



The Parkinsonian

The Quarterly Magazine of Parkinson's New Zealand

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PLANNING OUR FUTURE



In 2008 Parkinson's New Zealand turned 25 years old and celebrated many of the achievements made since we started. Our next step is to look at what we need to achieve in the years to come. We want to review what we do and what we want our Society to be so that we can ensure we are providing the best possible services to our members.

This means that during the next twelve months we will be conducting a review of our services and how they will be delivered.

The objective of this exciting and extremely important project is to find answers to the following questions:

- What services should PSNZ deliver? – needs, wants, desires, essentials.
- Who should PSNZ do this for?
- How should the services be delivered?
- How will PSNZ monitor the quality of services delivered?
- How will National Office support divisions?
- How will divisions support the National Office?
- What activities should be in the centre, what activities should be in the field?
- What operating model and structure best supports this plan?

We have employed Effective Governance Ltd to act as facilitators and to help lead the process.

The first phase of this project will be to conduct a comprehensive survey of stakeholders using a professional survey firm; Perceptive Insights Ltd. The survey will be mailed to all members and people will also be able fill it out electronically. We will also distribute the survey to people with Parkinson's who are not members, health professionals and other people with an interest in Parkinson's.

In September we will run workshops in Auckland, Rotorua, Palmerston North, Christchurch and Dunedin. This will provide people with Parkinson's, their families and friends, health professionals and other stakeholders with an opportunity to let us know in person what they think and we encourage everybody to attend.

This vital information will then be consolidated and used to plan our future, and we would appreciate your involvement.

WE NEED YOU

To ensure that we have the best possible information to do the best possible job we need all members, supporters and interested parties to take part. So please do take the time to fill out a survey and/or attend a regional meeting. Dates of meetings will be advertised soon.

NATIONAL DIRECTOR'S REPORT



Kia ora,

Welcome to another edition of *The Parkinsonian*. The last few months have had so many exciting events; it is hard to know where to start!

In March I had the pleasure of attending the 2009 UPBEAT Weekend in Christchurch, which was a fantastic experience. The next one will be held in the lower North Island. Shortly after this was the Outward Bound course which we have not stopped receiving thank you letters from, so by the sounds of it, a great time had by all! Later that same month was our 2009 Annual General Meeting and workshops. This was an informative two days surrounding what we have accomplished so far and our goals and plans for the future.

One of the ways we hope to reflect on our future is the upcoming review of services discussed in the front page article. This is such an important project through which the whole future direction of our Society will be decided. We really do need your help in order to do this successfully. Apparently it is notoriously difficult to get feedback and input into this sort of thing and often people think they have little of value to add or that it will just be another paper filling activity and that what they have to say will not affect anything. Be assured that all input will be valuable and we really do need your help. So please get involved with the upcoming survey and workshops and have your say.

During the last few months we have been pleased to work with a fantastic group of Public Relations students from Massey University. They have created a Social Media Campaign (Social Media encompasses many of the new internet websites and technology). The aim is to raise awareness of Parkinson's and our Society amongst some of the audiences we find harder to reach – in particular those under 40. The main focus of the campaign is a short film they have made interviewing a number of our members, Dr. Barry Snow, Field Officer Jenni Hurn, PSNZ Ambassador Jordan Luck and actor Nicole Whippy with her dad who has Parkinson's. This was launched on 2 June and will be circulating on the world wide web. I encourage you to view the film.

Also in the next few months is the Field Officer's conference 30th – 31st July in Wellington. The programme for the two days is packed full of exciting seminars and workshops, and is part of our ongoing commitment to education.

On a more personal note I am delighted to let you know that my husband Malcolm and I welcomed a beautiful baby son into the world on 26 May 2009. Xavier Thomas Rewiti Aitken is our first child and despite the tiredness we haven't stopped smiling since he was born.

Naku noa

Deirdre and the Parkinson's NZ team.

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UPBEAT WEEKEND FANTASTIC SUCCESS



UPBEAT Weekend attendees

On Friday the 27th March, 50 UPBEAT members from across New Zealand descended on the Airport Gateway Motor Lodge in Christchurch. With 2 days of seminars, group sessions and outings planned, the group were in for a fantastic conference.

