

Stand *by* Me

Issue 123 Autumn 2015



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MAURICE GREEN: CABINET MAKER

For Maurice Green, the progression of his Parkinson's symptoms has been relatively slow.

every new symptom or symptom progression as just another challenge. A mind game to be mastered. Each one releases a burst of creativity, ten fantastic tables for his grandchildren or a special home cooked birthday meal.

Now, in his mid eighties, it is harder to manage alone. But Maurice sees

Read more about Maurice in our cover story on page 5.



FROM THE PRESIDENT



Andrew Whitton,
President Parkinson's NSW



Lion cub at dusk



Beautiful clear water at Kuda Bandoas -
Maldives

Happy New Year to everyone! As it is a new year and as you have a new president, it is appropriate to tell you a little about myself and my attitude towards PD.

Firstly, why the connection with Parkinson's NSW? That is simple, I was diagnosed with PD in 2007 and my neurologist suggested that I contact PNSW, to find out what support and information was available.

I mention this as it is important that word gets out about our services and your neurologist is in a good position to promote PNSW's services. A second thing, was that I do my banking at Bendigo Bank and they just happened to have flyers in their branches promoting the first Unity Walk in 2008 - I subsequently registered for the walk and have participated in fund raising and the walk every year to date.

Obviously every PD sufferer is different in the way the disease manifests itself and how the individual responds to treatment. I am not qualified to give you medical advice, but I do believe that the old adage "use it or lose it" has some validity - my philosophy is keep active, stay social, use your brain and most of all stay positive. Exercise is important to your general health and even more so to people with PD, fitness and strength can help to reduce the incidence of falls. Keeping up an active social life also has positive implications, it is no secret that many people with PD suffer from depression.

Some cognitive impairment is also a possibility, so keeping an active mind, whether it be reading or doing puzzles can't hurt. Where am I going with this discussion - when I was diagnosed with PD my first question to my neurologist was, should I consider going on an extensive trip

that we were planning to Southern Africa. He gave me the go ahead and not only did we travel to Africa in 2008 but we have travelled every year since then.

Travelling covers all the bases - we do a lot of walking whilst travelling - so exercise is covered, you are always learning something new, which satisfies keeping the grey matter working and you invariably meet people and are doing exciting things, so there is no cause to feel low!

I am reasonably active and sail on a 38 foot yacht every week (plenty of exercise there as I am on the winches most weeks). Up until this year I have played baseball and I do some cycling (I have done three MS Sydney to the Gong rides since my diagnosis) and I joined up with Punchin' Parko's (a boxing/exercise group specifically designed for people with PD).

So overall I try to follow what I have outlined above - exercise the body and the mind, live your life to the fullest.

My wife, Karen, and I are avid travellers we have just come back from Kenya and a cruise across the Indian Ocean. It was truly a fantastic trip and so full of activity, I didn't have time to worry about my PD. Masai Mara in Kenya was one of our favourite places we visited - this is one of many lion cubs we saw in the wild.

Finally the year ahead brings in some new challenges. PNSW will probably have to relocate their offices sometime in the first half of the year. There are several positions vacant on the staff and we are going to launch a new website. Not to mention that we have to find new and better ways to raise funds so that we can continue to provide services to the PD community.

Andrew

FROM THE CEO



Miriam Dixon,
CEO, Parkinson's NSW



CUZZINS Treats 2 Treat Cafe menu

Welcome to our first edition of 2015! We are pleased to announce that we are adopting the new national logo. We will be rolling this out on all our publications and it will feature on our new website. I hope you like the new look!

New Nurses!

I am thrilled to let you know that we have welcomed two new nursing positions. We have a part-time Neurological Nurse, Vincent Carroll in Coffs Harbour and Suzie Basford based in Moruya with the Southern Medicare Local. They are featured in this issue of *Stand By Me*.

On a sad note we farewell Marilia Pereira our Neurological Nurse Educator. Marilia is moving to Western Australia and will be sadly missed. Nina Cheyne will be stepping into the role. We will introduce Nina in the next edition of *Stand By Me*.

On-Line Exercise Program

Can you help us locate Parkinson's friendly exercise services? Do you have a gym, a bowling club, a Tai Chi group, Yoga instructor, Golf Club, Dance Group, walking Group, Running Group or any physical activity program in your area? We

would love to hear from you so that we can create a directory of Parkinson's Friendly activity/exercise program across NSW.

If you could send a brochure to PO Box 71, North Ryde BC, NSW 1670, email details to pnswn@parkinsonsnsw.org.au or call 1800 644 189.

A Big Thank you!

We have had some wonderful fundraisers since our last edition. There have been multiple Pancakes for Parkinson's events. One special fundraising effort was carried out by three grandchildren of the late Rev Lester James.

They called their event Cuzzons 'Treat to Treat' Café which was held at their family Christmas gathering, in honour of Rev Lester James, who succumbed to Parkinson's, after a 25 year battle, back in September 2012.

If you would like to hold a fundraising event, our fundraising team is here to help. Please contact Claire on 02 8875 8915 or email claire@parkinsonsnsw.org.au.

Parkinson's NSW Patrons

I am pleased announce that His Excellency General The Hon David Hurley AC DSC and Mrs Linda Hurley have agreed to become our new patrons of Parkinson's NSW.

