.com*
- *Michael J Fox Foundation*
- *Union Tribune*
- *PHARMAC*

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.

## WE CARE! CAMPAIGN

Carers are New Zealand's biggest health workforce whose unpaid work has an annual economic value of over \$5 billion. The We Care! Campaign recently launched by Carers NZ and the NZ Carers Alliance, of which Parkinson's New Zealand is a member, aims to recognise, celebrate and support carers.

Caring is something we can all expect to give or receive during our lives. Caring can be for a short time or for a lifetime. Any of us can become a carer overnight (after an accident or health trauma) or over time, as a loved one's needs increase. Caring is an unsung role, something Kiwis have always provided for family/whanau and friends, but carers don't always get the recognition and help they deserve.

### The We Care! Campaign aims to:

- Recognise and celebrate carers and their contribution to families, society, and the national economy
- Ensure thoughtful leadership for carers across every political party, and across government agencies as every party and agency has to deal with looming care challenges in our ageing society
- Encourage the Prime Minister, John Key, to take a direct interest in the work and welfare of family carers like prime minister's and presidents in other countries do

- Ensure that carers are respectfully recognised across government in key policies, documentation, strategies, and support/service development
- Ensure that supports and services for carers are flexible, relevant, and truly reflect carers' wishes and needs, and that carers have free access to nationally consistent, high quality information and learning to support their role
- Ensure that carers of workforce age can make the choice to participate in paid work if they wish
- Ensure that carers who give 24/7 support are not exploited, undervalued, or experience discrimination on the basis of old-fashioned arguments based on 'natural support' or 'social contract' obligations
- Remind everyone that caring is a precious social and family value. We need to care for our carers, otherwise they might not be able to continue to care

You can get involved in this campaign and send an email with your own message about caring to Prime Minister John Key or submit a photo for the visual petition at [www.wecare.org.nz](http://www.wecare.org.nz)



## KAPITI SEMINAR

**DATE:** Tuesday 23 August • **VENUE:** Coast Community Church, 55 – 65 Hinemoa Street, Paraparaumu

- TOPICS INCLUDE:**
- Role of the carer – Kevin Miles
  - Brain Stem Cell Research – Dr Maurice Curtis, Co-Director of The Brain Bank
  - Parkinson's and Anxiety – Dr Matthew Croucher, Consultant Psychiatrist
  - Complimentary Therapies – Jeannette Clark, registered nurse and chartered natural therapies practitioner

**COST:** Members \$45 or \$30 early registration • Non members \$70 or \$55 early registration  
Early registrations must be received with full payment by 27 July

To register, or for more information, phone 04 904 4240 or email [kaphoro@paradise.net.nz](mailto:kaphoro@paradise.net.nz)

## 🔥 Auckland

A number of Auckland Division members sing as part of the CeleBRation Choir, a group of singers with speech problems caused by neurological conditions or stroke. Although some people may have difficulty speaking, they can still sing and singing seems to act as a form of speech therapy. The CeleBRation Choir recently performed as part of Brain Day in Auckland.



*Celebration Choir – Laura Fogg*

As part of Brain Awareness week the Centre for Brain Research ran the Auckland Brain Day. One of our field officers presented a session on “I have PD: What now?” running through some positive approaches to living with Parkinson’s disease. This was well attended and resulted in many people gathering information pamphlets and membership forms, all keen to know about our service. Communications and Liaison Manager for CBR, Laura Fogg estimated over 2,000 people attended the event, allowing the public to find out about all aspects of the brain and conditions that result from changes in neurological function.

World Parkinson’s Day on April 11th was marked by a free public lecture by neurologist Dr Barry Snow. Attended by over 200 people, this event was a great success, each person going away with a better understanding of the approach to treatment of Parkinson’s using the multi-disciplinary team as well as current medications. The occasion also allowed the team to introduce their newest addition, Janine Colquhoun, who will take over the field officer service in the South Auckland area. Over the next few months there will be a lunch for carers with a community dietician to talk about reviewing what we eat with Parkinson’s. Also newly diagnosed younger members are invited to a mid-winter breakfast seminar with hospital neurologist Dr Mark Simpson.

