

## NEW PARKINSON'S NEW ZEALAND WEBSITE

The image shows two overlapping screenshots of the Parkinson's New Zealand website. The top screenshot displays the homepage with a navigation menu including 'HOME', 'ABOUT US', 'WHAT IS PARKINSON'S?', 'CARERS AND FAMILIES', 'NEWS & RESEARCH', and 'OUR DIVISIONS'. A 'FUNDRAISING' section is visible, along with a search bar and a text size adjustment tool. A photograph of a family is featured on the right. The bottom screenshot shows a 'What is Parkinson's?' page with a sidebar menu listing various topics like 'MOTOR SYMPTOMS OF PARKINSON'S', 'NON-MOTOR SYMPTOMS', and 'DEEP BRAIN STIMULATION'. The main content area includes a definition of Parkinson's and a list of news items such as 'Swimming Legends' races for charity' and 'Neurological Foundation - Brain Awareness Week'.

With a host of new features, services and functions, members are likely to find the new Parkinson's New Zealand website a far more useful and enjoyable tool.

Launching on March 22, the site has already proven during testing to be easier to use than its predecessor, with a simple, functional layout and enhanced usability features, such as adjustable font size.

As well as being easier to navigate, the site includes a host of new information. One of the most exciting features of the upgraded site is more up to date information about what is going on in all parts of the country, as each Parkinson's division is now able to update their own section.

Existing information for members and other interested parties is also easier to find and use, and is backed up by current research and news available on the home page of the site, which will be constantly updated.

Another great feature of the new site is the opportunity for a far greater level of engagement and interaction both with and between members, using blogs and community forums.

This is backed up by a new subsite for UPBEAT that will help ensure that the specific needs of UPBEAT members are met. One of the really valuable aspects of UPBEAT is networking and meeting new people and the new subsite will really enhance this by providing a way for members to stay in touch online.

The new site is a huge step forward in terms of accessibility and visibility for Parkinson's New Zealand, and both the public and members will find it a useful and valuable resource.

Log on to [www.parkinsons.org.nz](http://www.parkinsons.org.nz) and take a look around.

- In This Issue**

  - Parkinson's and Fatigue
  - Payments for Family Caregivers
  - New Research at Otago University

# NATIONAL DIRECTOR'S REPORT

## Tena Koutou e hoa ma

A belated Happy New Year to you all. I hope that the Christmas season was a happy one for you and your family and that the summer months treated you well.

You will have read reports in previous issues about the Organisational Review that the Society began last year. A final report and set of recommendations have been circulated to the Council, divisions and staff. The Council will meet at this year's AGM and Workshops in Wellington on 16 and 17 April to discuss and determine the Society's future direction. I look forward to updating you on their decisions in the next *Parkinsonian*.

Seeing New Zealand researchers contribute more and more to a better understanding of how Parkinson's works in the search for cause, prevention and treatment is very satisfying. We are delighted to be able to support the work of Dr John Reynolds and his team at Otago University (page 10) and look forward to keeping you updated on their developments, and the work of other New Zealand researchers.

In this issue Carers Corner covers the very important question of payment for family members who are caregivers. Many of you will have followed the recent court case reported in the media and the Government's response. This article examines the Government's position. Our thanks to Sharon Blaikie who wrote this for us.

My best wishes and congratulations to the 12 UPBEAT members heading off to Outward Bound in April—have a great time.

For those of you with access to a computer, I encourage you to log on our new website, look around and let us know what you think.

Enjoy the last warmth of summer.

Naku noa



Deirdre and the team at National Office.

## THANK YOU



## NOTICE OF AGM

The Parkinsonism Society of New Zealand's Annual General Meeting will be held in Wellington on 17 April. It will be preceded by workshops on the 16 April.

**11 APRIL  
2010, WORLD  
PARKINSON'S DAY**

World Parkinson's Day commemorates the birthday of Dr. James Parkinson on April 11.



