



The Parkinsonian

The Quarterly Magazine of Parkinson's New Zealand

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ELECTION MANIFESTO

Parkinson's New Zealand is part of the Neurological Alliance which was established in 1999. Twelve organisations representing a neurological disease or condition belong to the alliance and work together to make representations on matters of common interest and raise awareness to ensure the needs of people with neurological conditions are met.

In this election year, the Neurological Alliance has produced a manifesto calling for, amongst other things, the Government to establish a 'Neurological Desk' within the Ministry of Health or National Health Board.

The Parkinsonian sent this Manifesto to all of the political parties and asked for their response. Only Labour, National, The Maori Party and Act responded. Their replies are printed on pages 3 to 5.

Neurological Alliance manifesto for 2011 General Election

Today a significant number of New Zealanders and their families are affected by neurological conditions. The majority of the support and information provided for people affected by neurological conditions is given by specialist community organisations. This reduces the impact on the Government's Health and Disability budgets. We know that neurological conditions such as Alzheimer's, Epilepsy, Muscular Dystrophy, Parkinson's and Stroke account for a high proportion of severely disabled people of all ages. The impact of this extracts a huge physical, emotional, mental and economic toll on the health of New Zealanders.

The Neurological Alliance consists of 12 organisations that represent over 200,000 New Zealand families, of all ages and ethnicities, from all sectors of our society. With our ageing population these numbers are predicted to increase rapidly over the next two decades.

We of the Neurological Alliance of New Zealand call on all Members of Parliament from all political parties to work with us to ensure the needs of the thousands of New Zealanders affected by a neurological condition are identified, strategically planned for and met. Such planning is essential if we are to minimise the potential and growing economic and social burden that our country will face in the future, and will struggle to carry. The Neurological Alliance requests that you consider and commit to the following solutions.

ISSUES	SOLUTIONS
<p>Planning Neurological conditions significantly impact our health system and society. Our ageing population is a major factor in growing numbers.</p>	<p>That the need for a neurological policy and service is clearly acknowledged, developed and actioned within the Ministry of Health/National Health Board. The establishment of a 'Neurological Desk' within MOH/NHB is recommended.</p>
<p>In-community support Services that are unavailable elsewhere are provided to people living with neurological conditions by specialist community organisations such as the members of the Neurological Alliance. These organisations and their workforces save DHB resources by providing specialised care in the community. However this work receives little recognition or support. This results in multiple agencies, government and Non Government Organisations (NGOs) working in isolation creating unnecessary silos with duplication and gaps.</p>	<p>That people with neurological conditions, their families and the organisations that work with them are recognised and supported. Government agencies should work in active partnership with the Neurological Alliance and its member organisations to create the best outcomes for our people and our health system. This includes recognition of the NGO workforce and providing training and financial support.</p>
<p>DHB support Many people with neurological conditions are not receiving equitable service or timely diagnosis. Rehabilitation and disability supports are limited and inconsistent across the country.</p>	<p>That the development of clinical networks is actively supported to improve diagnosis, clinical care, rehabilitation and social supports. The establishment of a 'Neurological Desk' within the MOH/NHB would greatly assist with this.</p>
<p>Access to medication Timely and affordable access to medicines is a key priority for people with neurological conditions.</p>	<p>That the Government continues to support the recently developed New Zealand Medicines Strategy through continued consultation between consumers, NGOs, PHARMAC, Government agencies and the pharmaceutical industry.</p>
<p>Research There is limited coordination of New Zealand's research budget in this area. Scientific, clinical and welfare research into neurological conditions could be better targeted.</p>	<p>The research into neurological conditions is actively supported at a clinical and scientific level to improve treatment options and rehabilitation/disability supports. That forums are provided for active dialogue between relevant stakeholders.</p>

A WORD FROM THE CHIEF EXECUTIVE

TENA KOUTOU KATOA

I hope you enjoy reading this pre-election issue of The Parkinsonian and find the responses from the political parties to the Neurological Alliance manifesto of interest. If you will be speaking with candidates in your electorate over the coming months and would like a copy of the manifesto to pass on to, or discuss with them, please get in touch with National Office or your local division.

I read with interest the article on page 6 about the Coenzyme Q10 trial that has been cut short. We often read in the media about 'exciting new' studies which we then never hear of again. While it may be disappointing to learn of a 'failure', announcements like this can actually help us have more trust in successful trials.