Yours in Parkinson's friendship

Miriam

IN THIS TOGETHER
parkinson's
NSW

THE CHALLENGES - ACCEPTING AND FIGHTING PD

by
Maurice Green

My name is Maurice Green and I live in a villa in Warrina Village (part of the Anglican Retirement Villages complex at Castle Hill). I now live alone as my wife died on 1st January 2014, a few months short of our 60th wedding anniversary. Apart from a cleaner once each fortnight I care for myself with the help of my two daughters who each visit once a week to take me shopping or to medical appointments.

In 2000, the first inkling I had of Parkinson's (PD) was when a friend commented that my voice had changed to a softer and higher pitch. She had a friend with Parkinson's who had that symptom. My GP referred me to an ENT Specialist who advised that my vocal chords were irritated due to frequent clearing of my throat.

Four years later I was in hospital for an angiogram and the cardiologist asked me if I had Parkinson's. I replied "no - why do you ask". He indicated that he had noticed a lack of facial expression and a tendency to walk without moving my right arm. I saw a neurologist before leaving the hospital and he confirmed a diagnosis of PD.

In 2005 we moved from the Central Coast to Castle Hill to be nearer the family. I began a program of regular exercise including Better Balance classes. I also continued woodwork hobby in the Village workshop. I subsequently became manager of the workshop - a position I still hold.

I also began brain-training exercises. This covered memory, reaction, flexibility, speed, attention and problem solving. My overall score increased over the first year, then it plateau'd and has decreased gradually since December 2013.

The PD symptoms progressed slowly until 2011 when I began to notice an increasing stiffness and every few weeks, that greater effort was required in my exercise program. I was becoming increasingly slower and less adept in performing tasks such as tucking my clothes in, buttoning my shirt and writing. Also other symptoms allied with PD were encountered - urinary incontinence, constipation and dry eyes.

My medications and their timing were regularly adjusted but did not seem to slow the progress of PD. At the end of 2011, at age 81, I began to accept the progression of PD - but I decided I would resist (fight) by setting myself a challenge that would give me a purpose for getting moving each morning.



One of the 10 tables Maurice made for his grandchildren

I decided to make a table for each of my ten grandchildren. I had some pieces of beautiful wood gathered over many years and I bought a number of highly grained pieces that would really stand out. I drew up three basic designs - two low coffee tables and one hall or side table.

I worked in the workshop each morning, six days a week and spent about a quarter of my time on the tables, the rest of the time I shared in the projects the group undertook. The tables were finished at the end of 2013 and were presented to each grandchild. Two of the tables were made so that they could be posted interstate as a 'flat pack'.

Having finished the tables, this year I have been making segmented bowls and vases out of the off-cuts. I continue to work in the workshop each morning but I have accepted a new challenge; inviting each grandchild to dinner shortly after their birthday. If they have a partner or special friend the invitation extends to them also. I enjoy cooking and this gives me the opportunity to cook a special meal and have the company of young people.

The progression of PD symptoms this year is noticeable particularly in brain/hand coordination and my difficulties are compounded by not having the assistance of my wife. More tasks are becoming difficult but I accept each one as a challenge - persevere or find a way around it - no matter if it takes a long time.

The Occupational Therapist in the Village has been most helpful in suggesting ways or aids to make tasks easier. But the greater challenge is not to get agitated or frustrated - I am convinced that with practice and effort this challenge can continue to be met.

My greatest challenge is to maintain my independence and remain in 'independent living'.

I am working hard to meet it.

DRIVING WITH PARKINSON'S DISEASE

by
Dr Paul Clouston

Parkinson's disease is a complex slowly progressive neurological disorder. The disease not only affects motor function but may also affect cognition including attention and planning.

Parkinson's disease is a complex slowly progressive neurological disorder. The disease not only affects motor function but may also affect cognition including attention and planning.

PD may also subtly affect visual perception. What makes the disease even more complex, is that some of these symptoms may fluctuate on an hourly basis and that other symptoms (e.g. somnolence) can also occur as a side-effects of pharmacologic treatment.

It is not surprising therefore that people with PD have an increased risk of motor vehicle accidents. It is also not surprising that PD patients are often unable to estimate their own suitability to continue drive a motor vehicle.

In NSW it is the responsibility of the driver to report to the driver licensing authority (NSW Roads and Maritime Services) any illness that may affect his or her ability to drive safely.

Parkinson's disease is such a chronic illness. It is the responsibility of the caring health professional, usually a neurologist, to assess and monitor the patients fitness to drive in light of the diagnosis of Parkinson's disease. Once the driver licensing authority has been notified that

a patient with PD is driving, license renewal is dependent on mandatory periodic review (yearly or six monthly) by the caring health professional.

If there is any doubt about a patients suitability to continue driving, a practical driving test is recommended, This test is usually administered by an occupational therapist, often as onroad test or possibly using a driving simulator. It can be arranged by a caring physician (neurologist) who must adhere to its recommendations.

Recently there has been interest in identifying by screening tests, those patients with Parkinson's are particularly 'high risk' of a motor vehicle accident. Using such tests would help reduce the responsibility of the caring physician to identify such patients. Such 'high risk' patients could be referred for a driving assessment immediately. This screening could be done using a combination of neuropsychologic, visual and motor testing. Currently no battery of tests to identify 'high risk' drivers is of sufficient reliability to warrant widespread use, although this remains an area for ongoing research.

