Parkinson's Awareness Week 1–7 November 2013

The new edition of this booklet was officially launched at a reception at Old Government House, University of Auckland on Monday 4th November. The event was well attended by members from Parkinson’s Auckland and other guests. We were particularly pleased to welcome Health & Disability Commissioner Anthony Hill, Professor Richard Faull and other researchers from the Centre for Brain Research, Alison Charleston from Parkinson's New Zealand's Medical Advisory Panel, and doctors from around the Auckland region.

The Guide is specifically for New Zealanders who have just been diagnosed with Parkinson’s. It covers what Parkinson’s is, the medication and non-medication treatment of Parkinson’s and details other help and information that is available.

Copies of Parkinson’s: a guide for the newly diagnosed are available from your local division or from Parkinson’s New Zealand. Call 0800 473 463 or email info@parkinsons.org.nz to request a copy. It can also be downloaded from the website www.parkinsons.org.nz

World Parkinson Congress

The third World Parkinson Congress (WPC) was held in Montreal, Canada 1 – 4 October. Over 3,330 people attended from 64 countries creating a vibrant atmosphere.

Every moment of every day there were multiple things happening. There were, as you would expect, speakers to listen to, workshops to attend and round table discussions to participate in. There were also films to watch and a theatrical performance of a musical based on the life of a celebrated Canadian playwright with early onset Parkinson’s.

The renewal room provided a programme of alternative activities. You could start your day with early morning Yoga or Tai Chi. Extend your voice with singing or laughter sessions. Unleash your fighting spirit by trying boxing. Or learn some new moves with salsa or merengue dancing.

In the exhibit hall you could stop by the many hundreds of posters submitted on a huge range of topics. Poster tours each day offered a little more insight into the topics as there was an opportunity to meet some of the authors. There were also stands and information available from a multitude of suppliers of medications, equipment and services for people with Parkinson’s.

The social aspect of the congress was also invaluable in making attendees feel like they were part of a big family. The opening ceremony set the scene for the congress with motivating speeches from inspirational people. The function afterwards gave us a chance to try the local speciality 'poutine' while meeting new people. The closing function gave us the opportunity to say goodbye to new friends and swap contact details.

This edition of the Parkinsonian is largely dedicated to the information & research studies that were presented at the congress.
IN THE NEWS
Thank you to all the members who shared their stories with their local newspapers. There was very good coverage and it helped get the ‘We live with Parkinson’s’ message across.

Parkinson’s Tauranga President Ian Fletcher and Field Officer Joeline Morris made their TV debut. They were interviewed by Central News, the news programme for local TV Station tvCentral which broadcasts in Waikato and Bay of Plenty. You can watch the video on our You Tube channel. See page 4 for details.

NORTH ISLAND EVENTS
Central Plateau held an education seminar in Rotorua on 1 November, as a joint venture with QE Health. Entitled Living well with Parkinson’s, attendees heard from Neurologist Dr Barry Snow, Psychologist Dr Debra Fraser as well as the QE Health interdisciplinary team and local field officer Betty Gooding.

Challenging Symptoms was the title and topic for the seminar run by Parkinson’s Taranaki on 5th November in New Plymouth. The over 110 people attending heard from Geriatrician Dr Di Stokes on motor symptoms, Psycho-geriatrician Dr Candy Fox on non-motor symptoms and speech therapist Julia Redwood. It was a wonderful positive day.

Many divisions and National Office were also out fundraising with street appeals and collections in shopping malls. Parkinson’s Wellington was assisted by a wonderful turnout of volunteers. Volunteers are essential to the success of Awareness Week. A huge thank you to everyone around the country who volunteered their time to help, we couldn’t do it without you.

SOUTH ISLAND EVENTS
During the week South Canterbury Parkinson’s had a display in the hospital foyer and at the Timaru District Library. They also held a fashion parade with clothes from the Hospice shop featuring four members as model. The fashion parade was very well received.

MS and Parkinson’s Canterbury held their Annual Footloose Fun Walk at North Hagley Park, Christchurch on 3 November. The event was started by Christchurch Mayor Lianne Dalziel and they had over 100 people taking part.

Volunteer Award
In late October Parkinson’s Central Plateau were also very proud to receive a Regional Commendation in Health and Wellbeing Section at TrustPower Spirit of Rotorua Awards, “presented in recognition of an outstanding contribution to the Rotorua District Community.”
Tena Koutou Katoa

It was a privilege to be able to attend the 3rd World Parkinson Congress (WPC) in Montreal. I would like to thank the Lottery Minister’s Discretionary Fund, Sir David Levene and the Neurological Foundation for funding my travel. The congress is truly a global movement organised and attended by people from all over the world. I was honoured to be invited to sit on the Communication Committee for the congress and for the past two years have got up in the wee small hours of the morning every month for telephone conferences to do our part in making this meeting a success. One of the main roles of the Communications Committee was to promote the congress as widely as possible using both traditional methods and social media. We also launched and ran the ‘buddy scheme’ where people with Parkinson’s attending the congress from outside Canada were matched up with Canadians with Parkinson’s attending the congress.

