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Issue 121 Winter 2014

THE RESEARCH ISSUE

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Chief Executive Officer
Miriam Dixon

02 8875 8901
miriam@parkinsonsnsw.org.au

PA to CEO/Office Manager
Rachael Chippendale (M-F)
02 8875 8908
rachael@parkinsonsnsw.org.au

Accounts
Linda Luben (T/W)
02 8875 8914
linda@parkinsonsnsw.org.au

Event & Community Manager
Natalija Gajic (M-F)
02 8875 8913
natalija@parkinsonsnsw.org.au

Fundraising/Admin Assistant
Claire Tester (M-F)
02 8875 8915
claire@parkinsonsnsw.org.au

Major Donor/Bequest Officer
Isabelle Clark
0403 324 486
isabelle@parkinsonsnsw.org.au

Glenda Weaving
02 8875 8900
glenda@parkinsonsnsw.org.au

Membership and Donations
Chris Searle (T/Th/F)
02 8875 8902
chris@parkinsonsnsw.org.au

Marianna Sain (T/W)
02 8875 8909
marianna@parkinsonsnsw.org.au

Julie Anderson (Part-time)
02 8875 8902
julieann@parkinsonsnsw.org.au

Counselling
Deborah England (T/W/Th)
Shushann Movsessian (M/T)
Freecall 1800 644 189
infoline@parkinsonsnsw.org.au

Education
Julie Austin (T/W/Th)
Deborah England (T/W/Th)

Information/Resources
Julie Austin (T/W/Th)
Penny Mawer (T/W/Th)
Lois Finn (M/W/F)
Susan Tait (F)
Margi Edmondson (Th)
Freecall 1800 644 189
infoline@parkinsonsnsw.org.au

Support Group Coordinator
Antoinette Riley (M-F)
02 8875 8903
antoinette@parkinsonsnsw.org

CONTACT THE INFOLINE FOR
YOUR NEAREST SUPPORT GROUP
Freecall 1800 644 189

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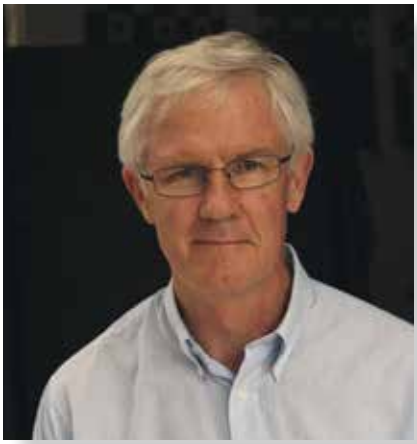
FROM THE PRESIDENT



In an ideal world, rational allocation of resources would ensure that the health, ageing and disability dollar would be allocated according to genuine need.

After dipping a toe in the water ahead of the last federal election, and in view of our commitment to winning more neurological nurses; there is a growing national appetite for the Parkinson's community to be better represented to governments at all levels.

To deliver any meaningful results in what is becoming an increasingly competitive situation among charities, we have to face up to running a permanent, professional campaign that puts steady pressure on everyone who counts. This will require individuals who live with Parkinson's; support groups; state organisations and Parkinson's nationally to work coherently towards clear, well articulated goals.

The foundation on which the campaign is to be built is a grassroots effort, which makes it clear that there is a significant constituency of 80,000 people with Parkinson's, plus about twice as many whose lives are affected somehow. There has to be a steady flow of information and contacts, so that local authorities; health and ageing agencies; elected representatives and ministers are constantly reminded of the needs and concerns of the Parkinson's community. Individuals need to write personal letters to their local Members; support groups need to invite Members to speak to them; and local media need to receive pertinent stories about our situation.

We need to understand our members' priorities and to assemble strong evidence to support our case for nurses in particular and for services in general. We need to identify local champions who will organise and communicate; especially people who have strong community networks. Federal Members need to be kept in touch with their constituents; at home and in Canberra.

