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JAN CUMMING: ARTIST

For Jan Cumming creativity provides a focus and a distraction with both a reason for sociability and "a room of one's own". Jan was diagnosed with Parkinson's Disease in 2001 which changed her life forever.

Her art relates directly to her life and family, travel, experiences and current issues, striving to be original and different. Paint is her primary medium, as she loves colour and brushwork. Recently Jan is exploring printmaking especially monotypes, varying the format and dimensions of her work to challenge her picture making skills.

In 2011, she won the Contemporary Section of the Lane Cove Art Prize, held an exhibition with a fellow art student and participated in the making of the Lane Cove mosaic. In August 2014, she held a one-person show in the Willoughby City Council's Art Space on the Concourse. A lot of work - but worth the effort.

Jan is a member of Parkinson's NSW Lower North Shore Support Group and elected President for the last five years. Through this group Jan was invited to join the Access Committee of the City of Willoughby (WCC), which meets monthly as an interface between Council and the community. Jan has participated in the WCC Open Studio Weekend every year from 2003, which is a great opportunity for artists in the local area to talk about their work and hopefully make a few sales. A bonus for every artist.



FAREWELL WORDS FROM THE RETIRING PRESIDENT, CHRIS DAVIS



I subscribe to the position that, while I have Parkinson's disease; it doesn't have me.

After four years in the chair at Parkinson's NSW I have stepped down. I don't believe an organisation like ours should have one leader for too long; it poses a risk of too much influence and a single-minded approach.

At the same time, people with Parkinson's will be well aware that stress is no friend to Parkies. The Presidential role carries ongoing pressure and, while I am still relatively well, I would like to reduce stress levels.

I do hope to continue as PNSW's representative on Parkinson's Australia and, at the time of writing, I harbour an optimistic view that we will soon have a national campaigner in Canberra, to fight for the rights of PLWP.

Thanks to the dedication of our staff and volunteers, I am confident that we will continue to provide vital services to everyone affected by PD. Funding is, of course, an ongoing battle and we have had mixed success. In 2015 there will be new initiatives to put PNSW on a stronger financial footing and I urge everyone involved to

help us in whatever way suits your circumstances.

In the ten years since my diagnosis, I've realised that the Parkinson's family is simply a microcosm of the broader Australian community. There is a marvellous esprit de corps and it's good to interact with people who understand your situation. I subscribe to the position that, while I have Parkinson's disease; it doesn't have me. I am going to see more of my grandchildren and will pursue non-PD activities.

I would like to take this opportunity to congratulate Andrew Whitton on his appointment as President of PNSW. I would also like to acknowledge the Board Members for 2014/2015; John Hassett (Vice President), Phillip Maundrell (Treasurer), Graham Dawkins (Secretary), Samuel Chu, Assoc. Prof. Kay Double, Sandra Elms, Colin Hall, Vera Heil, Malcolm Irving, Lloyd Rothwell, John Silk OAM and Rebecca Silk.

May the future for the Parkinson's community improve thanks to PNSW's efforts and I am confident our paths will cross.

Cheers

**Chris
Retiring Chairman,
Parkinson's NSW**



Thank you to Cromwell Property Group Foundation for their generous donation for an online exercise program.

Cromwell Property Group Foundation

It is with delight that I am able to tell you that Parkinson's NSW has received a donation to assist us in developing an on-line exercise program. We are currently working with Assoc. Prof Colleen Canning (Uni of Sydney), Jeremy Horne (Calvary Wellbeing Program), Melissa McConaghy (Advance Rehab Centre) and Dr Natalie Allen (Uni of Sydney) and Christine O'Brien (Physiotherapist and Researcher in Canberra) to develop this program.

Part of the donation from the Cromwell foundation will be used to help develop a new website.

Are you someone who is not actively undertaking exercise? Would you like to share your views on what would lead you to undertake an exercise routine as part of your daily life.

What would be helpful to be included in an on-line exercise program? Email us at pnswn@parkinsonsnsw.org.au, drop us a note, PO Box 71, North Ryde BC 1670 or call 1800 644 189 to share your views.

Maureen Morrison

It is with great sadness we acknowledge the passing of Maureen Morrison from the St George Sutherland Parkinson's Support Group. Maureen was diagnosed with Parkinson's in 1995 at the age of 52 and became involved with Parkinson's NSW by reviewing books for a column in *Stand By Me*. She became a great advocate helping to raise awareness of Parkinson's, speaking to

students at local schools, community groups and aged care facilities. Together with David, her devoted husband, they were regulars at expos and community events.

Maureen will be sorely missed.

Parkinson's Passport

We would like to track the impact of the passport on making hospital admissions easier for people living with Parkinson's disease. A survey has been designed to help us capture your experiences. You can download the survey from our website or you can ring the InfoLine 1800 644 189 to have one posted to you. .

I look forward to hearing your comments.

Her Excellency Professor The Hon. Dame Marie Bashir AD CVO

Parkinson's NSW would like to acknowledge and thank Dame Marie Bashir and Sir Nicholas Shehadie AC OBE, for their patronage to our organisation since 2002.

We would also like to take this opportunity to congratulate Dame Marie on her work as the 37th Governor of New South Wales and wish her all the very best for the future.

Season's Greetings

Best wishes for the coming festive season. We look forward to a happy and productive 2015.