## 🔥 Tauranga

The Rotorua Ramble proved popular with members who enjoyed this social occasion in April. The day

started with coffee at a garden centre and a wander amongst the plants. Next stop was an educational walk at the Eastern Bay Fish and Game Ngongotaha trout hatchery followed by a visit to the Wingspan Birds of Prey Trust. This is New Zealand’s only bird of prey centre featuring morepork owls, ruru and Kahu harrier hawks, and the threatened NZ falcon the Karearea. Members enjoyed ‘Close Encounters of the Bird Kind’ – an opportunity to get up close to these wonderful birds.

In May the Brainwaves and Silver Singers entertained the members with an entertaining afternoon on music.

## 🔥 Wanganui

Nordic Pole Walking continues to be popular with the division running weekly sessions. There are now two physiotherapy sessions each week held for members. Social occasions this year have included members enjoying a visit to the Waiouru Army museum earlier this year. The division held its 21st Annual General Meeting in April.

In May the division took part in a Disability May Day Display. Schools were invited to attend special programmes and visited the displays along with the general public.

## 🔥 Kapiti/Horowhenua

The Levin Scrap Metal Drive, organised by member Gary Tonks, has raised over \$4,000 for the division over the last couple of months. A team of volunteers delivered flyers in the Levin area asking people to donate any scrap metal they had lying around. People phoned to say they had metal to collect and Gary picked it up or arranged for it to be collected. Gary had negotiated trade rates with the scrap metal yard to get the best price possible for the scrap he collected, resulting in the huge success of this fundraising effort.

Sandy Wright Miles, Kevin Miles, Jeannie Symons and Field Officer Vanessa Shaw, took part in the 5km fun walk at Waitere Beach. Kevin and Sandy raised over \$500 in sponsorship for this event. Division member Irene Taylor completed the 10km run that was part of this event.

## 🔥 Wellington

Wellington Division has been raising much needed funds by collecting outside local supermarkets in Wellington and the Hutt.

At the division’s recent AGM over 40 people attended and Mary Daly, Nurse Practitioner for the older person’s team at Hutt Hospital gave a well received talk.



# NEWS FROM AROUND THE COUNTRY



25th celebration



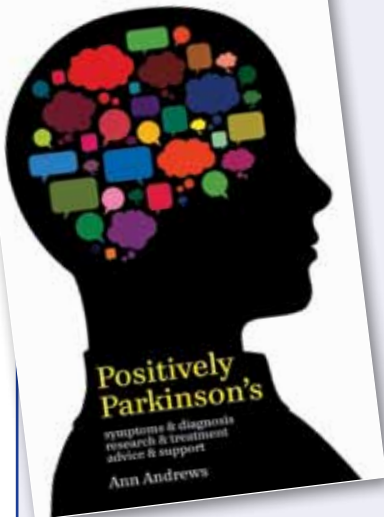
The Pink Bunnies

## 🍷 South Canterbury

Parkinson's South Canterbury was fortunate to be one of the beneficiaries of the South Island Charity Bike Ride this year. The three day bike ride covered 363km taking in the Upper Waitaki hydro lakes, McKenzie Basin from Timaru via Waimate, Kurow, Omarama, Tekapo, Fairlie and back through Pleasant

Point to Timaru between February 24 and 26. As a benefiting organisation, the division put on a delicious lunch for riders on the second day. Bev and Graeme Wallace acted as drivers over the weekend for the team of riders called 'The Pink Bunnies'. The division received a donation of \$15,750 from the funds raised from this event.

The division also celebrated their 25th Jubilee with a lunch on 20 April. 51 guests attended including a number of former committee members and Presidents. The division's first President Roy Clark and first field officer June McIntyre helped current President Janet Grieve cut the cake.



## POSITIVELY PARKINSONS

When Aucklander Ann Andrews was diagnosed with Parkinson's disease, she went looking for information and guides that would give her advice to help with the difficulties she was experiencing.

Still working in television and theatre as a producer and researcher, she had

the skills to track down what she needed to know as various symptoms presented themselves.

