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Research Issue

Seed Grants

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The inaugural Big Ride 4 Parkinson's – a great success.

On Saturday May 4, 111 Big Ride bikers set out from Sydney Olympic Park, along Olympic Boulevard for the 360km Big Ride to the western NSW town of Parkes and the iconic Big Dish, made famous in the movie The Dish.

The journey took them across the Blue Mountains via Blackheath and Lithgow, to Bathurst and Orange then on to the Big Dish with the bikes forming a 'fishbone' cavalcade of honour right up to the radio telescope. We called this the 'money' shot.

From there we proceeded to the Parkes Showground for a special Saturday evening function with food, entertainment and an opportunity for locals to come out and view the bikes, greet the riders and join in the festivities.

Everyone had a fantastic time including a rocking performance by Angry Anderson at Parkes Showground.

We would like to thank all of our sponsors and supporters and of course, most importantly, our riders! A special mention goes to Mark Atherton and Bruce Davis from Tenebris Veneficus who originally approached PNSW to help raise money and awareness.

Major Event Sponsors

Fraser Motorcycles
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We had just under \$8000 of prizes and giveaways. The companies who donated were:

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Woolworths Petrol
Mercure Kooindah Waters
Ventura

To view photos of the event please visit the Parkinsons' NSW facebook page. <http://on.fb.me/10od70o>

National Disability Insurance Scheme becomes DisabilityCare Australia

by Christine Regan

At National Level

The National Disability Insurance Scheme (NDIS) legislation passed through both houses of Federal Parliament in mid-March and has now been signed into Australian law by the Governor-General.

NCOSS welcomes the new legislation and along with the NSW Disability Network Forum, will continue strong advocacy to improve both the provision and implementation of the NDIS for people with disability in NSW.

And the NDIS has a new name, DisabilityCare Australia. NCOSS has joined with many in the disability sector, both nationally and locally, in decrying the new name. It harks back to a time of segregation and compassion rather than the inclusion and control that the objectives and principles of the NDIS promote for people with disability.

In summary, the NDIS legislation provides that an eligible person with disability becomes an NDIS participant and may receive a funding allocation which can be used to purchase necessary and reasonable supports according to an approved individualised plan. Also, a person with disability not requiring funding can go to the NDIS for advice and referral to mainstream and other supports. The Objects in the NDIS Act speak of the importance of the person's choice and control, the independence and social and economic participation of people with disability, the United Nations Convention on the Rights of Persons with Disabilities and important Australian legislation. The Principles

in the Act reflect the person's rights, their participation and contribution, their need for support and certainty and other principles afforded to other people in society.

The NDIS legislation has undergone many changes since its initial exposure draft. The finalised version contained 78 amendments which clarified, altered or added clauses to the Act. Notably, the upper limit age entry criterion of 65 years for participants has been confirmed.

The Objects of the Act have been re-ordered to prioritise people with disability. The Act now includes a clause covering principles for people who act on behalf of children, as well as principles for the NDIS Agency in relation to participants' plans. There are refinements to the disability and early intervention requirements and their application in the Rules. These requirements are the criteria under which a person with disability can become participant of the NDIS. There are some changes around participants' plans as well as to registered providers of supports.

Other amendments involve the establishment of the roles, operation and reporting requirements of "reviewing and scheme actuaries". NCOSS understands that this means the actuaries will collect and report on data that describes the financial status and sustainability of the NDIS as well as the numbers of people with disability, what types of supports they are using and projections. There are amendments involving decisions of the Agency Board and between Commonwealth and State and Territory jurisdictions. Regarding children with disability, there is now an obligation under the NDIS that actions are undertaken "in the best interests of the child".

Disability advocates have had a win with the amendment that deletes the word "severe" from the clause involving the suspension of a nominee in cases of physical, mental or financial harm. Another significant improvement is in the area of compensation. People can now choose to transfer their right to seek compensation to the NDIS Agency to take such an action on their behalf.

Importantly, there is a separate amendment included in the legislation that now recognises the importance of advocacy to support people with disability under the NDIS.

Unfortunately, the amendment does not stipulate the independence of that advocacy from the NDIS system. NCOSS and the NSW Disability Network Forum will continue to promote and advance the need for independent advocacy and information to support people with disability and their families and carers to promote choice and control as well as inclusion and participation in everyday life.

The NDIS legislation gives effect to the Rules, which will be the mechanism by which the legislation is implemented. The Rules accompanied the legislation on its passage through Parliament. A Rules Discussion Paper immediately preceded the release for consultation of seven sections of Draft Rules covering eligibility, plan management, supports, information, providers, children and nominees. NCOSS is informed that, now the amendments are finalised, the Rules will be changed accordingly. The NSW Disability Network Forum response to the Discussion Paper is available at <http://bit.ly/16dKtyN> and the NCOSS response to the Draft Rules is available at <http://bit.ly/12Xlf3T>

While the NDIS Act provides for a two year review, NCOSS is assured that the Rules can be amended over time, much more easily than the legislation. Underpinning the Rules will be the Operational Guidelines that will provide much more nationally consistent detail for the NDIS Agency.

At NSW Level

The NDIS continues to gather speed towards the commencement of the Launch site for 10,000 people with disability in the Hunter from July 2013. The Hunter Launch will be staged according to locations with Newcastle commencing in the first year, followed by Lake Macquarie in the second year and Maitland in the third year. With the passage of the NDIS legislation and the establishment of the NDIS Agency in the Hunter, recruitment is underway for Agency staff in time for the start date.

The long awaited Ability Links auspice has been announced by Minister Constance. The first regional area to commence will be the Hunter area and the new auspice has been awarded to the St Vincent de Paul Society. The Ability Links Program will form part of the Local Area Coordination functions under the NDIS.

The historic Heads of Government Agreement signed on 6 December 2012 establishes that the full NDIS will roll out for all eligible people with disability in NSW from July 2016 to be completed by 2018. NSW is the only state with such an Agreement at this time. Minister Constance has said he is keen to continue with the Stronger Together Plan to implement individualised portable funding arrangements from 1 July 2014 and that this will inform the implementation of the NDIS in NSW and Australia. As part of the Heads of Government Agreement between the Commonwealth and NSW, \$6 billion will be spent on the NDIS in NSW. Part of this Agreement

involves in-kind contributions from NSW including EnableNSW, the Assisted School Student Transport Scheme and some TAFE activities. NCOSS is advised that the exact nature and scope of the in-kind contributions will be finalised by mid-July 2013.

The NSW Disability Services Act and associated legislation was under consultation in February under the banner Reforming NSW Disability Support. NCOSS is advised that the resultant draft legislation will be available for comment later in the year. The NSW Disability Network Forum response to the Discussion paper is available at <http://bit.ly/17q4LDO>

STOP PRESS NDIS

Full NDIS for SA

On 18 April, the Australian and South Australian Governments agreed to roll out the full NDIS, DisabilityCare Australia, to all 33,000 eligible people with disabilities by July 2018. This builds on the SA NDIS Launch from July 2013 focussing on children aged up to 5 years, and up to 14 years progressively over the 3 year period of the Launch.