Yours in Parkinson's friendship

Miriam
CEO, Parkinson's NSW

"ON THE HORIZON" FUTURE DRUG DEVELOPMENT IN PARKINSON'S DISEASE

by
Dr Paul Clouston

When neurologists discuss new developments in the treatment of Parkinson's disease it is common to talk about treatments that are 'on the horizon'. The problem is that the horizon can be a long way off. It can take up to ten years of clinical trials and regulatory review for a new drug to be approved for use in people with PD.

Drugs in Clinical Trial

It would be an advantage if the drug was already in use for another medical condition as this would shorten the time required for clinical trials needed for its approval in PD. At the moment there are several such drugs in clinical trial: isradipine a medication already in use to treat high blood pressure also blocks calcium channels on neurons to protect them from damage; inosine that elevates uric acid in the blood and may act as an anti-oxidant; exenatide a drug used in diabetics that may improve energy efficiency in neurons and protect them from damage. All of these drugs have been shown to slow progression in animal models and it is hoped for a similar effect in PD sufferers.

Targeting Alpha Synuclei

The concept of a vaccine for PD is an intriguing one. The neurons affected in PD are characterised by the accumulation of abnormal protein within the cells. This protein

is called alpha-synuclein and is probably toxic to the neurons that accumulate it. Indeed alpha-synuclein may spread from cell to cell within the brain. A vaccine that has antibodies against alpha-synuclein is being tested to theoretically target this protein and prevent its spread. In addition other medications are being trialled that prevent alpha-synuclein clumping within neurons.

Better Delivery of Levodopa

The other area of future interest in PD management is how to better deliver levodopa to the brain. The complication of motor fluctuations due to the 'wearing off' of levodopa can be debilitating. Current strategies including rapid acting oral levodopa (e.g. Madopar Rapid), nevertheless often too slow acting, or subcutaneous apomorphine injections, too cumbersome and inconvenient. These strategies may ultimately be replaced by a very rapid acting inhaled form of levodopa (CVT-301) similar to a puffer used in asthma. As well a pump-patch system of delivering levodopa and carbidopa continuously, under the skin (ND-0612), to reduce motor complications, is also under development.

In summary, although it might take a considerable time, the enormous efforts undertaken to seek further drug treatments for Parkinson's are likely to reap new and exciting breakthroughs

ROLE OF PHYSIOTHERAPY AND OCCUPATIONAL THERAPY IN PARKINSON'S DISEASE



Parkinson's disease is a slowly progressive degenerative neurologic disorder for which there is no cure and which may eventually lead to significant disability. Both physiotherapy and occupational therapy have a significant role in the management of disability in Parkinson's disease.

Physiotherapy is mainly useful in the assessment of gait in Parkinson's disease with the aim of preserving function as long as possible and preventing secondary complications such as falls.

Occupational therapy is useful in helping patients where disability has affected activities of daily living such as feeding, personal care, house-keeping, functional mobility, work and leisure.

Evidence for the utility of both these modalities in the management of Parkinson's disease continues to accumulate.

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PHYSIOTHERAPY FOR PEOPLE LIVING WITH PARKINSON'S DISEASE

by
Dr Natalie Allen, PhD, BAppSc
Physiotherapy, Hons

Research has shown that, even on diagnosis, people living with Parkinson's disease (PLWP) tend to be less physically active than other people of the same age.

While reduced activity is likely to be due to the physical and emotional symptoms of Parkinson's disease, it can also accentuate these symptoms. "Exercise is medicine" has been among the latest catch-cries in the media - and it is recommended that we all should try to be physically active every day.

This physical activity can be in the form of structured exercise sessions - but it can also include incidental physical activity built into our daily routine (e.g., walking to the local shops instead of driving). Neurological physiotherapists are specialists in helping people with neurological conditions, including Parkinson's disease, to undertake

structured exercise and increase their overall physical activity. Structured exercise programs prescribed by physiotherapists have been shown to benefit PLWP in a variety of ways.

These benefits include improved mobility, balance, muscle strength and fitness, as well as a possible reduced risk of falls. As well as these physical benefits, exercise also seems to help with mood, anxiety and cognition. Physiotherapists can tailor the program to suit each individual, their movement problems, personal preferences and goals. Research suggests that early intervention is important to maximise the benefits of physiotherapy and therefore assist PLWP to function optimally.

However, those with more advanced disease can also benefit from physiotherapy programmes. If you have other medical conditions, such as heart disease, arthritis or diabetes, you should also consult your medical practitioner to ensure that structured exercise is appropriate for you.

Physiotherapists with experience in prescribing exercise programs

for PLWP can be accessed in the following ways:

- Public hospitals: Get a referral from your local doctor for a physiotherapy rehabilitation outpatients department at one of your local public hospitals (check to ensure the department caters for people with neurological conditions). The fee for this physiotherapy service is covered by Medicare for Australian citizens.
- Private physiotherapists: Contact the Australian Physiotherapy Association (www.physiotherapy.asn.au) and click on the Find a Physio button on the right of screen) and search the contact details of physiotherapists in your local area using the treatment category 'neurology' or 'gerontology' (i.e. aged care). You can also search for therapists who have their own private rooms, or for those who offer a mobile service (i.e. the therapist comes to you). Private services charge a fee - please request details from the provider.



OCCUPATIONAL THERAPY AND PARKINSON'S DISEASE

by

Katie Balderi BAppSc OT, Hons.

Occupational Therapist, Parkinson's Disease Clinic- Concord Hospital

Occupational Therapy aims to facilitate and increase a person's independence in meaningful activities; this is done by modifying the task or environment to better support a person's occupational performance (*World Federation of Occupational Therapists, 2012*).

