Parkinson’s Awareness Week 1-7 November 2016

A heartfelt thank you to all of the volunteers who helped us raise awareness and funds to make a difference to life with Parkinson’s—from cups of tea to seminars—thank you to everyone who participated.

This Parkinson’s Awareness Week reinforced Parkinson’s New Zealand’s ongoing goal: Connecting people. Changing lives.

One of the key highlights of Parkinson’s Awareness Week was our partnership with Val Morgan Cinema Network, who gave us over $140,000 of donated screen time on over 360 cinema screens for our award winning campaign commercial.

Parkinson Canada liked it so much they have adapted it for their awareness week. They were delighted when it was so well received that the Toronto International Film Festival played it before films and on the side of mobile ad trucks.

Thank you to all of the volunteers who helped with our street collections and events during Parkinson’s Awareness Week. We are really thankful to the members who shared their stories with their local newspapers as well. It helped get the “Connecting People, Changing Lives” message across.

Volunteers are vital for all our branches and divisions throughout the year. Whether it is stuffing envelopes, giving someone a ride or holding a collection bucket, a little bit of your time can make a big difference. If you or members of your family can help please contact your local branch or division. A full list of our divisions and branches and their contact details are available at www.parkinsons.org.nz.

ANNETTE KING MP AND SHAE ARACI COLLECTING AT WELLINGTON INTERNATIONAL AIRPORT.

CHRIS BISHOP MP COLLECTING AT NEW WORLD LOWER HUTT

DAVID SEYMOUR MP AND STEPHEN GOODMAN COLLECTING IN NEWMARKET AUCKLAND
PARKINSON'S AWARENESS WEEK

Awareness Week around the Country

Around the country people ran information stands, street appeals and seminars to help raise awareness of living with Parkinson's and the work of Parkinson's New Zealand. Here is just a selection of what our volunteers and members have been up to.

NORTHLAND

About 200 people attended the presentation hosted by Parkinson's Northland at Barge Park. Professor Richard Faull, director of the University of Auckland Centre for Brain Research (CBR) and director of the Neurological Foundation Human Brain Bank, was one of the presentation speakers.

“Our ability to attract to Northland such a prestigious group of researchers is also all about the power of connections,” says Peter Garelja, from Parkinson's Northland.

WAIKATO

Neurologist Dr Matthew Phillips talked to a large audience at a public seminar hosted by Parkinson’s Waikato. In addition Waikato team members took on the challenge of running Round the Bridges to raise funds and awareness. The 6km Round the Bridges course takes in the river walks and bridges of Hamilton. Peter Huron and his friends and family have raised over $3,500.

BAY OF PLENTY

Bay of Plenty had a display at Tauranga Hospital along with a raffle and interactive display during the main visiting and appointment hours.

CENTRAL PLATEAU

Central Plateau hosted a Positively Parkinson’s Well-being seminar with senior Speech Language Therapist Robin Matthews, author of Positively Parkinson’s Ann Andrews and author of NZ bestselling non-fiction novel What Abi Taught Us Dr Lucy Hone. Central Plateau team members, The Parkinson’s Pacers, participated in the Ekiden Relay raising funds and awareness.

WAIRARAPA

Wairarapa hosted a popular “Living with Parkinson's” seminar at the Masterton Club. More than 80 people from the Wairarapa and nearby regions attended to hear presentations on medication, mental and physical well-being and safety in the home.

MARLBOROUGH

Marlborough and Brain Research New Zealand held a community forum with neurophysiologist Dr Louise Parr-Brownlie who spoke about optogenetics and Parkinson’s. For more information about optogenetics see the December 2014 issue of The Parkinsonian.

OTAGO

Otago hosted a seminar attended by almost 50 people. Speakers gave presentations on medications, sleep and well-being. Otago also partnered with Rotary Clubs in Dunedin, Alexandra and Cromwell for their street appeals.

Many divisions and branches and National Office were also out fundraising with street appeals, raffles and collections in shopping malls. A huge thank you to everyone around the country who volunteered their time to help.

VOLUNTEER AWARDS

Rod Sutherland, long-serving volunteer and Parkinson’s Wairarapa committee member, has been named Wairarapa Older Person of the Year for 2016. Here Rod is (pictured in centre) with Masterton Mayor Lyn Patterson (left) and his wife Ruth Sutherland (right) at the Ageing With Attitude Expo in Masterton, where the award was announced.