Grassroots advocacy needs to be well coordinated: for consistency and to build a strong profile. We hope soon to see a national presence for Parkinson's in Canberra – managing activities; gathering evidence and being a familiar face to the relevant denizens of Parliament House. There is a group called Parliamentary Friends of Parkinson's – those loyal supporters need to be kept in touch with the latest thinking in PD.

In an ideal world, rational allocation of resources would ensure that the health, ageing and disability dollar would be allocated according to genuine need. Of course, we don't live in an ideal world, so money flows to where a strong case is made and where large, vocal constituencies are evident to both bureaucrats and their political masters.

Not everyone has the stomach or the energy to buy into this sort of activity, but there are many who do; so we invite interested people to get involved. Advocacy works for the good of the whole Parkinson's community and the stakes are high. Some of the action will be in Support Groups, but there is also plenty of room for individuals to play a role.

Life for people living with Parkinson's can be better – we can make sure that it is.

Chris Davis
PRESIDENT

& the CEO

Spring Ball 2013

It was with great pleasure that I attended a morning tea at State Parliament House on 24 March to receive a cheque from the October Parliamentary Spring Ball.

The Speaker of the House, The Hon. Shelley Hancock spoke about the valuable work that charities perform for the people of NSW. She made particular reference to our Neurological Nurse educator Marilia Pereira who had received the Shoalhaven Citizen of the year award. Story on page 20-21.

Parkinson's NSW received $13,400 from the Spring Ball. This money will assist us to provide support services for people living with Parkinson's. We extend our thanks to the Spring Ball sponsors, Members of Parliament and, in particular, The Hon. Shelley Hancock for nominating Parkinson's NSW as charity beneficiary of the Spring Ball. (photo p23)

New members of the Parkinson's Team

Please welcome our four new staff members.

Antoinette Riley – Support Group Coordinator

Antoinette is a clinical nurse consultant with a wealth of knowledge and experience working with carers, and people living with dementia. She has facilitated many support groups. She is also an experienced educator.

Natalija Gajic – Community and Event Manager

Natalija commenced working with us full time in February and was instrumental in the success of our Big Ride. Natalija comes to us from a corporate background with just under 10 years experience working on a wide range of events.

Glenda Weaving – Donor Relations/ Bequests – Part-time

Glenda has been involved with the Parkinson's community through her volunteer work with the Blacktown Support Group. Glenda has a nursing background. She has worked in palliative care and started her career as a district nurse in the UK and currently works at the Norwest Private Hospital. Glenda will work with Isabelle Clark in Donor Relations/ Bequests

Claire Tester – Fundraising/Events and General Administration Assistant

Claire will be working with Natalija Gajic our Community and Events Manager. Claire recently graduated from Southern Cross University with a Bachelor of Business Management in Events and Conventions. She has worked in retail and events management. Some may have already met Claire as she volunteered last year at the Golf Day and attended a fundraising morning tea with the Illawarra North support group.

Julie Anderson – Accounts/ Membership Support

Julie commenced work with us in February and works part-time, Mondays and Thursdays. She has a PhD in Computational Chemistry from the University of Mississippi and bachelors degrees in Computer Science and Chemistry from Abilene Christian University. She has worked in software design for Epiphany Games and completed internships with IBM and DuPont Dow Elastomers.

Unity Walk & Run 31st August 2014

Our 7th Unity Walk & Run is here again. It's a wonderful opportunity for families to come together to show their support for Parkinson's. Many walk beside their friend or family member living with Parkinson's while others walk to honour a family member or friend who has passed away.

It's very moving to sometimes see as many as four generations of family members coming together on the day.

The event's focus is a leisurely stroll or for the fit, an additional 4km or 8km run. It gives a voice to all those living with or touched by Parkinson's. We have a fantastic prize for the 8km run male and female winners – a trip to Fiji. Following on from last year's success, the Unity Walk & Run Raffle is back with even bigger and better prizes in 2014. Fifty percent of the money raised supports services like our counselling and InfoLine. The other fifty percent funds research.