The programme for the weekend included:

- A presentation by Prof. Tim Anderson on medical developments in Parkinson's, in which he discussed new research and trials.
- A talk by Field Officer Paula Ryan on her creation of a Deep Brain Stimulation support group.
- Sessions by physiotherapists Lucie Hartfield and Jessie Snowdon on the importance of physiotherapy and exercise in Parkinson's – as well as some audience participation!
- A talk by Psychiatrist Dr Matthew Croucher on anxiety and Parkinson's which included a lot of sharing and helpful coping tips.
- A trip to Orana Wildlife Park where UPBEAT members were able to get up close and personal with the inhabitants.
- A presentation on maintaining healthy eating and weight by Dietician Julian Jensen.
- Group discussions in small teams of carers and people with Parkinson's, as well as a full-group discussion on tips and hints for daily living.
- A session on the future of UPBEAT by founder Bruce Cutfield and National Director Deirdre O'Sullivan.

The weekend was enjoyed by all, with many leaving feeling rejuvenated and reinvigorated having learnt new things, made new friends and having shared their experiences with others.

NEW NEUROLOGY UNIT AT WELLINGTON HOSPITAL

The new Clinical Measurements Unit at Wellington Hospital includes a spacious new neurology section. The 4 Neurologists, 2 registrars and house surgeon now have their own area in the large unit which also encompasses cardiology and respiratory. The specialties share the spacious new consult rooms between them, but each have their own 'wing'.

Patients now wait in the shared waiting room of the Clinical Measurements Unit, which is the first department in the newly built main entrance of Wellington hospital in Newtown.

The new entrance is a far cry from the dark linoleum-lined reception of the past. The doors open up to a large, brightly lit foyer which includes a gift shop and café. The area is a hub of activity, linking patients, staff and visitors to the surrounding departments, such as Neurology.

"This new area has more room and much nicer surroundings" say Neurology research nurse Liz Goode of the team's new unit.

Neurologist Stuart Mossman says that he feels the patients feel more at ease in their new surroundings. "The patients definitely like it."



Neurology research nurse Liz Goode with patient

🔥 Computer Games Help People With Parkinson's

A group of seven people with and without Parkinson's took part in a New South Wales pilot project, and they were put through an almost daily regime of playing the Nintendo Wii.

The home entertainment device is controlled through arm movements, while a Wii 'fit board' was also added. This required the seated participants to interact with on-screen objects using their feet.

Southern Cross University Associate Professor Rick van der Zwan said the initial findings were positive, as it showed the participants (mostly older people) were prepared to embrace an unfamiliar technology.

"Lots of older people, when you talk to them about computer games they think about shooting up spaceships... they're not so interested." Dr Van der Zwan says.

"They were quite prepared to try it as a therapy or potential form of treatment, but when they do they are quite surprised. They find it fun...not a chore like taking your blood pressure, it becomes an engaging part of their routine and that's exactly what we want."

Dr Van der Zwan said computer games could offer people with Parkinson's a safe and enjoyable way to boost their activity levels without leaving their home, or even their chair.

Source: Australian Associated Press

🔥 Funding Given to Speech and Parkinson's Study

Slurred and distorted speech (dysarthria) is a common problem in Parkinson's. It is usually found in older people, and can reduce quality of life. To date, speech rehabilitation research has tended to use young adult listeners rather than older adults who are more likely to interact with people with dysarthria. This New Zealand study – by

Dr Megan McAuliffe, Dr Catherine Moran and Prof Tim Anderson – will determine the ability of older individuals to understand the speech of people with dysarthria and if this understanding is affected by age or hearing loss. The researchers will also investigate if speech therapy improves comprehension. This research will allow the development of new speech rehabilitation techniques benefiting older partners of people with dysarthria.

Source: Headlines

🔥 Spinal Cord Stimulation May Help Treat Parkinson's

A small device implanted on the spinal cord could one day offer a better way to treat Parkinson's, according to a Duke University Medical Centre (U.S.) study.

Lead author of the study, Romulo Fuentes, said that the study is important due to levodopa's tendency to reduce in effectiveness after time.

"Patients are left with few options for treatment, including electrical stimulation of the brain [deep brain stimulation] which is appropriate for only a subset of patients" says Fuentes.

The device involved in the study applies electrical stimulation to the spinal cord's dorsal column, which is a main pathway from carrying tactile information from the body to the brain. The device has so far shown success in trials on mice and rats.