Having faith in the advice we are being given, or the services we receive, regarding our health and wellbeing is vitally important. Sometimes, despite the best will in the world, things can happen to undermine this trust. The article on page 9 is a helpful reminder of what we can do if inappropriate or unsafe advice or services are provided. While most of us find it very difficult to make a complaint, helping get an issue resolved benefits not only you or someone you care for, but also others who may have had a similar experience.

Approximately 1,000 of our members will have received a letter in the post from Sridhar Maddela inviting them to take part in a study he is doing into the difference in thought patterns between people with and without Parkinson's. Unfortunately there have not been enough respondents yet for him to complete the project. Therefore the criteria has been loosened somewhat to include people who don't have Parkinson's as well. If you received one of the letters and think you may be able to take part, or have a family member prepared to answer it, we would really appreciate it if

you could complete the survey and return it to him in the envelope provided.

You will find on page 11 a request for financial assistance towards the work of our Society. If you or someone you know is able to support us we would be extremely grateful. I'm sure you will agree the work we do providing information to people with Parkinson's, training our Field Officers so they can give the best possible service to their clients and lobbying for better support for people with Parkinson's is essential. We can only do this work by raising much needed funds.

As we head towards summer the more ambitious amongst us may be tempted by one of the many sporting events, runs, triathlons etc taking place. If you or someone you know is keen to challenge themselves and support Parkinson's, please let us know. We can send a Get Going for Parkinson's fundraising pack which includes sponsorship forms and other information. There are also plenty of opportunities for those who prefer more sedate activities.

Parkinson's Awareness Week takes place from 1-7 November. Please help us raise awareness through supporting any activities your division is running. In addition you could ask for copies of our publicity materials and help distribute them around your community e.g. GP surgery, local library, shops etc.

Kind regards

Deirdre O'Sullivan

THANK YOU



WALTER & RANA NORWOOD
CHARITABLE TRUST



If you or your company can support the work we do for people living with Parkinson's locally or nationally please get in touch with your local division or National Office.

NEUROLOGICAL MANIFESTO – LABOUR PARTY RESPONSE

Labour is committed to enhancing the well-being of all New Zealanders, so they can live longer, healthier lives. To do this we need to shift thinking away from seeing health policy in isolation, and from seeing healthcare as something that begins in a hospital or doctor's surgery, and ensure that all our policies enhance the well-being and health status of New Zealanders.

We must address the inequities that are contributing to poor health outcomes. This will require particular attention to policies in terms of education, income equality, housing, taxation and social development and how they impact on health. There is not a bottomless pit for expenditure, but investments now in proven early interventions should reduce the need for expenditure not only in the health system but in other areas of government including social development and corrections.

We agree that a strategic approach is needed to work on neurological conditions. With an ageing

population we do need to plan ahead to ensure that we have the services in place that meet the needs of that population. A key element for Labour is ensuring that we have the qualified workforce needed to diagnose, treat and support those with neurological conditions. This is not only in terms of clinicians, but those who work as caregivers. There needs to be a comprehensive programme to provide training that will boost the quality of care and lift skills and wages in this sector.

As with other areas of health, a number of key principles need to be applied in the delivery of services to those with neurological conditions. Early intervention, coordination across services and development of strong clinical networks are among these principles.

We must also support research into a range of conditions, particularly in the neurological areas and ensure that the results of this research is disseminated and acted on across New Zealand.

NEUROLOGICAL MANIFESTO – NATIONAL PARTY RESPONSE

The Ministry of Health is in the early stages of establishing a Neurological Disease Clinical network. The community and the sector have asked for extra attention in this area and we're delivering it.

This network follows on from the successful Cardiac Network that's been established and is ensuring people receive treatment when they need it, and clinicians work together to get the best out of the service they provide.

The Neurological Disease Clinical Network work programme is being developed and will work to ensure patients have equitable and timely access to treatment.

It is being led by Dr Andrew Wong, who is a doctor specialising in rehabilitation.

National recognises the challenges people with neurological conditions face, and the impact on families. In Budget 2011 we put an extra \$44 million into dementia care and an extra \$130 million into disability services.

District Health Boards work closely with providers in the Alliance to provide necessary services, like support for Alzheimer's patients.