The most important issue is that if you are driving with Parkinson's disease, you must notify NSW Roads and Maritime Services

MINIMALLY-SUPERVISED EXERCISE IMPROVES MOBILITY IN PEOPLE WITH PARKINSON'S DISEASE AND PREVENTS FALLS IN PEOPLE WITH MILDER DISEASE

A team of NSW researchers led by A/Prof Colleen Canning (University of Sydney) have published a large randomised controlled trial of exercise for fall prevention in Parkinson's disease in *Neurology*[®], the medical journal of the American Academy of Neurology. The paper is a featured article in the January 20 edition (*Neurology* 2015;84:304-312) and it also the subject of a *Neurology* podcast which is available freely online at: <http://tinyurl.com/q39a5t4>. Summary provided by A/Prof Colleen Canning, The University of Sydney

The objectives of this randomised controlled trial were to determine whether a, minimally-supervised exercise program could

- reduce falls and
- improve physical ability, fear of falling, quality of life, and health and well-being in community-dwelling people with PD.

Participants with Parkinson's disease were recruited from metropolitan Sydney and regional and rural NSW, via Parkinson's NSW support groups, as well as referrals from neurologists and physiotherapists. 231 participants were randomised into a usual-care control group and an exercise group.

The exercise program included 40-60 minutes of progressive balance and lower limb strengthening exercises three times a week for six months, as well as evidence-based cueing strategies to reduce freezing of gait. Most participants attended a monthly exercise class and performed the remaining exercise sessions at home.

The exercises were progressed by the physiotherapist at the class and two to four home visits were carried out by the physiotherapist over the six months. Twenty two exercise groups were conducted throughout NSW, with an average of 3.5 participants per group (range = 2 to 6). A small proportion of exercise participants performed all exercise sessions at home. For these home-based participants, eight to ten of these home sessions were supervised by a physiotherapist and exercises progressed over the six months. Overall, a physiotherapist supervised 13% of the exercise sessions. The control group received their usual care from their medical practitioner and community services. Standardised fall prevention advice in the form of a booklet was provided to both groups.

The exercise group had a trend towards a 27% reduction in falls compared to the control group. Participants with milder disease showed a reduced rate of falls while those with more severe disease showed a trend towards an increase in falls. The exercise group performed better than the control group on physical performance, fear of falling, positive affect and health and well-being measures.

Acknowledgements

I would like to acknowledge the 231 people with PD who participated in this study and the 37 physiotherapists who provided the exercise intervention. We are also grateful to Parkinson's NSW, in particular, Miriam Dixon, Trish Morgan and Chris Searles for their support and assistance with recruitment and to the Parkinson's NSW Support Groups who participated: Manly/Mosman, Pittwater/Warringah, Lower North Shore, Central Coast, Maroubra, Shoalhaven, Milton/Ulladulla, Illawarra North, Illawarra South, St George/Sutherland, Southern Highlands, Newcastle, Bathurst, Orange, Canberra, Goulbourn, Manning Great Lakes, Port Macquarie, Coffs Harbour, Tamworth, Dubbo, Wagga Wagga, Snowy Monaro and Ballina.

I would also like to acknowledge my collaborators: Prof Catherine Sherrington, Prof Stephen Lord, Prof Jacqueline Close, A/Prof Stephane Heritier, Dr Gillian Z Heller, Prof Kirsten Howard, Dr Natalie Allen, Dr Mark D Latt, Ms Susan M Murray, Ms Sandra D O'Rourke, Dr Serene S Paul, Dr Joeeun Song and A/Prof Victor Fung.



Examples of strength exercises. Participants wore weighted vests to provide progressive resistance.



Examples of balance exercises

TAKE HOME MESSAGES

Minimally-supervised exercise program should be offered to people with mild to moderate PD as both a method of improving mobility and reducing falls

Minimally-supervised exercise should be used cautiously in those with more severe disease - these individuals may benefit from more extensive risk factor assessment and management, including: medication review; reduction of environmental hazards; and more closely supervised exercise and training in strategies to minimise fall risk, but the efficacy of this type of multifactorial approach has not been tested to date.



See page 21 for information on physiotherapy and exercise services

Train your brain, to unfreeze your feet!

Volunteers needed - last chance to take part!



THE UNIVERSITY OF SYDNEY



We are currently conducting a clinical trial to see whether brain training can improve freezing of gait. We suggest that by improving your concentration and speed of thinking, we can decrease the impact of freezing!

This is your **last chance** to participate in this novel research study, which is funded by the Michael J. Fox Foundation and headed up by A/Prof Simon Lewis and Prof Sharon Naismith at the Brain & Mind Research Institute.

For information, contact Mr Courtney Walton
Phone: 02 9351 0770
Email: courtney.walton@sydney.edu.au

What is involved?

- Attending the Brain & Mind Research Institute in Camperdown for **two sessions per week, over 7 weeks** (some funding for transport may be available)
- Each session lasts 2 hours and involves group-based discussion, educational information and computer-based brain training exercises
- You will also complete some medical and memory/attention tests before and after the 7-week program.

Who can participate?