When the device was turned on, the slow and stiff movements off the mice and rats (depleted of dopamine in order to mimic the effects of Parkinson's) were replaced with the active behaviour of healthy animals. Improved movement was typically observed within 3.35 seconds.

The stimulation also reduced the low-frequency seizures often seen in patients with Parkinson's.

Small leads are implanted over the

spinal cord and then connected to the small portable generator, capable of producing mild electrical currents. The generator used in the trial is external, but would be implanted below the skin if approved for use in humans.

"If we can demonstrate that the device is safe and effective over the long term in primates and then humans, virtually every patient could be eligible for this treatment in the near future" said senior author Miguel Nicolelis.

The device will likely mirror similar spinal cord stimulator technology currently used to treat chronic pain, if it is approved for use on Parkinson's patients, Nicolelis said.

Source: Health Day News

🔥 Light May Help Detect Parkinson's

A light as bright as a million-watt bulb could help identify early signs of Parkinson's, British researchers have said.

The Keele University team told an American Association for the Advancement of Science conference that a "super-microscope" could spot changes in brain cells before the disease destroyed them.

Keele's Dr Joanna Collingwood said that the technique was "pioneering" and told the AAAS that she believed patients could be treated sooner as a result.

Dr Collingwood said the team had been using a synchrotron (which is a large particle accelerator) that fires particles at just below the speed of light, focusing them into a beam less than a single cell in diameter. This allows researchers to observe iron levels in individual brain cells, which are affected by Parkinson's.

Dr Collingwood said "We have been able to investigate human tissue with such precision that metal ions, particularly iron levels, in and around individual cells can be mapped."

She said she hoped the team's work would help doctor's detect early

signs of Parkinson's, eventually through MRI.

"Early diagnosis is the key because we know that by the time a typical individual presents with the symptoms of the disease, chemical changes have already caused significant cell death of vulnerable motor neurons," she added.

Source: Newsworthy Notes

🔥 Google Founder Starts Study After Diagnosis of Parkinson's Mutation

Sergey Brin, the co-founder of the internet search giant Google, is to spend millions of dollars on an innovative genetic study of Parkinson's after learning that he has a mutation that confers a high risk of Parkinson's.

The program will invite 10,000 Parkinson's patients to have their DNA analysed for a token fee to investigate inherited and environmental factors that contribute to the disease and to advance research into new treatments.

Genetic data from the patients will be compared with information from healthy customers from the company 23AndMe, which supplies scans that assess people's chances of developing 105 diseases, from breast cancer to baldness.

The donation by Mr Brin who is married to Anne Wojcicki, the co-founder of 23AndMe, means that Parkinson's patients will pay just \$18 for the company's service.

The goal is to identify DNA variations that are more common among people who have Parkinson's, which could be linked to its development.

Both Parkinson's patients and 23AndMe customers will be asked to fill in detailed life-style questionnaires, which could reveal how environmental triggers may interact with genes to cause Parkinson's.

Mr Brin's mother had Parkinson's, and when he took the 23AndMe test last year he learnt that he has inherited a mutation of a gene called LRRK2, which raises his risk of developing the condition to between 20 and 80%.

Ms Wojcicki gave birth to the couple's first child in December and says that they are highly motivated about Parkinson's because of Mr Brin's chances of developing it, but also because of their son.

Source: The Australian

🔥 Adult Stem Cell Research Shows Positive Results

Scientists have published a paper in a stem cell journal describing the results of the world's first clinical trial using autologous (from the patient) neural stem cells for the treatment of Parkinson's. A leading bioethics watchdog says the results show more money should be put behind adult stem cells.

University of California researchers published their results in the *Bentham Open Stem Cell Journal*, which outlines the long term results of the trial.

"We have documented the first successful adult neural stem cell transplantation to reverse the effects of Parkinson's disease and demonstrated the long term safety and therapeutic effects of this approach," says lead author Dr Michel Levesque.

The paper describes how Levesque's team was able to isolate patient-derived neural stem cells, multiply them in vitro and ultimately differentiate them to produce mature neurons before they are reintroduced into the brain.

The team was able to inject the adult stem cells without the need to immunosuppressants. Unlike embryonic stem cells, adult stem

cell injections don't cause a patient's immune system to reject the cells.

The adult stem cells were highly beneficial for the patient involved in the study.

"Of particular note are the striking results this study yielded – for the five years following the procedure the patient's motor scales improved by over 80% for at least 36 months."