I am looking forward to welcoming you to Cathy Freeman Park to enjoy a great day out with food, entertainment, rides for the kids and much more.

Yours in Parkinson's friendship

Miriam Dixon
CEO

RESEARCH Grants

Parkinson's NSW is proud to announce that $260k was given in research grants this year.

Professor Glenda Halliday received the Bendigo Bank grant with three Unity Walk grants to Associate Professor Colleen Canning, Doctor Bryce Vissel and Associate Professor Sharon Naismith. Three seed grants were awarded to Associate Professor Simon Lewis, Doctor Jin-Sung Park and Associate Professor Kay Double. We wish to extend our thanks to our donors who support research with additional funding coming from the Unity Walk & Run.

We are proud of our transparent and equitable selection process for research grants. Ads were placed in the Sydney Morning Herald and invitations to apply for grants emailed to Research Institutes and Universities in NSW.

Our Bendigo Bank and Unity Walk grants are up to $50k while seed grants are up to $20k. These grants enable researchers to do the initial work to gain vital data to enable them to go on to seek more substantial funding. Some of our research recipients from previous years have been successful in gaining large grants through the National Health and Medical Research Council (NHMRC).

An independent expert panel assesses the applications and provides recommendations to the Parkinson's NSW board. The board then allocates funds in order of their ranking. This year, the panel was led by Professor Malcolm Horne – Deputy Director of Florey Neuroscience Institutes, Dr Paul Lockhart – Bruce Lefroy Centre for Genetic Health Research at Murdoch Children's Research Institute and Dr Meghan Thomas – Founding Co-ordinator, Parkinson's Centre (ParkC), Edith Cowan University.

The successful recipients received their cheques at our World Parkinson's Morning Tea for life members and support group leaders at State Parliament House on 3 April, 2014.

Bendigo Bank grant recipient: Prof. Glenda Halliday

The Hon. Victor Dominello, MP & Prof .Glenda Halliday

How the major pathological protein definitive for Parkinson's disease (PD), alpha-synuclein, spreads through the brain remains unknown. Toll-like receptor 2 (TLR2), located on microglial cells, have been identified as the receptor responsible for the internalisation of alpha-synuclein by this cell. In assessing TLR2 in the brains of patients with PD, we have found that both PD neurons accumulating-alpha synuclein and the Lewy body inclusions themselves contain TLR2. This data suggests that neuronal TLR2 contributes to the spread of PD in the brain by promoting the uptake of alpha-synuclein into neurons, a theory requiring further biological evidence prior to therapeutic targeting. We will test this theory and provide the required evidence by tracking the expression of the receptor versus the uptake of alpha-synuclein into neurons using state-of-the-art biochemical localisation procedures in a series of brain tissue samples from patients at different stages of PD. We thank Parkinson's NSW for the funds to be able to complete this research work

Unity Walk grant recipient: A/Prof. Colleen Canning

The Hon. Victor Dominello, MP & A/Prof .Colleen Canning

There is an expanding evidence-base demonstrating benefits of exercise for improving balance and mobility in people with Parkinson's disease (PD). Yet the role of exercise in improving arm and hand function has been neglected to date. This randomised controlled trial will address this knowledge gap. It will evaluate the *ActiveArms* exercise program – a novel and engaging program utilising interactive videogames to improve arm function in people with PD. Difficulty performing upper limb activities is associated with poor quality of life. Thus the development of effective, sustainable and engaging exercise programs to improve upper limb function is an urgent research priority.

Unity Walk grant recipient: Dr. Bryce Vissel

We address two unmet needs for Parkinson's disease: neurodegeneration and L-dopa induced dyskinesias. We found that the growth factor activin A protects dopamine neurons in two models of Parkinson's disease. Furthermore, when administered after neurodegeneration occurred, activin A induces motor recovery, in combination with low doses of L-Dopa, a first step to suggesting that activin A can reduce dyskinesias independently of its neuroprotective actions. We will extend our finding by (1) undertaking essential experiments to fully confirm activin A neuroprotective effects and (2) examine if activin A delays onset and/or reduces severity of dyskinesias. This exciting study offers a potentially novel therapeutic approach.