Full NDIS for ACT

On 19 April, the new agreement between the Australian and ACT Governments guarantees the full NDIS, DisabilityCare Australia, beyond the ACT Launch. ACT will progressively implement DisabilityCare Australia for 5,000 people by July 2016 and provide certainty after the Launch concludes.

NDIS Launch for NT

On 19 April, the agreement between the Australian and NT Governments establishes an NDIS DisabilityCare Australia Launch in the Barkly region from July 2014 for 6,500 eligible people with disability. This will provide valuable experience in implementing DisabilityCare in remote areas to inform future roll out across Australia.

Full NDIS for Victoria

On May 5, the Australian and Victorian Governments reached an agreement to roll out the full NDIS or DisabilityCare beyond the Barwon launch site across Victoria by July 2019. This is expected to benefit approx. 100,000 people with disability in Victoria.

Article supplied by NCOSS News May 2013

DisabilityCare Australia: new name but old attitudes?

There is so much in a name and so much hope in the National Disability Insurance Scheme (NDIS). The scheme has the very real potential to significantly change the lives of people with disability by including and empowering them, protecting their rights and building their strengths as equal and contributing members of society.

But now the scheme has been renamed DisabilityCare Australia. People with disabilities and their families want resources, opportunity, choice and control to enable them to enjoy their rightful place in an inclusive Australia. Not an Australia that views them as just people in need of care. This has been the persistent and patronising aspect of the past and current broken system and this is what the NDIS can change. The NDIS is a momentous initiative for people with disability and their families. Let's not defeat its worthy aims by belittling, even inadvertently, the very people it seeks to empower. The new name is both patronising and self-defeating.

John Le Breton
Chief Executive Officer

Greystanes Disability Services

FROM THE PRESIDENT



Some water has travelled under the bridge since my last column; we met with Parkinson's Australia (PA) and agreed that our top priority is to work for the overall good of the Australian Parkinson's community.

Accordingly, negotiations about the future structure of our organisations are shelved until October, after the election. We agreed that Parkinson's NSW (PNSW) will not use the name Parkinson's Foundation of Australia, at least until after the election; and we also agreed to join forces for a major lobbying campaign, leading up to the September Federal Election. For that purpose, a 50:50 partnership, dubbed the Parkinson's Alliance, has been formed between PA and PNSW.

A steering committee of four has been set up and a strategic plan for the election formulated. Step one was to attend a budget breakfast in Parliament House on the morning of 16th May, to hear from Health Minister Tanya Plibersek and Mental Health and Ageing Minister Mark Butler. We had hoped to meet them there, but a division was called in Parliament, so all MPs raced into the House and a meeting was not possible.

Step two, on the same day, was to visit Liberal MP, Josh Frydenberg and Minister Butler's adviser. Both gave us a sympathetic hearing and Josh Frydenberg invited members in his electorate of Kooyong to meet him for tea at his

office. At the time of writing, we were awaiting appointments for a second round of visits.

Our key campaign goals are to:

- remind the Coalition that it promised \$50m over four years to expand the Dementia program, to include other chronic degenerative neurological conditions such as Parkinson's disease
- seek a matching commitment from Labor
- push for recognition of Parkinson's as a priority chronic disease nationally
- request a four-year commitment to placing 100 or more specialist neurological nurse educators around the country
- achieve better services for people who are diagnosed with PD at a relatively early age.

In pursuing these, and other lesser goals, the help of Support Groups and members generally is going to be crucial. Initially, making contact with your local Member and explaining our problems and goals will be enough to ensure awareness; but the energy behind the campaign may have to be increased if we don't make tangible progress quickly.

The time for Parkinson's to be a neglected problem has passed – with your help, we can put it in proper perspective and ensure better support for those affected.

Chris Davis
President
Parkinson's NSW

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*Westmead Clinic on Wednesday

** Concord Hospital
Clinic on Wednesday

***War Memorial Hospital
Clinic on Tuesday

FROM THE CEO



The InfoLine continues to be a good source of information on Parkinson's. Our nurses are able to provide information on symptoms of Parkinson's disease and general information about medication and treatments.

The InfoLine can now be accessed by mobile. Call the InfoLine if you have concerns or questions about diet or medication.

Our Recently Diagnosed Program for people who have had a diagnosis in the last 12 months was held over two days and featured information on living with Parkinson's disease, treatments, medication and exercise. If you have been recently diagnosed, or know someone who has and would like to attend this program please call the InfoLine to register 1800 644 189.

If you are new to Parkinson's NSW and would like to visit our office and meet the staff, why not book in for a coffee morning information session. Call the InfoLine to register.

With the upcoming Federal election,

the need for Parkinson's awareness is greater than ever. The Unity Walk and Fun Run are always looking for people to share their story. If you would like to help us raise awareness by sharing your story in your local paper or on radio, please call the InfoLine or go to the web and download the form. You can fax or email it back to the office.

With Volunteers' Week in May, we would like to extend a huge thank you to all our volunteers whether you work on our events, in the office or with our support groups. Parkinson's NSW could not survive without your support!

Surgical Intervention Seminars have been held in Springwood, Dapto and Gympie with the support of Medtronic. These seminars provide an opportunity for people to gain first hand understanding of Deep Brain Stimulation – the positives and the negatives.

Unity Walk and Fun Run

This is our 6th Unity Walk and Fun Run so please help to make it the best ever. Held on Sunday 25 August we are once again being provided with free travel by the State Government. I look forward to seeing as many of you as possible at Olympic Park.

Miriam Dixon
CEO, Parkinson's NSW

Research Grants



The Hon. Victor Dominello MP &
Assoc. Prof. Colleen Canning



Professor Michael Kassiou



Assoc. Prof. Simon Lewis



Dr Nicolas Dzamko &
Chris Davis

World Parkinson's Day Life Members Morning Tea & Presentation to Research Grant Recipients

This year we held our morning tea in the Strangers Dining Room at State Parliament House. We were thrilled to be able to announce seven research grant recipients to the value of \$228 576.

We were assisted this year with a substantial bequest from a member of Parkinson's NSW for research. This year also saw the announcement of the inaugural Bendigo Bank Research Grant, awarded to Assoc Prof Simon Lewis.

Each year we call for expressions of interest from the scientific community. Ads are placed in the Sydney Morning Herald and with research institutions. An independent panel of leading researchers in the field assess the scientific value of the expressions of interest and make funding recommendations.