He said he hoped a larger clinical trial would replicate the findings.

Source: LifeNews.com

🔥 Parkinson's And Melanoma May Be Linked

People with a family history of skin cancer may be more vulnerable to Parkinson's disease, new research suggests.

A link between melanoma and Parkinson's was already suspected, as previous studies have shown people with Parkinson's have an increased risk of developing cancer.

The new study showed individuals who had a family history of melanoma were nearly twice as likely to develop Parkinson's as those who did not.

Scientists looked at almost 157,000 people who had not shown any symptoms of Parkinson's. The participants in the study were asked if their parents or siblings had been diagnosed with melanoma, one of the deadliest forms of skin cancer.

Researchers then traced their project for 14 to 20 years, and during that time 616 of the group were diagnosed with Parkinson's. The author of the study, Dr Xiang Gao from Harvard University said "The results from this study suggest that melanoma and Parkinson's could share common genetic components. More research needs to be done to examine the relationship between these two diseases."

Source: The Press Association

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.

SWALLOWING AND DRIBBLING



An aspect of Parkinson's which does not often receive attention is the loss of involuntary movements – the loss of armswing while walking, infrequent blinking, lessened facial movement and the focus of this fact sheet – reduced swallowing and dribbling.

The medical term for swallowing difficulty is 'dysphagia'. Dysphagia and problems with dribbling are more common in the later stages of Parkinson's, however they can occur earlier on when associated with other Parkinsonism disorders (e.g. multiple system atrophy).

What happens when problems with swallowing and dribbling occur?

The loss of the automatic swallowing movements leads to the pooling of saliva in the mouth. There is also a tendency for closure of the lips to be impaired with dysphagia, which gives rise to dribbling. There is no increase in the production of saliva, however it is interesting to note that we each produce more than a litre of saliva each day.

We produce the most saliva at mealtimes, when the swallowing of food can often help someone with

dysphagia keep up with the production of saliva. This means that dribbling may be reduced. However, with the constant production of saliva between meals, albeit at a reduced rate, dribbling can be hard to combat.

Swallowing at mealtimes is an issue itself, with as many as 40% of people with dysphagia experiencing 'silent aspiration' – this is when food or drink enters the airway without eliciting a reflexive cough, this can cause pneumonia (chest infection). Food/drink is able to enter the airway due to the slow initiation of swallowing, leaving the airway unprotected.

In a few people, usually when Parkinson's has been present for 10-15 years, dribbling is a major problem. It can be socially embarrassing as the person with Parkinson's is well aware of the dribbling but cannot react quickly enough to stop it from occurring.

What are the signs of swallowing difficulty?

The following may be problematic during mealtimes:

- Swallowing hesitation or inability to swallow

- Food sticking in the throat
- Swallowed food does not go down correctly – can back up into nose
- Choking
- The need for repetitive swallowing
- Throat clearing
- Coughing after swallowing
- The need to “wash down” food with drink

What can be done?

Because weight loss is common in Parkinson's, it is important to keep an eye out for any eating difficulties and report them to your health professional.

Medications to dry the mouth (e.g. atropine) do not seem to reduce the dribbling unless the mouth is made unacceptably dry or there are side effects such as blurred vision. The best management may be to use a small towel and/or tissues. In social situations it may be helpful for a carer or loved one to sit close to the person with Parkinson's and quickly wipe away any dribble.

Surprisingly, chewing is usually not a problem. It is more common for eating to be very slow, than for people with dysphagia to experience choking. However if choking does occur, posture while eating or drinking is important – try sitting upright with the head bent forwards.

In order to make mealtimes easier, it might be necessary to alter your diet with the help of your medical professional. The following may be helpful:

Possible problem foods:

- Foods which are hard, dry, crumbly or stringy
- Foods with mixed textures
- Food which can easily get stuck in the throat – e.g. nuts, grains, seeds

Foods that may be easier to swallow:

- Milk, cream, custard, and yogurt
- Omelets and pancakes
- Casseroles, soup, and soft boiled rice
- Banana and soft fruits

Issues with swallowing and dribbling may seem embarrassing or troublesome, but with the help of your health professional and loved ones, changes can be made to make mealtimes and social events easier.