The role of an occupational therapist (OT) can be vastly different across clinical settings as well as condition-specific areas; therefore OTs can provide assessment, support, education and therapy in many different ways. OTs working with patients with Parkinson's disease work within many clinical settings and provide acute, rehabilitation, community, outpatient and home based therapy (just to name a few). Most work within hospitals, rehabilitation centres, community centres, outpatient clinics, private practice and home based therapy.

The role of an OT working with people with Parkinson's disease is to review activities of daily living, assess how Parkinson's disease may be affecting participation in these activities, and then assist you to continue to complete, or return to completing these activities. OTs assist you to increase your independence in meaningful activities, usually by modifying the environment, adapting the task or providing you with strategies to make the task easier for you.

Some of the symptoms of Parkinson's disease such as tremor, bradykinesia, dyskinesia, rigidity, and cognitive impairment can all impact on a person's ability to complete activities independently. OTs can provide you with specific strategies to manage different symptoms and maintain independence. It is important to discuss the difficulties you are having to your neurologist and GP, so they can refer you to an OT. Alternatively you can search for an OT on the OT Australia Website.

It is useful to see an OT when you are first diagnosed to familiarise yourself with their role, how an OT can best support you and provide you with strategies to keep you as independent as possible, for as long as possible. An OT can provide an assessment of current function, improvement of skills, introduce new strategies, as well recommend equipment or aids, which aim to increase independence and safety. Areas that OTs assess and examples of recommendations include:

- Personal activities of daily living: Showering, dressing and toileting (e.g. modify the task, equipment, assistance).

- Bed mobility (e.g. cues and equipment).
- Meal preparation, cutlery use (e.g. larger handles), grocery shopping and household tasks.
- Medication management (e.g. Webster pack, alarms).
- Handwriting (e.g. pen with larger grip, using lined paper, resting forearm on table, timing, practice).
- Cognition (e.g. assessment and provide feedback, strategies to compensate).
- Home modifications (e.g. rails at steps or in bathroom).
- Equipment and aids (e.g. shower chair, bed rail, hospital bed, dressing stick, long handled aids).
- Driving (e.g. RMS legislation and referral to assessment if required).
- Workplace assessments (e.g. workstation set up, referral to specialised vocational services).
- Energy conservation.
- Falls prevention (e.g. strategies to reduce falls).
- Carer support (e.g. referral to social services/ counsellor, future care planning information).

Carers of people with Parkinson's disease can also utilise OTs' expertise, to help continue caring, reduce stress and consider alternative strategies to assist in activities. Social supports and a person's engagement in leisure activities is also an important consideration for an OT, and when identified, referrals to other allied health professionals, such as social workers and counsellors, can be made to ensure the psychological and emotional well being of people with Parkinson's disease is addressed.

In summary, an OT is a health professional that can provide assessment, therapy, education and support to increase and maintain a person's independence and safety in meaningful daily activities. An OT works with people and their carers to promote engagement in activities, by managing symptoms, improving on current skills or recommending environmental changes, or task adaptation's to facilitate independence. Early intervention is important; however any OT intervention will aim to support you, your family and carers.

Useful Links:

Independent Living Centre. Catalogue for adaptive aids and equipment.

www.ilcnsw.asn.au

Occupational Therapy Australia: Find an occupational therapist

www.otaus.com.au/find-an-occupational-therapist

References:

Occupational Therapy Australia:

www.otaus.com.au

Parkinson's NSW: www.parkinsonsnsw.org.au

IRISH SCIENTISTS AWARDED MAJOR EU FUNDING FOR PARKINSON'S RESEARCH

by
Dr Gavin Davey



The European Union has agreed to fund an interdisciplinary research program into the fundamental causes of Parkinson's disease. Researchers in the School of Biochemistry and Immunology in Trinity College Dublin, led by Dr Gavin Davey, have secured €3.8 million funding for a prestigious Marie Curie PhD training network project, training in neurodegeneration, therapeutics intervention and neurorepair (TINTIN).

The research focus is on the dopamine neuron and the role it plays in Parkinson's disease, as well as other dopamine related conditions in the brain.

There is an urgent need to produce a new generation of scientists with multidisciplinary skill sets so they can discover the fundamental mechanisms that underlie major diseases and disorders in society. TINTIN will train 12 PhD students and two post-doctoral scientists how to undertake research projects on metabolism, neurodegeneration, computational biology, stem cell biology, neurotherapeutics and neurorepair systems.

The plan is to provide expert training for junior researchers so that they will develop the necessary skill sets required to

make discoveries in how and why neurodegeneration takes place in the Parkinson's brain. Along the way, the participating laboratories in eight universities will work closely with seven companies that specialise in biological discoveries and drug development.

It's been just over two years since the Vatican organised a meeting on *Neuroprotection for Parkinson's disease* where some of the world's leading scientists and clinicians gathered to discuss the latest advances in Parkinson's research. In the Pontifical Academy of Science in Vatican City the participants presented their latest research on neurodegeneration mechanisms, surgical interventions, early biomarkers of Parkinson's and human stem cell interventions. Since then, new therapeutics are

being tested and used by patients with Parkinson's, however, there is still a major deficiency in our knowledge of the fundamental cause of Parkinson's.

The funding of TINTIN is the latest reaction by the EU to address this deficit and the hope is that using this new multidisciplinary approach TINTIN researchers will discover new targets in neurodegeneration that will facilitate repair and regeneration of neuronal systems in the Parkinson's brain.