# ANTHONY MOSSE GETS GOING FOR PARKINSON'S



*Anthony Mosse  
at the Edinburgh  
Commonwealth  
Games*

As reported in the last issue of *The Parkinsonian*, Swimming New Zealand and Parkinson's NZ have teamed up with Olympic and Commonwealth Games medalist Anthony Mosse. Anthony will be captaining the Parkinson's Team in a Swimming Legends Relay race. The race is part of a Festival of swimming which is being held in Waitakere from 5 to 10 April. The charity race is on 10

April at 10.15am. The festival also includes the New Zealand Open Championships that double as the Commonwealth Game trials, school finals and an inaugural Awards dinner. The relay will be broadcast on Sky TV but please let National Office know if you would like to go along to support Anthony in person. A number of swimming legends are raising funds for their chosen charity and the charity that raises the most money will also benefit on the day. Other team Captains and charities include:

- Danyon Loader – The Asthma Foundation
- Paul Kingman – Organ Donation NZ
- Rebecca Perrott – Stroke Foundation
- Gary Hurring – Diabetes NZ
- Anna Simcic-Forrest – Heart Foundation
- Toni Jeffs – NZ Swimming Trust
- Mark Treffers – Arthritis NZ

To support Anthony and make a donation please visit his fundraising page:

[www.fundraiseonline.co.nz/AnthonyMosse](http://www.fundraiseonline.co.nz/AnthonyMosse)

Other Get Going for Parkinson's participants around the country have been doing a fantastic job to meet both physical and fundraising challenges. Our thanks and congratulations to them all, they include:



*Viv Hodge*

- Viv Hodge, the daughter of Northland division's co-president, aims to take part in the 2010 New York Marathon.
- Shelley Musk, whose father has Parkinson's, set herself two goals: to compete in the 2009 New York Marathon and raise \$5,000 for Parkinson's in the process. She succeeded in both and raised funds beyond her expectations. On 26 March she will present a cheque for \$6,536.20.
- Simon Williams raised \$266 and Victoria Elliot \$150 - they successfully completed marathons in Auckland and Southland respectively.
- Last year Michael O'Connor organized a bowling event that was so successful it made a profit of \$1,500. And in February this year he organized another one!!
- And Robin Atkinson whose father has Parkinson's completed a car rally from London to Mongolia in a car with a one litre engine and sent us \$148.

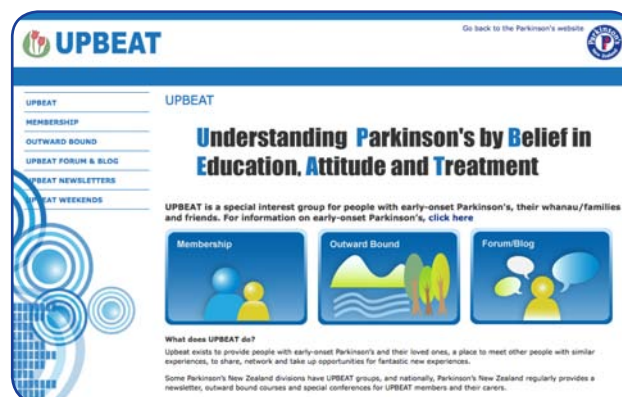
## UPBEAT

During 2010 we will be celebrating UPBEAT's 10th Anniversary.

An UPBEAT weekend will be held in Palmerston North 5 to 7 November (the end of Parkinson's Awareness Week). Those with early onset Parkinson's in their 20's, 30's, 40's, 50's and early 60's are invited to join us for a weekend of education, information, support and friendship. See the next edition of the UPBEAT newsletter to find out more.

The new website (see front page) has a dedicated UPBEAT subsite which includes a forum and blogs. Get online and check it out. If you are interested in blogging for us let us know.

If you do not receive the UPBEAT newsletter and wish to be added to our mailing list or wish to become an UPBEAT member, contact National Office on 0800 473 463 or email [upbeat@parkinsons.org.nz](mailto:upbeat@parkinsons.org.nz)



The screenshot shows the UPBEAT website interface. At the top left is the UPBEAT logo. Below it are navigation links: UPBEAT, MEMBERSHIP, OUTWARD BOUND, UPBEAT FORUM & BLOG, UPBEAT NEWSLETTERS, and UPBEAT WEEKENDS. On the right, there is a main heading: "Understanding Parkinson's by Belief in Education, Attitude and Treatment". Below this heading is a paragraph: "UPBEAT is a special interest group for people with early-onset Parkinson's, their whanau/families and friends. For information on early-onset Parkinson's, click here". There are three buttons: "Membership", "Outward Bound", and "Forum/Blog". At the bottom, there is a section titled "What does UPBEAT do?" with a paragraph: "UPBEAT exists to provide people with early-onset Parkinson's and their loved ones, a place to meet other people with similar experiences, to share, network and take up opportunities for fantastic new experiences. Some Parkinson's New Zealand divisions have UPBEAT groups, and nationally, Parkinson's New Zealand regularly provides a newsletter, outward bound courses and special conferences for UPBEAT members and their carers."