By Dr Jon Simcock – Neurologist

MEDICINES AND SWALLOWING

If you have trouble swallowing, you may also have trouble taking your medicines. Some medicines can stick in your throat and cause a blockage, or irritation at the site where they are stuck. It may also mean that the medication does not work properly. If you are not able to swallow your medicines properly anymore you should contact your specialist, GP, or pharmacist.

For some medicines this problem can be solved by crushing the tablets. However it is important to note that not all medicines can be crushed. This is because of potential problems with too much medicine being in your body as soon as you take the medicine, and not enough being left in the body later in the day. Some medicines will need to be changed completely and you will need to get a new prescription from your doctor.

Some common medicines which cannot be crushed:

- Sinemet CR
- Madopar HBS
- Metoprolol CR (Betaloc CR)
- Any medicine with CR, LA, SR, OROS abbreviations as these are medicines that release over a longer period of time and the tablet needs to be intact for this to work

Some common medicines which can cause problems in people with swallowing difficulties:

- Fosamax (Alendronate)
- Slow K / Span K (Potassium Chloride SR)
- Doxycycline
- Any medicine that is in a capsule (if not taken with enough fluid)

Joanna Hikaka – Pharmacist Team Leader in the Home and Older Adult Services Unit for Waitemata DHB.



SHOULD YOUR FAMILY MEMBER MOVE IN?



When your loved one goes through a period of ill health that brings into question their ability to live alone, it can often lead to discussions surrounding whether they should move in with their family members.

Sometimes this can be due to the extent to which their Parkinson's has progressed and the need for help from carers, or it can be because of a lack of community health or other family support.

This situation is very common although it may feel like an overwhelming and difficult decision to make. Some of the following options are typical outcomes from this situation:

- The person with Parkinson's moves into another family member's home.
- A family member moves into the person with Parkinson's home to care for them
- A purpose built dwelling or flat is built on a family member's property.
- The person with Parkinson's goes into a care facility.

Discuss the options with your family and seek guidance from health professionals, particularly ones who know your loved one. Someone who knows the specific needs of your loved one will be realistic about the amount of support your family will need in any of the above options.

When it comes to discussing the pros and cons of your options, weigh up the person with Parkinson's support needs and what kinds of help that would realistically be available to them should they live with you or vice versa. These could include personal care, home or nursing help, respite care, day care, Meals On Wheels, assistance with shopping and getting around etc.

It is wise to consider arranging a trial period for the option that seems to suit you and your loved one best, this can help you to establish any flaws in the plan so you can make any necessary changes or

re-think your options. Remember to also consider your own wellbeing and happiness in any situation, and be realistic about your limitations and how a change of living may impact your work, family dynamics and health.

If your loved one's needs are beyond what you can give, do look at care facilities with an open mind. Many people are happy living somewhere that meets all their daily needs and offers social, emotional and medical support.

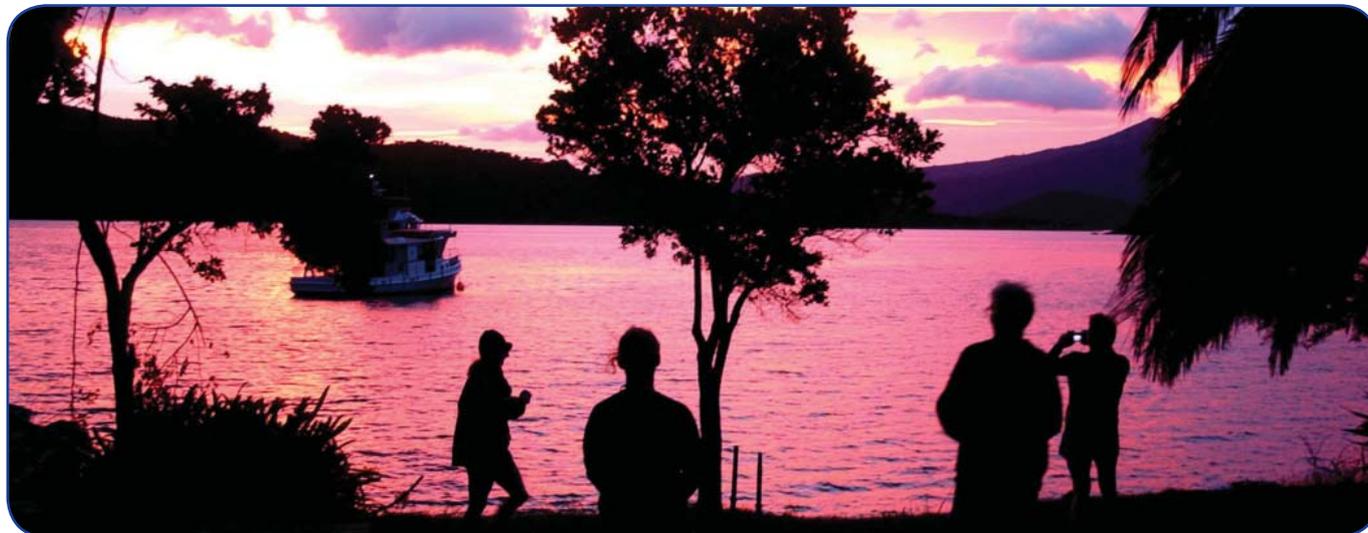
Home sharing – things to think about:

- Consider your loved one's level of health needs and dependency – have they been assessed as needing rest home or hospital-level care?
- Weigh up family dynamics, your health, employment, other commitments, financial implications etc.
- Will this be a short or long-term arrangement? Will they be moving into a new environment, away from established social connections?
- How will their ongoing medical needs be met? Will their new home be close to medical facilities? Will they need to change their GP? Would this involve waiting lists etc?
- How will your loved one blend into the existing family unit? Will everyone be comfortable? Will it be a relationship where both parties feel they are contributing?
- Is this move in the person with Parkinson's best interests? Who will benefit most from the arrangement?
- Does the environment need to be modified to cater for your loved one's needs? Is there financial assistance available for housing and other changes?
- What will happen if the older person's health deteriorates or the arrangement does not work out for whatever reason?

Source: Family Care New Zealand

"TIME TO GET EXCITED FOLKS"

A personal account of the 2009 UPBEAT Outward Bound course by attendee David Steven



This call was a favourite expression of Hayden, one of the Outward Bound instructors, and a warning that he and our other instructor Amy were about to throw another challenge at us. These challenges included the straight physical challenges that you automatically associate with Outward Bound, and others aimed at overcoming fears and attitudes that can hold you back.

We were a motley crew from all over New Zealand, with a diverse range of backgrounds and abilities, thrown together for 6 days as 'Hathorne Watch'. And yes we were challenged, both as individuals and as a team, but we succeeded – we all achieved things that gave us a glow of satisfaction. We also had great fun. 'Would I recommend it to others?' Too right, it was a magnificent opportunity.

It began at the Picton ferry terminal at 12.30pm Saturday 4th April, where we were loaded aboard for the short voyage up the Sound to Anakiwa. Once arrived we were welcomed with a Powhiri, and then members of our course were gathered together and dispatched to Hathorne, the dorm that was to be our home for the next 6 days. At this point cellphones, wallets and reading material, all distractions from the world outside Outward Bound, were taken into safekeeping. A challenge for some!



Our watch had 11 members, 6 men and 5 women, including 2 Parkinson's NZ Field Officers as Support Officers. We ranged in age from the mid-30s to 65, and in Parkinson's from unnoticeable to the shakingly obvious. The people thrown together in Hathorne were one of the highlights of the course, and our two instructors were excellent, also complementing each other well. They knew when to push and when to ease off.

The most challenging activity for me was the wires high up in the trees. I've never had a marvellous head for heights and it has not improved with age or Parkinson's, however I was determined to do this. Hayden's urging while I was walking on the single wire, clutching both hand wires, to let go and see how many times I could clap resulted in a single short clap – but at least I managed one! The most enjoyable activity was sailing the cutter. The cutter needed teamwork, as did many aspects of life at Outward Bound.

Outward Bound aims to challenge people on the motivational level as well as the physical. A session on values made me realise that my work gives me more satisfaction from being both intellectually stimulating and useful, rather than being simply a source of income. But the main lesson was to challenge and set aside the "lids" in my life – those ideas whether generated by others or yourself that stop you doing things, stop you even trying. To some people Parkinson's is a lid that limits what they will try; but it shouldn't be. You don't know what you can achieve until you give it a go.

Do I miss the early morning dip in the sound each day – no way! Did I have a ball at Outward Bound and actually gain from the experience – yes! Would I recommend this to others, those with Parkinson's, carers and field officers – yes, most definitely! It is a marvellous opportunity, one that I am very glad I took.