Prior funding by members of the PAI is gratefully acknowledged by the Davey laboratory in Trinity. It has facilitated basic research over the previous 4 years, enabling new funding to be accessed through EU mechanisms.

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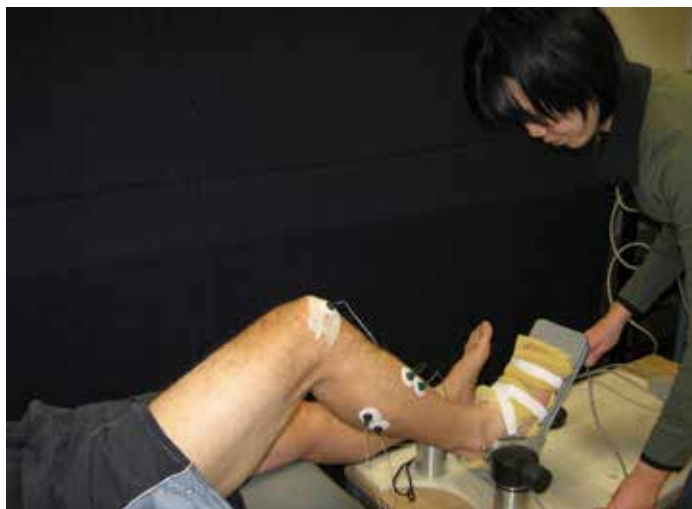
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IS MY CALF MUSCLE MAKING MY ANKLE STIFF?

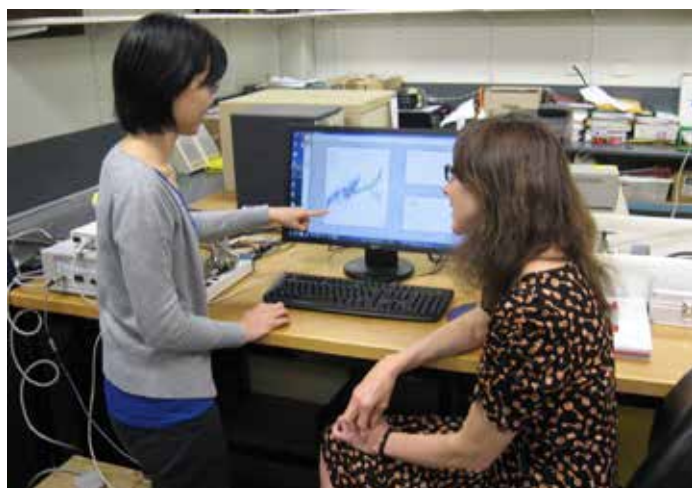
by
Dr Joanna Diong, The University of Sydney

Rigidity is an increase in joint stiffness and is a common symptom of Parkinson's disease, as well as in other neurological conditions such as stroke and spinal cord injury.

People with Parkinson's disease often experience rigidity as muscle tightness or stiffness during movement. The increased stiffness makes moving difficult, and may lead to permanent loss of joint movement, pain, difficulty walking and a higher risk of falls. Therefore, reversing or preventing joint stiffness is a priority in the rehabilitation and treatment of Parkinson's disease.



Ankle stiffness is measured using a custom-built footplate. The foot is firmly secured in the footplate during testing. Surface electrodes are used to check that muscles stay relaxed.



Dr Joanna Diong (left) and Assoc. Prof. Kay Double discuss their research data on ankle stiffness.

The reasons why joint stiffness occurs in Parkinson's disease are not well understood but our recent studies of muscle length and stiffness in patients with stroke or spinal cord injury found that joint stiffness is due to increased calf muscle stiffness or shortening of muscle fibres. We now plan to use these same methods to investigate if muscle length and stiffness is changed in Parkinson's disease. Once we understand why muscle stiffness occurs in Parkinson's disease our longer-term aims are to develop strategies to prevent or reverse these problems.

The research will be conducted by Dr Joanna Diong and Assoc. Prof. Kay Double from the Sydney Medical School, The University of Sydney. Dr Diong is a physiotherapist and Lecturer with a special interest in human movement in neurological conditions, while Assoc. Prof. Double is a neurochemist and Parkinson's disease researcher.

How you can help

We are now seeking participants to help in this new research. You are invited to be involved if you are between 45 to 80 years old and have been diagnosed with Parkinson's disease for at least 2 years. We need to compare our data with healthy people, so you are also invited to be involved if you are between 45 to 80 years old and do not have Parkinson's disease (for example, if you are a partner, relative or carer). Participation involves a one-time visit to a testing centre at the University of Sydney Cumberland Campus at Lidcombe for approximately two hours. We will test your ankle stiffness by moving your foot in a footplate up and down with your knee in different positions, and we will ask you to remain relaxed. We will use surface electrodes only to check that your muscles stay relaxed while we move your ankle. (That is, no muscle stimulation will be given.) If you have Parkinson's disease, you can continue to take your normal medications as usual on the day of testing.