The successful recipients are:

Bendigo Bank Research Grant

Associate Professor Simon Lewis

Unity Walk Research Grant

Associate Professor Colleen Canning & Dr Jooeun Song
Marie Jönsson PhD

Seed Grants

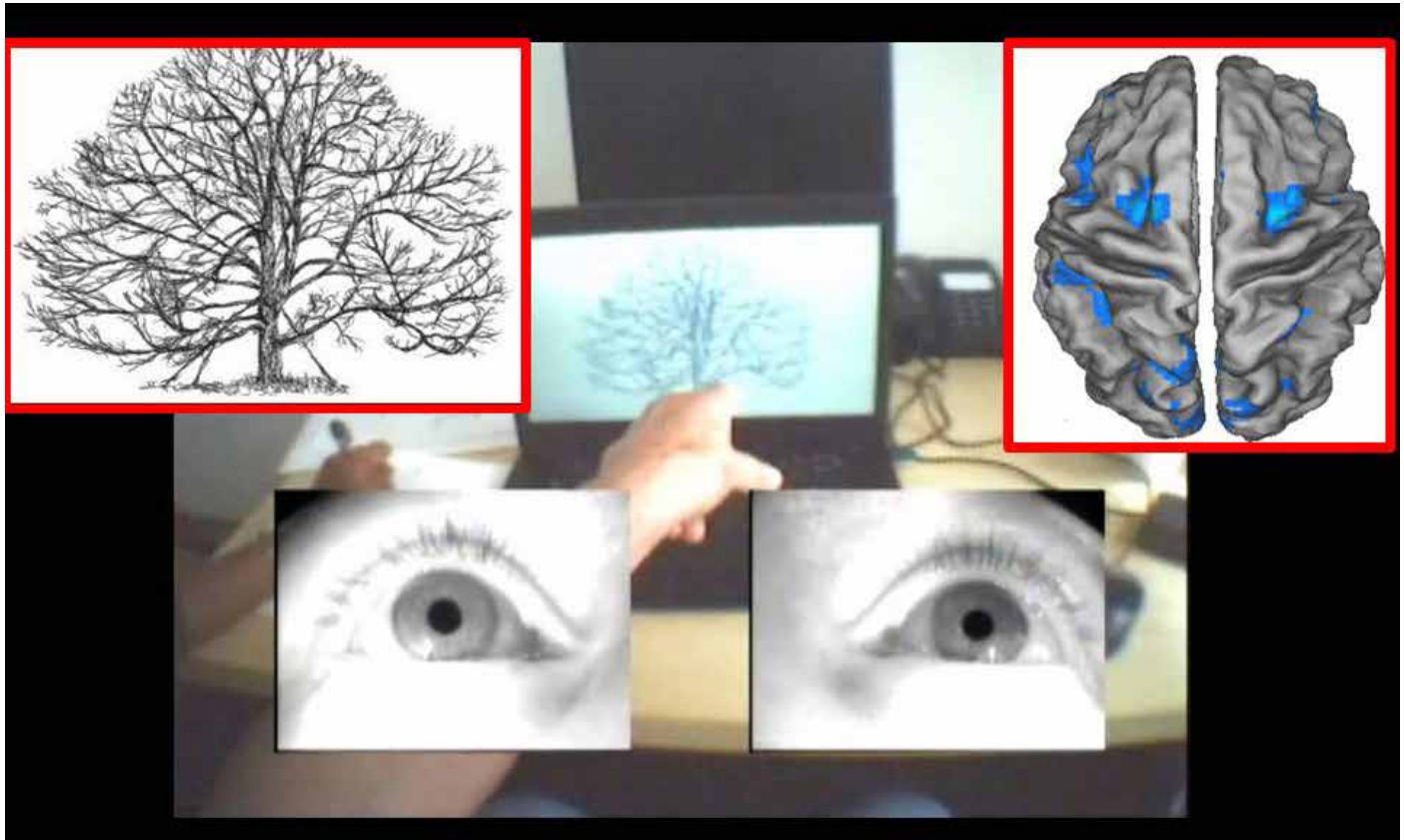
Associate Professor Kay Double
Associate Professor Sharon Naismith
Dr Nicolas Dzamko
Professor Michael Kassiou

Tricks of the Mind

Understanding Visual Hallucinations in Parkinson's disease

Bendigo Bank Research Grant

By Associate Professor Simon Lewis, Brain & Mind Research Institute



This figure shows the 'first-person' perspective of a subject with Parkinson's disease performing the Bistable Percept Paradigm, with two small cameras 'tracking' the movements of each of their eyes (displayed in the bottom half of the image). The insert in the top-left of the screen shows the image that the subject is asked to interpret for the presence of 'hidden' images, of which there are none in this picture. The insert in the top-right of the screen shows the pattern of decreased brain activity seen when subjects who 'hallucinate' (see something that isn't there) are compared to the subjects who perform the task effectively. The pattern of brain activity missing in these patients maps onto those regions we normally use to 'focus' our attention.

Visual hallucinations and the development of psychosis (e.g. paranoia, mistrust) are a major cause of distress in Parkinson's disease and often lead to a loss of independence. Initially, the symptoms may be mild, perhaps just sensing a presence out of the corner of the eye. However, in the advanced stages of disease patients can experience well formed and often disturbing images that seem very real. Unfortunately, a poor understanding of the mechanisms underlying visual hallucinations in the brain has severely limited progress in the development of effective therapies.

Recently, our research team has proposed a model that suggests visual hallucinations arise from failing networks across the brain. Normally these networks process available information and allow individuals to make correct responses to what they are seeing. Imagine walking home in the dark after watching a frightening movie – every tree could represent a shadowy threat. However, the brain kicks in and allows you to rationalize that you live on a tree-lined street. In Parkinson's, we believe that the brain's networks intermittently "break down" when having to deal with this type of processing, allowing the mind to play tricks, which results in the emergence of disturbing hallucinations.

To test our hypotheses, we have developed a computer based test that can trick the brain. We have shown that performance on this test can discriminate between patients with and without hallucinations. Furthermore, we have been able to correlate the performance of patients on this test with the severity of their hallucinations and

demonstrate how this relates to changes in the structure and function of specific brain regions using MRI scanning.

When patients develop troublesome hallucinations they often need to reduce their Parkinson's medications. This suggests that dopamine may be affecting the failing networks that underlie this symptom. If we could understand how dopamine is affecting these networks to "drive" hallucinations then we hope to be able to develop more effective treatments that will stop patients entering nursing homes.

With support from a Parkinson's NSW Seed Grant funded by the Bendigo Bank, our upcoming study will perform MRI scanning in patients with hallucinations once 'on' their dopamine treatments and once having stopped their regular Parkinson's medications overnight. Comparing these pictures will allow us to see which areas of the brain are being affected by the treatment, giving us vital insights in to how the brain's networks are "misfiring" to cause hallucination.

If you would like to help with this study please contact us:

The Parkinson's Disease Research Clinic
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Email: pd.clinic@sydney.edu.au
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Stepping training in Parkinson's disease

Unity Walk Research Grant
by Dr Joeeun Song and Associate Professor Colleen Canning

A randomised controlled trial of an interactive video game



This new study led by Associate Professor Colleen Canning has been funded by Parkinson's NSW and is about to commence.

Most people with PD will develop balance problems and suffer falls as the disease progresses. The ability to make a quick step is critical to maintain balance, avoid an object or turn to a different direction as well as prevent falling.

Recently, Professor Stephen Lord and his research team at Neuroscience Research Australia has demonstrated that home-based stepping training using an interactive videogame is effective in improving stepping performance in older people living in a retirement village, thereby reducing fall risk. This interactive videogame program uses a modified Dance Dance Revolution (DDR, Konami).

To play the game, the person stands on a mat marked with targets and makes rapid step responses in the direction indicated by randomly presented arrows displayed on a computer screen. The DDR videogame has built-in motivating features and instant feedback on performance, thereby enhancing its potential for application to the PD population. These features may be particularly useful in promoting exercise for people with PD, since a recent study conducted by Assoc/ Professor Canning, Professor Lindy Clemson and Ms Christine O'Brien at the University of Sydney suggests that lack of motivation and limited information about performance during exercise makes participation in exercise difficult for people with PD.