A very big 'Thank You' to Douglas Pharmaceuticals who generously sponsored this special course, and to UPBEAT, the special interest group of Parkinson's New Zealand, for making it possible.

Government Announces Funding for Carers

Associate Social Development Minister Tariana Turia says \$3.5 million of annual funding will be used to make carers aware of sources of help, and provide financial assistance to some 24 hour carers.

Minister for the Community and Voluntary Sector Tariana Turia said that there would be \$1.3m put towards this project in the first year, to be announced in this month's budget.

"I've managed to secure some budget for 250 carers in the interim leading on to 500 in the long term," she said. "What we've got is a strategy where carers who take care of their own families have never ever had a resource to be able to do that and what we're doing is moving towards having a look at whether people can receive payment for taking care of their own."

Carers New Zealand, the national peak body for family carers, and the NZ Carers Alliance, a coalition of 45 national non-profits including Parkinson's New Zealand, have welcomed the Government's pre-Budget announcement of new funding for the 420,000+ Kiwis who act as carers.

The last government introduced a Carers' Strategy and five year Action Plan for carers. "The extent to which the new coalition government would build on this progress is now becoming clear" says Carers Alliance chair John Forman.

"Any new funding for carers is welcome. Carers are a large, invisible, and unsung community of New Zealanders whose unpaid work has an annual economic value of billions. It's great to see the new government taking the Carers' Strategy forward."

The Carers Alliance called for the Strategy in 2004 and worked closely with government agencies to develop the Action Plan.

Carers NZ, the Secretariat for the Carers Alliance, says family carers are New Zealand's biggest health workforce and, in an ageing society, will have an increasingly vital role.

Sources: www.tv3.co.nz, Carer's NZ.

Ministers' Group to Oversee Disability Policy

A new ministerial oversight committee has been established to "ensure the Government's multi-billion dollar annual disability spend is meeting the needs of disabled people fairly and effectively", said Disability Issues Minister Paula Bennett.

"The Ministerial Committee on Disability Issues will provide coherent overall direction for disability issues across government," Ms Bennett said.

"Currently, no group oversees the Government's substantial disability spending channeled through several agencies. This committee will ensure that disability support works well for disabled people, is distributed fairly, and represents value for money."

Ms Bennett will Chair the Committee. Other members are the Ministers of Finance, Justice, Health, Education and Transport; the Associate Minister of Education; and the Associate Minister of Disability Issues. Other ministers will be invited to provide input to the committee from time to time. The Committee will be supported by the Office of Disability Issues, based in the Ministry of Social Development.

However, lobby group the Disabled Persons Assembly (DPA) said the committee would not be able to deliver for disabled people unless it listened to them and understood their needs.

"I feel very strongly that it's window dressing," DPA president Wendy Neilson said.

"There is no Minister of Economic Development, who should have been part of that team. Also, as far as I am concerned, we have not been consulted as the advocacy group, and we should have."

The Government signed up to the United Nations Convention on the Rights of People with Disability, which very strongly advocates nothing about us without us.

To my mind if they were forming this committee they should have brought on people with disability who are movers and shakers in the disability sector to work alongside them."

Sources: www.beehive.govt.nz, The Press

2009 ANNUAL GENERAL MEETING

Parkinson's New Zealand held its 26th AGM in Wellington on Saturday 18 April which was preceded on the Friday afternoon with presentations and workshops.

To kick things off, Mike Lynch our President welcomed 19 divisional delegates from around the country, 9 observers, and the nominees for the new board to the conference.

Awareness Week 2009 was a good way of starting the afternoon with a healthy discussion around the room. National Office told us all that they were planning to launch multilingual material which will help us to reach out to different communities and build strong relationships.

This was followed by a presentation from Alasdair Finnie – Director of the Office for the Community and Voluntary Sector. This was a very interesting talk outlining the following statistics:

- There are 97,000 non-profit organisations in the country (2005)
- 2,210 were in the health sector.
- 15,090 employees work in the non-profit health sector & they contribute \$466.8m to the GDP.
- There are 256,000 volunteers – an estimated \$103.7m donated to the sector in 2004.

Alasdair also discussed the impact of the downturn in economy will have on this sector. It will not be easy to bring non-profit organisations in on budget over the next year or two, and management of our funds and staff will be under pressure.

Delegates then outlined their 2009 plans; it was interesting to see the different ways the delegates structured their priorities. Most concentrated on fundraising events, with discussion also arising about what they were doing in their communities.