I was pleased to see that nine of our members were able to attend the congress. Throughout this edition of The Parkinsonian you can read the impressions of the meeting of a few of these people. I am delighted that New Zealand was represented by Andrew Johnson’s poster abstract which was accepted and displayed. It was also a very proud moment for us New Zealanders when Andy McDowell’s film Smaller won the video completion.

I learnt a lot of new things from the congress. I was also extremely proud that the service provided by our field officers continues to be seen as ground breaking by the global Parkinson’s community. It was also good to know that the programme development we have planned is moving our service in the right direction.

I hope you enjoy reading this World Parkinson Congress edition of The Parkinsonian which highlights just a few of the presentations that were given at this meeting. Unfortunately Canada was too far for most of our members to travel, so we have worked hard to share the information from the congress. Some of you will have followed the Twitter and Facebook posts we put out during the congress. I hope you have also had the time to watch our interviews with speakers at the congress on our You Tube channel. For details on how to watch these videos see page 4.

With best wishes for a happy and safe holiday season from all of us at Parkinson’s New Zealand.

Nga mihi nui

Deirdre O’Sullivan

NEW ZEALAND IN THE SPOTLIGHT AT THE WPC 2013

Smaller, a short film by Andy McDowell

It was a very proud moment for New Zealand when Andy McDowell from Auckland won both the Grand Prize in the WPC2013 video competition and the People’s Choice Award. 113 videos were entered for these awards.

Smaller is a poem written by Andy to explain Parkinson’s to his two young daughters Lily and Pearl. With the help of friends Ross Kinnaird, David Craggs and the team at Franklin Rd Studio, Smaller was animated with Lily narrating the film.

Andy says “to win was really very special, but more because of the feedback and reception that we received at the congress itself. People were constantly shaking our hands or hugging us and telling us how it had helped them explain Parkinson’s to a family member/friend. That kind of stuff is life enhancing!”

There is a link to Smaller on our website parkinsons.org.nz

PARKINSON’S – IT’S ALL IN YOUR HEAD, A Poster Presentation By Andrew Johnson

Andrew Johnson, a member of our Auckland Branch, produced a poster which was displayed at the congress. The message of Parkinson’s – it’s all in your head is that because Parkinson’s affects everyone differently, by developing an awareness of the unique characteristics of your condition it can help you, your doctors and loved ones understand and track the progression of your condition. You can also use this new found awareness to take control of your future as best you can.
WHAT IS THE WORLD PARKINSON CONGRESS?
The 2013 World Parkinson Congress was the third meeting of its kind. The World Parkinson Congress' (WPC) mission is to provide an international forum for the latest scientific discoveries, medical practices and caregiver initiatives relating to Parkinson's. The congress brings together physicians, scientists, allied health professionals, caregivers and people with Parkinson's. The aim of this is to bring the Parkinson's community together to share their experiences. By doing this it is hoped that best treatment practices for Parkinson's will be shared and a cure for Parkinson's will be found more quickly.

HISTORY
In 2002 the head of the National Institute of Health in the United States of America asked leaders in the Parkinson's community why they didn't have a meeting for all members of the Parkinson's community. As a result of this, the US based Parkinson's Disease Foundation agreed to get the organisation up and running and Dr Stanley Fahn agreed to head the new organisation as President. You can watch a short video of Dr Fahn talking about the history of the WPC on our YouTube channel.

In 2004 the organisation gained not for profit status and nearly 60 volunteer committee members set about organising the 2006 World Parkinson Congress in Washington DC. 3,150 delegates attended this congress from 56 countries. In 2010 the World Parkinson Congress was held in Glasgow, Scotland. It was decided to hold the congress every three years and in 2013 the congress was held in Montreal, Canada. Parkinson's New Zealand played a part in organising this congress with Chief Executive Deirdre O'Sullivan sitting on the communications committee. The next congress will be held 20 – 23 September 2016 in Oregon, USA.

WHAT HAPPENS AT THE CONGRESS?
The congress is a huge mix of activities that take place over three days. Each day starts with 'Hot Topics' where the authors of four of the hottest topics from the abstract posters give a 15 minute presentation on their cutting edge work.