Parkinson’s Hawkes Bay Community Educator Karen Trewick won a Kiwibank Local Hero Award. This award “recognises the enormous contribution, sacrifice and commitment of Kiwis who selflessly work to make their communities a better place”.
It was a privilege to be able to attend the 4th World Parkinson Congress (WPC) in Portland, Oregon. I would like to thank the Lottery Minister’s Discretionary Fund and The David Levene Foundation for helping to fund my travel. I was honoured to be asked to present to leaders of worldwide Parkinson’s organisations about our Parkinson’s Community Educator Service. I was also pleased to present Parkinson’s New Zealand’s poster abstract on Health Literacy and Parkinson’s which was accepted and displayed. My thanks to National Office staff members Julianne Ryan and Claire Sonntag for co-authoring the poster abstract. It is gratifying to know that the service provided by our Parkinson’s Community Educators continues to been seen as innovative by the global Parkinson’s community.

I was happy to see that some of our members were able to attend the Congress. In this edition of The Parkinsonian you can read impressions of the Congress by some of these people. I was also delighted that New Zealand was represented by World Parkinson Congress Ambassador Dilys Parker. Glen Prestidge from Taranaki had an interview on Radio Parkies. Aucklander Lloyd Jenkins presented a poster abstract that was also accepted and displayed. We were thrilled that Aucklander Andy McDowell’s presentations on living with Parkinson’s and the experience of Deep Brain Stimulation (DBS) were among some of the highlights of the Congress.

I hope you enjoy reading the WPC reports in this issue. Unfortunately Portland was too far for most of our members to travel, so we will work hard to share the information from the Congress. Some of you will have followed the Facebook and Twitter posts during the Congress. I hope you will also watch our interviews with speakers at the Congress on our YouTube channel.

As you can see from the Parkinson’s Awareness Week stories things have been busy here in New Zealand. Thank you to all of the volunteers and staff who have worked so hard to raise awareness and funds. Our partners at Val Morgan deserve a special mention. We are so grateful for the opportunity they have given us.

Many readers will have already heard from their local division about the Parkinson’s Pathway Project that is currently underway. At the AGM in 2016 the Society agreed that we needed to look at our current structure. A large number of recent and upcoming legislative changes and a number of challenges to service provision across the country mean we need to strengthen our organisation. The Parkinson’s Pathway Project is a collaborative process which asks, “How might we structure Parkinson’s NZ to achieve the best possible support for all people living with Parkinson’s?” There is no easy or immediate answer, which is why an options paper has been produced by a working party. These are being presented at meetings around the country. If you haven’t been informed about one in your area yet please contact your local division or National Office.

With best wishes for a Happy Christmas and New Year from the team at Parkinson’s New Zealand.

Nga mihi o te Kirihimete

Deirdre O’Sullivan

NEW ZEALAND IN THE SPOTLIGHT AT THE WPC 2016

PARKINSON’S HEALTH LITERACY
Parkinson’s New Zealand Chief Executive Deirdre O’Sullivan presented a poster at the Congress on building health literacy. Our research showed that our publications such as The Parkinsonian are important resources. However we concluded that health literacy needs to extend beyond our written materials. Health literacy also involves changing the health care environment and how information is shared. Our goal is to help build health literacy knowledge and skills to reduce the demands that are placed on people with Parkinson’s, their families and carers.

A PICTURE IS WORTH A THOUSAND WORDS, A POSTER PRESENTATION BY LLOYD JENKINS
Lloyd Jenkins, committee member of our Auckland branch, produced a poster which was popular at the Congress. He used his own experiences to monitor and record “on” and “off” periods relating to the timing of his medication. The message of “A picture is worth a thousand words” helps develop awareness that Parkinson’s affects everyone differently.

WPC AMBASSADOR DILYS PARKER AND ANDY MCDOWELL
It was a proud moment for New Zealand when WPC Ambassador Dilys Parker and Andy McDowell from Auckland took the stage for their presentations. Dilys spoke beautifully about the power of communication, and Andy gave an excellent speech about living with Parkinson’s. Andy’s speech can be viewed on the Parkinson’s New Zealand Facebook page.
Research review: What's on the horizon?

There were a number of developments in Parkinson's research discussed at the World Parkinson Congress, many of these describing research breakthroughs as well as new work in the treatment of Parkinson's.

A number of developments in Parkinson's research were highlighted at September’s World Parkinson Congress (WPC) in Portland, Oregon (United States).