The Hon. Victor Dominello, MP & Dr. Bryce Vissel

Unity Walk grant recipient: A/Prof. Sharon Naismith

This study will investigate the effectiveness of two approaches for improving cognition (e.g. memory) and wellbeing for people with Parkinson's disease. Specifically, the study will evaluate whether a 'Memory Plus' program is more effective when delivered by a health-professional (where it will be individually-tailored to a patient's needs) or whether it can simply be delivered via workbook allowing more wide-reaching access to patients. The study has been designed to immediately translate to practice, since the program can be implemented according to either a) a Medicare model of 10 sessions of 'Focused Psychological Strategies' or b) broad dissemination of the workbook.

The Hon. Victor Dominello, MP & Dr Lauren Mowsgowski for A/Prof. Sharon Naismith

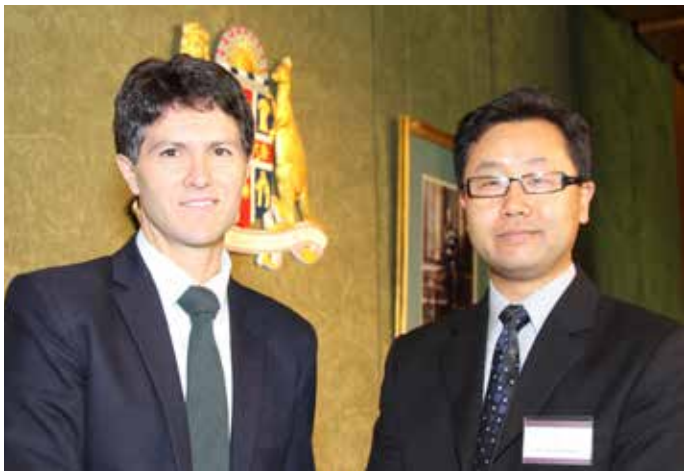
Seed grant recipient: A/Prof. Simon JG Lewis

Currently there are no reliable diagnostic tests that can differentiate between Parkinson's Disease and the range of Parkinson Plus conditions that exist including Lewy Body Dementia (LBD), Multiple System Atrophy (MSA) and Progressive Supranuclear Palsy (PSP). Recently our research group has identified that overnight core body temperature recording can be correlated with Rapid Eye Movement Sleep Behaviour Disorder (where patients act out their dreams), a frequent symptom across the synucleinopathies (LBD and MSA) but rare in tauopathy (PSP). The proposed study will establish whether relationships between disturbed thermoregulation and RBD are present in Parkinson Plus patients, thus offering a potential diagnostic biomarker in future clinical practice.

The Hon.. Victor Dominello, MP & A/Prof. Simon JG Lewis

RESEARCH Grants

Seed grant recipient: Dr. Jin-Sung Park



The Hon. Victor Dominello, MP & Dr. Jin-Sung Park

The mechanistic cause of Parkinson's disease (PD) is unknown, but 18 genetic loci have been found in association with PD. Among the PD-related genes, a gene called ATP13A2 (also designated as PARK9) has been associated with Kufor-Rakeb syndrome (KRS), a rare form of familial Parkinsonism. KRS patients present with typical PD symptoms as well as additional features such as dementia and generalised brain atrophy. The ATP13A2 gene encodes a protein which likely functions as a zinc transporter and loss of ATP13A2 protein by KRS-associated mutations in the gene has been demonstrated to be pathogenic by causing abnormal cellular metabolisms including zinc dyshomeostasis as well as defects in energy production and protein degradation. Recently, several studies have reported the presence of single heterozygous ATP13A2 mutations in a significant proportion of PD patients, suggesting their role as a risk factor for PD. However, the role of these mutations in PD remains unknown due to lack of research. Therefore, in the research project which will be funded by Parkinson's NSW seed research grant, we will investigate whether such mutations in ATP13A2 contribute to the development of PD using patient-derived cell models. The research outcomes from the project may advance our understanding in PD pathogenesis and also provide a basis for the development of a novel therapeutic target for the disease.