IS IT WORTH ATTENDING?
It really is. Please read the impressions of the congress from some of the 15 people from New Zealand who attended that feature throughout this edition of The Parkinsonian.

Watch more from the WPC!
Parkinson's New Zealand recorded short interviews with many of the presenters at the congress. To watch these go to our YouTube channel youtube.com/user/parkinsonsnewzealand.
Webcasts of some of the presentations from the congress are also available on their website worldpdcongress.org
WORLD PARKINSON CONGRESS

Hot Topics

There were hundreds of poster abstracts displayed at the congress, many of these describing new work in the treatment of Parkinson’s. In the Hot Topics session each day a few of these posters were selected and presentations were given by the authors on their cutting edge work. This session is considered to be a ‘sneak preview’ of work that may be published in the future.

NICOTINE AND NICOTINIC RECEPTOR DRUGS TO TREAT L-DOPA INDUCED DYSKINESIA

Maryka Quick, Centre for Health Sciences, SRI International, USA

Dr Maryka Quick presented the research she has been involved in for over 10 years which she said has found that L-dopa induced dyskinesias are improved by using nicotine or nicotinic receptor drugs. Nicotinic receptor drugs act selectively in the brain and have less side effects than nicotine.

Dr Quick’s told us that early research work carried out by her team showed that nicotine decreases dyskinesias in rats, mice and monkeys (so works across species) and that nicotinic receptor drugs decrease dyskinesias in rats.

The most recent study investigated the dosage that would be required to treat dyskinesia. Squirrel monkeys were given MPTP which causes them to become parkinsonian. The symptoms they display are very similar to that seen in humans with Parkinson’s—freezing, tremor, postural difficulties etc. They are treated with L-dopa and usually after a few weeks dyskinesia develops.

Two sets of monkeys were used in this study; both sets were treated with L-dopa. One set of monkeys was also treated with nicotine which is put in their drinking water. The dosage was similar to that amount a human smoker might take each day. After about two weeks the researchers reported that there was an average 30% improvement in dyskinesia and the maximum effect was seen after five weeks when there was an average 60% improvement. The control group showed no improvement in their dyskinesias. After 30 weeks the monkeys receiving nicotine treatment were still showing on average a 60% improvement.

It was also reported by Dr Quick that when the nicotine treatment was removed, it took six weeks for they dyskinesia to return to the same level as seen in the monkeys in the control group. However when these animals were again treated with nicotine, there was an almost immediate improvement in the dyskinesia, she said this was because the animals had been ‘primed’ to the effect of nicotine.

The next part of the study was to look at whether giving the nicotine before starting L-dopa treatment would result in a bigger reduction in dyskinesia. A different group of monkeys were used. The researchers reported that the average improvement was still only 60%; they concluded that there was no benefit from pre-treatment with nicotine.

There are nicotinic receptors in many parts of the body. For example in the heart nicotine can affect blood pressure and heart rate. However the receptors in the heart are different from the receptors in the brain. A nicotine agonist that only affects the type of receptors found in the brain was also trialled. This drug, ABT-894, has already been approved in the USA for clinical trials to treat pain and Attention Deficit Hyperactive Disorder (ADHD). The study showed that in doses well below those used in trials for pain and ADHD, ABT-894 produced a dramatic improvement in dyskinesia (approx. 60%) and was also shown to be long acting.

Dr Quick said a clinical trial to determine the correct dosage of nicotine or nicotine agonists to treat dyskinesia in humans is required.

MEMBER REPORT:

Dyllis Parker

I attended the last congress in Glasgow and got a lot out of it. Being newly arrived back in New Zealand (after living in Great Britain) I saw this congress as an opportunity to connect with people I know from Great Britain and Europe. I also wanted to find out where the research is at and be energised. If I thought I was going to find out about new and exciting research I’d have come away disappointed.

The World Parkinson congress is unique with a mix of clinicians, scientists, people with Parkinson’s and their support people. All of us have equal status and are equally important. I was excited by the building of a world wide Parkinson’s community. The congress allows this community to be more joined together and this movement will give us more of a united voice. It is really good that New Zealand is part of something global, we are often forgotten about by the bigger players in the Parkinson’s world but we are still important.

I was inspired by the young people with Parkinson’s, they had more of a presence than I’d been aware of before. These people have a lifetime with Parkinson’s ahead of them and I was in awe of their resilience.
HOT TOPICS – CONTINUED FROM PREVIOUS PAGE

MEMBER REPORT: Lloyd Jenkins

This was the second WPC I’ve attended. I found the Glasgow WPC bewildering as I had only been recently diagnosed. Back then I didn’t know a dopamine agonist from a Lewy Body! This time a group of five couples (we called ourselves ‘Parkin-fly’) planned for 18 months to attend. We met up in Montreal on the first night and kept in touch throughout the congress. We were all really proud when one of our group, Andy, won the video competition.