Health Workforce New Zealand is including the role of NGOs in their workforce development. Professor Des Gorman met with them in late August to discuss their roles in looking after people and their families and how they can be supported and developed. NGOs have an important place in the care of people with neurological conditions.

The Government provides more than \$4 billion worth of funding to NGOs each year – and that's increased by \$1.5 billion over the last three years.

District Health Boards have been funded to provide better and improved services to patients for rehabilitation and diagnosis.

Waikato Hospital has a dedicated stroke ward and recently established a Stroke Rehabilitation Clinic. More than 650 people are admitted to the hospital every year with strokes or transient ischaemic attacks.

The Auckland District Health Board offers a memory service for in-depth screening and problem-solving for those who have memory problems. Further referrals are made, if needed, to diagnostic services or specialists including geriatricians, psychogeriatricians and psychologists.

The Government will continue to support the new Medicines Strategy. National has invested an extra \$180 million into medicines since 2008. This includes funding for new medicines, and wider access to other medicines. Notably, this includes funding for the first subsidised Alzheimer's drug.

Research will play an important part of the new Neurological Disease Clinical network.

There will be closer links with academics, as research plays an important role in dealing with neurological diseases.

The Government is due to release its response into the Health Select Committee's report into Clinical Trials

next month. The Select Committee has made a number of recommendations which we are considering.

EDITOR'S NOTE:

Parkinson's New Zealand and the other members of the Neurological Alliance of New Zealand were delighted to hear that the Ministry of Health was working on a Neurological Disease Clinical network and that Workforce development is being looked at.

However it is both surprising and disappointing that this work has been undertaken with no consultation with those of us who work in this area and does not reflect the National Party's statement that they value NGOs role in the care of people with neurological conditions.

NEUROLOGICAL MANIFESTO – ACT PARTY RESPONSE

We are yet to finalise our health policy for the 2011 election, but I can outline the general principles that ACT adheres to when looking at health.

ACT is convinced that the key to high quality care in all fields is ensuring that the focus is on the patients.

ACT believes in choice and personal responsibility in healthcare. Individuals should be able to make their own decisions, wherever possible, about the kind of care they receive and have a range of choices available to them.

It is often the case that families are the first support network for people when they need assistance. ACT sees the continuation and support of this as vital; families know their loved ones far better than the state or other agencies. For this reason many people with Parkinson's and other neurological conditions choose to, as long as it is practicable, remain in their own home to be cared for by their family.

ACT supports a system of funding following the user and encourages people to save towards funding their own healthcare. This would take place under a system where there is a much lower tax burden, where people keep more of their money. This places the decision for healthcare in the hands of the users and their families – so they can afford the drugs, the treatment, and the carers however they choose. This system is so much fairer than the one-size-fits-most monopoly of public healthcare.

Such a system will also greatly benefit carers. They often make significant personal and financial sacrifices. Under a health system run by a state monopoly, people have little control of their own healthcare and people like family carers miss out. ACT would put the choice in the hands of the user and the user's family – if they choose to transition into residential care or if they choose to remain in their homes with family carers the funding would be the same.

Unfortunately New Zealand is not at the forefront of countries with regard to medicines. Lack of access to new, quality treatments is compounded by a shortage of neurology specialists. PHARMAC has a brief to keep costs down and does so ruthlessly. We have no problem with cost efficiency but the brief is too narrow as it looks at the drug cost alone and ignores wider costs. Medications that allow people to function independently should be available and accessible to patients and is often cheaper for the state. That saving is never included in PHARMAC calculations. ACT would broaden PHARMAC's brief to look at all health costs including patient costs.

Providing choice in healthcare is the most effective way of solving the inequities in the current system. When the Government makes all the healthcare decisions, many people miss out. When people choose for themselves they can direct their health money to the areas they think are best from them – and many New Zealanders choose to be looked after by their own families.

The priority of Maori Party policy is to ensure that our whanau are firmly in control of achieving their own outcomes.

It can be as simple as having good information and the confidence to act on it for the wellbeing of your family.

The starting point is that whanau hold the key to determining the wellbeing of all its members. They are the best people to define their own solutions and make their own decisions. This is the focus of our 'flagship policy': Whanau Ora. But there are other aspects to Whanau Ora – and that is the transformation of social services delivery to focus on the needs of the whanau. The whanau must be at the core of this transformation.