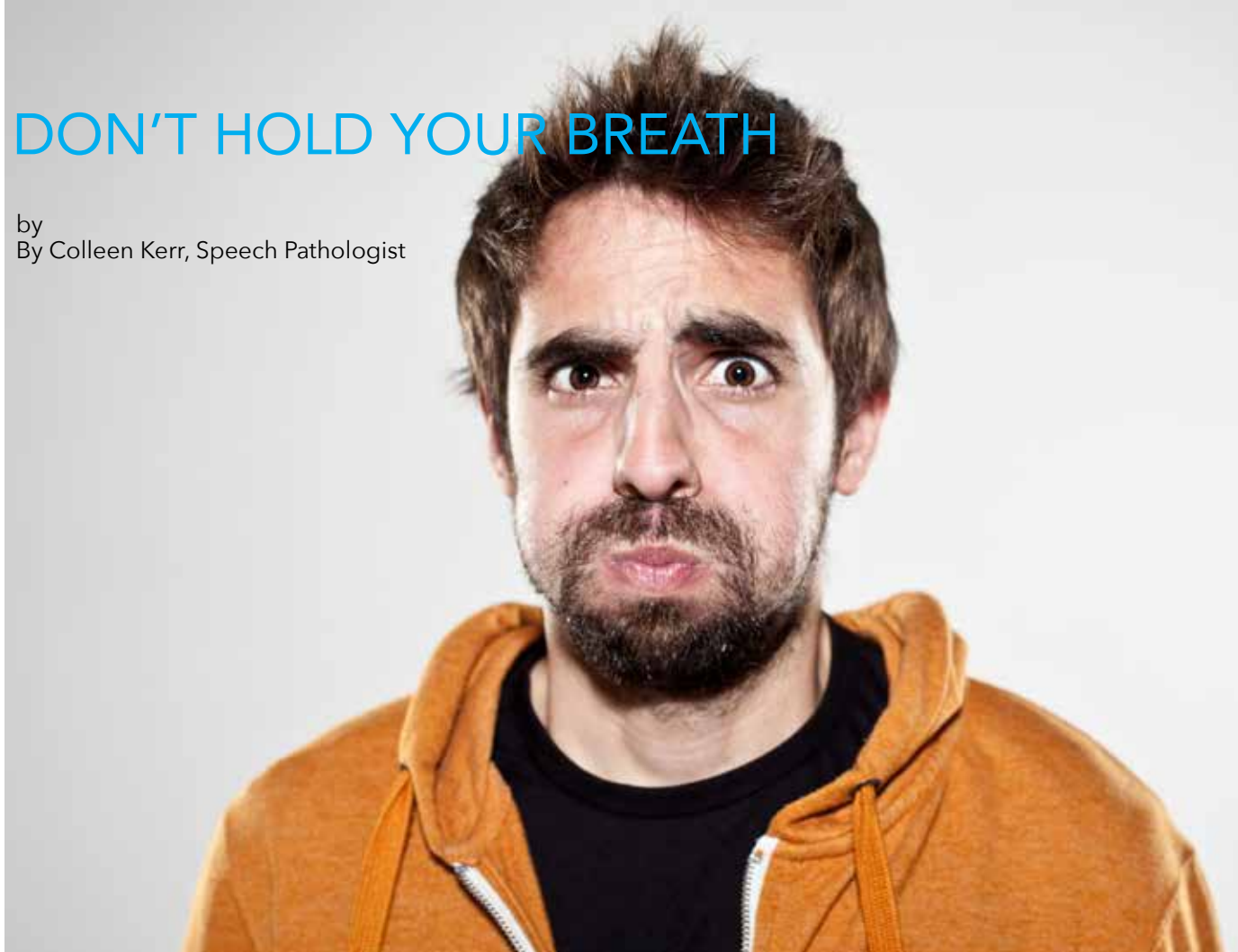
Your participation in this study will help us better understand how muscle length and stiffness changes joint stiffness, and may help us identify strategies to prevent or reverse these unwanted changes in future.

If you wish to participate or to find out more information about this study, please contact:

Dr Joanna Diong
T: (02) 9351 9094
E: pdanklestudy@gmail.com

DON'T HOLD YOUR BREATH

by
By Colleen Kerr, Speech Pathologist



We know that PD is characterised by disrupted movement patterns - but with that knowledge comes power, as new patient-driven treatment approaches emerge.

Movements in PD may become slower, less precise, weaker or rigid - and these alterations to the motor system may also impact on the muscles involved in breathing, coughing, swallowing and voice. For some this may impact on the ability to eat and swallow safely, while others may simply experience some loss of vocal power or perhaps just a sense of not being able to breathe deeply.

Respiratory Muscle Strength Training has emerged from the Sports Science Literature as a well-supported approach for improving exercise tolerance and reducing respiratory fatigue. RMST includes both expiratory (EMST) and inspiratory (IMST) techniques. It has been successfully applied to diverse populations including multiple sclerosis, chronic obstructive airways disease, elite athletes and vocal performers.

Over the past ten years a group of researchers from the University of Florida have devoted their efforts to systematically evaluating the impact of EMST on respiratory function, voice, cough and swallow in PD. Experiments have incorporated a calibrated hand-held device with a one way spring-loaded valve, the EMST-150. The tension in the device can be systematically upgraded

to effectively overload the expiratory muscles in much the same way as you would gradually increase weights in a gym program.

Like all good gym programs, results depend on how often and how hard you work - and the Florida team have devised well-evidenced protocols based on motor learning paradigms. Their device-driven program does require daily discipline but most participants in research studies have reported that it is not time consuming and is relatively easy to use.

And the emerging results are promising. Randomised clinical trials (including 'sham' devices to control for placebo effects) are reporting significantly improved expiratory pressures, improved strength of cough and improved swallow function. Studies looking more specifically at impact on voice and quality of life are ongoing and experimental groups are being tracked to see how the gains hold up over time.

There are contra-indications for this approach so as always any rigorous exercise program needs to be discussed with your doctor and voice professional. The device cost is low and can be ordered online - but it is generally cheaper to source through a local supplier. In Australia the EMST-150 is already up and running as one component of voice projection interventions by some Speech Pathologists so don't hold your breath - make a call.