To finish off the workshop session, delegates discussed membership structures and fees. I am sure most would have picked up ideas or two from this debate to take back to their divisions

The AGM dinner was held that night at FINC Dining Room which was a most enjoyable evening.

On Saturday we began with an election of new board members. The four candidates who were present introduced themselves to the meeting with a short summary of themselves, so that delegates could then vote for who to fill the three vacancies on the board. The outcome was that Margaret Adamson, Dr Gary Cheung and Maurice Nicholson were elected.

Next, Deirdre O'Sullivan the National Director of Parkinson's New Zealand gave an overview of 2008 on what the national office had achieved in the year. This was quite impressive, and highlighted the energy which the staff have in driving the organisation.

We then broke up into small groups to discuss lobbying and advocacy – an important part of Parkinson's New Zealand. A number of good ideas and items were raised in this session.

Next up was the actual AGM meeting itself. The main part involved remits, of which there were three – two of which were passed on the first reading, the third was hotly debated but passed. It was great to see some healthy discussion with a good outcome.

As this was my first Parkinson's AGM it was interesting to see how other divisions work. I enjoyed the unity that was evident through out the two days and found the whole experience very worthwhile.

A report by Canterbury delegate Malcolm Rickerby

BOARD OF 2009

Andrew Dunn	Kathy Jenkins
Jeanette Clark	Tony Jones
Leo Gambitsis	Maurice Nicholson
Margaret Adamson	Mary Searley
Dr Gary Cheung	



2009 AGM Delegates

NEWS FROM AROUND THE COUNTRY

🔥 Auckland

During late February and early March Parkinson's Auckland held presentations with members to give them a better understanding of how the Society operates and what it can offer.

All ten of the local Parkinson's groups had the opportunity to take part in these presentations and often very lively discussion ensued. It was good for members to see who is involved at the different levels: Executive Committee members, all the field officers – with their areas well defined on a map; and to gain some understanding



Auckland's Reg Stewart and Roger Hicks, part of the team giving presentations.

of exactly what each of these people do. The funding, shown as a pie-graph, was discussed thoroughly, especially from the point of view of group participation in fund-raising.

🔥 Hawke's Bay

On 30 April 2009 Hawkes Bay opened their new offices in Taradale. An open day for members and community worker groups was held, with the official opening in the evening. The day was very successful with people popping in for a cuppa and to show their support – all giving positive feedback.



Chairperson Jeanette Barker cutting the ribbon watched by Co-ordinator Barbara Billington and Field Officer Morag Murray.

🔥 Central Plateau

At the recent A.G.M held in Rotorua, Bill Dales was made an honorary life member of the division. This is the first life membership to be given by the division and recognises the commitment and passion Bill has shown. Bill stood down from the chairmanship at this meeting, an office he has held for the past twelve years. However he will continue to serve on the committee.



Central Plateau's Bill Dales with his life membership certificate

🔥 South Canterbury

In March the division had a very successful AGM where patron Dr Hills spoke to attendees on Parkinson's and developments. On April 3rd a Street Day Appeal was held, and the collectors were pleased with the amount they raised for the division. Later in April, a social was held where local man Alan Stewart spoke about the many years he spent as an announcer on radio which the group enjoyed immensely. The division was also pleased to have one member attend Outward Bound and five members attended the UPBEAT conference in Christchurch. They all enjoyed their experiences.

🔥 Kapiti/Horowhenua

The division has set up a new Men's Group in Kapiti with a pleasing response to the first meeting. The April Support meetings had Eric and Heide Harper speaking. Eric is on a trial of Duodopa Intestinal Gel, which involves the direct delivery of levodopa into the upper small bowel. He has found the resulting treatment extremely beneficial and has allowed him to resume activities that had become impossible for him. It was an inspirational talk to listen to.

🔥 Otago

The division organised a fundraising bowling tournament in conjunction with the local Queenstown Bowling Club. The event was a huge success with over 100 bowlers attending, and \$1500 being raised for the division.



Bowling club president Bev Terry presenting a cheque to Otago division's Michael O'Connor.

🔥 Northland

Author and former Firefighter Anne Barry spoke at three Northland division meetings in April – donating \$5.00 from each book sale to Parkinson's. The division has also recently moved shop and we look forward to seeing photos once it is refurbished.



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