The congress brings people living with Parkinson’s into direct contact with clinicians and scientists. I was particularly interested in the World Parkinson’s Movement’s campaign “no research about me without me”. This group is working to steer the focus of research to the areas of greatest need and interest to the people who actually have Parkinson’s.

I gave Rock Steady Boxing, a non-contact boxing inspired fitness programme a try and loved it. I’d like to continue this training and have even bought boxing gloves so I can try it at home.

DOES A SPECIALIST PARKINSON’S UNIT IMPROVE OUTCOMES FOR HOSPITALISED PARKINSON’S PATIENTS?

Dr Rob Skelly, Derby Hospitals, UK

It is known that when people with Parkinson’s go into hospital they don’t always get their medications or they are not given on time. In one study it was found that 71% of people with Parkinson’s who were hospitalised in the UK missed doses of their medication.

Specialist units in hospitals have been shown to improve the care of stroke and cardiac patients, so Dr Skelly’s team consulted with medical staff, patients and carers to develop a Specialist Parkinson’s Unit. The core features of the unit were mandatory staff training, care led by a geriatrician with specialist training in Parkinson’s, an enhanced stock of Parkinson’s medications on the ward, and use of Parkinson’s clinical management guidelines.

An education training programme was devised, training videos were developed, and 60 staff (nurses, nurse aids, pharmacists, therapist and junior doctors) undertook the training programme.

The unit was set up in part of a 28 bed general ward. During the study the ward continued to act as a general ward as well as the Parkinson’s unit. Typically there were between two and six Parkinson’s patients on the ward at any one time. Only people with Parkinson’s who needed urgent admission into hospital, for example for pneumonia or urinary tract infections, were included in the study. It did not include people who needed admission to other specialist units (e.g. coronary care) or those who could not speak English. Where patients lacked the mental capacity to consent to being part of the trial, advice was sought from family members over their inclusion so that elderly or confused patients were not excluded from the study.

The study collected data from 20 people being cared for in the general ward and 24 patients cared for in the specialist Parkinson’s unit. The groups were well matched for age, gender, condition stage etc.

Patients and carers were asked to complete a patient satisfaction survey and care on the specialist Parkinson’s unit was rated significantly better than on the general ward. Dr Skelly reported that the average length of stay decreased from 13 days on the general ward to 9 days on the specialist ward.

An electronic drug prescription and administration system was used to collect accurately timed drug data. It was found that on the general ward 20% of medication was missed compared to 13% on the specialist ward. The specialist unit gave medications on time 64% of the time, this was only 50% of the time on the general unit.

Dr Skelly concluded that the level of care on a specialist unit was improved, most notably because of the shortened length of stay. He suggested that further studies on specialist care units should be undertaken and these should include an economic evaluation.

BALANCE DIFFERENCE IN PEOPLE WITH AND WITHOUT FREEZING OF GAIT IN PARKINSON’S.

Ryan Duncan, Washington University in St Louis, USA

Many people with Parkinson’s experience freezing of gait and those who experience this tend to have more falls. However, while it is recognised that the gaits of ‘freezers’ and ‘non-freezers’ differ, researchers have not used standardised clinical balance assessments to see if balance differs between these two groups.

Participants were selected for the study who had idiopathic (not genetically inherited) Parkinson’s and who were taking Parkinson’s medications. They underwent three tests: the Balance Evaluation System Test (BESTest), mini-BESTest, and Berg Balance Scale (BBS). People who reported experiencing freezing at least once a week were classified as ‘freezers’.

Mr Duncan presented the results of this project that showed that on average ‘freezers’ had worse motor symptom severity, longer condition duration, and higher freezing of gait questionnaire scores than ‘non-freezers’.

As a result of this study, Mr Duncan suggested that the BESTest and mini-BESTest were a more effective tool to be used by clinicians to evaluate balance in people with Parkinson’s and that the BBS may not be sensitive to balance differences between ‘freezers’ and ‘non freezers’ so should not be used.

Mr Duncan said that the significance of this study was that because ‘freezers’ may have deficits in postural responses and
stability in gait, any rehabilitation or physiotherapy should
include exercise to improve balance when treating people
with Parkinson’s who experience freezing.

MEMBER REPORT:
Nikki Matthews
My husband Roger encouraged me to
attend the congress but I probably wouldn’t
have gone if the others from Auckland hadn’t
been going. I enjoyed the congress and as a medical
professional found the idea of patients being present
at a medical conference interesting.