Dr Martin Ingelsson from Uppsala University, Sweden’s lecture on the potential in immunotherapy was greeted with great interest. Dr Ingelsson focussed on how immunotherapy targeting the protein alpha-synuclein has evolved as a potential therapeutic strategy for Parkinson’s. Two approaches are being explored. Active immunisation, in which the body is prompted to produce an antibody against alpha-synuclein, and passive immunisation, in which an antibody is introduced directly. A number of studies on cellular and animal models have produced promising results.

The clinical development of immunotherapies is a field in constant evolution. For example, researchers at Johns Hopkins School of Medicine in Baltimore (United States) have announced that they have discovered a way to block the spread of alpha-synuclein between neurons, which is believed to be at the core of the progression of neurodegeneration seen in people with Parkinson’s. The researchers say their study in mice and cultured cells suggests that an immunotherapy already in clinical trials as a cancer therapy should also be tested as a way to slow the progress of Parkinson’s.

The study was published in September 2016 in the journal Science. It emphasised that if the trials prove the drug is safe, the path to testing it in people with Parkinson’s may be relatively short.

One of the study’s leaders, Dr Ted Dawson, said the new findings hinge on how alpha-synuclein aggregates leave one cell and enter another. The researchers believe that finding could be key to stopping the propagation of alpha-synuclein clumping.

A few years ago, Dawson says, a researcher at a German University published evidence for a novel theory that Parkinson’s disease progresses as faulty alpha-synuclein aggregates spread from brain cell to brain cell, inducing previously normal alpha-synuclein protein to aggregate.

The spread of misfolded protein aggregates reminded researchers of how prions could cause previously normal proteins to “turn bad.” Studies have shown that the aggregates spread from the lower regions of the brain—holding dopamine neurons that control movement—to the outer regions that control cognitive functions such as memory. The neurodegeneration of neurons follows in the wake of alpha-synuclein clumping.

The study team knew they were looking for a certain kind of protein called a transmembrane receptor, which is found on the outside of a cell and works like a lock in a door, admitting only proteins with the right “key.” They first found a type of cells alpha-synuclein aggregates could not enter—a line of human brain cancer cells grown in the laboratory. The next step was to add genes for transmembrane receptors one by one to the cells and see whether any of them allowed the aggregates in. Three of the proteins did, and one, LAG3, had a heavy preference for latching on to alpha-synuclein aggregates over non-clumped alpha-synuclein.

The team next bred mice that lacked the gene for LAG3 and injected them with alpha-synuclein aggregates. “Typical mice develop Parkinson’s-like symptoms soon after they’re injected, and within six months, half of their dopamine-making neurons die,” Dawson says. “But mice without LAG3 were almost completely protected from these effects.” Antibodies that blocked LAG3 had similar protective effects in cultured neurons, the researchers found.

“We were excited to find not only how alpha-synuclein aggregates spread through the brain, but also that their progress could be blocked by existing antibodies,” says Dr Xiaobo Mao, Ph.D., a research associate in Dawson’s laboratory.

Dawson notes that antibodies blocking LAG3 are already in clinical trials as cancer immunotherapy. Dawson said that he has initiated discussions with potential sponsors about testing such antibodies in people with Parkinson’s. He envisions such a treatment could benefit people ranging from pre-symptomatic up to mid-stage Parkinson’s.

The possible use of the immunotherapy antibodies targeting LAG3 for Parkinson’s as well as cancer, points towards a repurposing of therapeutic drugs. Drug repurposing can accelerate a therapeutic through the development pipeline. A drug that has already been approved for one indication may have beneficial effects for those with another condition. Researchers are evaluating drugs for their impact on Parkinson’s.

One of the three recipients of the World Parkinson Congress Award for Distinguished Contribution to the Parkinson Community, Tom Isaacs from the UK, is the founder of an organisation that has such repurposing at the centre of its agenda.

The award was created to honour those whose efforts embody the goals of the WPC: to inspire more community building and expand collaboration on basic and clinical research, medical practices, care partner initiatives, and advocacy that impacts the Parkinson community.

Diagnosed with Parkinson’s at 26 years old, Tom has dedicated much of his life since to searching for a cure or better treatments for Parkinson’s. He is the founder of the Cure Parkinson’s Trust (CPT), a London-based charity.
In 2012 the Trust (CPT) set up an international panel of experts called the Linked Clinical Trial Committee, to “prioritise the most promising existing drugs and treatments that may be potentially suitable for repurposing in Parkinson’s with the specific aim of changing the course of the disease.”

One of the great advantages with repurposing drugs is that if a drug is already available and well characterised, it can progress more quickly through the lengthy drug development, testing and approval processes.