The aim of the study is to determine whether a home-based exercise using this interactive, stepping videogame is effective in improving stepping ability, balance and mobility in people with PD. Volunteers with PD who are eligible to be included in the study will be randomly allocated to a control group or an exercise group. The exercise group will exercise using the videogame for 15 minutes per session, 3 times a week for 3 months.

A physiotherapist will prescribe the exercise and will supervise 4 sessions at home over the 3 months. Between home visits, the physiotherapist will monitor progress by telephone. To enhance exercise participation and engagement, participants in the exercise group will also have the option to contribute to an on-line blog to share their experiences of exercising using the videogame with other exercise participants and the researchers.

If found to be effective and engaging, the interactive videogame has the potential to provide accessible, sustainable, enjoyable, evidence-based balance exercise to improve balance and prevent falls, and to contribute to the development of other interactive exercise videogames for people with PD.

You may be eligible to participate in the study if you 1) are diagnosed with idiopathic Parkinson's disease, 2) are able to walk for 30m or more without any aids, 3) have a stable response to medication, and 4) do not have substantial cognitive impairment or medical conditions that would interfere with exercising at home.

To enquire about participation in this study or to find out more information, please feel free to contact Dr. Joeeun Song at the University of Sydney on 02 9351 9436 or 0430 376 078 or email at joeeun.song@sydney.edu.au.

Elucidating striatal transcriptional differences underlying the cognitive impairment in Parkinson's disease

Unity Walk Research Grant
by Marie Jonsson PhD



Our ability to exert behavioural control over the environment is determined by two processes: (i) goal directed actions – which are rapidly acquired and can be very flexible, but require enormous cognitive resources associated with attention and working memory to monitor specific actions and their consequences; and (ii) habitual actions - which are acquired more slowly and are more rigid or automatic in execution, thus requiring fewer resources beyond basic perceptual processing.

A prominent cognitive impairment seen in Parkinson's disease (PD) patients is the decreased ability to retain, develop and perform routine, automatic or habitual actions. This inability to transfer routine activities to a simpler, less resource intensive process 'traps' PD patients in goal-directed actions and they are unable to execute fast, automated actions, which has a detrimental effect on normal daily activities.

Recent analyses of the neural systems that subserve the learning processes underlying the goal-directed and habitual motor control systems has established that they are instantiated in distinct, corticostriatal networks involving: the dorsomedial striatum (DMS) in the case of goal-directed actions and the dorsolateral striatum (DLS) in the case of habitual actions (3). We have developed a battery of tests that allow us to distinguish between these two behavioural processes and determine which process is controlling an animal's action. These tests allow us to investigate an animal's ability to develop goal-directed and habitual actions.

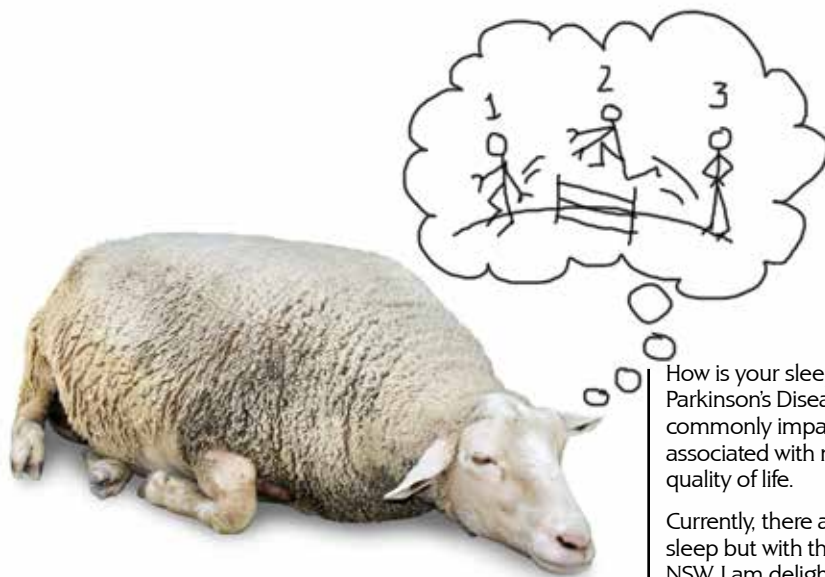
A common animal model used to study PD is achieved by lesioning the nigrostriatal dopaminergic innervation using 6-hydroxydopamine, which selectively kills dopaminergic (DA) neurons. This is a well defined model characterised by impaired motor function. If performed bilaterally, it can also be used to study impaired habit formation. Another approach to studying PD in animals is the use of transgenic mice. In this project we propose the use of the transgenic mouse K3, in which where mutated human tau is over-expressed in neurons of the substantia nigra (SN), resulting in decreased striatal dopamine levels and parkinsonian symptoms such as tremor, bradykinesia, abnormal gait, and postural instability.

Although the neural systems involved in goal-directed and habitual learning processes have largely been established, the underlying transcriptional activities that support them are not well understood. With this research proposal we attempt to unravel temporal and spatial transcriptional differences between cognitive PD models and controls by investigating the DMS and DLS during the early and late phase of training i.e. during the acquisition of goal-directed and habitual behaviour. An increased understanding of the differences of transcription in PD may provide a more direct means of discovering novel therapeutic targets for cognitive impairments.

Sleeping well?

Seed Grant

by Associate Professor Sharon Naismith, Brain & Mind Research Institute



How is your sleep? Chances are not great. Indeed, most patients with Parkinson's Disease (PD) have significant sleep disturbances, which commonly impact on their spouse too. Disturbed sleep in PD is associated with memory complaints, depression and a reduced quality of life.

Currently, there are very few proven treatments that can restore good sleep but with the support of a research grant provided by Parkinson's NSW, I am delighted to announce that the Parkinson's Disease Research Clinic at the Brain & Mind Research Institute will be trialing an exciting new group program for sleep problems. In this research study we will be offering patients with PD the opportunity to participate in the 'Sleep Well Think Well' educational program.

The 'Sleep Well Think Well' program has been successfully piloted in a group of older adults with memory problems. Our preliminary data analysis looks promising with improvements in not only sleep but also thinking and memory. This collaborative study will have input from Consultant Neurologist A/Prof Simon Lewis, as well as a specialist Sleep Psychologist A/Prof Delwyn Bartlett and Clinical Neuropsychologist, Dr Zoe Terpening.

We are now recruiting participants with Parkinson's disease who are troubled by problems with both sleep disturbance and their thinking. The study involves attendance at the Parkinson's Disease Research Clinic for assessments both before and after the program. The program itself would require your attendance once per fortnight over an eight-week period. Each visit will allow participants to have a group discussion with experts from our team. Patients will learn about the factors that are responsible for their poor sleep and receive helpful advice on how to improve their symptoms.