There were a number of presentations I found inspiring.
Bob Kuhn, the WPC Ambassador who visited New Zealand
to promote the congress spoke about his concept of ‘we’
not ‘I’. He said we are part of a bigger family and this
decreases the smallness of our world. Pam Quin, a dancer
from the USA who had worked out strategies to allow her
to continue her passion of dance. David de Bronkart who
explained the concept of participatory relationships and
explained that because we have a progressive condition
the best treatment or concept for improving our lives
today probably has greater value than the best treatment
if discovered in a year’s time. He said we need to live our
lives till they find a cure. And Rich Clifford, the astronaut
who is my new hero! NASA doctors backed him to go
into space after his diagnosis and trusted him to do a
six hour space walk. They assumed that just because he
had been diagnosed it didn’t mean his performance had
changed and they let him loose with millions of dollars
of equipment. Unlike the Army doctors who stopped him
flying just because he had been diagnosed and assumed
this would affect his performance.

I’ll be making minor changes to my life as a result of
attending the congress. I saw a really interesting poster on
dental problems in Parkinson’s which told me Levadopa
medications are very acidic and it is important to take them
with a large glass of water to protect your teeth. I’ll be
doing that from now on!

CONCURRENT ARM SWING-STEPPING TEST FOR DUAL TASK RELATED MOVEMENT INCOORDINATION AND HESITATION IN PARKINSON’S.
Dr Bin Hu, University of Calgary, Canada
The Concurrent Arm Swing-Stepping Test (CASS) came about
by accident during a study into AmbuloSono, a musical walking
program for people with Parkinson’s. This programme uses an
iPod to provide musical and auditory cues and stepping to train
and reward patients based on the size of each walking step.

Music will play if they are taking the right sized steps.
This improves their automatic gait control.

Dr Hu reported that during this test it was discovered that while
stepping improved, participants also reported that their arm swing
was improved substantially. His team needed to find a way to
clinically study the arm swing to develop a way to quantify
and standardise the way to trigger frozen arms and legs.

This will enable them to go on to test and develop new treatment
therapies.

The CASS test involves synchronised swinging of the arm
opposite the leg moving forward, called reciprocity. Coordination
scores were developed to measure the level of freezing or
inconsistencies in reciprocity. The researchers then compared
the Falls Efficacy Scale (FES) ratings of people to their CASS
test scores. Dr Hu said they found that those with higher FES
scores show greater hesitation or freezing. Most patients who
score in the normal range on the FES score also show only mild
incoordination or normal coordination. The study also found that
age, duration since diagnosis and variable coordination were not
related to hesitation and freezing problems.

Dr Hu said the next step in this study is to test a de-freezing
training programme that has been developed.

MEMBER REPORT:
Andy McDowell
I attended the WPC with my wife Kate as my
short film Smaller was shortlisted for the video
competition.

I also thought it would be a great opportunity to learn
more about Parkinson’s. I found the experience of the
congress humbling, terrifying and inspiring. I had the
opportunity to hear fantastic speakers and meet amazing
people – Bob Kuhn’s gave an excellent speech at the
opening ceremony; Sara Riggare from Sweden (check
out her blog www.riggare.se) is truly inspirational; and
the WPC’s organiser Eli Pollard who works tirelessly to
organise the congress and make it an amazing event.
On a social level, meeting up with new friends and having
it turn into a jam session led by Joe D’orso. Joe plays with
Bruce Springsteen’s band Jersey Shore and raises money
for Parkinson’s through the Light of Day concert series.

My key takeaway from the congress is that exercise is
the only thing that I can control. I’m back in the pool
swimming now, I’ve purchased Nordic walking poles
and I’m organising some resistance training.
MILD COGNITIVE IMPAIRMENT IN PARKINSON’S IS LINKED WITH EXTENSIVE CORTICAL THINNING, A LONGITUDINAL ANALYSIS

Dr Alexandru Hanganu, University of Montreal, Canada

Cognitive impairment is a problem in a subset of people with Parkinson’s but to date we haven’t known why this is. Dr Alexandru Hanganu presented on his group’s research into this. He told us that previous studies have shown that in the early phase of Parkinson’s up to 40% of patients have mild cognitive impairment. These people show a measurable cognitive decline but without any significant interference to their daily activities. It was also known that 62% of people with Parkinson’s who have mild cognitive impairment develop dementia, compared with 20% of people with Parkinson’s who don’t.