A news item on the CPT website noted how a diabetes drug was being considered as a potential Parkinson’s therapy under the Linked Clinical Trials initiative, a programme spearheaded by the CPT in collaboration with a research institute in Michigan. In recent years Parkinson’s researchers have investigated diabetes drugs because of their action on pathways also believed to be involved in Parkinson’s. It is hoped that findings from clinical trials testing the efficacy and safety of diabetes drugs to treat Parkinson’s will lead to further Parkinson’s research.

Dr Peter LeWitt from Henry Ford Hospital, Detroit, Michigan (United States) presented at the World Parkinson Congress on novel approaches to delivering levodopa to people with Parkinson’s. Dr LeWitt’s presentation reflected and built on the work he covered in a scientific update in late 2015 on the WPC website which was about new Parkinson’s treatments in the pipeline.

In that update Dr LeWitt said that old therapies are being rediscovered and repurposed. New concepts that have arisen about the circuitry of the brain go way beyond the simple notion that Parkinson’s is a deficiency of dopamine in the brain. Clearly it is, but there is a lot more to it, Dr LeWitt said.

Dr LeWitt referred to proteins that are integral to the healthy functioning of brain cells, a growing focus on the function of energy reserves of cells and the ability to transmit information more effectively between cells using chemicals other than dopamine as “all part of the revolution of the last decade.”

Dr LeWitt spoke of “repositioning pharmacology.” He stressed that 50 years of neuroscience has shown the importance of levodopa as a vital dopamine precursor. Levodopa has positively changed the lives of so many people with Parkinson’s. Many Parkinson’s symptoms improved within minutes of taking levodopa.

Scientists have been seeking ways of delivering levodopa in a continuous stable manner to enable people with Parkinson’s to stay “on” more of the time. The dopaminergic agonist Ropinirole is just one of the two dozen drugs that have been used over the past 25 years with levodopa or as a substitute to provide longer action and target parts of the brain more specifically.

But more work is required. Agonists are under development that are less likely to cause hallucinations or impulse disorders and can be used with other drugs. There is a push to reduce troublesome dyskinesias. Dr LeWitt praised some of the cutting edge products such as Duodopa, a carbidopa-levodopa gel that can be continuously delivered directly into the small intestine through a permanent tube with a portable pump. Duodopa was approved by MedSafe in New Zealand in 2015.

Dr LeWitt listed the unmet needs of current anti-Parkinsonian medications as: the inability to treat all the symptoms of the disorder (though often quite effective for motor impairments); adverse actions; cost-effectiveness; and inconstancy of effect (levodopa formulations are short-acting and irregularly taken up). He noted that problems with advancing Parkinson’s may be related to the chronic use of levodopa therapy (motor fluctuations, dyskinesia).

As well as novel mechanisms of action he spoke of improved levodopa formulations. Pro-drugs have been an area of interest for Dr LeWitt for some time. These are drugs that turn into levodopa once consumed and are better absorbed than orally induced levodopa. Additionally drugs that work on the whole gastro-intestinal tract, and not just part of it, show promise.

Gastric retention drug formulations are another important area (with a pill that goes into the stomach and slowly releases over 8-10 hours, in contrast to the existing rapid transit through the stomach. Many people experience it as a 15- or 30-minute “ride” and then symptoms return abruptly). Subcutaneous infusion of levodopa using apomorphine and even rapidly acting inhalable rescue therapies were also mentioned.
Dual tasking’s benefits gaining attention

Dual task training is a subject that is gaining increasing attention and was featured at the World Parkinson Congress (WPC) in September in Portland, Oregon (United States).

People with Parkinson’s are often especially challenged when it comes to doing more than one thing at a time. Dual task training is doing two things at the same time intentionally to get better at it (for example walking and reciting the alphabet at the same time, or standing on an unusual surface and throwing and catching a ball).

Dual task training for Parkinson’s can help with both motor symptoms and non-motor symptoms of Parkinson’s, improving cognition and reducing falls.

Doing two things at the same time is difficult for the Parkinson’s brain because of the severe lack of dopamine that is required for both movement and cognition processing. In the Parkinson’s brain there’s simply not enough dopamine to go around. Typically, the result is motor failure. A classic scenario: you’re walking and the phone rings. You’re so busy listening to the phone and thinking about who may be calling that you don’t think about placing your right foot on the ground the correct way and you fall over. Due to the lack of dopamine your brain does not provide enough to the parts of your brain that control movement while thinking at the same time and it is often your movements that stop or become smaller. The neuroplasticity of your brain means that over time your brain will continue to adapt to only send dopamine to one area which will result in more of your movements stopping or freezing. If you do not train your brain to dual task it will develop negative habits and as your Parkinson’s progresses you get worse and worse, which is brain plasticity in the negative sense (your brain changes to entrench a bad habit).