- People with a diagnosis of Parkinson's disease
- **People who experience Freezing of Gait (i.e. feet 'sticking' to the floor)**
- People without dementia

THE PARKINSON'S DISEASE WELLBEING PROGRAM

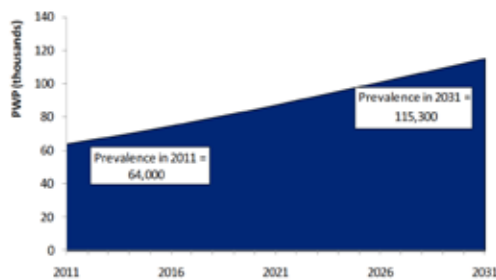


An initiative of Southern Neurology and Calvary Health Care, Sydney

According to research conducted by Chan et al 2005, Sydney has one of the highest prevalence estimates of Parkinson's disease in the developed world. Projections by Access Economics (2011) report an 80% increase in its prevalence over the next 20 years (fig 1). Unfortunately, service provision remains poor, for what is the world's second most common neurological condition.

The need for a more comprehensive service for Parkinson's disease clients in Southern Sydney was initiated by Dr Raymond Schwartz and Associate Professor Denis Cordato of Southern Neurology. The neurologists' at

Fig 1. Projected PD prevalence, 2011-2031



Southern Neurology (est. 1996) provide one of the most comprehensive services in Sydney for those suffering from Parkinson's disease. In addition, they participate in investigator driven and pharmaceutical sponsored clinical trials providing their clients with the opportunity to access potential new therapies.

In collaboration with Calvary Health Care Kogarah, a model of care has been developed supporting a clear referral pathway, exercise, education and long term holistic management for people with Parkinson's disease (PwP). This model ensures multidisciplinary input for the varied needs of PwP resulting in timely intervention rather than delayed reactive management.

Research shows that medication combined with exercise provides comprehensive control of Parkinson's symptoms. Non-pharmacological treatment plays a significant role in the

long term management of Parkinson's disease. This includes exercise, education and counselling.

Studies by Ellis et al 2005 & Ridgel et al 2009 suggest exercise treatment brings benefits in functional performance for individuals with Parkinson's disease which is greater than isolated medication use and surgical procedures.

The *Parkinson's disease Wellbeing Program* is an exercise, education and lifestyle program designed to empower people with Parkinson's disease by maximising their physical and psychological function in a bid to better manage the progression of their symptoms.

Exercise (physical, mental & social) is the foundation of the program, however education, group discussion and social support provides a more holistic approach. The ultimate goal is to provide a framework for Parkinson's disease clients to better manage the disease, get more out of life and take control.

The programs answers the common questions people with Parkinson's have when diagnosed with this complex, chronic, progressive, neurodegenerative disease:

- what do I need to do?
- how do I do it ?
- why am I doing it?

The program aims to improve the quality of care for PwP resulting in improved wellbeing and hence quality of life. The result, better outcomes and potentially lower health system costs as PwP contribute and participate more in all aspects of daily life.

Self-management through empowerment is developed by improving clients knowledge, skills and confidence in managing their health condition. By maximising physical fitness, using compensatory strategies to manage disease



WELLBEING PROGRAM (cont.)

symptoms and preventing secondary, inactivity related health conditions, wellbeing is enhanced. We address the questions posed through what we call the "Active 8 elements". These are 8 important elements that have been highlighted by past clients and health professionals that need to be understood and actively managed to help maintain wellbeing in PwP. These elements are: Exercise, Nutrition, Medication awareness, Team support, Emotional wellbeing, Communication, Relationships and Lifestyle. All are discussed in detail during the education component of the program.

In the last decade, research has provided health care professionals with a greater understanding of the motor needs and types of exercise suitable for the physical and functional improvement of Parkinson's disease clients. The role of exercise in promoting brain reorganisation and self-recovery has led the way in the management of Parkinson's disease through evidence based practice (Hirsch & Farley 2009, Smith & Zigmoid 2003).

It is well documented that it is important for PwP to increase their general fitness and wellbeing through participation in a regular exercise program (Goodwin et al 2008). The benefits are:

- Increased cardiovascular fitness
- Increased strength and flexibility
- Increased balance and co-ordination resulting in reduced falls
- Improved posture
- Increased confidence in performing daily activities
- Reduced stress
- Improved quality of life through preventative, proactive strategies.

The wellbeing program calls the exercise component 'Parkincise', which aims to maximize, compensate and prevent where possible through group exercise sessions that are adapted and progressed to improve gait, strength, power, balance, flexibility, agility, body awareness and mental ability. It utilises the latest research that shows that physical and mental stimulation can improve general fitness and alter your metabolism, enhancing hormone/ neurotransmitter response resulting in increased wellbeing. (Petzinger et al 2013, Hotting & Roder 2013)

The Parkinson's disease Wellbeing Program is conducted in the Day Rehabilitation Unit at Calvary Hospital Kogarah, which includes a fully equipped gymnasium, hydrotherapy pool and dining area, all in the one unit. Reserved parking directly outside the entrance to the facility makes for stress free, easy access for all clients attending the program.

In conjunction with the program, a new support group for the St George and surrounding area has started in 2015.

The Botany Bay support group runs on the fourth Tuesday of the month in the conference centre at Calvary hospital, 9:30

am to 11:30am, all Parkinson's NSW members are welcome to attend.

The Wellbeing Program team consists of the following Calvary health professionals: Rehabilitation Specialist, Physiotherapist, Exercise Physiologist, Dietitian, Speech Pathologist, Social Worker.