Latest research suggests that for most people with Parkinson's, quality medical care, support and a positive outlook can create the conditions for a productive life for many years after diagnosis.

Yet for many Maori, limited access to primary, secondary and tertiary prevention or intervention services often acts against their general health and wellness.

For example Maori receive fewer referrals, fewer diagnostic tests and less effective treatment plans from their doctors than do non-Maori patients, they are offered treatments at substantially decreased rates, interviewed for less time, and prescribed fewer secondary services such as physiotherapy, chiropractors and rehabilitation (Bacal, Jansen and Smith, 2006).

We recognise that the health of whanau is affected by determinants outside the health sector including political, social, economic and environmental impacts. The health status of New Zealanders clearly varies by ethnicity, with Maori experiencing a greater burden of disease than non-Maori.

The incidence of Maori with Parkinson's Disease is expected to increase in line with demographic changes expected in the Maori population. Between 2006 and 2026 the Maori population 65 and over is expected to increase three-fold – with Maori making up a larger proportion of the total population aged 65 years and over (up from 5% to 7%).

The rising incidence will place increased need for support or care for family members afflicted with Parkinson's Disease, particularly as their condition worsens. We recognise that the rights of whanau to be included in health plans, and believe that all health professionals must be culturally competent to be responsive to whanau, hapu and iwi.

This will require the health system to be culturally safe, such as incorporating Maori models of practice and approaches into delivery and provision, or utilising whanau members in training programmes.

We believe that tangata whenua are entitled to determine their own health priorities for development, and to participate in all decisions that affect them. This may require recognition of their traditional medicines (rongoā), and the preference for kaupapa Maori health practices.

Whanau, hapū and iwi also need to be involved in Parkinson's research, including that utilising human embryos, given the ethical issues which arise.

The Maori Party believes that whanau, hapu and iwi have a right to the highest attainable level of health and wellbeing. Our vision is a land in which all people achieve our health potential. The Maori Party will therefore design arrangements for the timely access to high quality and appropriate health care, also irrespective of the ability to pay.



FIELD OFFICER CONFERENCE

Parkinson's New Zealand's annual Field Officer conference was held 28 – 29 July in Wellington.

Speakers presented on topics including Parkinson's and Pain, Occupational Therapy, Deep Brain Stimulation (DBS), Cultural Safety and Parkinson's and Palliative Care.

The conference was also an opportunity for Field Officers to network and exchange ideas.

🔥 Trial of antioxidant Coenzyme Q10 is cut short

The National Institute of Neurological Disorders and Stroke (NINDS) in the USA has stopped a large clinical trial of the antioxidant Coenzyme Q10 for the treatment of early stage Parkinson's.

The study was halted after disappointing interim results suggested that continuing would be futile. It was comparing doses of 1,200mg or 2,400mg of Coenzyme Q10 to a placebo in 600 people with early Parkinson's in North America.

The results showed that while taking the supplement seemed to be safe, even at high doses and for up to 16 months of treatment, there was no evidence of any tangible benefit.

🔥 Rhinorrhea (runny nose): a common feature of Parkinson's disease

A recent study published in *The Movement Disorders Journal* looked at the frequency of nasal discharge in people with Parkinson's. They found that, after other possible causes (eg colds, allergies) had been excluded, the incidence of rhinorrhea was five times higher in people with Parkinson's.

No relationship between age or other Parkinson's symptoms was found except that 52% of those with nasal discharge also complained of light headedness.

🔥 Low intensity treadmill exercise is best to improve walking in Parkinson's

Preliminary findings from an investigation comparing the effectiveness of different exercise regimes for people with Parkinson's suggest that low intensity treadmill walking may be best for mobility.

A US study randomly assigned 67 people with Parkinson's to one of three exercise groups: walking on a treadmill at low intensity for 50 minutes, higher-intensity treadmill for 30 minutes, and using weights and stretching exercises.

Participants exercised three times a week for three months.

The researchers reported positive effects with all three types of exercise, but the low-intensity training showed the most consistent improvement in gait and mobility.

🔥 New gene linked to Parkinson's and cellular sorting

Two research groups have independently identified a new gene linked to an inherited form of Parkinson's. The studies on two families, one in Switzerland and the other in Austria, found the same gene mutation in both.