The Parkinsonian spoke with Auckland based neurological physiotherapist Gillian Davy about the opportunities for dual task training in New Zealand. Information about neurological physiotherapy and the principles of exercise for Parkinson’s is available from Gilly’s website [www.connectneurophysiotherapy.com](http://www.connectneurophysiotherapy.com).

Going back a few years, Gilly says, people with Parkinson’s were warned against dual tasking because they clearly were not good at it and it was seen as risky. However, not to tackle dual tasking is unrealistic as we all do it all of the time and avoiding dual tasking is now regarded as old school thinking and it comes highly recommended. Dual task training has been strongly advocated vis-a-vis Parkinson’s for the past six or seven years, especially the last four or five, Gilly says.

Although it isn’t so well known, there are a couple of hundred neurological physiotherapists who specialise in this area in the country and Gilly says that after an initial consultation, people can be provided with dual training routines to do at home.

You may be doing a movement class such as tango or boxing, which Gilly says is definitely worthwhile — after all tai chi, boxing, dancing and other such classes involve dual tasking, and they have a positive social component. But it’s still recommended you have a one-to-one every six months with a neurological physio to assess and progress your program as Parkinson’s is extremely individual and you need to ensure your program is going to get you the best results. The advances in rehabilitative neuroplasticity and neuroprotection in the past five years or so have been massive and it’s important people are regularly reviewed for these skills.

Gilly herself says she treated over 400 people with Parkinson’s, often using dual task training, with impressive results.

Some neurological physios are available through hospitals and interested people can find a neurological physio through the Physiotherapy New Zealand website at [www.physiotherapynz.org.nz](http://www.physiotherapynz.org.nz) under “find a physio” (select neurology/stroke under area of practice).

For people for whom it may be hard to attend a face to face consultation with a specialist, video conference is another option.

You can speak with your Parkinson’s Community Educator about whether there is a neurological physio in your area specialising in the latest evidence based treatment of Parkinson’s.
WHY OHSUMI’S NOBEL PRIZE IS IMPORTANT

The 2016 Nobel Prize in Physiology or Medicine has been awarded to Japanese biologist, Yoshinori Ohsumi, for his work on how cells dispose of and recycle their waste—a process known to be linked to Parkinson’s.

Waste disposal and recycling in cells happens through a process called autophagy. Thanks to Ohsumi’s work, we now know that there are different types of autophagy in our cells.

Our brain cells work like a complex manufacturing unit. They use energy to build new cell parts and recycle old or damaged components.

Researchers have found that a number of steps in this manufacturing line are affected by Parkinson’s—with waste recycling and disposal amongst the functions that go wrong.

One of the reasons researchers are particularly interested in autophagy in Parkinson’s is because of a protein called alpha-synuclein.

In Parkinson’s this protein builds up and forms sticky clumps in brain cells, eventually leading to their death.

However, if scientists could boost autophagy they may be able to stop the build-up of this protein and prevent the cells being lost, which would stop symptoms progressing.

Source: parkinsons.org.uk | forbes.com

NEW DRUG OPICAPONE LAUNCHES IN UK

A new drug treatment for opicapone has been launched in the UK by international pharmaceutical company Bial.

Opicapone was approved by the European Commission in July 2016.

A recent study showed that taking opicapone alongside levodopa is helpful for people who experience ‘wearing off’ — when their Parkinson’s medication stops working before the next dose is due and symptoms become unmanageable.

Opicapone is a type of drug called a COMT inhibitor and similar to others already in use.

COMT inhibitors reduce Parkinson’s symptoms by blocking an enzyme that breaks down levodopa, prolonging its effect.

However unlike other COMT inhibitors, opicapone only needs to be taken once a day and so could reduce the overall number of tablets required.

It is also smaller than other COMT inhibitors which may be beneficial for people with Parkinson’s with swallowing problems.

Source: parkinsons.org.uk | bial.com

STUDY FINDS CAFFEINE COMPOUNDS TO TACKLE PARKINSON’S

New research published in the journal ACS Chemical Neuroscience has identified caffeine-like compounds that may tackle the underlying causes of Parkinson’s.