The program also has access to community health team nurses, occupational therapists and neuropsychologist's who all collaborate to manage the multi-factorial nature of Parkinson's disease through the evolution of treatment goals for the disease at its various stages and complexity.

Frequently Asked Questions and Answers

When does the program run?

The program runs four days a week at two different times, 2-5pm Monday/ Wednesday and 11am-2pm on a Tuesday/ Thursday. Clients attend a minimum of two pre-program sessions to prepare, followed by the 10 education and exercise sessions. The pre-program sessions are conducted in a one on one format with the Physiotherapist and Exercise Physiologist on a Monday, Wednesday and Friday at various times. It is recognised that while patient needs will be similar, everyone is at a different stage in their disease progression and this requires a program that meets the needs of the patient in their current phase of the disease process. The exercise component is adapted to meet the needs of the individual within a format of core exercises to manage the motor and non-motor limitations imposed by Parkinson's.

Long term adherence to an exercise program is a major goal of the program. At the completion of a block of intensive therapy, clients are set up with a home program and referred to local community exercise groups such as PD Warrior, SHARE and over 60s strengthening. All clients return for follow-up at 6 to 12 months for review and the next phase of the program. This will enhance the long term management and support of clients as Parkinson's disease is a long term degenerative disease which requires long term commitment from both the health care provider and recipients. It also encourages clients to maintain their exercise adherence as they will be monitored at regular (6-12 month) intervals, these reviews maintain a time frame for goal setting. The follow up also allows for feedback and motivation which is important in any long term exercise program. Another goal is for exercise to become habitual, a natural part of every day that happens without opposition and which is enjoyed and adapted to meet the changing symptoms of Parkinson's.

What can participants expect in their first session?

Using current best practice for Parkinson's disease management, participants are required to attend a two hour assessment session where they undergo tests such as:

- 2 min walk test
- 10 meter walk with dual tasks
- Timed up and go test
- Berg or Minibest balance tests

- 4 point step test
- Dexterity tests
- Posture assessment
- Muscle strength and flexibility testing
- Quality of life, fatigue, sleep, depression and anxiety questionnaires
- Parkinson's knowledge test
- Body mass index calculation
- Lung function tests (spirometry)

After the assessment, the Physiotherapist and Exercise Physiologist devise an exercise program individualised for each client. Diaries are used to track client success with exercise adherence and provide the motivation for lifestyle change.

Who can attend?

Any person diagnosed with Idiopathic Parkinson's disease (stage 1-3) who live in the St George Local Health District. If you live outside the St George area you may still be able to attend but special conditions apply. All participants must be able to mobilise independently, either on a frame or unaided, be able to self administer medications and follow basic instructions consistently. Participants must also be able and willing to integrate into a group setting.

Partners and family members are encouraged to attend the education sessions, they can also spend time other partners who attend in the dining room in a quasi carers support group and gain strength and encouragement from other people in a similar situation.

How long does the program run for?

Participants are required to attend 2 sessions per week for 5 weeks and at least 2 pre-program introduction sessions. At the completion of the program clients are given a home exercise program to continue with along with information on local exercise groups until follow up in 6-12 months depending on need and progression of symptoms. No more than 2 therapy blocks are allowed in a 12 month period.

How will your neurologist be involved?

The referring Neurologist will be kept up to date with each client's progress through our multidisciplinary team case conferences. A discharge letter on completion of the

program outlining the results, plans for future treatment and goals will be sent to the treating Neurologist.

How do I get started?

A referral from either your GP or treating Neurologist is required to start on the program. Once received, potential clients will be contacted and booked in for an initial assessment. On completion of the initial assessment and acceptance onto the program, participants will be given their session times ready to start at the soonest possible date.

Who can I call for more information?

Phone Jeremy Horne (Senior Physiotherapist and program co-ordinator) on 02 95533023

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MY DAD BRIAN

by Lloyd Rothwell

My Dad Brian was diagnosed with Parkinson's in his late 30s, an age not much older than I am now. He lived with the disease until he sadly passed away in January 2014.

I only really knew Dad when he had Parkinson's; for all intents and purposes I never knew any different. Over the years I learnt much from my father, and gained much respect for the way he lived his life and faced the many challenges that come from living with Parkinson's. He was not one to complain and simply got on with life as best he could.

Over more recent years I have begun to engage with the Parkinson's community; my wife and I, and later my baby daughter, have participated in a number of Unity Walks and we also made a lump sum donation when we were married in 2011 on behalf of our guests in lieu of bomboniere gifts.

After my Dad died I quickly realised I wanted to give more to supporting PLWP and, of course, see more funding for research to ultimately find a cure. In April I made somewhat of a decision to undertake a "personal journey" by walking 40km at the 2014 Unity Walk (10 laps of the course), with the aim of doing something special to commemorate my

Dad and also hopefully raising a good amount of money for PNSW. Two close friends joined me for the entire 40km, which started just after 4:00am and finished with the main group of walkers.

I received great support from the team at PNSW in the lead up to the walk and not long after I resolved to make an ongoing commitment to the Parkinson's community. I've since been welcomed onto the Board of Directors for PNSW by fellow directors, members and staff alike. I'm excited and honoured to have the opportunity to make a contribution to the ongoing success of PNSW.