Dr Hanganu’s group wanted to find out if there are changes to any regions in the brain’s cortex that differentiate those with cognitive impairment from those who have no cognitive impairment. Their study involved taking scans of the brain and doing a neuropsychological evaluation of: 17 people with Parkinson’s who also had mild cognitive impairment; 15 people with Parkinson’s who didn’t have mild cognitive impairment; and 18 healthy control subjects. The MRI scans and neuropsychological evaluations were repeated again 20 months later to see what changes had occurred.

Results reported from this study show for the first time that mild cognitive impairment in Parkinson’s is linked with a faster rate of grey matter degeneration in a number of areas of the brain. Dr Hanganu also said the results showed that the more thinning shown in the brain, the higher the person scored on the Montreal Cognitive Assessment Scale (which tests for mild cognitive impairment). He said that as the middle occipital lobe and temporal lobe showed a more significant degree of thinning these areas might be considered as markers to predict cognitive decline in Parkinson’s patients.

The researchers also noted that in Parkinson’s, dopamine depletion starts in the dorsal striatum and progresses to the ventral striatum. So in early stage Parkinson’s the dorsal striatum is severely depleted of dopamine while the ventral striatum remains intact. Dr Hanganu said this study suggests that it is possible that in people with Parkinson’s and mild cognitive impairment the ventral striatum has a higher level of dopamine depletion which results in mild cognitive impairment. People with Parkinson’s who do not have mild cognitive impairment have less dopamine depletion in this area of their brain.

It was also noted that people with higher levels of mild cognitive impairment also have increased levels of anxiety, depression, fear so the researchers suggest that the ventral stratum region might also be associated with this.

MEMBER REPORT:
Jocelyn Grantham

Last year my husband Chris and I attended the Brisbane conference on Parkinson’s. One night we met up for dinner with two other couples and decided to keep meeting once a month when we got back to NZ as a way of supporting each other. We decided we would all try to attend the WPC in Montreal.

I enjoyed the congress. It was good to feel connected with a global group of people affected by Parkinson’s and be strengthened and inspired by others stories and experiences, albeit that it was mainly North American and European voices. I still think of some of the saying or quotes that were shared at the congress. One speaker shared her realisation that “time is limited so this encourages you to harness creative energy and to focus it. Your perspective changes and sharpens your understanding of what is important in life”. Michael J Fox was quoted as saying “We are not defined by our challenges, but by our actions”. Bob Kuhn encouraged us to work as a community and called us to consider that “illness starts with an ‘I’ but wellness starts with a ‘we’”. Another speaker told us “Every moment is a gift, my life is a song, sometimes in major, sometimes in minor but always beautiful.”

I was disappointed to hear that L-dopa was discovered as a treatment for Parkinson’s about 50 years ago and there has been no major advance on it. There was a strong plea to find something to stop the dyskinesias caused by the drugs so that quality of life for people with Parkinson’s can be enhanced.

A real highlight was when Andy McDowell won the Grand Award and the People’s Choice Award for his video Smaller. We New Zealanders wished we’d prepared a Haka or Waiata, but made do with cheering, clapping and a bit of screaming instead!

Save the Date
SEPTEMBER 20–23, 2016
Professor Lee's presentation outlined the theory that the progression of symptoms.

...get Parkinson's. In the same way smoking and caffeine... 

Behaviour considerations are mostly in terms of lifestyle. Recent analysis of data shows very small increased risk factors due to behaviour. But the levels of risk are so small that they can't alone account for Parkinson's. In the same way smoking and caffeine are considered to lower the risk, but plenty of smoking coffee drinkers get Parkinson's.
Parkinson’s should be classified into three phases: preclinical, where there are no clinical signs or symptoms but pathology assumed to be present; pre-motor, where there is the presence of early non-motor symptoms eg fatigue or pain; and motor Parkinson’s, where dopamine deficiency is sufficient to cause motor and non motor symptoms.

On average a person with Parkinson’s will have six to eight non-motor symptoms however these are often neglected in clinical practice. Dr Chaudhuri spoke of a study which found up to 68% of clinic consultations did not address non-motor symptoms. Undeclared symptoms included apathy 61%, incontinence 66%, and sexual difficulties 61%. It was found that these symptoms were often not addressed as patients were unaware that they were symptoms of Parkinson’s. The study also found that symptoms patients were too embarrassed to discuss include hallucinations, delusions, falls and constipation. Not addressing these things has implications on treatment and health related quality of life. Dr Chaudhuri said clinicians need to prompt their patients through screening or a questionnaire to find out the non-motor symptoms they have.

Professor David Burn from Newcastle University talked about how neuropsychiatric disorders often precede motor symptoms in Parkinson’s and also commonly accompany dementia. Neuropsychiatric features include depression and anxiety, apathy, psychosis (delusions and hallucinations), impulse control disorder and sleep disorders. They are frequently underdiagnosed.