The researchers in Canada set out to make compounds that could protect the dopamine-producing cells that are lost in Parkinson’s. They produced compounds based on molecules that have potential effects in Parkinson’s—such as nicotine and caffeine.

Using a yeast model of Parkinson’s, they found that two of their caffeine based molecules were able to target the alpha-synuclein protein.

Alpha-synuclein is a protein that occurs naturally in our brain cells. In Parkinson’s, alpha-synuclein becomes misfolded and forms sticky clumps that cause problems inside nerve cells, eventually leading to their death.

In this study, the researchers found that their caffeine-like compounds could stop these clumps, called Lewy bodies from forming.

The role of caffeine in Parkinson’s has been the subject of many studies, with research showing there are potential protective effects from caffeine on Parkinson’s symptoms.

Another recent clinical study published in the journal Parkinsonism and Related Disorders links higher caffeine consumption to slower development of Parkinson’s symptoms after diagnosis.

Researchers studied the progression of Parkinson’s symptoms over 4 years in 79 people who had been newly diagnosed with the condition.

They found that higher caffeine consumption, from drinks like tea and coffee, was linked to the development of fewer motor and non-motor symptoms, and lower symptom severity.

The study also found that people who drank more caffeine started Parkinson’s medication, such as levodopa, later compared to those with lower caffeine consumption.

More evidence from larger clinical trials is needed before it can be recommended that people with Parkinson’s should increase their consumption of caffeine. People should talk to their GP or Parkinson’s Community Educator before making any significant changes to their caffeine intake.

Source: parkinsons.org.uk | medicalnewstoday.com

NTCELL CLINICAL TRIAL UPDATE

New Zealand biotechnology company Living Cell Technologies Limited (LCT) recently announced that it has completed the first stage of a clinical trial underway in Auckland of its planned treatment for Parkinson’s.

LCT reported that it has completed treatment of all six participants in group one of its Phase 2b clinical trial, with four participants having NTCELL capsules implanted into their brain.

To date there are no safety issues with any of the participants.

The research led by Auckland based neurologist Dr Barry Snow involves surgically placing tiny capsules containing cells from Auckland Island pigs into the brains of people with well-established Parkinson’s who were no longer responding to traditional therapy.

Dr Snow recently presented data from the Phase 1/2a clinical trial to prospective participants and their partners and supporters at meetings organised by Parkinson’s New Zealand. A video of Dr Snow’s presentation can be viewed on the Parkinson’s New Zealand YouTube channel.

For more information about the NTCELL trial see the March 2016 issue of The Parkinsonian.

Source: lctglobal.com
BOOKS WERE IN THE SPOTLIGHT AT THE WPC. The WPC Book Nook was new to the WPC. The Book Nook was a space where people could have a look at recently published books about Parkinson’s. It gave people a chance to connect with authors and publications. Here are just a few of the books that caught the eye of The Parkinsonian.

10 BREAKTHROUGH THERAPIES FOR PARKINSON’S
Internationally respected neurologist and researcher Dr Michael Okun’s many books are filled with up-to-date and practical information. In Parkinson’s Treatment: 10 Steps to a Happier Life, Dr Okun unmasked the important secrets for a happier life for people living with Parkinson’s. In his latest book, 10 Breakthrough Therapies for Parkinson’s, Dr Okun discusses recent breakthroughs in Parkinson’s research and therapies. He reviews the knowledge gained and describes the latest research in medications, vaccines, devices, genetics, care and behaviour. Dr Okun is known for inspiring people with Parkinson’s and their families and carers, as well as health care professionals and researchers. He makes science easy to understand in this book about delivering new and better Parkinson’s treatments—and one day a cure.

PARKINSON’S DIVA
Parkinson’s Diva: A Woman’s Guide to Parkinson’s is a description of a doctor’s experience with Parkinson’s in many realms of her life—from doctor, caregiver, and as a young person with Parkinson’s herself. Dr Maria De Leon covers the important basics of Parkinson’s and also shares personal and gender-specific concerns that young women with Parkinson’s face. This book is about embracing your own style in your journey with Parkinson’s.

BOTH SIDES NOW
Dr Alice Lazzarini, an internationally recognized researcher in neurogenetic disorders, shares her personal and professional journey. A member of the team that discovered the first Parkinson-causing gene mutation in the synuclein protein, Dr Lazzarini realized that she was developing symptoms of the very condition that she had researched. In Both Sides Now: A Journey From Researcher to Patient, Dr Lazzarini describes facing Parkinson’s. She also tells the story of learning that the gene she helped discover is responsible for song learning in the male zebra finch.