Reprinted from *Optimal SP Parkinson's News*, Spring, 2013. www.optimalsp.com.au

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LOUISE ZADRO: A GRACIOUS SUPPORTER



Louise with her husband Terry on their 60th wedding anniversary

A High Tea was held at Cardinal Gilroy Village to celebrate Louise Zadro's 90th birthday. The Zadros were both immigrants to Australia from North Italy, arriving in their childhood. They met in Sydney. Mr Terry Zadro was a market gardener and later became a teacher's aid working at West Parramatta School. After he retired he was diagnosed with Parkinson's and lived with the illness for 25 years.

The High Tea was a ladies event. Mrs Zadro led the singing accompanied by her niece on the guitar and her daughters for the seventy guests. Donations were made in lieu of presents to Parkinson's NSW. Over \$2,000 was raised. This is not the first time Mrs Zadro has contributed through her family celebrations, to Parkinson's NSW. Her 50th and 60th wedding anniversary celebrations were also marked with donations to Parkinson's NSW in lieu of gifts.

Mrs Zadro was devoted to her husband. They enjoyed being part of Parramatta/Dundas Support Group for over 20 years and enjoyed the support offered by the group's members.

Mrs Zadro is a keen gardener and runs the garden stall at Cardinal Gilroy Village fete. Singing is her love. She's a gregarious and effervescent lady loved by all, especially her two daughters and their families who hosted the party.

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DON WILCOX

TEACHER & POET



Don grew up in the Coogee/Randwick area and was a Science teacher for 30 years with the last 14 years at Strathfield Girls High School. He led an active life, bushwalking, rock climbing, cross-country skiing, and ice climbing in New Zealand. In 1998, Don was diagnosed with Parkinson's.

He said it gave them a chuckle. "Putting prose to well known songs, then singing them is my passion."

A quotation from Michael Argyles book, *The Social Psychology of Leisure* has inspired Don. Argyles wrote, "the best guarantee of long term happiness is serious leisure that is a hobby or activity that involves the whole being."

Don finds writing very therapeutic and especially being able to express humour and make others laugh. As he says, "Hobbies take you away from your own miseries; it's not wise to be self centred. So give it a try". Parkinson's NSW have published a volume of his poems, *Shaky Stanza's* and *Vibrating Verses*. "I continually donate and have left a bequest to Parkinson's NSW because over the years I have been pleased by their ongoing progress in supporting people to live worthwhile lives. I appreciate their support for research"

Two years later at 58, he had to retire.

After retiring Don began to write. "Since my school days I had always been interested in writing, both prose and verse but never had the time to pursue it. I enjoy writing verses for special occasions and have probably written over 500 pieces."

Don was a member of the Lower North Shore Support Group, starting each meeting with reciting a poem.

Bequests can offer the best of both worlds. You keep full control of your assets without depleting them now, while helping to ensure Parkinson's NSW continues to grow and thrive into the future.

If you would like to find out how you can support Parkinson's NSW for future generations please feel free to contact our CEO Miriam Dixon T: 1800 644 189 or E: bequest@parkinsonsnsw.org.au

In Memoriam and Celebration donations from 1 February to 30 September 2014

In Memoriam

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Gordon Trevanion
Mavis Veigel

Len Ward
Anthony White
Don Williams
Harold Williams
Evyonne Wilson
Graham Wilson

Celebrations

100th Birthday Juanita Victor
50th Birthday Dipen
60th Birthday Angela Hamilton
70th Birthday Pauline Albon
70th Birthday Beth Berman
80th Birthday Marilyn Davis
90th Birthday Louise Zadro
Birthday Geoff Waugh
Birthdays Victor & Carol Grynberg
Birthday Colin Morey
Birthday Cheryl D'Abbara
25th Wedding Anniversary of Dipen & Neeta

RAISING MONEY FOR PARKINSON'S ONE TREAT AT A TIME

Sweets by Sweets is a student group from Macquarie University who run events for those with a sweet tooth and a commitment to social justice. Raising funds for charities, one bake sale at a time!

Sweets by Sweets have held a Pancakes for Parkinson's event two years running to help raise funds and awareness for Parkinson's NSW. The group regularly raises around \$200 and helps highlight the need for younger people to understand the disease as well as raise funds for the research.

Parkinson's NSW would like to thank Belinda Harris and the entire Sweets by Sweets group for holding a Pancakes for Parkinson's event at Macquarie University.

If you would like to hold a Pancakes for Parkinson's event at your school or workplace please contact the InfoLine 1800 644 189



THE UNIVERSITY OF
SYDNEY

THE 1000 NORMS PROJECT

Are you over 30?

Be a part of our project investigating how physical ability changes across the lifespan:

The project will provide valuable information about healthy ageing and development. Results will form a database of normal values that will assist disease management around the globe. Personal details are not shown.

1000 healthy volunteers are needed to take part!

If you consider yourself reasonably healthy for your age you may be eligible.

Participation involves 2-3 hours of your time once only at The University of Sydney Cumberland Campus in Lidcombe.

During the assessment you will perform basic physical tests and complete several questionnaires. You will also be invited to provide a saliva DNA sample to investigate the 'gene for speed' (no disease risk associated with this gene). Travel reimbursement is available.

Interested?