Depression often co-exists with anxiety and apathy. It may predate onset of motor features and occurs in around 35% of people with Parkinson’s. Anxiety is very common and up to 40% of people with Parkinson’s experience it. In Parkinson’s this involves generalised anxiety disorder, panic attacks and social phobia. Apathy is also thought to affect 35% of people with Parkinson’s.

Psychosis (hallucinations) can be tactile (feeling of being touched) or auditory, but predominantly visual. Up to 60% of people with Parkinson’s will experience psychosis at some time. Once they start they tend to persist and progress. Prof Burn said psychosis can be a predictor of cognitive decline and often leads to nursing home placement.

Dementia in Parkinson’s has wide ranging impacts (increased mortality, carer strain etc). It is often not diagnosed. The incidence of Parkinson’s dementia increases with age and studies suggest men are more likely to get it than women. The manifestation of Parkinson’s dementia is varied but includes lack of executive function (being able to plan or multi task, or complete previously familiar tasks). Memory and visuospatial deficits are common but unlike Alzheimer’s, language problems are uncommon.

Dr Burn said there is very little treatment for mild cognitive impairment and dementia for people with Parkinson’s. He said ‘brain training’ can lead to an improvement, however much more study is needed to find out how much is the optimal amount of training and how long it lasts.

Dr Antonio Strafella from the University of Toronto gave an interesting but quite technical presentation on the contribution of functional neuroimaging to the understanding of non motor manifestations of Parkinson’s. He explained that functional neuroimaging can be used to identify the neural networks involved in non-motor complications. This can show an area of the brain as under or over functioning.

The final speaker of this plenary session was Dr Janis Miyasaki from the University of Toronto. Her presentation was about the impact of other medical conditions on the course of Parkinson’s and gave her recommendation on staying healthy. She spoke of a study that looked at the other conditions that increase the death rate in people with Parkinson’s. High blood pressure, diabetes, COPD and osteoarthritis were all contributing factors.

A lot of the complications of Parkinson’s result in additional medications and every time you add a medication you also add to the complexity of the condition. This makes it more difficult for the person to manage their medications and that combined with decreasing cognition increases the risk of medication errors.

To reduce the risk of cognitive decline Dr Miyasaki said you need to stay mentally active. Sitting in front of TV does not do this. Work in novelty, don’t just do the same activity over and over.

Dr Miyasaki recommended:

- Keeping blood pressure just right – not too high or low. Studies indicate low blood pressure results in people being confused and having more falls.
- Ensuring your cholesterol is at a healthy level so you are giving your blood vessels the best advantage.
- Exercising safely for your ability to the point where you break into a sweat, and doing it every day.
- Sleep apnoea appears to be more common in people with Parkinsons and that will further reduce cognition because you are just not as sharp as you should be, so wear your CPAP machine. It will make a difference.
- Keeping an eye on blood sugar as diabetes is a risk factor and if you are glucose intolerant you should treat it.

**DAY 3**

**New views on the treatment of Parkinson’s**

Dr Marten Munneke from the Parkinson Centre in Nijmegen, The Netherlands started the session with a presentation on lifestyle interventions. He described lifestyle interventions as diet, exercise, mindfulness, creativity, dance, avoiding stress, and avoiding falls.

He said that in the general population, physical inactivity is the fourth leading risk factor for global mortality after high blood pressure and tobacco use. It is equal to high blood sugar as a risk factor. For people with Parkinson’s there are reasons they may become inactive which includes physical impairments, mental impairments (apathy) and fear of falling.

There is a two-way interaction between the impairments caused by Parkinson’s and a sedentary lifestyle. Motor symptoms like gait alterations will get worse without exercise, but may also be the reason a person doesn’t want to exercise. There is a similar relationship with other motor symptoms like postural instability and falls, and non motor symptoms like depression, apathy,
cognitive decline, constipation, sleep problems and fatigue. All of these things may be improved by exercise.

Dr Munneke talked about a number of studies into exercise for people with Parkinson’s. This included a recent study comparing progressive resistance (strength) exercise aimed at arms, chest, back and legs against a control group who did balance, breathing exercises and non-progressive strengthening. The study lasted for 2 years and concluded that progressive exercise therapy demonstrated a clinically significant reduction in scores on the Unified Parkinson’s Disease Rating Scale. The study concluded that this exercise was a useful adjunct therapy to improve Parkinson’s motor signs. However further research is required to find out what exercise is best, at what frequency.

