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IN THIS TOGETHER
parkinson's
NSW

FROM THE PRESIDENT

I would like to start off by offering a very warm welcome to our new CEO, Jo-Anne Reeves.

Jo-Anne joins us after a long career in the Not-For-Profit sector spanning over 25 years including health, education and disability. Most recently Jo-Anne was the General Manager of Communications and Fundraising with Disability Services Australia.

A major focus of her role included developing and implementing strategies focusing on change management, financial security and changing the culture to become customer focused and redesign of the operating model in a rapidly changing environment. These are also important for Parkinson's NSW and I am sure you join me in wishing her every success here.

I was very pleased to see Adrian Unger listed in the Australia Day awards. My sincere congratulations to Adrian on being awarded a Medal of the Order of Australia (OAM). Adrian is behind Punchin' Parkos, an exercise class for PWP. See on page 5 how Punchin' Parkos will be included in our new PD Fit program, which will soon be rolled out across NSW.

2017 is also a milestone for PD – it is 200 years since Dr. James Parkinson first described Parkinson's disease in his work "An Essay on the Shaking Palsy". He described in detail the symptoms of the disease, which was to become known, some years later, as Parkinson's disease, in recognition of his work.

Another major date for PD was marked 50 years ago with the introduction of levodopa as a treatment for PD in 1967, and it is still the "gold standard" of modern drug treatment of PD. To complete the time line it was another 20 years before Deep Brain Stimulation became a possible treatment for PD. Following the decrease in the time between these major developments in PD the next major breakthrough might be in the next 5 to 10 years with a little luck!

Andrew Whitton
President



FROM THE CEO

Firstly, I would like to thank you for your warm and positive response to my appointment. It is an absolute pleasure to be here and I look forward to getting to know you personally.

Since commencing as CEO in January, I have been learning about the wonderful and inclusive Parkinson's community, the organisation and the vital role that support groups play. I believe there is enormous potential for us all to work together growing the organisation so that we can expand the services that Parkinson's NSW provides.

Initially I will be focusing on providing more nurses out in our regional areas, our counseling services and providing extra help to our support groups.

Additionally I see a vital need to support more research which is critical to make life better right now, but essential in focusing on finding a cure for the future.

The Parkinson's NSW Board has given me an ambitious goal to raise a large amount of money over the next five years. To achieve this, I will be implementing a new organisational structure. I will communicate the details of these changes to you over the coming months.

Over the coming year, I will be travelling throughout NSW and I intend to visit many Support Groups. I welcome your feedback and I hope to meet you in person soon.

Jo-Anne Reeves
CEO



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THE 4TH WORLD PARKINSON'S CONGRESS

Andrew Whitton (PNSW President) & Malcolm Irving (PNSW Vice President)

With a mission to share, converse, and learn together, the 4th World Parkinson's Congress held in Portland, Oregon saw 4,500 attend from all walks of life. It was held over 5 days and participants flew in from over 70 countries.

The seriousness of the event was clear from the outset, with People Living with Parkinson's (PLWP) mingling with those who have dedicated their lives to alleviating its effects and to finding a cure. In particular, inspirational stories were an essential part of the congress.

For a first timer, attending the congress was like choosing candy in a huge sweet shop; it was impossible to be everywhere, although teaming up with the Australian and New Zealand attendees certainly helped. The choices of workshops and talks were extensive and ranged from stem cells to singing, exercise to eating, depression to deep brain stimulation.

Speakers included Muhammad Ali's daughter, Maryum Ali, who gave the keynote address and was truly inspiring. Brian Grant, a former NBA sports star who was diagnosed with young onset Parkinson's just 2 years after retiring from professional basketball, mentioned in his speech how he was "scared and humbled" yet motivated to launch the Brian Grant Foundation for those with Parkinson's who want to lead active and fulfilling lives. Another inspiration speaker was Linda Olsen, a triple amputee, who spoke about her diagnosis of Parkinson's, some 30 years after the accident that robbed her of her limbs.

There were many other inspiring stories, but the takeaway message was 'Stay in the Race', 'Live your best every day' and 'Find the new you!'. Those messages are ones we can all benefit from.

ORGANISATIONAL LEADERSHIP

In a welcome move, a full day was devoted to many organisations like Parkinson's NSW, where we were able to meet up and share our collective experiences.