I am an experienced senior manager in the sports industry with a philosophy of making a positive difference to people's lives. I am currently a member of the Board of Directors for the Aquatic and Recreation Institute, the peak body for facilities in our industry. I hold a Master of International Sport Management (Southern Cross University) and a Bachelor of Arts (UNSW), and hope to conduct further academic research in the sport industry.

I am passionate about raising awareness of Parkinson's in the wider community, with particular reference to early onset PD, the impact PD has on families as a whole, and the benefits of exercise for PLWP.

I'm married with a two and a half year old daughter and another child due at the end of February.

L to R Cameron McDonald, Lloyd Rothwell and Tim Shepherd





FAREWELL MARILIA

After five years and four months, it's time to say good bye to the beautiful Shoalhaven region and my role as the Shoalhaven Neurological Nurse Educator.

I have decided to join my husband in Western Australia where he has been living for the last year. Though the thought of being unemployed is a little scary, I am certainly looking forward to having some time off and being "a lady of leisure".

My nursing career took a huge turn from an acute care setting to the primary health care sector when I took on the role as the Shoalhaven Neurological Nurse Educator, initially on a part time basis in November 2009 and then full time in February 2010 as a two year pilot project.

It has been a pleasure to be working with Parkinson's NSW and the Brain and Mind Research Institute at the University of Sydney. There are so many people that have been involved in the Shoalhaven Neurological Nurse Educator Service and I would sincerely like to thank them all for their ongoing support, advice and mentorship, of course the staff of PNSW, Associate Professor Simon Lewis, fellow nursing colleagues in Parkinson's and Movement Disorders as well as my fellow nursing colleagues in the Community Sector.

I realised very quickly that the people of the Shoalhaven are very generous when it comes to community issues they are passionate about, from the Parkinson's Community and local community members to local state and federal parliamentary ministers and councillors, the Shoalhaven Mayor, local businesses such as the Bendigo Bank and now the Shoalhaven Ex-serviceman's Club in providing an invaluable car, a necessity in providing a community based specialist service.

Parkinson's is certainly a big topic in the Shoalhaven at the moment. To the Milton-Ulladulla and Nowra Parkinson's Support Groups, your tireless lobbying in favour of the service has been remarkable and I thank you sincerely. You have played no small part in ensuring the success of the Shoalhaven service in the past and into the future. To all the clients and carers, I will certainly miss every single one of you. You have allowed me to come into your homes and have treated me as not just as a health professional but as a family member or friend. I must admit that this has been the most rewarding position of my nursing career as I have gained and learnt so much from every single client who have allowed me to play a big part in their lives and to help me understand the individualised complexity of Parkinson's and other neurodegenerative conditions from the client and carer perspective. Keep up all your amazing inspirational work in maintaining a good quality of life.

I am sure you will all welcome Nina Cheyne into your homes as you welcomed me five years ago as she takes on the challenging role as Shoalhaven's Neurological Nurse

Educator.

We have achieved quite a lot in the short 5 years such as, an integrated multidisciplinary approach to managing Parkinson's in the Community and the home, changes in managing residents in Residential Aged Care Facilities living with Parkinson's, in particular around the issue of "Medication on Time Every Time". We have managed to start a new Nursing specialist service in a regional area, commencement of two Carers of Parkinson's specific Support Groups per month, three Dancercise classes per week for people living with a Neurodegenerative condition and their Carers, the first Tulip Day for World Parkinson's Awareness Day, an Exercise Physiology individualised program for people living with Parkinson's and Community awareness and tolerance.

I will continue to be involved in a number of projects that are ongoing at the moment in the Shoalhaven, in particular around the topic of exercise and Parkinson's, something I am very passionate about as I have seen the positive results first hand.

Though I am sincerely saddened as having to leave the Shoalhaven and the role as Neurological Nurse Educator, I am looking forward to starting the next chapter in my life and hope to see and catch up with you all sometime in the near future.

Wishing you all the best and happiness always.

Your friendship in Parkinson's

Marilia Pereira
(Ex) Shoalhaven Neurological Nurse Educator

OUR NEW NURSES

VINCE CARROLL & SUZANNE BASFORD

Parkinson's NSW is delighted to welcome two new neurological nurses, Vince Carroll in Coffs Harbour and Suzanne Basford in Southern NSW.



Vince Carroll



Suzanne Basford (see next page)

In January Parkinson's NSW welcomed Vince Carroll who joins other Parkinson's nurses across New South Wales as the Neurology Clinical Nurse Consultant for the Coffs Harbour, Nambucca and Bellingen local government areas.

This three year project is funded by a private donor and is a partnership between Parkinson's NSW, North Coast Medicare Local and the Mid North Coast Local Health District. The Parkinson's Support Group and a Coffs Harbour local charity, the 'Pink Silks', are supporting the project by providing a car and services.

The Neurology Clinical Nurse Consultant is a part time position 16 hrs/week. The service will be co-located with the Mid North Coast Brain Injury Rehabilitation and Rural Spinal Cord Injury Services on a health campus site in Victoria St, Coffs Harbour. The service will begin with a focus on the Coffs Harbour region, however it may be rolled out, as far as practical, consistent with the boundaries of the Local Health District and Medicare Local. The position will work with the Health Service, visiting Neurologists and GPs in supporting people with Parkinson's disease and other nominated neurological conditions, keeping patients functioning to individual level and avoiding inappropriate hospital and/ or Residential Aged Care Facility admission.