Dave deBronkart is from the Society of Participatory Medicine and spoke about empowered patients and how they can help improve healthcare. He described patient empowerment as an approach that treats patients as co-producers with authority and control over decisions. ‘E-patients’ are equipped, engaged, empowered and enabled. He said that because of the web patients can connect to information and each other.

He spoke of the problems with scientists controlling research. He said scientists want certainty, they want to understand every last little detail and why something happens. Whereas for a patient with a progressive condition a treatment today may be worth more than a better treatment next year, as their condition will have also progressed.

The value of a treatment is the efficacy of it at that time, and it is assumed efficacy will improve as the treatment is developed and tested. He said patients want more say in when a treatment is available to them.

Dr Nir Giladi from Tel-Aviv University spoke about the roles for healthcare professionals in the multidisciplinary care of Parkinson’s. He gave examples from his work within a multidisciplinary team.

Dr Giladi said the multi-professional approach was an important advance to improve the care of families with Parkinson’s. As a chronic progressive condition with no cure so many different aspects of Parkinson’s have to be dealt with. This includes both motor and non motor symptoms. These problems are so varied that even the best doctor can’t be expected to be able to treat them all at that same time and this is why a multi-disciplinary team is important.

In the early stages symptomatic treatment can be very good, however as Parkinson’s advances the symptomatic treatment becomes less effective and palliative care is introduced to improve the quality of life. It is only in recent times that palliative care and end of life experiences has started being discussed for people with Parkinson’s. This is an area that needs further research.

Throughout these stages care needs to be given as a group by a multi disciplinary team. He listed people who might be in the team: neurologist, Parkinson’s nurse, physiotherapist, OT, speech-language therapist, psychologist, psychiatrist, social worker, dietician, rehabilitation specialist, sexologist, sleep specialist, geriatrician.
A big issue for people with Parkinson’s is hope. When it disappears, people may decline visibly and quickly. Through the entire conference we were encouraged not to give up hope, but to remain inspired. I couldn’t help but notice how many young people with Parkinson’s attended the congress, wanting to learn as much as they could from some of the world experts. I was in awe of those who were courageously living with this condition. Some were still searching for hope, and others were reveling in it. Tim Hague, winner of the 2013 Amazing Race Canada, said he likened his race experience to his Parkinson’s. His message was that “many thousands of people are putting their time and energy into trying to find a cure and making life better for people with Parkinson’s. A massive number of people are behind us, so don’t give up.”

A lot of people attended the congress with their service dogs. These ranged from the small – a Boston Terrier and a Yorkshire Terrier, through to a Great Dane. The dogs are trained in three key areas: to stabilize balance and help people walk at a normal rate instead of shuffling; to cue their owner to break a ‘freeze’; and to assist following a fall either by bracing so the person can get up again or by fetching help in the form of another person or a telephone.

I got some real gems of information from the congress that I have brought back and will use to help the people I work with.

- Prof Bastiaan Bloem, Neurologist from Radboud University in the Netherlands talked about the complexity of Parkinson’s. He said motor symptoms are just the tip of the iceberg and that non-motor symptoms are the ones that tend to affect quality of life. He also said that someone who is 35 has very different needs and wishes when it comes to their care than someone who is 85 and that health professionals need to tailor their care to suit what the patient wants.

- Joseph Freidman from Brown University, USA, said fatigue is often an early symptom of Parkinson’s. The feeling of lack of energy is not helped by having a nap, but is actually helped by doing exercise. He also recommended good sleep hygiene such as having a regular bed time, no alcohol after dinner, reducing day time naps, Cognitive Behaviour Therapy and alternative therapies to help fatigue.

- Gila Bronner is a certified sexual therapist at Sheba Medical Centre in Israel. She said 49% of people will not discuss their sexual problems with their doctors and discussed ways to make the impossible possible. She suggested having sex to music. The music can be a helpful cueing tool. She also suggested trying different things and not to give up on intimacy. Her take-home message was to focus on what is possible, try different things, and make sure you let your health professional know if you are having problems.

- Dr Blair Ford from Columbia University, USA spoke about pain being an often over looked and under treated symptom of Parkinson’s. He said in treating pain first it needs to be decided if the pain is Parkinson’s related and if it is, is this because of the timing of medications or is there a relationship to dystonia. He said there are many different ways to manage pain: have a good night’s sleep; remain active and engaged; cognitive behaviour therapy; physiotherapy; and suitable analgesics.

I left Montreal with a new depth of information and great appreciation for all the wonderful people I was fortunate to come in contact with. I personally look forward to taking some ideas from the WPC and developing them further. I’d like to thank the committee of Parkinson’s Otago Division for allowing me the opportunity to attend the congress.

A full version of Paula’s congress report is available on our website parkinsons.org.nz