Please join us at the Brain and Mind Research Institute for this opportunity to evaluate the 'Sleep Well Think Well' program. If you would like to obtain further information about this study or about our Parkinson's Disease Research Clinic in general, please call our clinic on 02 9351 0702

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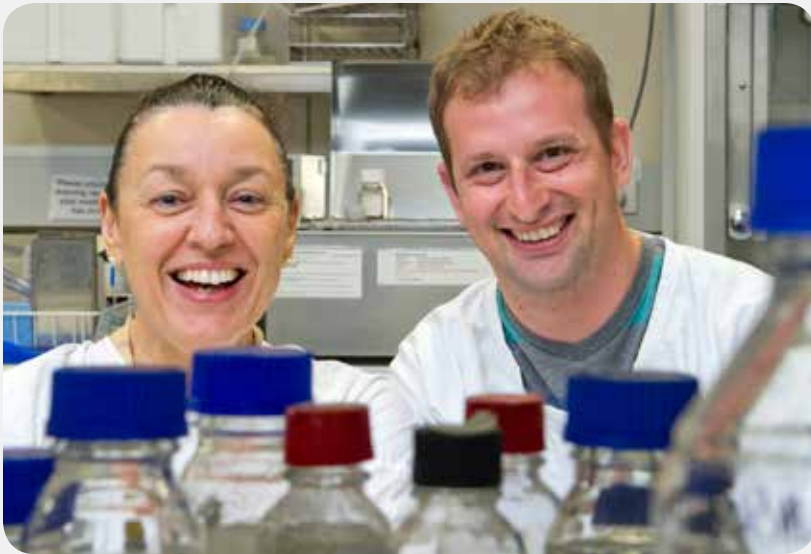
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What the heck is LRRK2?

Seed Grant

by Dr Nic Dzamko and Professor Glenda Halliday



Dr Nic Dzamko and Professor Glenda Halliday

In 2004, two groups of scientists in the UK and Germany discovered that mutations in the Leucine-Rich Repeat Kinase 2 gene (LRRK2, pronounced lark two or lurk two depending on the part of the world you are from) could cause inherited Parkinson's disease. This was not the first Parkinson's disease causing gene to be discovered, indeed there are now 16-18 genes associated with increased Parkinson's disease risk. For a number of reasons however, LRRK2 has emerged as one of the more interesting research candidates.

LRRK2 mutations are inherited in an autosomal-dominant fashion, meaning only one of the two copies of each gene in the body needs to be mutated for disease. This differs from recessive Parkinson's causing genes, such as Parkin, that need both copies of the mutated gene to be inherited for disease. This makes LRRK2-associated Parkinson's disease easier to inherit and also suggests that mutant LRRK2 has a strong effect on the body, enough to overcome the normally functioning second copy of the gene. It is currently thought that LRRK2 mutations account for 1-5% of Parkinson's disease, with the rest being largely sporadic or of unknown cause. Interestingly, the age of onset and clinical symptoms of LRRK2-associated Parkinson's disease are largely indistinguishable from the more common sporadic form of the disease. The only way to tell if a patient has a LRRK2 mutation is through DNA genotyping. It is therefore thought that LRRK2 dysfunction may be common to both LRRK2-associated and sporadic Parkinson's disease, the former by mutation and the latter by an as yet unknown mechanism.

One of the main reasons that LRRK2 has piqued interest from the scientific community is that it belongs to a family of 500 enzymes called protein kinases. Protein kinases function in pathways that transmit signals detected by receptors on the surface of cells. For example, after eating, secreted insulin is detected by the insulin receptor resulting in the activation of the protein kinases of the insulin signalling pathway that tell the cell to store the just eaten fat and sugar. Another example of protein kinases in action is the activation of the growth factor signalling kinases, following detection of growth hormones, telling cells to grow and divide. Mutations in the protein kinases of cell growth pathways can cause cancer. This often results as the mutation makes the protein kinase always activated and therefore always telling the cell to grow and divide. Intriguingly, the most common mutation found in the LRRK2 gene, the G2019S mutation, changes the LRRK2 protein in such a way in that it is also always activated.

Drugs that can block the activation of protein kinases have been successful in the treatment of cancer, in particular certain forms of

leukemia and melanoma where mutations in certain protein kinases can be identified. As a result the major pharmaceutical companies have millions of drugs that can be screened to see if they block certain kinases. Indeed, a number of research papers have now been published, by both academic laboratories and pharmaceutical companies, demonstrating the development and optimisation of LRRK2 blocking drugs. Unfortunately however, we have made little progress on understanding what LRRK2 actually does. Without knowing what LRRK2 does in a cell it is difficult to know if a drug is working or if a drug is safe. It is also difficult to know how effective LRRK2 blocking drugs will be in Parkinson's disease patients that don't have the activating G2019S mutation. These are the issues we are currently addressing at Neuroscience Research Australia.

It has become established that the LRRK2 protein is highly expressed in white blood cells, the cells of the body's immune system. Our recent work suggests that LRRK2 is part of the protein kinase signalling pathway that regulates the inflammatory response to infection. This is interesting as increased inflammation is often associated with Parkinson's disease. Although we think we know which pathway LRRK2 is involved in, exactly what it does is still a mystery. We are using a number of approaches to try solve this including treating immune cells with drugs that block LRRK2, and by studying inflammation in immune cells in which LRRK2 has been genetically deleted or in cells from patients with the G2019S mutation. We have also investigated LRRK2 in white blood cells of sporadic Parkinson's disease patients. In this study, performed in collaboration with Professor Dominic Rowe at Macquarie University, we found that LRRK2 protein levels were the same in patients with Parkinson's compared to controls. We now need a method to measure the activity of LRRK2 in these cells to see if LRRK2 is more switched on. Finally we are also investigating LRRK2 in brain samples donated to the Sydney Brain Bank. We have discovered that LRRK2 interacts with alpha-synuclein, the major protein that causes the Lewy body pathology that defines Parkinson's disease. In this study, LRRK2 protein was increased in Parkinson's disease brains in areas where alpha-synuclein was present. We are doing more work to see if increased LRRK2 expression occurs early or late in the disease process.

We hope our work will enable the progression of LRRK2 blocking drugs to therapy but more work needs to be done. Early results with prototype LRRK2 inhibitors and pre-clinical models are encouraging, as is the investment of industry. We are thankful for the funding from Parkinson's NSW that will contribute to our on-going work.

Novel drugs for Parkinson's disease

Seed Grant
by Professor Michael Kassiou & co-principal Lenka Munos

Parkinson's disease is characterised by death of dopaminergic neurons in the midbrain.

The death of these neurons leads to shaking, rigidity, slowness of movement and difficulty of walking, the most prominent signs of Parkinson's disease.

Excessive activity of an enzyme called leucine-rich repeat kinase 2 (LRRK2) in the brain causes Parkinson's disease, in particular for people of two ethnic background – Ashkenazi Jewish and North African Berbers. Therefore, we urgently need drugs that can turn-off LRRK2 activity. Our aim is to develop such drugs.

To discover a new drug is an extremely expensive process taking approximately 10-15 years. To discover a drug for the brain diseases is even more complex. This is because drugs that act in the brain must cross blood-brain barrier. Blood-brain barrier is a layer that protects our brains. However, as it is protecting, it restricts the entry of drugs into the brain tissue. Therefore, blood-brain barrier

permeability is the bottleneck in the discovery of new drugs for brain disorders, including Parkinson's disease.

We have developed a compound that is able to turn off the LRRK2 activity. However, this compound is not able to cross the blood-brain barrier, and thus cannot be used as a drug for Parkinson's disease.