The project aims to ease the symptoms and financial burdens on those living with Parkinson's disease and other

neurological conditions, their carers, families and the community as a whole by implementing innovative and personalised patient care systems. Vince joins the team at the Neurology Outreach Clinic where Associate Professor Aggarwal visits on a monthly basis. The new position will provide follow up and support for patients who visit the clinic.

Vince has over 30 years experience as a nurse having worked across a variety of clinical and administrative areas within acute hospitals and aged care. Recently he has been working in the role of Clinical Nurse Educator in Aged and Dementia Care, and has completed a Masters in Science (Dementia Care) at the University of Wollongong in 2012.

The project is based on a successful British model, which has seen the creation of an effective network of over 200 Parkinson's nurses throughout the UK. The presence of the Neurological Clinical Nurse Consultant in Coffs Harbour will prove invaluable to the people in the area living with Parkinson's disease and other neurological conditions. It is hoped the position will evolve into a full time role like other positions in NSW.

People with Parkinson's in southern NSW now have access to a neurological clinical nurse consultant. Suzanne Basford, a registered nurse of more than two decades experience, has been running clinics for patients and carers since late last year when she joined the Southern NSW Medicare Local clinical team for the new role.

Suzie is already finding the work rewarding, saying the transition from working in an urban health network in Melbourne to an expansive rural region has been a great experience. "The people I have spoken to from the Parkinson's support groups have been very welcoming and helpful, and happy to have a registered nurse-led service operating in the area".

Suzie had been working in the eastern suburbs of Melbourne as a clinical nurse consultant in infection prevention and control before the Medicare Local tempted her to relocate to the Bega Valley with her young family.

With over 20 years nursing experience in general medical, neurosurgical, residential care facilities, short stay/emergency unit and rapid assessment medical units, as well as a stint in the UK in a day procedure ward, Suzie has nursed people with Parkinson's and understands the challenges.

"Maintaining independence and quality of life is extremely important," she says. "The carers of people with

Parkinson's take on a special role to their loved ones, and support for both the patient and the carer is fundamental to our service."

The service operates three days per week and Suzie has set up clinics in Moruya, Bega and Cooma to cover the large geographical area. She spent time with Marilia Pereira, the clinical nurse specialist in the Shoalhaven, to better understand the role and how best to support people living with Parkinson's disease.

"A doctor's referral is all you need to get an appointment with me," says Suzie. "All the GPs in the region are aware of the service and their feedback has been positive.

"We offer individual appointments for clinical assessment, needs assessment and education and support, as well as referrals to other services as required. Follow up appointments are determined by individual needs, and importantly, support people are welcome at the clinics."

For more information, contact Suzanne at the Medicare Local Bega office on 02 6499 0400 or visit snswml.com.au.

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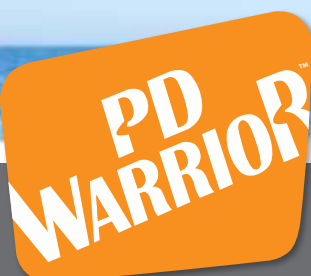
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FUNDRAISING

70TH ANNIVERSARY SANDAKAN DEATH MARCH

Every now and again members of Parkinson's NSW find truly enlightening ways to raise funds to keep our services available.

In May, 2015 Bruce Evans will be participating in a 12 day trek in Borneo to mark the 70th Anniversary of the Sandakan Death March. The original march occurred at the end of World War 2. This walk commemorates the path of those who were forced to participate in one of Australia's worst wartime tragedies.

Bruce's uncle John sadly died during the Sandakan Death March in Borneo in 1945. His official cause of death was malaria, which most likely means he was too weak to continue walking and fell behind. This usually meant

death at the hands of the Japanese. Bruce will be walking the path over a 12-day trek to honour his uncle John. The walk is being organised by Lynette Silver, a noted historian and author of the book Sandakan A Conspiracy of Silence.

Bruce's wife suffers from Early Onset Parkinson's Disease and has been forced to give up work. Bruce believed that this was a perfect opportunity to help raise funds for Parkinson's NSW through sponsorship of the walk.

Look out for updates on his walk and his fundraising efforts in the coming months on social media.

<http://parkinsonsnsw.gofundraise.com.au/page/SandakanMarch>



STRAIGHT AS A ...



On 16 January 2015 Mick Bourke was awarded a world record for the longest time 'planking' in the 75 pounds on your back category. Mick's current world record now stands at three minutes eight seconds; which beat the previous record by three seconds.

Mick performed his world record attempt with an extra two pounds 16 ounces making it 77 pounds 16 ounces or 35kg.

Mick, aged 60, has had Parkinson's disease for over 10 years and was aware of the many health benefits of exercise on symptoms of Parkinson's disease.

Mick was put onto the 30 day planking challenge by his daughter and progressed from the 5 minutes max of the challenge over the next 8 weeks to 25 minutes.

Parkinson's NSW would like to say a huge congratulations to Mick.

To view Mick's amazing record plank head to <http://tinyurl.com/mrjvkuy>

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LOOSEN UP: PRANCING WITH PARKINSON'S

Where did it start?