*New UPBEAT website*

People with Parkinson's have lower levels of the neurotransmitter, dopamine, than other people. Why are their brains not making sufficient amounts of this chemical? How is the lack of dopamine producing symptoms associated with Parkinson's? And how do medications work to reduce those symptoms? In this issue we report on several pieces of exciting new research that aim to help throw light on these questions that scientists believe are a key to finding better treatments for the disease.

## 🔥 A Genetic Risk Factor Identified for Parkinson's

A team of doctors and human geneticists from universities in Munich, Germany and Newcastle University in the United Kingdom have investigated brain cells (neurons) to see which genes modify their activities in Parkinson's disease. Among their findings, they detected increased activity of what is known as the pyridoxal kinase gene. They then compared this gene in 1,200 Parkinson's patients and 2,800 healthy subjects. They found that people who had a particular variant of this gene were more likely to get Parkinson's.

The researchers think that this gene variant may affect the amount of an enzyme, pyridoxal kinase (PDXK), produced in the brain or how it works. PDXK converts Vitamin 6B from food into the physiologically active form neurons need to produce dopamine.

Dr. Matthias Elstner of the Institute of Human Genetics at Helmholtz Zentrum Munchen, the study's lead author, said the research showed how genetic and environmental factors such as diet affect the development of Parkinson's. Although this variant is responsible for only a slight contribution to the overall risk of Parkinson's, the findings could aid in developing individual therapies.

*Source: Helmholtz Zentrum Munchen  
Re a key to finding better treatments for the disease.*

## 🔥 New Compounds May Help Develop Drugs for Parkinson's

Proteins in neurons are supposed to 'fold' in specific ways. Misfolded proteins are a common factor in degenerative nerve diseases such as Huntington's, Alzheimers - and Parkinson's.

Scientists at Duke University, Washington DC, have identified compounds that improve a cell's ability to fold proteins properly. They work by activating a master regulator of gene expression in the cell to produce more 'protein chaperone' molecules. These protein chaperones prompt other proteins to fold properly.

The current study explored one of the compounds, Heat Shock Factor (HSF1), to learn whether it would work in model systems of Huntington disease.

The research showed HSF1 stimulated the growth of protein chaperones in cells without causing cellular stress or inhibiting other important protein chaperones. When HSF1 was used to pre-treat cells, there was much less damage to rats in the early stages of the disease and the neurons of fruit flies with a Huntington-like disease also suffered less damage.

This study points the way to new approaches to inducing proteins to fold properly not only in neurons affected by Huntington's but Parkinson's as well.

*Source: PLoS Biology  
(Public Library of Science)*

## 🔥 Cleaning Agent Tied to Parkinson's

A population based study undertaken by the Parkinson's Institute in Sunnyvale, California has shown workers exposed to trichlorethylene (TCE) are 5.5 times more likely to become Parkinson's sufferers than those with no exposure.

The researchers sought out 99 sets of twins from among World War II veterans and identified cases where one twin had Parkinson's and the other did not. The compiled work histories of the twins were subjected to a blind analysis by industrial hygienists and preventative medicine specialists.

The results are not surprising since animal testing has revealed TCE kills cells that generate dopamine in an area of the brain called the substantia nigra, a part of the brain known to have a major effect on Parkinson's

TCE was once used as a metal cleaner, drycleaning solvent and even as an anesthetic. In the past dry cleaners, electricians, machinists and mechanics were all exposed to it. Because of its toxicity, today it is only employed in metal cleaning.

*Source: American Academy of Neurology press release,  
7 February 2010*

## 🔥 A New Computational Model Helps Our Understanding of Parkinson's and How Medications Work

The physical symptoms of Parkinson's were identified 320 years ago (see the article on page 11) but it is only during the last two decades neurologists and experimental neuroscientists have become aware the disease can also affect memory, attention and learning. These impairments also diminish a patient's quality of life.

Scientists have been using a relatively new field of research known as computational neuro-science to help explain why people with Parkinson's suffer motor dysfunction and how medications work to relieve shaking, difficulty in moving, freezing and other physical symptoms of the disease.

Now a new computational model shows how reduced levels of dopamine in the prefrontal cortex can explain many of the non-motor symptoms found among people with Parkinson's.

Consistent with earlier observations, the model also demonstrated how dopamine medications enhance a patient's ability to concentrate when learning. Drs Ahmed Moustafa and Mark Gluck at the Centre for Molecular and Behavioural Neuroscience at Rutgers University who devised the model intend to test other predictions made by the model.