HOW ARE WE GOING TO TELL THE CHILDREN?
Children’s books were a hot topic at the WPC. Adele Hensley, a book author and person with Parkinson’s diagnosed at the age of 38, spoke about the annotated bibliography of the children’s literature about Parkinson’s in her non-scientific Hot Topics talk “How are we going to tell the children? An overview and review of the children’s literature about Parkinsons.”

Although Parkinson’s is a condition that strikes adults, and most often older people, people with Parkinson’s often have children or grandchildren, with whom conversations about the condition may be difficult to initiate. Each book in the bibliography can be used as a starting point for a conversation, and books range from fact-based to fictional. Their topics also range from more general, such as “what is Parkinson’s” to very specific. Hensley included notes on recommended ages or reading levels. For more information about the annotated bibliography visit wpc2016.org.

CHILDREN’S BOOKS
- Grandma’s Brain by Ann Andrews
- Shaky Hands: A Kid’s Guide to Parkinson’s by Dr Sonia Mathur
- My Grandpa’s Shaky Hands by Dr Sonia Mathur
- Does It Hurt, Granny? by Dawn May
- I’ll Do It, Granny by Dawn May
- Carson and His Shaky Paws Grampa by Kirk Hall
- Monica, Mama and the Ocotillo’s Leaves by Adele Hensley
- Face It: Making Peace with Fear by Adele Hensley

For more books from the WPC Book Nook visit wpc2016.org. A number of excellent books for people with Parkinson’s and carers are available from Parkinson’s New Zealand’s Library. Visit www.parkinsons.org.nz for a full list or ask your Parkinson’s Community Educator.
Dilys has been a WPC Ambassador for the past three years. Her presentation and facilitation skills are excellent.

The World Parkinson Congress (WPC) is a tremor free zone, that is you are free to tremor without people thinking it odd. It is also a place where the clinicians and scientists see us away from the artificial clinical environment and get to see what life is like for us ‘in the wild’ as one friend called it.

My husband John and I had been to two previous Congresses and so in Portland we were looking forward to meeting up with old friends as well as making new ones. The three hectic days of the Congress passed all too quickly. The programme was full on and it was hard to choose what to attend with so many interesting topics. If we were to name three things that stood out they would be the active role New Zealand played in this Congress, the power of people’s stories, and the friendly atmosphere.

New Zealand had our highest profile yet at any Congress. Author Ann Andrews had her New Zealand books accepted for display and Auckland committee member Lloyd Jenkins had a poster on display. I co-chaired a panel of experts, gave a 30-minute presentation and facilitated a round table discussion, while Andy McDowell from Auckland also had several speaking commitments, one of which was an impressive presentation to the whole Congress.

I have spoken a number of times on Radio Parkies in the last few years but this was their first time at the Congress and DJ Madonna of Australia interviewed New Zealand delegate Glen Prestidge. This recording is available for replay. As a link to previous Congresses, the Parkinson’s quilt created in 2010 was again on display. It includes a number of squares made by Parkinson’s New Zealand members.

There were many personal stories that inspired us like that of Jasmine, a 22-year-old person with Parkinson’s, who has developed gastroparesis and now cannot eat or drink. She amazed us all with her positive outlook and when she described how she used her chemistry knowledge to solve the problem of how to mix and administer her medicines.

Every Congress develops its own character. The mood of this Congress was of a community of people from around the globe who are committed and are becoming more and more united. People with Parkinson’s felt they truly belonged and their input was not just welcomed, it was expected. Rather than being passive recipients we left encouraged to be active participants in every area of Parkinson’s life and decision making. In his closing address at the final ceremony Dr A. Jon Stoessl, said, “In the clinic, we focus on what you can’t do, but at the WPC 2016, we see all the things you can do.”
After my wife Averil was diagnosed with Parkinson’s eight years ago and I became involved with the National Board of Parkinson’s New Zealand, we heard a great deal about previous Congresses, but we were amazed by the sheer size of the Fourth World Parkinson Congress. The Convention Centre easily catered for over 4,500 delegates in the beautiful city of Portland.

When you have specialists, neurosurgeons, neurologists, health care workers, pharmaceutical companies, people with Parkinson’s and their carers, you have a unique blend of individuals.