Presentations, panel sessions and networking helped everyone to appreciate what more can be achieved through innovative programs like medical students becoming PLWP buddies; specialist PD training to nursing students; initiatives to focus on 'unmet' needs such as those for young onset; women with PD; and carers support.

SCIENTISTS

This is some of what the scientists had to say:

Stem cells: Are all stem cells the same?

Embryonic stem cells (ES) can only be derived from embryos, however Induced Pluripotent Stem cells (IPS cells) are a type of pluripotent stem cell that can be generated directly from adult cells. IPS clinical trials are expected in 2017.

There are many factors to consider, and considerable risks, but progress is being made.

Tracking the change in your Parkinson's: What can our gut tell us?

Microbes help us digest our food, and are a key part of our immune system. Examining the microbiota in the human gut can indicate Parkinson's before PD is observed, introducing the possibility of creating a PD microbe biomarker.

Data and technology: Can we learn more from collecting and analyzing the vast amounts of personal data now becoming available?

Individual needs and uses differ widely but great possibilities are emerging. For example, wearable and home-detection devices sensor measurements can predict if you are in danger of a fall, or can better inform 'on' and 'off' periods helping to control medication timing. These are early days but the possibilities are exciting, and should play a major part in the next WPC in 2019.

Exercise physiology, dancing, boxing, yoga, speech therapy and massage therapy

Various forms of activity have become more scientific in their application and are now recognised as part of coping with PD.

NUTRITION

For PLWP there are 'good' and 'bad' diets. The Mediterranean diet rated a mention as a positive place to start. The message is quite simply: 'Eat well and Eat Right for Parkinson's'.

The congress was most uplifting and well worth attending. Andrew and I hope to see you at the 5th WPC 2019 in Kyoto, Japan. Above all, the prevailing message is one of hope for those with PD and their carers.



THINK OF EXERCISE AS MEDICINE

WHAT'S YOUR DAILY DOSE?

Professor Colleen Canning

WHY EXERCISE?

Did you know that even when first diagnosed, people with Parkinson's disease are already 30% less active than people without Parkinson's? Yet there is now gold-standard evidence that with regular exercise you can move and balance better, get more out of life and reduce the impact of the disease. There is even emerging evidence that exercise may slow disease progression.

There is strong evidence, individually or combined, for: physiotherapy and prescribed exercises targeting balance, walking including on treadmills, standing up and sitting down, Tai Chi, muscle strength, and exercise capacity; there is also emerging evidence for dance.

SO WHAT ARE THE BENEFITS?

Well, the benefits depend on the type of exercise and the dose. Benefits specific to people with Parkinson's disease include improved:

- Mobility (such as standing up, getting out of bed)
- Walking
- Balance
- Muscle strength
- Exercise capacity (can do more)
- Quality of life
- Cognition

Positive benefits also include reduced:

- Impact of motor symptoms of PD
- Falls

Some additional likely benefits (but more research is required) include:

- Reduced fatigue, depression and constipation:
- Improved cognition and sleep
- Depression

WHAT TYPE OF EXERCISE IS BEST?

First, some exercise is better than no exercise. Some types of exercise will be more appropriate for each individual, based on your unique movement problems and other Parkinson-related problems (such as memory problems) or unrelated problems, such as arthritis.

It is important to consider the evidence, but also your own preferences for type of exercise (such as Tai-Chi compared to treadmill walking or walking over ground) and weigh these up against the benefits, risks, inconveniences, costs, location, and level of supervision.

DO YOU HAVE TO WORK HARD TO ACHIEVE GAINS?

You definitely need to work harder than you normally do to achieve benefits. We use a scale (known as the Borg scale), to give you an idea of how hard you should be working. On this scale, where 6 = no exertion at all and 20 = maximal exertion, you should aim to working at minimum at 13 = somewhat hard and maximum at 17 = very hard: Also, there can be some trade-off between intensity and duration of exercise, i.e., the lower the intensity, the longer the exercise session to gain benefits.

SO HOW DO YOU WORK OUT THE DETAILS OF AN EXERCISE PROGRAM THAT ACHIEVE YOUR GOALS?

Working out the best program for you can be complex and it is recommended that you consult a physiotherapist for initial assessment and exercise prescription.