*Source: Rutgers University News Release*

## 🔥 Brain Abnormalities in Parkinson's Patients Develop before Symptoms Occur

Usually people with Parkinson's notice symptoms on one side of the body before they appear on the other. The motor network that governs that side of the body is the first to become abnormal but by the time the first symptoms appear, the other side of the brain has already been affected. These are the findings of a study at the Feinstein Institute for Medical Research in New York which measured glucose

and dopamine levels in the brains of Parkinson's patients. Their average age was 58. The aim of the study was to see if the brain scans could detect areas of brain not working properly before symptoms actually started.

The symptoms on the other side of the body of patients who took part in the study began to appear about two years after the symptoms began on the first side.. Scans taken at year two showed new abnormalities, this time in the brain networks governing thought processes. So far none of the patients have developed problems with their cognition or thinking abilities.

Investigators are using the insight they gained from the study into what the brain is doing before the symptoms appear to identify new therapeutic targets to slow or actually prevent the onset of clinical disabilities in Parkinson's.

*Source: Science Daily, 24 January 2010*

## 🔥 \$1 million for Research to Develop Dyskinesia Treatments

The drug levodopa which converts to dopamine in the brain can relieve stiffness, tremors and rigidity in Parkinson's patients. Use of the drug can, after time, cause dyskinesia (involuntary muscle movements).

Drug companies have been reluctant to get into areas of research that could result in new anti-dyskinesia treatments because of the difficulty in showing improvements. So far the US Food and Drug Administration have not approved a single therapy but some doctors prescribe a drug called amantadine (an antiviral medication found to have properties which release more dopamine at nerve ends in the brain) which is thought to help some patients for a limited time.

AUS\$1.5 million grant from the Michael J Fox Foundation aims to remove a major road block to researchers seeking the causes of dyskinesia and new remedies to counteract it – the ability to measure degrees of dyskinesia. An international team led by Christopher Goetz and Glenn T. Stebbens of Rush

University Medical Center in Chicago will seek to quantify the degree of changes in dyskinesia severity when patients are treated with amantadine. This will enable them to develop a framework for testing new treatments by establishing clinical scales to measure changes in the severity of dyskinesia.

*Source: The Michael J Fox Foundation for Parkinson's Research*

## 🔥 A Stomach Hormone Protects Against Parkinson's

Professor Tamas Horvath of Yale Medical School has led a study looking at the action of ghrelin, a hormone produced in the stomach that circulates through the body. The study concluded ghrelin is protective of the brain's dopamine producing neurons and responsible for their direct activation.

The researchers conducted their experiments on mice whose ghrelin systems are thought to be similar to ours. Some of the mice were given a ghrelin supplement while others were deficient in the hormone and receptors (sites on the cell wall that allow the hormone to enter). When the neurons of these mice were compared to those of the control mice, the mice with impaired ghrelin action lost more dopamine.

Besides being involved in dopamine production, ghrelin is associated with loss of appetite, learning and memory difficulties and changes in the motivational circuitry for the brain that is involved with, food cravings, all symptoms found in people with Parkinson's. Other recent studies have linked measures of excess stored fat and diabetes to Parkinson's and shown that obesity is a risk factor for neurodegeneration in mice.

Professor Horvath and his team will now try to measure ghrelin levels in healthy individuals and people with Parkinson's to determine whether altered ghrelin levels may be biomarkers of the disease's development and vulnerability to it.

Because the hormone circulates through the body, they are also hopeful

that the hormone can be used to boost resistance to Parkinson's or to slow its development.

*Source: Lab News, findings published in the Journal of Neuroscience*

## 🔥 A Special Yeast Leads to a New Understanding Of Parkinson's

Abnormal deposits of a protein called alpha-synuclein are found throughout the damaged brain regions in Parkinson's patients. These deposits spread and increase as the disease advances. However why this happens and what exactly the deposits do is not clear.

At the Whitehead Institute for Biomedical Research, Cambridge, USA researchers carried out a series of experiments that throw new light on the phenomenon.

When alpha-synuclein genes were inserted into yeast, that doesn't normally have that gene it produced alpha-synuclein with some of the same abnormal 'folds' seen in the proteins of people with Parkinson's. They inserted higher levels of the gene in yeast and even more of the abnormalities found in the neurons of Parkinson's patients appeared. These abnormalities included problems with mitochondria and the accumulation of free radicals providing the first link between these features known to be abnormal in Parkinson's and alpha-synuclein.

Next the researchers tested 115,000 bioactive compounds (chemicals known to affect live cells) and found several that appear capable of reversing these yeast cell abnormalities resembling those in Parkinson's.