We are therefore currently working on development of drugs that will switch-off LRRK2 enzyme and also are able to cross the blood-brain barrier. The seed grant from Parkinson's NSW is a great financial help to advance our research and obtain sufficient preliminary data crucial for larger funding.

Our final goal is to develop a drug that can both reach the brain and block LRRK2 activity. Such a drug represents a novel avenue in the treatment of this devastating disease.



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Dr Rodney Marsh – Neuropsychiatry Consultant,
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Do the 'Parkinson proteins' α -synuclein and LRRK2 reduce the birth of new brain cells?

Seed Grant

by Associate Professor Kay Double, University of Sydney
& Professor Glenda Halliday, Neuroscience Research Australia

Assoc Prof Kay Double,
The University of Sydney



Prof Glenda Halliday,
Neuroscience Research
Australia



A body of research around the world is looking at the potential of stem cells to repair the damaged Parkinson's brain.

While this research is exciting it is also true that new brain cell birth – which results from the division of stem cells in the brain – is reduced in the brain in patients with Parkinson's disease. This suggests that the brain in Parkinson's disease is less able to support and nurture new cells for reasons that are as yet unknown. In this project we will investigate the number of new brain cells born in the Parkinson brain compared to individuals who do not have this disorder.

We will investigate if the abnormal behaviour of two proteins known to play an important role in Parkinson's disease, called α -synuclein and LRRK2, are the reason why fewer new cells are born in the Parkinson's disease brain. Data from animal experiments suggest that changes in these proteins results in a reduction of new brain cell birth but to date the effects of these proteins on cell birth in the human brain has not been investigated.

This project will help us understand the complex biology of stem cells and the effects of Parkinson's disease upon these cells. This is important as implantation of stem cell-derived cells into the Parkinson's brain will only be successful if the environment of the brain is able to support the survival and normal function of the implanted cells. Our results will have implications for the development of effective stem cell-based treatments which we hope one day will be used to repair the damaged Parkinson's brain.

JOIN THE 6TH ANNUAL PARKINSON'S NSW UNITY WALK & RUN



Sunday 25 August 2013 | Sydney Olympic Park



Register at www.unitywalk.com.au
or www.unityrun.com.au

In Australia someone is diagnosed
with Parkinson's disease every hour
of every day. Join us to provide

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or www.unityrun.com.au

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The Unity Walk & Run Sunday 25 August at Sydney Olympic Park

Now in its sixth year, this great event offers a wonderful opportunity for people of all ages and families to get out in the open and exercise, connect and just have a good time. You can run 4 or 8kms or walk 4km.

There are great prizes including a trip to Hawaii with return airfares and six nights accommodation at the Holiday Inn Waikiki Beachcomber for both the female and male winners.

For participants and supporters there is food, entertainment, rides for the kids with a carnival atmosphere, which makes the Parkinson's Unity Walk & Run one of the most popular of its kind in the country.

The State Government provides free train and bus travel to and from Sydney Olympic park for participants including Country Link for those who come from out of town.

If you would like to be part of the day, and are not a runner or walker, then perhaps volunteering is the way to go. We need volunteers to assist with registration, set up and marshallng.

So, if you are free on Sunday 25th of August from 6:00am - 3:00pm then please complete a volunteer form available on our website and return to Parkinson's NSW.

<http://tinyurl.com/l7ve6wh>



Transdermal Parkinson's treatment listed on the PBS

Neupro™, often referred to as the 'Parkinson's patch' has been available in Australia as a private prescription since 2006. It has recently been listed on the Pharmaceutical Benefits Scheme (PBS), reducing its prescription cost, making it more widely available to those living with Parkinson's who may benefit from its use.

Neupro patches contain the active ingredient rotigotine, which is a type of medicine called a dopamine agonist.

Rotigotine works by mimicking the activity of the brain chemical dopamine, which is depleted in the brains of those diagnosed with Parkinson's).

Neupro is similar to another dopamine agonist, Pramipexole (brand names include Sifrol and Mirapex). However Neupro is delivered as a patch that is applied to the skin, and which slowly releases the drug over 24 hours.

The patch would appeal to those who have difficulty swallowing pills or who need to take a large number of pills. The patch also means consistent release of the drug into the system, which can reduce the incidence of 'wearing off' and the return of visible Parkinson's symptoms.

As a dopamine agonist, rotigotine carries all the same precautions and side effects as other medications that fall into this class. Some people may develop impulse control disorders and skin irritation can occur where the patch is applied.

For more information please contact the InfoLine or refer to the Consumer Medicine Information sheet.

This article was originally published in the Parkinson's Victoria newsletter, *Signpost* (winter 2013, vol.12:issue 2)



SPECIAL SATIN SHEETS for people with Parkinson's

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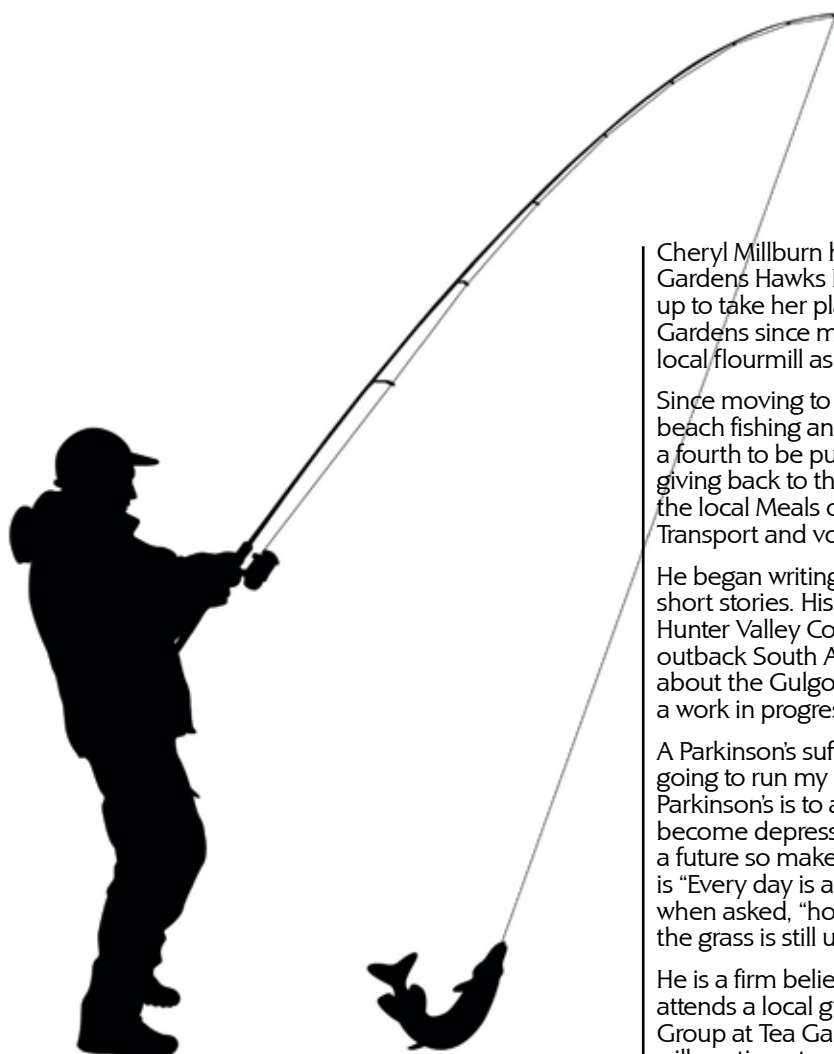


This combination allows greater ease of movement in the middle section of the bed, whilst the top and bottom portions allow for grip while turning. Fully elasticised edges help maintain its position on the mattress. Machine Washable.