The challenge is to undertake a program that is effective but also safe and fun (at least some of the time)! Physiotherapists understand that there may be a number of hurdles to overcome, such as fear of falling, apathy and fatigue, and will help you develop strategies to manage these.

SO WHAT IS THE TAKE HOME MESSAGE?

- Move more
- Sit less
- Get support
- Have fun!



PD FIT PROGRAMME IS UP & RUNNING!

Thanks to the tenacity and foresight of Exercise Physiologist Alyson Blanks, the new PD Fit programme will soon be rolled out across NSW. This new programme will not only be a first for NSW, but we believe it to be a first for Australia.

When Alyson first joined Parkinson's NSW two years ago, she realised that there was a urgent need for a cohesive and coordinated plan when it came to exercise for Parkinson's clients.

So the exciting PD Fit programme was started and Parkinson's NSW are linking with local communities to create 'Exercise Hubs'. Some regions currently have exercise programs running, but the plan is to expand and have a large variety of specific exercises and activities available. Ensuring that there would be an exercise or activity available every day in every region, ultimately improving the quality of life for those living with Parkinson's.

Knowing that exercise is only second to medication in controlling symptoms and that it can play a vital role in improving the quality of daily life, this programme became a priority for Alyson.

Additionally, Alyson also agrees with Melissa McConaghy, author of the PD Warrior Programme, who writes:

"It is important not to wait for symptoms to impact on your daily life before getting involved. Investing now to slow your Parkinson's down will enable you to control your Parkinson's – before it controls you."

Initially two regions or 'Exercise Hubs' have been established, in Shoalhaven and Coffs Harbour, with the support and coordination of Neurological Nurses Nina Cheyne and Vince Carroll, helped along by the incredible dedication of the support groups.

Parkinson's NSW is assisting to expand the variety of exercise programmes in various regions by offering annual scholarships for interested instructors to train in the exercise styles that will be included.

We are excited to announce a new licensee in Coffs Harbour. Amanda Sleeman will be opening up her PD Warrior clinic in the next few weeks. We look forward to supporting the mid-north coast of NSW further!

The programmes that we are expecting to include are:

PD WARRIOR – MELISSA MCCONAGHY

PD Warrior is a 10-week Challenge. This will teach you how to move better, feel better and slow your symptom progression, not just over the 10 weeks, but long-term.

The exercises are targeting specific Parkinson's symptoms such as freezing, posture, balance and rigidity. The course is run by specially trained and qualified instructors.

PUNCHIN' PARKOS – ADRIAN UNGER

'Punchin' Parko's' is a carefully crafted approach to exercise using non-contact boxing techniques in an atmosphere combining activity and fun for both Parkinson's sufferers and carers.

DANCE FOR PARKINSON'S – ERICA ROSE JEFFREY

The Dance for Parkinson's Australia program offers specialised dance classes with music for people with Parkinson's, their caregivers, family members and friends. Taught by professional teachers, it includes modern, ballet, tap folk and social dancing; all designed to engage the participants' minds and bodies to create an enjoyable social environment.

No experience is needed and participants report that the classes boost their confidence levels, transform their attitudes about living with a chronic illness, and help to manage their symptoms; as well as helping to combat the social isolation and depression that often accompanies this illness.

BRAINFIT EXERCISE PHYSIOLOGY – BRODIE CAMBOURNE

Brainfit Exercise Physiology offers a range of small group and larger group classes to encourage participants to complete their individually designed exercise programs in a group atmosphere.

Brodie combines exercise, music, drawing and team work in all her exercise programs and has now created the Brainiac Team Training programs to promote exercise and assist with managing symptoms of Parkinson's Disease.

PARKINCISE COMMUNITY EXERCISE PROGRAM – JEREMY HORNE

Parkincise is a community exercise program for people with Parkinson's disease. Whilst it is currently in the development stages with the YMCA, it has enormous potential and promise.

Aimed at taking control of your health and empowering you through regular, planning and purposeful exercise, the Parkincise programme aims to maximise your physical, mental and social health. Compensate for disease symptoms through conscious movement and prevent age and inactivity related decline through active living. Parkincise involves various exercise routines with instructors.