Please contact Marnee or Jennifer
T: 02 9036 7435 to register your interest
E: 1000.norms@sydney.edu.au



@1000Norms

1000 Norms Project

FIGHTING BACK AGAINST PARKINSON'S DISEASE

by Jim Preece
Action Potential Physiotherapy

PD Warrior is an exercise-based treatment program helping people to fight back against Parkinson's disease. PD Warrior is now available to people living with Parkinson's in the NSW Far North Coast region, who until now have had little or no access to any specialised services for Parkinson's.

What is PD Warrior?

PD Warrior is an exercise program developed by specialist neurological physiotherapists at Advance Rehab Centre in Sydney, based on the latest research into exercise and PD. PD Warrior integrates elements of high effort exercise, large amplitude movements and complex physical and mental 'multi-tasking' into a combination of home exercise program and challenging circuit class. Boxing while counting backwards in sevens or marching while turning an arm crank and naming the countries in Europe are typical sights in a PD Warrior circuit class. Working on these challenging and complex exercise combinations translates into PD symptoms improving and everyday movements becoming easier.

How does it work?

PD Warrior addresses the primary impairments of PD directly by engaging and challenging the movement pathways and cells in the basal ganglia. This drives neuro-plastic and neuro-restorative changes in the basal ganglia, as well as normalising central motor output. In other words, it can 're-wire' the brain and dramatically improve the symptoms of Parkinson's. Moreover, exercise induces production of endogenous neurotrophic factors in the brain, resulting in a neuro-protective effect and potentially slowing down the progression of the disease. Currently, exercise is the only intervention we know of with this potential to actually alter the disease course.

Research clearly shows that sedentary behaviour actively contributes to and accelerates degeneration in PD, so the earlier people with Parkinson's start exercising, the better. PD Warrior hopes to create a paradigm change in the management of early PD, whereby people are seen as close as possible to the time of diagnosis to maximise the window of opportunity and disease reversibility. It is important to



emphasise that to achieve the levels of motor output required to drive neuro-plastic change, and hence to get the most out of PD Warrior, an optimum regime of PD medications is essential.

PD Warriors

Iffat Farah is a retired university professor from Ballina who was diagnosed with PD in 2012: "At first my left arm wouldn't 'go'. Not being able to swing the arm and feeling that the arm was heavy came first, and that started affecting my walking. I love walking, but I can't walk as fast as I could. Next was pain in the shoulder, then came tremors in my hand, followed by my fingers becoming tight and 'claw like'. It affected my confidence in what I can do." Iffat started PD Warrior in April this year and she now does the exercises six days a week: "Each movement is very specific and is helping me, where there is rigidity, for example. Some exercises I found very difficult with coordination at first, but today I can do them without thinking, and I realise 'my leg and arm are really moving as they should move!' I notice that on the days I have done the exercises, I walk better. I think I have more confidence, because the more I push myself in the exercises and don't topple over, I feel like 'oh, I can do this! I can push myself'. I know it won't cure me, but it will make my life better."

Another recent PD Warrior is a 52 year old high school teacher, who contacted me one week after being diagnosed with PD. Her main concern was right hand tremor, which made it impossible for her to write on the white board, to the point where she had resorted to writing left-handed. After 2-3 months of exercises she reported that her tremor was not even recognisable most of the time and she was again able to write legibly on the white board. By controlling and

improving her symptoms with exercise, she has also been able to delay starting on Parkinson's medications.

Exercise as Medicine

Dr Bob Lodge is a Specialist General Physician practicing at Bangalow Consulting Centre. He believes that physiotherapy for PD has been under-recognised and under-utilised: "The results to date - and I've probably referred about 8-10 patients to PD Warrior - have been all positive for a start, and there have been a couple of quite dramatic improvements in patients. The dramatic improvement has been not only in their functional capacity, but also in their confidence that they can self-manage this condition or deal with it using methods other than just medications, and that does give people a huge amount of confidence.

"PD Warrior, now that it's available in our region, should be openly and warmly embraced and considered for all patients with a recent diagnosis and during the first few years of therapy. It would be really useful if GPs

thought 'PD Warrior' at the same time as they were thinking 'L-dopa'"

We can't afford to understate the role of exercise in improving mobility, confidence and quality of life in PD. Exercise is medicine & we need to start prescribing it correctly. PD Warrior is about getting people to take control and fight back against PD so they can continue to live active and full lives.

About Jim Preece and Action Potential Physiotherapy: I am a physiotherapist with a special interest in Parkinson's disease, having spent 8 years working with a specialist Parkinson's team on the NSW Central Coast. I moved to Mullumbimby earlier this year to bring PD Warrior to the NSW Far North Coast. Action Potential Physiotherapy is my mobile service covering the Ballina, Lismore, Byron and Tweed areas.

For more information, contact Jim Preece at Action Potential Physiotherapy on 0403 880817,

www.actionpotentialphysio.com actionpotentialphysio@outlook.com.

PD WARRIOR™

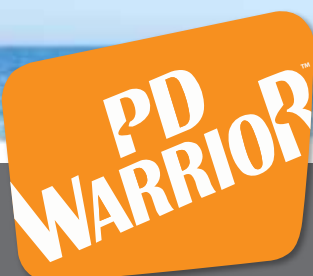
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- Re-train your brain
- Get back into life!

PD Warrior™ is a unique exercise program designed to fight the symptoms of Parkinson's disease



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UNITY WALK & RUN

The 7th Annual Parkinson's NSW Unity Walk & Run, held on Sunday August 31st, was once again a great success.

Since its inception, this event has become an eagerly awaited fixture on the sporting calendar, attracting a growing numbers of top athletes, participants, fundraisers and sponsors. This year, total attendance was 2100 ensuring that 2014 was our biggest event to date.