Dance for Parkinson's Disease is a project that started in 2001 when Olie Westheimer, director of the Brooklyn Parkinson's Group, approached the Mark Morris Dance Centre about the possibility of the centre leading a programme of serious, dance classes for members of her group.

Westheimer knew how valuable the dancers' expertise in balance, rhythm, control and sequencing might be to those with Parkinson's disease. Learning to dance might allow them to push against the physical and creative limitations imposed by the disease. Two members of the Mark Morris Dance Group, with a composer and pianist, began giving free monthly classes for the Brooklyn group. The sessions have since developed into an extensive programme and variations are offered in nine countries.

Why Dance for Parkinson's?

- Dance develops flexibility and confidence.
- Dance is first and foremost a stimulating mental activity connecting mind to body.
- Dance breaks isolation.
- Dance invokes imagery in the service of graceful movement.
- Dance focuses attention on eyes, ears and touch as tools to assist in movement and balance.
- Dance increases awareness of where all parts of the body are in space
- Dance tells stories
- Dance sparks creativity
- The bases of dance is rhythm
- The essence of dance is joy

It Feels Good

Dance is one of the most enjoyable of human activities. Person with PD dance because it feels good. It's fun. Initiating and sustaining sequences of movement does become much more difficult with PD. Persons with PD often discover ways that help them move, such as walking close to another person to feel or "catch" their pace, stepping over lines on the floor to start moving, listening to a rhythm while moving or thinking about a movement before and during the movement sequence. These same techniques enable persons with PD to dance. In fact dancing is often easier for persons with PD than everyday movements. Very similar techniques enable dancers professionally trained in ballet and modern dance to perform movements that are very difficult to learn and execute. In Dance for PD classes®, persons with PD dance together with their dance leaders, using all of these techniques.

Course Leader is Margaret Connor, Occupational Therapist and Accredited Dance Teacher.

For more information you can contact Margaret on 02 4861 2294, 0466 166 866 or email margaretvconnor@gmail.com



Photo courtesy of Amber Star Merkins Dance for Parkinson's



FAMILIES AFFECTED BY PARKINSON'S DISEASE SOUGHT FOR NEW STUDY

Researchers at Royal North Shore Hospital (RNSH) are seeking families affected by Parkinson's disease to participate in an innovative study to determine if an undiscovered gene causes the disease.

Dr Kumar is working with Dr Nicholas Blair and Professor Carolyn Sue. They are particularly interested in seeing patients with multiple affected family members, or those patients who have early onset Parkinson's disease (e.g. they had symptoms prior to the age of 40 years).

Families interested in the study require a referral from their GP or neurologist to the Neurogenetics Clinic at RNSH. The referral should be addressed to Dr Kishore Kumar and Professor Carolyn Sue.

For more information contact the Neurogenetics Clinic on Phone: (02) 94631737, Fax (02) 94631071. Sue Williams is RNSH Parkinson's Clinical Support Nurse and will help coordinate appointments.

FUNDRAISING MOVIE SCREENING

Dance for Parkinson's in association with Parkinson's NSW will be holding a fundraising movie screening to commemorate World Parkinson's Day.

The film *A Late Quartet* is a subtle, intelligent true story, based on the acclaimed Fugue String Quartet, where Peter the group's cellist is diagnosed with Parkinson's and the subsequent uncertainties that follows.

WHERE:

Palace Cinema, Norton Street,
Leichhardt

WHEN:

15 April 2015

COST:

\$35:00 (glass of Champagne included)

For bookings and further information please contact Dahlia Brigham on 0412381849 or via email dahliabrigham@yahoo.com.au

parkinson's
NSW

Dance for Parkinson's
AUSTRALIA

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Freecall 1800 644 189
infoline@parkinsonsnsw.org.au

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St Vincent's
Shushann Movsessian (M)
War Memorial
Shushann Movsessian (T)
Wolper
Shushann Movsessian (W)
Westmead
Deborah England (W)
Concord
Julie Austin (W)

Support Group Coordinator

Antoinette Riley (M-F)
T: 02 8875 8903
antoinette@parkinsonsnsw.org

CONTACT THE INFOLINE FOR YOUR NEAREST SUPPORT GROUP

Freecall 1800 644 189

EXERCISE OPTIONS (from page 8)

To access physiotherapy services:

Public or private hospitals: enquire whether the physiotherapy outpatients department offers services for people with neurological conditions

Private physiotherapists: contact the Australian Physiotherapy Association www.physiotherapy.asn.au and click on the red *Find a Physio* button on the bottom right of the screen) and request the contact details of physiotherapists in your local area with an interest in neurology or aged care (gerontology).

To access fall prevention/exercise classes (which generally are not specifically designed for people with PD, but which may be appropriate for some people with PD, go to the following websites:

www.activeandhealthy.nsw.gov.au

heartmoves.heartfoundation.org.au/

If you require further assistance in accessing physiotherapy services, please call the Infoline on 1800 644 189.

The information provided is for guidance only and is not a substitute for professional medical advice. Parkinson's NSW Inc. takes reasonable care (in the context of freely available information) to keep the information it provides accurate and up-to-date; however, Parkinson's NSW does not guarantee the correctness and completeness of the information. You should confirm that the information is applicable to your circumstances by checking it with your doctor or a qualified health care professional.





Photo courtesy of the Parkinson's Disease Wellbeing Program

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