ART FOR PARKINSON'S – WENDY DAVIS

Art for Parkinson's is an innovative art programme for people living with Parkinson's in the Sutherland Shire and Canterbury/Bankstown Council. Designed to provide a "can do" activity for people whose abilities have been compromised by Parkinson's, a typical class begins with informal chat and refreshments followed by a time to calm the nervous system and focus the mind. This is followed by gentle movements to kick start the body into action, using prompts and triggers.

Sincere thanks must be given to Professor Colleen Canning for her generous help in sharing her experience and expertise in programme development, which was invaluable.

If you would like to find out any further information about the new PD FIT Programme, please contact **Alyson Blanks** on **02 8051 1908** or email **alyson@parkinsonsnsw.org.au**

30th ANNIVERSARY FOR COFFS HARBOUR SUPPORT GROUP

When you get the type of camaraderie that the Coffs Harbour Support Group has, it's not difficult to understand why they are celebrating their 30th Anniversary on the 20th June this year.

Originally started back in June 1987 by Pat Neese and Sylvia Broadhurst with a group of only ten members, numbers have now increased to 136. And now, with Jane Gow as the President, it will be up to her and her dedicated team to take charge of the celebrations for the 30th anniversary party.

It has been a huge job for Jane and the committee to organize the celebration and it has required it's fair share of researching into the past history by Jane at the local library.

Jane explains that the reason she thinks the group has been so successful:

"We are always open to feedback and sometimes, when you or your partner has just been diagnosed you're just not ready for a support group, but we encourage people to come along and see how they feel, we always try to make them feel welcome and help".

She also mentioned feeling very responsible for ensuring that all the members, whether they be new or old, feel a sense of belonging, supported and that they have the latest information given to them regularly.

With regular guest speakers, topics have included pharmacists explaining about medication, Solicitors giving sound advice on Wills and Bequests and even a briefing from the fire brigade on how to safely protect yourself from fires at home. The guest speakers at Coffs Harbour Support Group are many and varied.

Anyone is welcome to attend the meetings, carers, loved ones, friends and of course, those who have Parkinson's.

"Our group is wonderful, so supportive and caring, I can't talk highly enough of them" said Jane. "If it wasn't for the support that I've received from them I wouldn't have been able to do the job. My husband has Early Onset Parkinson's and was diagnosed seven or eight years ago, but I have received so much support from our group".

If you would like to get in touch with the Coffs Harbour Support Group, then please call 6658 3355. They meet on the first Tuesday of every month.



NEWLY DIAGNOSED PROGRAM MEET & GREET

Each year Parkinson's NSW holds two Newly Diagnosed Programs at their offices at North Ryde.

THIS PROGRAM CONSISTS OF

- An introduction to Parkinson's by our Parkinson's Nurse
- Getting physical with physiotherapy and PD Warrior
- Lifting the Roof with Speech and Voice production
- Exploring some of the non-motor symptoms with one of Parkinson's NSW counsellors
- Meeting the NSW Parkinson's Team
- Rounding the day out with diet

If you or a loved one have been diagnosed within the last 18 months with Parkinson's, please feel free to come along. For further details please call 1800 644 189, bookings are essential.



SAILING FOR MY DAD - POPPY MOORE

I'm Poppy Moore. I immigrated to Australia from the UK 16 years ago to have an outdoors lifestyle with a focus on sailing and cycling.

My father was diagnosed with Parkinson's in 2006, which came as a shock, but we had insight into the condition as my father's eldest brother had died of Parkinson's and several other relatives also had Parkinson's.

Fortunately my parents had the chance to visit Australia three times prior to the onset of Parkinson's. Dad even came sailing at my local club for a Twilight Race.

My parents loved Australia and always hoped to retire here, but unfortunately this is no longer possible as my dad's condition has deteriorated to a state where he is now effectively housebound.

I spoke to my father and he mentioned that it would be great if I could do a fundraising event for Parkinson's. I have been a member of the Balmain Sailing Club for 16 years and taken up many voluntary positions to help run the day-to-day activities including being Race Director and Dinghy Captain.

I've always loved traveling and exploring new places so I decided to combine my passion for sailing and exploring with a fundraising event for Parkinson's. Given my parents would no longer be able to visit and explore Australia, I thought the next best thing would be for them to experience Australia by following a trip that I could do around the country.