The researchers came to the conclusion that the deposits are probably a normal physiological process for getting rid of unwanted proteins but in Parkinson's patients the system is overloaded. This could explain the tendency for a late onset of Parkinson's when the body's metabolism isn't working so well.

*Source: Ciencia Viva; Medical News Today, 15 January 2010*

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.

## FATIGUE AND PARKINSON'S



### WHAT IS FATIGUE?

Fatigue is often described as extreme tiredness, exhaustion and lack of energy. This can be felt both physically, emotionally and intellectually.

As fatigue is a feeling, it is subjective and thus hard to measure accurately, but as a general rule anybody can feel fatigued when they are over-working themselves in any way. For people with Parkinson's however, fatigue is particularly common, and for some it is their first symptom.

Fatigue is not specific to any stage of Parkinson's, and it can occur at anytime. Severity of fatigue is not affected by the length of time someone has had Parkinson's.

### WHAT CAUSES FATIGUE?

There is no current agreement by professionals on the root cause of fatigue in Parkinson's, however there are several theories. It is important to remember that due to medication, fluctuations in a person's mobility are inevitable throughout the day, so a person may have more energy and feel able to handle certain tasks better at different times.

Parkinson's symptoms such as tremor, slowness and stiffness can mean that activities which were previously automatic, now require conscious effort and muscles are working harder than they used to. This could be responsible for both mental and physical fatigue.

However, fatigue may not purely be related to motor symptoms of Parkinson's. It can often be related to more complex non-motor symptoms such as difficulty sleeping, low blood pressure or depression. Fatigue may also be a central nervous system symptom in its own right, something that is caused by damaged "energy" brain circuits. It is certainly strikingly present in many neurological conditions.

### WHAT DOES FATIGUE MEAN FOR ME?

If you are experiencing regular fatigue, it is important to speak to a health professional and identify the cause/s of your fatigue. It may mean that you need to make some lifestyle changes in order to help prevent, or better deal with fatigue.

### HOW CAN FATIGUE BE TREATED?

Firstly, it is important to identify the cause/s of fatigue. For instance, if your fatigue is related to Parkinson's motor symptoms, it may be necessary to discuss medication changes with your doctor in order to better manage your Parkinson's and thus your fatigue. Some medications may also make it worse, so check this out with your doctor too., especially if it got worse after a medication was started or the dose increased.

Depression is a common non-motor symptom of Parkinson's, and fatigue can be a side effect of depression. If fatigue is related to depression, the use of antidepressants may be an option.

Sleeping problems are another non-motor symptom of Parkinson's, and may contribute to feelings of fatigue. Causes of sleep problems can vary, and may

include problems with medications, inability to get comfortable due to motor symptoms and routine changes. If problems with sleeping are contributing to your fatigue, a short nap of 30-40 minutes may be helpful to rejuvenate you for the rest of the day. However, it is important to note that frequent naps, and naps close to bed time can make sleeping at night more difficult.

If identifying the root cause of fatigue is unsuccessful, the use of mild drug stimulants may be an option, but any additional medication may have adverse effects on your Parkinson's medication and must be discussed with your medical professional before any changes are made.

## WHAT CAN I DO MYSELF?

The following may be useful tips for helping to prevent and ease fatigue:

- Ensure you eat a balanced diet for general strength and wellbeing.
- Exercise regularly using both aerobic and stretching techniques to help energy levels and overworked muscles. Pace this carefully—it's a balance of not too much, not too little, and matching activity with medication times
- Where possible, schedule more demanding tasks for times when your medication and movements are working well.
- Establish a regular bedtime allowing yourself enough time to 'wind down' beforehand, and ensure you are getting enough sleep to leave you refreshed in the morning.
- Reduce your intake of caffeine and foods high in sugar - these can result in fluctuations in energy giving you a 'high' followed by a drop into lethargy.
- Keep mentally active - boredom can lead to fatigue.
- Drink enough fluids because dehydration can contribute to tiredness and lack of concentration
- Learn to say 'no' to activities or commitments that are not priorities if you feel they may contribute to fatigue.
- Develop ways to conserve energy where possible, e.g. try sitting while peeling the vegetables for dinner.
- If you are employed, try regular short breaks to help break up your workload - this can be as simple as a cup of tea or a chat to a colleague.
- Delegate tasks to others where possible.
- Know your limitations and be realistic about your abilities.
- Keep trying new ways to do things!



## THE QUESTION OF PAYMENT FOR FAMILY MEMBERS WHO ARE CAREGIVERS

By Sharon Blaikie

### INTRODUCTION

In *Atkinson and others v the Ministry of Health* (MOH) eight carers took a case against the MOH to the Human Rights Review Tribunal on the grounds that its policy of not paying family caregivers who reside in the same house as the disabled person is illegal under the Bill of Rights Act.