The mutation is in a gene that is involved in protein sorting and recycling within cells. The same gene (VPS35) has been linked to Alzheimer's. Other genes in the system have also been linked to a number of different neurodegenerative conditions.

Researchers believe that problems in the way cells sort and recycle proteins are a key factor in neurodegeneration.

🔥 Cultural, gender and ethnic stereotypes can distort treatment of Parkinson's

Researchers in the US and Taiwan have found that cultural, ethnic and gender stereotypes can significantly distort clinical judgments about 'facially masked' patients with Parkinson's. 'Facial masking' is a term used to describe the relatively unmoving, emotionless facial expression that some people with Parkinson's develop. It is already known that clinicians sometimes form biased opinions about people with Parkinson's due to their inability to show facial expressions.

284 American and Taiwanese healthcare practitioners were evaluated on their responses to videotaped interviews of 24 American and Taiwanese women and men with Parkinson's who had varying degrees of 'facial masking.' Practitioners judged the patients on their cognitive ability, depression and various aspects of social functioning.

The research found that despite their neurological expertise, practitioners had negatively biased impressions of people with higher masking and

those biases were notably more pronounced when facial masking clashed with cultural, ethnic and gender expectations.

Overall practitioners in both countries judged patients with higher masking to be more depressed and less sociable. This was most marked for the videos of women with facial masking. Masking was also linked to a stronger chance of biased thinking about lower sociability for Americans, and a stronger bias about poorer cognitive ability for Taiwanese.

The ethnicity of practitioner was also a factor with American practitioners being negatively biased in judgments of sociability and Taiwanese practitioners more biased on cognitive competence.

The researchers conclude that "health care professionals need to let go of their reliance on the unresponsive face and pay greater attention to what patients and family members tell them as well as to other cues."

🔥 People with Parkinson's who experience mental health problems may be taking unproven drugs

A new study highlights the problems in treating people with Parkinson's who experience hallucinations or delusions (psychotic symptoms) with medicines that have not been proven to be effective in clinical trials for people with Parkinson's.

A US study looked at the drugs taken by about 2,500 people with Parkinson's who were treated for hallucinations and delusions in 2008. Most of these medicines were antipsychotic drugs, also used to treat schizophrenia.

About half were prescribed medication for these symptoms but only 2% received clozapine (Clozaril or Clopine) - the only medicine for which there is reasonably strong evidence that it is helpful for hallucinations and delusions in Parkinson's. However, the side effects of clozapine are difficult for many.

Most people had been given quetiapine (Seroquel, Quetapel, DP-Quetiapine), a drug commonly used to treat psychosis but which

hasn't been proven to be beneficial for people with Parkinson's.

Of concern, the study also found that about three in ten people were taking drugs that can worsen the symptoms of Parkinson's, including some older types of antipsychotic medication.

It is well known that not enough clinical trials have yet been done to determine what the best treatments are for people with Parkinson's and mental health problems. More research is needed in this area.

Pesticides and Parkinson's disease: Working near sprayed fields increases risk too

California researchers who established a link between two commonly used pesticides (maneb and paraquat) and Parkinson's in 2009 have published a follow-up study in the *European Journal of Epidemiology*.

They examined the effect of a third chemical, ziram, and looked at the risks to people whose workplaces were close to fields sprayed with these chemicals, not just those who live nearby (as found in the earlier study).

The study demonstrated that environmental exposure to ziram is associated with a significantly

increased risk of developing Parkinson's. Ziram has previously been shown to be powerfully destructive to neurons in laboratory studies. Pesticide risks appear to be cumulative as the risk of Parkinson's increased with the number of chemicals people were exposed to.

Researchers also found the risk of exposure was higher in workplaces located near sprayed fields than it was in residences.

Ziram (sold as Mizar Granuflo) is a zinc-based fungicide, used primarily on stone fruit and pip fruit in New Zealand. It is on the Environmental Risk Management Authority's (ERMA) Reassessment Priority List.

Stem-cell scientists grapple with clinics

There is concern among stem-cell researchers about the worldwide proliferation of clinics offering regenerative medicine, or stem-cell therapies. While stem-cell research holds promise for improving human health, at the current time most of the treatments on offer are unproven and can be dangerous.