Prior to the official opening on the Tuesday evening, I was fortunate enough to attend a World Parkinson’s Leadership Forum which ran for a full day on Monday. Selected speakers from around the world, including Deirdre O’Sullivan, Chief Executive, Parkinson’s New Zealand, discussed the diverse range of issues that their respective national organisations face. On one hand, there are organisations from the US concerned with corporate governance, while on another level, many poorer nations struggle to get access to Parkinson’s medication that we here in New Zealand take for granted.

Some of the highlights of the Congress were (in no particular order):

1. Learning about the astronomical cost of getting one drug through the test phases, health board approval and onto the market. The chance of a drug making its way to the public arena can cost billions of dollars with a success rate of only 1.5%.
2. The information on ongoing stem cell research and trials.
3. Listening to former US basketball player Brian Grant, a humble giant of a man, talking of his Parkinson’s journey.
4. There is a growing awareness that exercise is medicine.

We come away from the Congress with a feeling of hope for a cure and hope for a better quality of life. We know that we are part of a global family.

Would we go to another WPC? Most definitely.

Would we recommend to others to go? A big yes!

Do not hesitate if you get the chance to attend the next WPC in Kyoto, Japan in 2019. You will not be disappointed.
My experience at the WPC was fantastic. When I arrived in Portland, at first I wondered if I had done the right thing in going. By the end of the first day I was buzzing with excitement. Just meeting so many people who have the same day-to-day problems as you and who can understand what you’re feeling. As someone else said, Parkinson’s has the biggest community family of any other condition.

A few inspirational people who made the trip worthwhile—Dilys Parker, New Zealand’s first ambassador for the WPC, Tom Isaacs of Cure Parkinson’s Trust, who not only is intelligent but very witty as well, WPC blogger Natasha McCarthy and Radio Parkies DJ Madonna Brady.

Another highlight was meeting Aucklander Andy McDowell. He was on the Parkinson’s world stage telling his story about living with Parkinson’s and he did us all proud.

There were presentations on the progress that is being made towards finding a cure for Parkinson’s, new improvements for daily living with Parkinson’s, including medications and delivery of medications, as well as the latest news on exercise you can do to help yourself, for example, non-contact boxing and dance.

There was so much information to digest, some over my head, but that was interesting as well. The WPC really broadens your understanding of Parkinson’s. If you’re thinking of going to the next WPC in Kyoto, Japan in 2019, I would thoroughly recommend it.

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.
**MOVAP**

(MOVAP apomorphine hydrochloride) is used for the management of Parkinson’s. It is indicated for the treatment of patients who experience motor fluctuations (ON–OFF phenomena) that cannot be adequately controlled by oral PD therapies.

**MOVAP** is the only dopamine agonist that has shown equivalent efficacy for the management of Parkinson’s symptoms to the gold standard therapy, levodopa. As Parkinson’s progresses, the response to oral levodopa changes and motor fluctuations occur, so alternative strategies are needed to control motor symptoms.

**MOVAP** is available in two subcutaneous formulations – Intermittent Injection and Continuous Infusion – which give physicians the flexibility to select the most suitable treatment option for their patient, depending on symptoms and stage of disease.

**MOVAP** injection can be administered whenever patients need it throughout the day in order to achieve a rapid and reliable ON state.

**MOVAP** infusion pump provides Parkinson’s patients with a continuous, reliable ON throughout the day, without the need for surgical intervention, and is easy and practical to use. The infusion pump is fully customisable for the patient’s needs and can be set up for the day’s treatment without needing further adjustment, allowing them to get on with their daily activities. In addition, the pump is small, lightweight, discreet and portable. The infusion pump is a suitable therapy for patients experiencing frequent or longer OFF periods and dyskinesias (hyperkinetic movements that can occur as a side effect of levodopa therapy) that cannot be controlled with optimised oral medication.

**MOVAP** pump provides these patients with smooth and predictable control of motor fluctuations and dyskinesias, and can reduce the burden of having to take multiple oral PD medications.

**MOVAP** is the least invasive continuous dopaminergic stimulation therapy.

**MOVAP** pump delivers a continuous infusion of apomorphine throughout the day, avoiding the peaks and troughs of intermittent oral levodopa administration and ensuring patients achieve a smooth and reliable ON state, thus improving quality of life.

**MOVAP** is suitable for PD patients with troublesome OFF periods that cannot be adequately controlled with optimised oral medication. The use of MOVAP can also reduce the burden of having to take multiple oral PD medications thus potentially improving patient compliance with therapy.

As it is administered subcutaneously, MOVAP bypasses the GI tract which is beneficial for PD patients who may have GI dysfunction.

For further queries contact your GP or Neurologist.