The Act provides a two step process for deciding if a policy or practice is illegal on the grounds of discrimination. Under section 19 the carers were required to prove that their circumstances were the same as those of non-family carers. When the Tribunal found the policy was discriminatory it was open to the MOH to argue the discrimination was justified.

The Tribunal found for the carers. They said that the policy discriminated on the grounds of family status and that it did not meet the criteria for justified discrimination under Section 5 of the Act.

From the Minister of Health, Tony Ryall's comments, the Government's main concern appears to be fiscal. It fears other claims based on the same reasoning would succeed, opening the floodgates for the Government to be made responsible for providing monetary compensation for other services in the community. Besides the potential cost of changing Government policy, MOH justified its position on the grounds that the current policy:

Reflects the social contract between families and the state which requires families to look after their own and as such they are the 'natural supporters';

- Provides for individual assessments aimed at the Government meeting any gaps in 'natural support';
- Still results in equity of outcome for disabled people;
- Avoids professionalising and commercialisation of family relations and families becoming dependent on a carer's payment thereby discouraging the disabled person's independence; and
- Ensures the MOH retains control over the services it funds.

We shall examine each of those arguments, particularly the question that occupied the Tribunal most – whether

general consensus in the community that families will look after their members throughout their life constitutes a social contract.

### THE CONCEPTS OF SOCIAL CONTRACT AND NATURAL SUPPORT

Prior to the industrial revolution, most people lived in extended family groups covering three or even four generations. In this situation families were expected to look after their own. With urbanisation the extended family structure began to break down with more and more households reduced in size to the nuclear family. As society evolved in a different direction, the governments in developed countries began to assume a greater role in caring for the aged and the disabled, putting in place systems for their financial support and for their care when they needed it.

Until recently one breadwinner in the family unit was the norm. In this circumstance if the spouse who was not in paid employment looked after a disabled family member the family finances did not suffer in comparison with the majority of families. They too had only one income. In the last twenty years the situation has changed. In most families all the adult members can be expected to join the labour market. The division of labour and structure of household finances in modern families does not account for the care of a disabled spouse or adult child. The conditions underlying the social contract have changed and the concept of the social contract must evolve to take those changes into account.

The Tribunal found no evidence of a social contract in modern New Zealand where it was understood families had an obligation to support family members in adulthood or that family members were natural supports for adult members. This undermined the MOH's claim that its role was to fill the gap when a disabled person had no natural support.

### EQUALITY OF OUTCOMES

MOH claimed their policy results in equal outcomes for the disabled. Yes, but that is not the point. It does



not provide equal outcomes for caregivers. If this is not currently the MOH's responsibility, it is the Government's to delegate responsibility (e.g. to MOH or the Ministry of Social Development).

### EFFECT ON FAMILY RELATIONS

The MOH points to the possibility of families becoming reliant on carer payments and therefore discouraging the independence of the disabled in their care. The carers in the Atkinson case pointed to the athletic achievements of the disabled in their care as proof to the contrary and the Tribunal acknowledged that in instances of severe disability independence was not a practical goal.

Against the dangers of commercialisation of family relations must be measured the negative impact on a family when a spouse or parent or other relative wishes to care for a disabled person but cannot afford to do so without it having a detrimental effect on the other members of the household. Caregivers also described how outside caregivers can intrude on family life particularly, as is often the case, they changed frequently or were culturally insensitive. Paying family caregivers is more likely to strengthen families than weaken them.

### MINISTRY OF HEALTH CONTROL ON FUNDING

The MOH maintains that its current policy allows it to set standards and monitor caregivers to see they live up to them. There is no reason, if a family caregiver is

paid they should not be expected to live up to those standards or be monitored by the Department. In fact, it could be argued that to achieve equality of outcomes the MOH should monitor the care of all disabled people irrespective of who is caring for them.

In the carers view, in practice the quality of care they provided, was often better than the care given by non family members. Concerns about low levels of training of professional caregivers were among the reasons they chose to provide the care themselves.

In some cases lifting policies adopted by caregiver organizations also impeded the quality of care of members. Lack of punctuality and no availability on weekends and public holidays also influenced decisions to provide the care themselves.

### THE EFFECT ON A DISABLED PERSON'S ABILITY TO CHOOSE

At the hearing some disabled persons said they did not like the idea of strangers providing intimate care. They pointed to the fact where the quality of caregivers in the market was often low and the quantity limited, the policy not to pay family members for their care, limited choices they might otherwise have and limited the pool of caregivers at large.