Thanks to the Internet and Skype they can follow what I'm doing in real time as I sail around this vast country. In the more remote locations I'll make video diaries of my experiences. I'd like them to feel as if they are part of the trip.

My parents are slightly worried but also excited about this adventure; hopefully it will give them something to look forward to participating in on a daily basis.

I bought Scaramouch in June 2015, she is an East Coast 31. It has taken me a year and a half to fit her out for the trip, including a new engine, plumbing in the toilet and sorting out some electrics, I'm now quite handy with power tools and know the boat inside and out!

I've also undergone extensive training, the equivalent to what is required for the Sydney to Hobart yacht race. I want to ensure I run a happy, safe boat for everyone who takes part in the adventure.

My aim is to set sail at the end of March 2017 on a journey that will take at least 1 year. I plan to explore as much of the Australian coast and coastal regions as possible, learning about the Australian and Aborigine cultures as I travel.

I'm inviting other sailors to join me for legs of the journey, to help fundraise and raise awareness of Parkinson's. I will be stopping off at sailing clubs along the way and taking part in sailing regattas.

I've setup a fundraising page and Facebook page and I will also be writing a blog so people can follow the trip.

FACEBOOK:

facebook.com/profile.php?id=100013808268464

FUNDRAISING:

give.everydayhero.com/au/scaramouch-parkinsons

If you are interested in becoming a crewmember please contact: scaramouchparkinsons@hotmail.com



RESEARCH VOLUNTEERS

If you would like to volunteer your time and participate in current research projects, please visit our website at www.parkinsonsnsw.org.au/about-us/media-centre/ for more information



SHOW YOUR SUPPORT

HOW YOUR GENEROSITY TODAY HELPS PEOPLE LIKE GAVIN

Gavin's neurologist had just told him he had Parkinson's disease at the age of 45. After he asked the first question that sprang wildly to his shocked mind, he was relieved to hear: "No." But immediately he wondered, how would he live with a disorder that was slowly robbing him of his control over his movement?

You probably know all too well that without outside support, people diagnosed with Parkinson's and their loved ones, especially their carers, can grow desperate. Each day, hope can fade more, as worry, helplessness, exhaustion, and despair take over.

As you would imagine, it's particularly difficult for people with Young Onset Parkinson's like Gavin. He's among the 1 in 5 people who are diagnosed at an age when they are usually still working and caring for their families.

"I was in shock too. I just didn't know what was going to happen. I got really down about it and dwelled on it. A big concern was how long I could keep working as a Navy helicopter mechanic, since there was no way I could ever go to sea again."

Also Gavin noticed his symptoms were getting worse. Where at first he'd had a tremor in his finger and a stiff shoulder, he was starting to struggle with his balance and getting out of a chair. His leg was shaking too. Gavin realised he needed some help – and he phoned Parkinson's NSW. In that instant, he connected in with the free support that is only available because of you and our other fantastic Parkinson's NSW supporters.

Thanks to your assistance, we could provide him with vital information and a home visit from a caring and knowledgeable Parkinson's Nurse, Nina.

"Seeing Nina was brilliant. She talked me through the concerns I had, and she reassured me I was on medication that would gradually help ease the Parkinson's symptoms. She also referred me to an exercise physiologist in my country town and that has just been the best thing."

Nina knew the importance of Gavin starting a tailored exercise program, because studies have proven that the right exercise can slow down the physical decline caused by Parkinson's. Acting on Nina's advice, Gavin has now been exercising for two years. And it has completely changed his life. Doing two paddle-boarding sessions a week with the exercise physiologist – with the goal of going for as long as possible before he has to use a walking stick – he has gained back the strength and balance he was losing, and kept fit. He also feels a lot less stressed and has more confidence and hope.

He has been able to stay working in the Navy, although in a different role. He has even tackled the Couch to 10K jogging program. At the beginning he couldn't run around the block. These days (although he says it's tough) he can manage 10 kilometres.

Gavin's story shows how much your donations can accomplish. However he has a long road ahead. He and other people with Parkinson's will keep needing you into the future, because as yet there is no cure for this disease. They face increasing challenges, both physically and emotionally.



Give easily online today:

parkinsonsnsw.org.au/support-us/donations