In May 2011 a clinic in Germany was closed down after it was linked to the death of a toddler and near-death of a 10 year old.

In a bid to help patients wade through claims about therapies, last year the International Society for Stem Cell Research (ISSCR) introduced a 'Submit a Clinic' service on its website. On it people could name clinics they had heard about and the ISSCR would look into whether appropriate oversight and other patient protections were in place for the treatments they offer.

The website was shut down in February after some of the clinics responded with threats of legal action. While the Society felt it was on firm legal ground, it decided that the cost of any lawsuits was not worth it and shut the service down.

While the ISSCR is no longer looking into or naming specific clinics, its website:

A Closer Look at Stem Cell Treatments www.closerlookatstemcells.org provides resources to help people evaluate claims about stem cell treatments and what questions to ask about clinics promoting them.

SOURCES:

Parkinson's UK, PubMed, viartis.net, sciencedaily.com, alzforum.org, LA Times, ScienceDaily.com, FruitFed, ERMA, eurekaalert.org, Nature, ISSCR

GET GOING FOR PARKINSON'S

Get Going is a way you, your friends or family can raise money to help Parkinson's New Zealand provide our vital services. You don't have to run a marathon to support us - although we don't mind if you do! There are many more sedate activities you can organise that are fun and will raise money. Here are just a few ideas.

Garden Party

Got a beautiful garden you love to show off? A garden party can be as big or as small as your garden will allow. Charge an entrance fee, ask someone musical to provide entertainment and provide morning or afternoon tea for your guests - scones with cream and jam make an inexpensive yet popular treat. You could even sell homemade preserves or crafts to raise extra funds.

Accessory or Clothes Swap

Are you bored of your collection of scarves? Is your wardrobe full of impulse buys you regret and have never worn? Your friends probably feel the same way, so why not swap them. Bring everyone and their less-

loved items together for a fun evening of 'shopping'. You can get everyone to pay a donation to attend or set a small price for each item (auctioning off the most popular items to the highest bidders).

Bowls Tournament

Bowls Clubs often run charity tournaments. Ask if Parkinson's can be the recipient of one of these. If your local club doesn't already run a charity tournament, organise one. Or if your retirement village has a bowling green, get some teams together for a 'friendly' match up.

For more information on organising an event, please email us at info@parkinsons.org.nz or call 0800 473 4636.

NEWS FROM AROUND THE COUNTRY



AUCKLAND: Anne Andrews, Dame Cath Tizard and Ken Richardson



TARANAKI: Quoits match at Taranaki's games day



KAPITI/HOROWHENUA: Dr Maurice Curtis



WAIRARAPA: Mike Lynch welcoming the gathering

🔥 Northland

The Whangarei support group luncheon in early September had Dr Deborah Young as a special guest speaker. Dr Young is Associate Professor in Pharmacology and Head of the Molecular Neurotherapeutics Laboratory at the Centre for Brain Research, University of Auckland. She gave a very interesting and understandable presentation on gene therapy approaches to treating Parkinson's. Deborah works with Matthew During, whose gene therapy work was featured in the June 2011 Parkinsonian.

🔥 Auckland

Ann Andrew's book *Positively Parkinson's* was launched in Auckland on 16 August. The launch event, held at the Women's Bookshop in Ponsonby, was well attended. "Packed to London-tube-carriage density" as one attendee described it. Ann spoke after Dame Cath Tizard, who did the official honours at the last minute when John Walker was too ill to come. Since the launch, the book has received a lot of good coverage in the media, including interviews with Ann on Kim Hill (Radio NZ) and in *The Listener* and *The Aucklander*.

🔥 Tauranga

Tony Lawson, Clinical Nurse Specialist – Health in Ageing at Tauranga Hospital spoke at the 14 June support meeting. Tony has a special interest in Parkinson's and dementia. He covered a host of subjects in his presentations including medication, anxiety, depression, bad dreams, cramp and constipation. He also answered the many questions put to him by the attendees.

🔥 Taranaki

The Division held its annual 'Games Day Challenge' at the TET Stadium on Tuesday 19 July. The successful and fun filled day was attended by nearly 30 people who were split into five teams. Games included a 'non-competitive' card game, quoits, skittles, balls into buckets and bat and ball, all with a bit of a twist, and a general knowledge quiz. The day ended with dancing.