If the High Court upholds the MOH's appeal, there is still room for family caregivers to lobby the Government for a fairer deal.



## A GUIDE FOR CARERS

The Associate Minister of Social Development and Employment, Hon. Tariana Turia, has launched a new booklet and flyer for people caring for family or friends who are older or have ill health, a disability or a mental health, alcohol or other drug issue.

The guide includes information on the government-funded services and supports available for carers, such as:

- financial help
- needs assessments (NASC)
- help at home
- help if you need a break
- health and disability rights
- equipment and modifications.
- This resource has been developed by Carers New Zealand, The New Zealand Carers Alliance and the Ministry of Social Development.

Hard copies can be sought by phoning Work and Income on 0800 559 009 or visiting [www.carers.net.nz](http://www.carers.net.nz) to download a copy.

## OTAGO UNIVERSITY INVESTIGATING THE CAUSE OF DYSKINESIAS



*Dr John Reynolds*

Dr John Reynolds of the Department of Anatomy and Structural Biology at the Otago University School of Medical Sciences working in collaboration with Assoc. Prof Peter Dearden in the Department of Biochemistry wants to test a theory about how dyskinesias develop in people with Parkinson's. Thanks to a generous grant of \$20,000 and Phil King's determination to fulfill his late wife's wishes, Parkinson's New Zealand has been able to assist Dr Reynolds to go ahead with a preliminary study.

People who do not have Parkinson's have brain cells specifically designed to produce dopamine. The dopamine remains in the nerve terminals of those cells until tiny electrical impulses release it on to target cells. The released dopamine causes reactions in the target cells that reinforce the movements the person wants to make.

In people with Parkinson's the ability to produce dopamine diminishes but their remaining dopamine producing cells can absorb levodopa and the cellular machinery of those cells can convert it into dopamine. Initially levodopa works well because there are enough dopamine producing cells to convert the levodopa.

However those cells continue to die off until there are not enough of them to do the job.

Recently it has been discovered that other neurons are adaptable enough to take up the leftover levodopa and produce dopamine. Unfortunately when these cells release their dopamine it does not give out the same signals to the target cells.

Dr Reynolds thinks the cells that are abnormally producing dopamine might be reinforcing movements, but not the ones the person with Parkinson's wants to make, in other words the involuntary movements that are called dyskinesias.

To test his theory Dr Reynolds will use a new tool called transcriptomics. Using state of the art equipment he will obtain a snap shot of the activity of all the genes in a cell at a given moment – which ones are switched on and which are switched off – and what electrical impulses they make the cell produce.

He will be looking for genes that switch on or off when dopamine is reduced and when levodopa is given to the patient. He wants to see if the cells show changes that are consistent with changes that occur in the brain when learning how to make movements and whether these changes are different to people without Parkinson's. This would indicate that the dyskinesias in people with Parkinson's are the result of abnormal reinforcement processes.

The money will also support the work of PhD student Lisa Smith who is very interested in the cellular mechanisms underlying Parkinson's.

*We look forward to updating readers on the results of his project in future issues.*

## GABRIELLE KING

Gabrielle King was a woman who loved life and the world around her. She traveled extensively and took an active part in the community on Waiheke Island, Auckland, making lots of friends there.

Long before the first symptoms of Parkinson's appeared six years ago Gabrielle supported disabled people in her community. As a member of the Waiheke Coalition she was in charge of helping the disabled participate in sport. She organized their transport to local fixtures, sports uniforms and trips to Auckland to take part in sports events there. Gabrielle was a keen potter and floral art enthusiast.

She was also a past president of the Waiheke Royal Agricultural Society.

Sadly, her form of Parkinson's was very aggressive. During the last two years of her life she lived at the Seaside Sanctuary on the island where fortunately Phil, her husband of 40 years, said the care and attention was tops.

"She was very brave, never complaining," he remembers. "She was very special, a wonderful lady."

She generously left a legacy to Parkinson's New Zealand and it was her wish that some of the money she left should be used for research to help people with Parkinson's.

## INAUGURAL CHARITY CRICKET MATCH



*Nuala Dunne from National Office and Brendan Pongia*



*Stuart Nash, Labour MP*



*Campbell Furlong, Central Districts Cricketer*



*Parkinson's NZ Ambassador Jordan Luck and band mate Bryan Bell*

Lawyers, Lawmakers, local personalities and celebrities came together for the Hawkes Bay divisions' inaugural Charity Cricket match. A team of local lawyers captained by Ian Taylor of Gifford Devine Solicitors squared up against a team made up of MP's Craig Foss, Stuart Nash and Chris Tremaine who were

supported by a team of celebrity players including former Tall Black Brendon Pongia and former All Black Taine Randell. Parkinson's Ambassador Jordan Luck provided half time entertainment along with band mate Bryan Bell. Many thanks to all the players and supporters.