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From tree change to sea change



Cheryl Millburn has stepped down as co-ordinator of Tea Gardens Hawks Nest Support Group and Garry Boyd stepped up to take her place. A published author, Garry has lived in Tea Gardens since moving from Gulgong where he worked for a local flourmill as office manger and later at a nearby coalmine.

Since moving to Tea Gardens, his sea change, he has enjoyed beach fishing and writing, having written three novels with a fourth to be published later this year. Garry believes in giving back to the local community being the treasurer of the local Meals on Wheels for 7 years, driving for Community Transport and volunteering at the Tourist Information Centre.

He began writing in 1997 publishing many bush poems and short stories. His three novels are, Black Gold, set in the Hunter Valley Coal Fields, Billy Two, set near Oodnadatta in outback South Australia in the fifties and Blind Hope, written about the Gulgong Gold Rush in the 1870s. Bower Bird is still a work in progress – a whodunit about Tea Gardens in 1954.

A Parkinson's sufferer, his attitude is simple "Parkinsons isn't going to run my life". He believes the key to living with Parkinson's is to adopt a positive attitude. It is easy to become depressed thinking of the future, but there is a future so make the most of it. A favourite expression is "Every day is a good day if you wake up." Another, when asked, "how are you?" Garry replies "fine thanks, the grass is still under my feet not over my head."

He is a firm believer in the benefits of regular exercise and attends a local gymnasium two days a week. The Support Group at Tea Gardens Hawks Nest, though only very small, will continue to support Parkinson's sufferers as best they can.

As the leader of the group we wish him well in this new role and give our heartfelt thanks to Cheryl for all her good work over the past years.

Parkinson's NSW Support Groups

Albury/Wodonga	Deniliquin	Macarthur	Southern Highlands
Armidale	Dubbo	Manly/Mosman	Speeding Vibrations
Ballina (Northern Rivers)	Dundas/Parramatta	Manning/Great Lakes	St George/Sutherland
Bankstown	Eastern Suburbs	Maroubra	Tamworth
Bathurst	Eurobodalla	Mid Western	The Medusa Club
Bega Valley	Fairfield/Liverpool	Myall/Tea Gardens	Tomaree Peninsular
Bingara	Glen Innes	Nambucca Valley	Tweed
Blacktown	Goulburn	Narrabri	Ultimo
Blue Mountains	Grafton	Nepean	Wagga Wagga
Broken Hill	Gunnedah	Newcastle	Parkinson's Working Age
Casino	Hawkesbury	Orange	Men's Network
Castle Hill	Hornsby/Ku-ring-gai	Parkes	Yamba
Central Coast	Illawarra North	Pittwater/Warringah	Yass
Chinatown Bilingual	Illawarra South	Port Macquarie	Young Women's Group
Coalfields	Kings Langley	San Remo	(Tulip Belles)
Coffs Harbour	Lismore	Shoalhaven/Nowra	
Cowra	Lower North Shore	Snowy/Monaro	

Are you suffering from Parkinson's disease?



Many people with Parkinson's Disease have symptoms of slow stomach emptying.

The GSK Medicines Research Unit is studying a new medication that may help to speed up emptying from the stomach and help with “on-off fluctuations” experienced by people with Parkinson’s Disease.

You may be eligible to participate if you:

- Have Parkinson's Disease
- Are taking daily medication containing L-dopa (eg. Sinemet, Madopar or Stalevo)
- Are between the ages of 40 and 80

Our trial participants are reimbursed for their time, travel costs and inconvenience



Contact: 1800 GSK GSK (1800 475 475)
Email: volunteers.4.trials@gsk.com

Prince of Wales Hospital
Level 10, Parkes Building East
High St. Randwick, NSW 2031

This study has been approved by Bellberry HREC, Ref no: 2012-11-1157 and operates within Australian & International guidelines for medical research
MOT115816 Print Version 02, 19 Apr 2013

Stiffness & Slowness in Parkinson's Disease

by Dr Paul Clouston. Neurologist. MBBS (Hons), PhD, FRACP



In previous articles I have discussed tremor and walking difficulties in Parkinson disease. Tremor is one of the diagnostic features of the disease along with rigidity (muscle stiffness) and bradykinesia (slowness of movement). Although tremor is usually the most obvious sign of the disorder, stiffness and slowness often have a much greater effect on people with PD

The cause of the muscle stiffness or 'rigidity' in PD is uncertain but it appears that many of the spinal reflexes involved in the control of muscle tone become overactive. This impairment of reflexes is mediated by abnormal descending electrical signals from the basal ganglia deep within the brain relayed down the spinal cord and via nerves to affected muscles. This rigidity affects both muscles of the trunk (core muscles) and limb muscles. It is likely one of the causes of pain in PD. Many people complain of back or limb ache in PD which usually responds well to treatment.

Often this rigidity may affect some muscles more than others. For instance those core muscles that flex the neck and back are more affected than muscles that extend those parts leading to the characteristic stooped posture with excessive back and neck flexion. It is also likely that rigidity of the affected limb contributes to some extent to the reduced arm swing of that limb when the person with PD is walking. It seems reasonable to perform stretching exercises regularly in an attempt to reduce the symptoms of rigidity, although unproven.

When an ordinary person thinks of Parkinson's disease, besides tremor, slowness of movement comes to mind. The medical term for slowing of the velocity of movement is called bradykinesia. Hypokinesia refers to a decrease in the amplitude of a movement and akinesia refers to a complete inability to move.

These features often merge together in PD and certainly akinesia cannot occur

without initial hypokinesia and bradykinesia. It is these three features that account for a lot of PD symptoms and signs. However not only may movement be slower or smaller in amplitude but the speed or size of movement may decrease over time. This phenomenon is called 'fatiguability' of a movement and also contributes to symptomatology. For instance both fatiguability and hypo/bradykinesia contribute to the feeling of 'weakness' of affected limb muscles in PD.

Knowing about bradykinesia and fatiguability of movement helps us better understand prominent PD features e.g. the speech is low volume and may progressively get lower; facial expression is reduced; hand writing may be smaller and even become progressively smaller as the person writes; the length of a walking stride may be reduced such that there is a shuffle or there may even be a progressive decrease in stride length till the person cannot walk at all (festination leading to gait freezing). An important point to note is that bradykinesia and fatiguability are involuntary (unconscious) and the affected person can often overcome these symptoms if they concentrate on the action they are undertaking. The problem is that we rarely concentrate on or are conscious of most of the movements we do regularly. Concentration on vocal or movement amplitude forms the basis of the PD speech therapy program LSVT LOUD and the PD physiotherapy program LSVT BIG.