As she gathered research papers here and pamphlets from there, quizzed others with Parkinson's and medicos, she gradually built up a dossier. She noted symptoms, and the services and courses that helped deal with her difficulties.

Ann also talked at length with other people with Parkinson's and found they had a fund of helpful information.

When yet another trip to the library in search of information revealed no new texts that dealt with her problems, Ann realised that she had gathered more than enough practical advice, information and insights from others with Parkinson's to write a book that would help others.

So – in short – that is what she did!

Positively Parkinson's covers symptoms and diagnosis, looks at current research and many treatments for various aspects of Parkinson's and goes further to give advice and list the support that is available. It publishes in New Zealand in August.

It has been a long road – four years in development. But Ann's manuscript was accepted by her New Zealand publisher, Linda Cassells of Calico Publishing, who has also successfully sold the North American rights to produce Positively Parkinson's in that market. Ann's greatest satisfaction has been writing the book she would like to have read at the critical time she was diagnosed with Parkinson's. It has been supported by Parkinson's New Zealand and by the Neurological Foundation.

### POSITIVELY PARKINSON'S:

Prepublication offer for The Parkinsonian readers

Order from the publisher direct and receive your copy for only \$32, including packing and delivery. It's easy!



Ann Andrews

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Phone orders also accepted on 09 6245674  
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Full details supplied with order.

Note: the full RRP is \$35, plus handling and delivery fee of \$5.50. You save \$8.50. Offer expires 1 August 2011.

## HEALTHY BOWELS

Good bowel health is important for everyone, especially if you have Parkinson's. The bowel processes the food we eat, extracts the nutrients that the body needs and then expels the waste products. Bowel problems are common in people of all ages, whether or not they have Parkinson's, and are something people are often embarrassed to talk about. As a result of this, many people don't seek the help they need to cure or manage problems as they occur.

It is by no means inevitable that all people with Parkinson's will experience problems

### What types of bowel problems can occur in Parkinson's?

#### Constipation

Constipation is one of the most common digestive disorders and the rate increases with age. Older adults are five times more likely to have problems with constipation than young people. The most common form of bowel problem caused by Parkinson's is constipation.

People have different ideas of what constipation is and can be unsure of what the normal number of bowel movements should be. Although there is no definitive answer, it is important to realise that healthy people can have between three bowel movements a week and three a day. As long as the stool is soft and easy to pass without undue straining there is nothing to worry about. People with Parkinson's should watch for regular bowel movements, not frequent ones.

Constipation is when stools are hard and difficult to pass – they can be either too small, too hard, too difficult to expel, or too infrequent. Some people use the term constipation to describe a feeling of incomplete emptying.

#### Diarrhoea

If you have Parkinson's you can still get diarrhoea for the same reasons as anyone else, eg a reaction to food, 'holiday tummy' or as part of an illness or infection. Diarrhoea may be more difficult to deal with if you have Parkinson's as it may not be easy to hurry to the toilet. You may also find you can't squeeze the sphincter muscles in your bottom to stop leakage on the way to the toilet. This means you may be more likely than other people to have an accidental leakage if you have diarrhoea.

#### Weak Sphincter

The anal sphincter muscle is easily damaged, especially during childbirth or minor operations in the area for piles or other conditions. A weak sphincter will usually cause difficulty in holding stools in once the urge to empty the bowl is felt and incontinence may result if the toilet is not reached quickly. Pelvic floor exercises may help if you have a weak sphincter.

### What are the causes of constipation in Parkinson's

The stiffness and slowness of Parkinson's can affect the muscles of the bowel wall. As dopamine is lost from the body, including the bowel, the movement of the gut propelling waste material out of the body, is slowed down and constipation results.

The relative lack of movement and exercise experienced by people with Parkinson's means the bowel doesn't get the stimulation to function as it should.

Some people with Parkinson's have problems with chewing and swallowing food. This can make it difficult to have a diet with plenty of fibre. Reducing your food intake, especially at breakfast, may make the bowel less active. Having something to eat early in the day triggers the emptying reflex, particularly if followed by a hot drink.