🔥 Wairarapa

A well attended Mid-Winter Lunch was held 23 June at Solway Park.

🔥 Kapiti Horowhenua

Parkinson's Kapiti Horowhenua hosted a very interesting and successful seminar in August. Kevin Miles drew on his personal experiences to discuss the role of the carer. Co-Director of the Brain Bank, University of Auckland, Dr Maurice Curtis gave a fascinating talk on his research on brain stem cells and neurodegenerative diseases and managed to make a challenging subject accessible.

After lunch Consultant Psychiatrist Dr Mathew Croucher got the crowd involved in his presentation about coping with anxiety. Registered Nurse and Chartered Natural Therapies Practitioner Jeannette Clark ended the day with a discussion on complimentary therapies.

🔥 Canterbury

It is six months since the devastating February earthquake in Christchurch. The Multiple Sclerosis & Parkinson's Society of Canterbury fortunately work from a building that was only minimally damaged so they were able to get back to working at full capacity fairly quickly. Although programmes were cancelled in March, since 4 April all home visits and activities have been running.

Jenny Boyer, MS+PD Manager would like to thank all the Parkinson's New Zealand Division members and staff for the love and support they gave Canterbury over the first few difficult months.

"We have all been so overwhelmed by the care and concern shown to us and the offers of accommodation and other practical help sent via emails and phone calls. Many thanks."

Her thanks extend to the Canterbury staff as well, noting that they have coped admirably having to deal with their own situations while supporting members at the same time. "They are really amazing."

It has been a long, tough year for the region since the first quake (4 September 2010). The Society wishes to remind members that they are available for earthquake support and to provide assistance, including referrals to other welfare agencies.

Lea-Anne Morgan, Parkinson's New Zealand's Clinical Leader

Making and resolving complaints

As carers you may find yourself in a situation where you, and/or the person you care for, believe the service a health or disability service is providing is not adequate. For example, you may have arranged for the person you care for to go into respite care. Once there you find the facility does not really understand Parkinson's and the importance of getting the right medication at the right time. Despite a couple of reminders, they are still not getting their medication in a timely fashion. Another scenario may be that you have arranged for home help from a home support agency. You are happy with the plan you, the person with Parkinson's and the team leader have agreed on, but the home help is not sticking to it. Should you make a complaint?

Absolutely! Everyone using a health or disability service has the right to make a complaint if they are not happy with the service they are receiving. This is a Right under the Code of Health and Disability Services Consumers' Rights. Making a complaint is also an important way of improving the quality of services. Providers can't improve if they don't know what they are doing wrong so most want to know when things aren't quite right.

How to make a complaint

In the first instance it is usually best to make a complaint to the person or people you are complaining about, or their manager. If you have already tried this without success, or you think the problem is one the organisation as a whole needs to deal with, the next step is to contact the person in the organisation responsible for receiving complaints. All providers (including Parkinson's New Zealand) are required to have a complaints procedure and a person responsible for it. Larger providers will usually have a brochure or information on their website detailing this. If yours doesn't, call them and ask for this information. They are required to let you know about it.

You may make a complaint in any form appropriate to you (by phone, letter or at a meeting), but make sure you request a written response and outline what you expect from the provider. For example do you want an apology and an explanation or do you want to know what policy or procedures they will be putting in place to stop it happening again (or both). Also, make sure that you agree a timeframe for receiving a response. This may be part of the organisation's procedures (10 working days is usual) but it does no harm to remind them when you expect to hear back. In general the more details you can include in your complaint the better. If possible, keep a note of when things happened and any conversations you had about them.

This may seem a bit daunting but there are people available to help you through the process. Your Parkinson's Field Officer has experience in this area and can give you information and support. The Health and Disability Commissioner (HDC) also provides a free Nationwide Health & Disability Advocacy Service. Advocates are independent and on the side of the consumer. They can explain your options and support and assist you in the actions you choose to take. Complaints are usually dealt with more quickly through advocacy, so they may be particularly helpful if your provider is being slow to respond. However neither your Parkinson's Field Officer or Advocate can make the complaint for you, it has to come from you.

If you are unhappy with the response you receive, you can make a complaint directly to the Health and Disability Commissioner. The Commissioner will assess the complaint and decide the most appropriate way to resolve it. This may include referring matters to other agencies (e.g. Ministry of Health) or starting a formal investigation. This is only required in a very small number of cases. Most complaints should be resolved well before they reach this point.