The basal ganglia are neurons deep within the brain that relay with neurons on the brain's surface (the motor cortex) to enable and amplify movement. This circuitry is very dependent on the neurotransmitter dopamine to function properly. It is the abnormal function of this circuitry that is likely responsible for bradykinesia. The good news is that rigidity and bradykinesia are the signs of PD that respond best to dopamine replacement with Parkinson's medication, often dramatically and for many years.

Volunteers needed

by Joanne Brady

A pilot study on Parkinson's disease at the University of Sydney

Understanding the meaning of living with Parkinson's disease in an Australian community setting: from the perspectives of the person diagnosed and their partner/carer.

Research on Parkinson's disease (PD) has focused on how the disease can be treated in order to reduce the person's symptoms and suffering and maintain their well being and functioning in society. However, the personal and social aspects of living with PD in Australia have only recently been addressed. For example, the study by Parkinson's NSW (2012) shows that people who are diagnosed at a younger age are at a different stage of life and therefore need different types of information and support than those who have been diagnosed later in life. What has not been reported generally is a detailed understanding of people's actual experiences and the reality of living with PD in an Australian community setting. The aims of this study are:

- To closely examine the reality of everyday life with PD by interviewing people who are diagnosed as well as their partner/carer
- To explore how PD has emerged within the person's life course and how the symptoms are managed when they are unpredictable and appear in social environments
- To write about people's individual experiences and stories on living with PD in an Australian community.
- This pilot study forms part of a larger study due to commence later this year.

I am a Doctoral Research Student in the Faculty of Health Sciences at the University of Sydney. I have a personal interest in PD because it has been a part of my family for over 10 years and I am an active member of the Dundas/Parramatta Support Group.

From my personal experience, I understand that PD is more than a chronic and degenerative illness that impacts a person's mobility. People are not always

prepared for sudden and seemingly unrealistic and irrational physical changes. Given this, I am interested in understanding your everyday experiences of living with PD and representing them as accurately as possible in the research. The University of Sydney Human Research Ethics Committee has approved my research project.

Volunteers

- People over 55 who are diagnosed with idiopathic PD and have a partner/carer who is also willing to participate in the study are invited to participate in this study.
- You may have a close understanding of PD, so are in a unique position to describe the disease, the drug treatments and how it affects personal identity
- Volunteers must speak fluent English, be coherent and audible, live in Sydney and be members of a local Parkinson's support group
- There will be two separate interviews with each participant and each interview will be for approximately one hour
- The person diagnosed and their partner/carer will be interviewed separately at a suitable time and location
- For the interview, you will be invited to talk about your life story and express your own views and experiences of living with PD

If you are interested in volunteering for the study or want to find out more about the study, please contact Joanne Brady by email jbra7852@uni.sydney.edu.au or phone 0421 728 647

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Partridge, E. (2012). Not Only an Old Person's Disease: Experiences and needs of people diagnosed with young onset Parkinson's disease. *Sydney: Institute for Sustainable Futures, University of Technology Sydney for Parkinson's NSW.*

Out & about

Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)

This scheme provides financial assistance to patients (and eligible accompanying person) who need to travel long distances to access specialised medical treatment not available locally. Patients travelling a cumulative distance of at least 200km per week to access the nearest treating specialist are eligible.

Any patient who is eligible for Medicare and lives in NSW can apply.

Please ring our InfoLine 1800 644 189 if you would like more information or visit www.enable.health.nsw.gov.au/ipaas



The Parkinson's Outreach Visitor's Program

Parkinson's NSW was delighted to receive a grant from the Australian Chinese Charitable Foundation to provide training for volunteers from both the Chinatown Bilingual Support Group and other Parkinson's Support Groups.

The training supports volunteers in their visits to members of support groups who can no longer attend meetings due to ill health.

The training program provided information on Parkinson's Disease, communication and Diversional therapy.

Over 20 people attended the training run over three days.

If you would like a visit or know of anyone who would, please contact our InfoLine on 1800 644 189.

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Parkinson's NSW is delighted we can provide face-to-face counselling in the Eastern Suburbs in Sydney, based in the War Memorial Hospital at Waverley on Tuesdays. This has only been made possible through the generous grant from the Lions Club of Bondi.

If you would like to make an appointment to see Shushann Movsessian please phone our toll free 1800 644 189.



We had two Pancakes for Parkinson's events in April, to raise awareness for Parkinson's disease. Green's General Foods Pty Ltd is our official partner providing pancake batter and syrup. Rotaract Club of the University of Sydney raised \$335.00 (right) and Sweets by Sweets (left) raised \$180.00 during their event held at Macquarie University.



Christmas in July

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Cycling for Parkinson's

by Lucy Harper



The idea of cycling across Australia, from Perth to Sydney, has been a dream of mine for about 10 years. Why this mad idea has stayed with me, I'm not sure, but it has. So, in August this year, I will push my much loved Surly Crosscheck bike out my front door and head east over the Perth hills and beyond. By the time I reach Sydney I will have cycled a total of 4230 km. And the main reason for this adventure is to raise awareness and money for Parkinson's disease (PD) research.

My Dad has had PD for over 20 years so it's a cause very close to my heart. Seeing the effects of this disease on him over all these years has without doubt been the main driver for keeping this epic cycling tour alive. Parkinson's is ever present in Dad's life. Although never asking for too much, he has said that he would like to have just 20 minutes without PD. I like to think that one day we can give him and other people with PD more than just 20 minutes. It's this thought that will help keep my legs turning during what I know will be some gruelling days ahead.

Preparations are in full swing and involve all manner of things, including researching the route for places to stay or camp, learning how my bike

works and how to fix a flat and mend a broken spoke. I've been building playlists, downloading audiobooks, have packed and repacked my panniers, and skilled up on bike maintenance and first aid courses. Critically too, while holding down my full time job as a curator at the Art Gallery of WA, I'm jumping in the saddle whenever I can to get as fit as possible and have spent many hours riding around Perth and beyond. I am excited by the thought of being on the open road and seeing some of Australia's most glorious landscapes.

Along the way, I will have friends and family join me, either to cycle or as support. Their support to date has been incredible and is helping me enormously while preparing for this mad but exciting challenge.

I hope you will join me too and follow the ride, so please - spread the word, find out about Parkinson's and donate if you can. Every bit counts no matter how big or small. Go to www.cycling4parkinsons.com for more information.

Thanks for all your support and see you on the road!

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WHAT'S ON

11

AUGUST
CITY 2 SURF

25

AUGUST
Unity Walk and Run

4

SEPTEMBER
Allied Health
Awareness Seminar
(Health Professionals only)

1-4

OCTOBER
World Parkinson's
Congress (Montreal)

24

OCTOBER
Bequest Lunch

14

NOVEMBER
Golf Day

Guest Contributors

A/Prof Simon Lewis
Dr Paul Clouston
Christine Regan
A/Prof Colleen Canning
A/Prof Sharon Naismith
Dr Nic Dzamko
Prof Glenda Halliday
Marie Jonsson PhD
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Editor

Linda Davies
(with the help of the Parkinson's NSW office)

Parkinson's NSW Inc

1800 644 189
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For your local Support Group please call
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NOVEMBER
AGM

To RSVP for events please call the InfoLine 1800 644 189

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