Some Parkinson's medications may cause constipation. These include drugs such as disipal (Orphenadrine) and cogentin (benatropine) that belong to the anticholinergic group and may be used in the early stages of Parkinson's.

Check with your doctor if you are taking anything in this group of medication. Some psychiatric medications may also cause or worsen constipation.

### How can I prevent problems?

Although many bowel problems are difficult to avoid, you can help make them less likely to lead to constipation or incontinence.

Get plenty of exercise. Living a healthy lifestyle and keeping active and mobile is important for people with Parkinson's. Exercise will stimulate your bowel to help prevent constipation and contribute to stronger pelvic floor muscles. Aim to do at least 30 minutes exercise each day.

# PARKINSON'S FACT SHEET

Drink 8 cups of fluid a day. Water is best, but milk, juice, tea, coffee, soup, jelly and iceblocks are also counted as fluids. You should increase your fluid intake if you drink alcohol as it is dehydrating.

## Add more fibre to your diet by eating more

- Bran based cereals such as weetbix, porridge and muesli
- Fruit and vegetables, with the skin on
- Replacing white bread and pasta with wholemeal and whole grain bread and pasta
- Legumes - dried beans, lentils, split peas and nuts can be added to casseroles, curries, pasta, boil up, soups and other dishes

It is important to add more fibre to your diet gradually to give your body an opportunity to adjust to your new diet. It is normal when increasing fibre to experience minor side effects such as bloating and gas. As your body gets used to the increased fibre these symptoms should subside.

Eat 5 servings of fruit and vegetables each day. Fruit and vegetables, especially if eaten with the skin on, are a great source of natural fibre. Fruit and vegetables can be fresh, frozen, dried or canned.

Eat regular meals. Have your meals at regular times and make sure you don't skip breakfast as this is a common trigger for the bowel to move.

Eat foods with a natural laxative effect. In a study by Auckland University, eating 2 or 3 kiwifruit a day was shown to improve the regularity and consistency of stools. Other foods with a laxative effect include prunes and chilli. Kiwi Crush is a frozen drink concentrate that is convenient and contains all the goodness of kiwifruit.

## What are the treatments for Constipation?

It may be necessary to use laxatives or a combination of laxatives. We recommend that you discuss this with your doctor or dietician as some laxatives, such as liquid paraffin should be avoided as they can interfere with the absorption of some Parkinson's drugs. Treatment options available include:

### Establish a bowel routine

Relax and give yourself time in the bathroom. Many people find that around 20 minutes after breakfast or a hot drink in the morning is a good

time to empty their bowel. Using a foot stool to improve your seating position on the toilet can also help, especially if your feet don't sit flat on the floor when you are using the toilet.

## Bulk forming laxatives

Bulk-forming laxatives contain wheat bran, cellulose, psyllium or other dietary fibre that pass through the digestive system undigested, but assist the movement of the waste through the bowel by increasing stool size and weight. Drinking adequate fluid is necessary if these fibre-based laxatives are used. While these bulk-forming laxatives may help you establish regularity, they usually take from 12 hours to several days to work. Bulking type laxatives are safe, and help prevent the complications of recurring constipation such as diverticular disease, rectal prolapse and anal damage.

## Stool Softeners

Sometimes you may find that you are straining or even have pain when you try to move your bowels. This could be the result of constipation associated with a medication you are taking, or it may be a side effect from recent surgery. When constipation is accompanied by pain or straining a stool softener makes the stools softer and easier to pass. They work by drawing more moisture into the stool while it is in the bowel.

## Suppositories

Suppositories provide fast relief from constipation and act by drawing water into the bowel or stimulating the walls of the colon and rectum to aid in passing the faeces. Talk to your doctor or pharmacist for more information about suppositories.

## Microlette

Microlette is a fast acting enema which increases the water content and volume of the stools and lubricates the bowel making stools softer and easier to pass. Microlette is available over the counter from your Chemist.

The information in this factsheet is intended as a general guide. If you find that the above tips are not helping, please consult your doctor.



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