### Who First Described Parkinson's?

Individual symptoms of Parkinson's, particularly tremors, have been reported since ancient times but James Parkinson, the man who gave his name to the disease, is generally thought to have made the first comprehensive, formal description in 1817. Not so.

In 1690, a Hungarian doctor by the name of Ferenc Papai Pariz described all four cardinal signs of what we now know as Parkinson's i.e tremor, bradykinesia (slowness in movement), rigidity and postural instability in his book *Pax Corporis*. Because Hungarian wasn't read by many people, his insight went unnoticed. The medical community at large had to wait another 127 years for Dr Parkinson to bring the disease to their attention.

*Source: Viartis, 3 December 2009*

### International Brain Awareness Week 2010

**March 15 to 21, 2010**

Your brain loves exercise, just like other parts of your body. In fact, it needs regular workouts to stay buff and healthy – and grow lots of shiny new brain cells. It also loves a good get-together with your mates.

That's why, this year, the Neurological Foundation is challenging you to hang out with your friends and grow bigger brains together. And help make EnZed 100 million brain cells smarter in just seven days. Visit [www.brainweek.co.nz](http://www.brainweek.co.nz) to find out more.

Brain Day lectures are being run throughout the week in all the main centres with a range of speakers. Visit [www.neurological.org.nz](http://www.neurological.org.nz) or phone 0508 272 467 for details.

# NEWS FROM AROUND THE COUNTRY



*Artist drawing a member*

## 🌸 Bay of Plenty

Parkinson's Tauranga had a fabulous year in 2009 attracting 34 new members. Its weekly physio classes in Tauranga and Te Puke, held at the same time as carers' meetings, were well attended and so were the meetings in Whakatane and Katikati.

Every month the division held a special activity. Some were for fun- a picnic and Kulim, a trip to Waihi Water Lily Gardens, a Chinese mid winter buffet, a performance by an impressionistic artist and a visit to Daltons plantation followed by a café lunch.

Other months had a more serious emphasis with talks by a hearing therapist, an ACC injury prevention consultant, a dietician and occupational and physio therapists.

They topped the year off with a Christmas lunch and raffles with some great prizes.



*Auckland Field Officers serving up delicious treats at the picnic*

The conversation flowed, the sun shone (with a light breeze!) and the tables were laden with a delicious combination of savoury platters, sweet slices, fruit and the ever popular Kiwi Crush.

The arrival of the Kiwi Ice Cream refrigerated truck with the generously donated 'Sweet Nothings' was a welcome change and was much appreciated.

We were lucky to have Jenny Stewart and Sandra Bassett from AUT to discuss and demonstrate the benefits of Nordic walking to our members and advise of an upcoming opportunity to participate in a Nordic walking research trial later this year.

## 🌸 Hawkes Bay

The Hawkes Bay division has certainly been busy since our last issue. Their Christmas lunch was a wonderful event with variety and much laughter. A local primary school choir sang: Sports Awards were given to members of the Exercise Class (the \$2 Shop did well): Santa arrived, and to add a bit of class, Ms Gillian Davies, a well known producer of musical shows, spoke about her experiences in the theatre. Gillian was a New Year Honours recipient and was awarded a Queens Service Medal. Their inaugural Cricket Match was held on March 2nd (see page 11) Moving forward they will be holding a World Parkinson's Day event on 15th April (just a few days after the official date).

## 🌸 Kapiti/Horowhenua

Forty members of the Kapiti/Horowhenua division attended a Christmas lunch at the new Ohau Café just north of Levin with bus and car transport and specialty assistance for those with mobility issues. It was a great chance for members throughout the area to catch up and for new members to meet longer established members.



*Father Christmas and a Christmas fairy*

## 🌸 Wairarapa

Father Christmas and a Christmas fairy paid a visit to the Wairarapa division Christmas Party. What a coincidence that it was just before they arrived that Chairperson Mike Lynch and Field Officer Kerrin Williams were called away.

## 🌸 Auckland

The Auckland division's Annual Picnic in one of Auckland's great picnic spots, the lovely Cornwall Park, was a great success. More than 75 members turned up from all parts of the city to join the Field Officer Team for a most enjoyable day.



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