Getting more information

A Guide for Carers, a useful resource produced by the Ministry of Social Development and available from Carers NZ includes a useful section on complaints. See their website www.carers.net.nz or call 0800 777 797 to request a copy.

The Health and Disability Commissioner produces a number of resources to inform you about and assist you with the complaints procedure. Look for their pamphlet, *Learning from Complaints*. Their website www.hdc.org.nz also contains a wealth of information and has a link to the Health & Disability Advocacy Service. You can contact the Service on 0800 555 050.

Right 10 – You have the right to complain and have your complaint taken seriously

- You may make a complaint in any form appropriate to you.
- You should be advised of your provider's complaints and appeals procedure.
- You should be kept informed about the progress and outcome of your complaint.
- You should be advised of the availability of advocates and the Health and Disability Commissioner to assist with your complaint.
- You should not be adversely affected as a result of making a complaint.

Taken from the Health & Disability Commission's Code of Rights

Differentiation of Essential Tremor from Parkinson's Tremor using Postural Tremor Analysis

Distinguishing between the tremor associated with Parkinson's and Essential Tremor is the subject of recent Parkinson's New Zealand funded research.

The Action, Brain and Cognition Laboratory in the Department of Psychology at the University of Otago have maintained a pool of people with Parkinson's who participate in research projects for over a decade. Recent research undertaken by this group looked at ways to distinguish between the tremor associated with Parkinson's and Essential Tremor.

As there is a large overlap in clinical signs, frequency and amplitude of the tremor in the two conditions, they can be confused resulting in misdiagnosis. The aim of the current work is to develop reliable algorithms to accurately distinguish between the tremor types and create a portable, easy to use diagnostic tool. This will hopefully be further developed to measure progression and the effects of medication on the tremor.

The work integrates the cognitive and attention testing tools developed by the Laboratory under Associate

Professor Liz Franz with the mobile computing tools developed by Dr Mariusz Nowostawski and the Department of Information Science. An initial study, conducted by MSc student Alan Woods, has recently concluded. For it each participant gave a brief history, took a survey on handedness, a rating of disease progression from the Uniform Parkinson's Disease Rating Scale (UPDRS) and six visual and concentration tasks that measure actual tremor during the tasks. The results are still being analysed but look promising.

Parkinson's New Zealand Chief Executive Deirdre O'Sullivan said:

"We are very pleased to be able to fund research like this which will improve the diagnosis for Parkinson's and Essential Tremor ensuring people receive the correct treatment for the condition they have as early as possible."

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WE NEED YOUR HELP

Parkinson's New Zealand has been helping people living with Parkinson's for nearly 30 years. In this time we have grown from a group of interested people sharing information and support for people with Parkinson's, to the organisation you know today. I'm asking for your help to keep our services available to people with Parkinson's. One of the most important areas of our work is the field officer service.

The difference our field officers make for the people they care for can be life changing. The assistance they give is holistic to assist with any area of the person's life and may not be linked to their Parkinsonianism condition.

One of our field officers told me this story of an elderly gentleman he visited:

It was my first home visit to this gentleman who had Parkinson's and was living on his own after his wife had died. To break the ice I asked him what he liked to watch on TV and he told me he didn't really watch TV as he couldn't see it very well. He could also no longer read books or the newspaper or drive because his vision was so bad and he was waiting on cataract surgery. I came to realise he was quite isolated because of his vision. He told me he had been waiting for a couple of years for surgery so I asked him if I could look at the letters he had from the hospital. With the gentleman's permission, I phoned the hospital to ask about his place on the waiting list. They said as his case was marked non-urgent he would be unlikely to have his cataract removed for another 12 months. Concerned that this would prevent him from doing many of the things he enjoyed and make it difficult for him to attend our support and exercise groups, I explained to the hospital how limited his life had become due to his condition. Half an hour after this conversation I got a call back from the hospital, my client could have one of his cataracts removed later in the week and the other in a couple of weeks time. A month later when I visited my client again he was a new man! He could watch TV, read the paper and go to the library. I was really proud to have helped.

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THANK YOU!



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For further information check the Consumer Medicine Information [CMI] at www.medsafe.govt.nz

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

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