The winner of the men's 8km run was Richard Roberts who ran the 8km in just 27minutes and 40 seconds. The women's winner, for the second year running was Jenny Blundell. Jenny has represented Australia at World Youth & World Junior level and represented Australia at the U/21 tour of Germany.

The walk was also an amazing success with one walker in particular Lloyd Rothwell setting himself the challenge to walk 40km on the day along with two of his best mates in honour of his father who passed away at the beginning of the year. Lloyd was cheered on by his family, friends and crowd as he crossed the finish line after an emotional 40km walk.

Entertainment was provided by the Sydneysiders Express and the Parkinsons Choir with more children's activities and entertainment than in previous years.

The fundraising winners

Team fundraiser.

WINNER: The St George/Sutherland Support Group raising \$16,289.

Everyone who raised \$150 and more received a ticket to a prize draw. The winners, **Shannen Perry** received a \$200 voucher from Outback Steakhouse and **Nicole Charwood** won a session with a Bendigo Bank Financial Planning Investment advisor, up to the value of \$1,500.

Top individual fundraisers

Andrew and Karen Whitton raised more than \$11,000 and won a 10 lap Formula Ford Experience donated by William Powers Racing.

Other invaluable support was provided by fundraisers who made more than \$2,000 each

Lloyd Rothwell
Jody Collins
Adrian Unger
Lindsay Burton
Garry Lobb
Ella Martin
Colleen Bartley
Erin Louise
Kellie Mork
Gina Russell.

Sponsors include loyal presenting supporter Bendigo Bank whose support, since the first Unity Walk, has enabled Parkinson's NSW to begin a Research Grant program. Proceeds from the Walk & Run helps finance researchers to understand, improve treatment and ultimately find a cure for Parkinson's.





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DO YOU HAVE MOVEMENT DIFFICULTIES THAT INTERFERE WITH YOUR ABILITY TO MANAGE DAY-TO-DAY ACTIVITIES?

The University of Western Sydney has a new study that is examining whether different types of cues (internal and external) can help people with Parkinson's Disease initiate motor movement.

The first stage of this project is to understand how cues influence movement and you are invited to participate!

How will the project work?

You will be asked to complete a 2-hour computer-based session. During the session you will be exposed to three different types of stimuli:

- internal cues (to imagine a cue before executing a movement)
- external cues (to execute a movement when you see a red dot); and
- no cue

and you will be asked to tap on a key with your finger in response to the cues.

You will receive training at the start of the session. This will enable you to practice the finger tapping sequences for each of the different cues. Rest breaks will be provided throughout the session as necessary. The researchers will record the accuracy and reaction time of your responses.

This session can take place at the University of Western Sydney, Campbelltown campus, or at a venue convenient to you. As part of your participation, you will be asked to give simple demographic information including your age, gender and previous medical history.

Who can join the study?

You are invited to participate if you:

- Have been diagnosed with Parkinson's Disease;
- Have a mild to moderate severity of Parkinson's disease;
- Do not have problems in attention, comprehension, and short-term memory functions.
- You will undergo a short screening to confirm your eligibility. The estimate time required is 15 minutes.

Our participants will be reimbursed with \$30 to compensate for their time and travel cost.

For more information, please contact:

Dr. Karen Liu, Associate Professor of Occupational Therapy
T: 02 4620 3432 or email at: Karen.Liu@uws.edu.au

Dr. Michelle Bissett, Lecturer of Occupational Therapy
T: 02 4620 3754 or email at: M.Bissett@uws.edu.au

THE BIG RIDE 4 PARKINSON'S

Each year hundreds of bikers set out from Sydney Olympic Park, along Olympic Boulevard for the 360 km Big Ride to Parkes. They will be on Harleys, Victories, Triumphs, Hondas, Kawasakis, Yamahas and Beamers but they will all have one destination in sight - The Big Dish - Parkes for Parkinson's.

All bike enthusiasts, from weekend warriors to corporate cowboys. From members of Ulysses to Long Riders and anyone who just loves those weekend rides to nowhere.

The Big Ride 4 Parkinson's was a concept that Parkinson's NSW developed when two motorcycle riders Mark Atherton and Bruce Davis from Tenebris Veneficus approached PNSW to help raise funds and awareness for Parkinson's disease. The two riders worked closely with the charity to develop the two-day road trip, which will be a memorable experience for all



REGISTER NOW



who participate. Parkinson's NSW thanks the boys for their input and their enthusiasm for a great cause.

The journey will take the riders across the Blue Mountains via Blackheath, Lithgow, Bathurst and Orange and on to the 'Big Dish' where the bikes will form a 'fishbone' cavalcade of honour right up to the radio telescope for the 'money' shot. From there the cavalcade will proceed to the Parkes Showground for a special evening function featuring food, entertainment and an opportunity for locals to come out and view the bikes, greet the riders and join in the festivities. Along the way there will be stopovers in major centres with locals in those areas coming out to support and cheer on the participants

Visit <http://thebigride4parkinsons.gofundraise.com.au/> for more information on the event.



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CONTACT THE INFOLINE FOR YOUR NEAREST SUPPORT GROUP

Freecall 1800 644 189

The office closes over Christmas and will reopen 5 January 2015

REGISTER NOW



JOIN US FOR
The Big Ride 4 Parkinson's
FROM SYDNEY TO PARKES

14 & 15th March, 2015

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NSW IN THIS TOGETHER

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Dancing for Parkinson's
Another great exercise routine



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