Seed grant recipient: A/Prof. Kay Double

The Hon. Victor Dominello, MP & Veronica Cottam on behalf of A/Prof. Kay Double

There is an urgent need for treatments that slow brain cell death in Parkinson's disease. The Parkinson brain is deficient in copper and, as restoring brain copper is beneficial in other brain disorders of copper deficiency, we suggest restoring brain copper will be beneficial in Parkinson's disease. We will test the ability of two drugs to restore brain copper in an animal model of Parkinson's disease and investigate if restoring brain copper reduces brain cell death. As these drugs have already been shown to be safe this approach could quickly be translated into clinical trials in Parkinson's disease patients

THE BIG RIDE

The Big Ride 4 Parkinson's was held on Saturday 29 – Sunday 30 March 2014.

With the weather on our side our 101 riders set out from Sydney Olympic Park for the 360km journey to Parkes raising just under $15,000.

Our riders were welcomed at stops in Yetholme, Lithgow, Orange and Parkes by locals, as well as Lions and Rotary Clubs who supported Parkinson's NSW by preparing food, which was generously donated by Woolworths, for our hungry riders.

Our riders not only took on the 360km ride they also participated in online fundraising purchasing mountains of raffle tickets to make our second annual Big Ride raffle a resounding success.

We had a fantastic showcase of entertainment including Australia's Number 1 Professional Street Bike Stunt Rider Dave McKenna, who performed a 15 minute stunt show and a special performance by Angry Anderson with local Orange band The Millthumpers.

This year we also welcomed back Brendan 'Jonesy' Jones from Sydney's Number 1 FM Radio station WSFM and former Rose Tattoo front man Angry Anderson who both took part in publicity for the event giving our ride and our cause a great boost.

We would like to thank our wonderful sponsors Fraser Motorcycles, Exodus Doors, Betta Motors, Woolworths Petrol, Coates Hire, CSIRO, Parkes Shire Council and The Pymble Wizard Handyman and Gardening Service for supporting The Big Ride and continuing to raise awareness.

We would also like to thank all of our riders, many who took part in our inaugural ride in 2013, for supporting this great event that will continue to see funds go into the vital services Parkinson's NSW provide for the Parkinson's Community across NSW. Especially in regional and rural areas, like Parkes.

A special mention to the organisations and companies that supported The Big Ride 4 Parkinson's: Kenma Australia, Sony Australia, Draggin Jeans, Starshots Caringbah, Motorbike Hire Toongabbie, Lions Clubs Australia, Rotary Australia and Independant Parts.

ARE TEETH THE KEY to Parkinson's disease?

That'd be IRON-IC.

When it comes down to it, teeth are hardly the first things we think of when searching for the cause of Parkinson's disease. However, these valuable souvenirs of our childhood might just contain a window into our past that can shed light onto how our brains become vulnerable to Parkinson's later in life.

Teeth put up with a lot in life. Every day we subject them assault after assault, from fizzy acid baths to literally bone-crushing forces, only to reward them with a 30-second or so scrub twice a day. Yet our teeth are remarkably resilient, remaining with us with just a modicum of care (and an often hefty dental bill).

In our ever-regenerating body, teeth are like a monument to the past. Our deciduous, or 'milk' teeth start forming in the embryonic phase of development, and our permanent teeth follow during the first few years of life. By the time our first lost tooth is swapped for fifty cents left under our pillow, the teeth we carry with us for life are quickly growing in the upper reaches of our gums, and in doing so are locking in a permanent record of our early-life nutrition.

Nutrition and diet has received a lot of attention in the Parkinson's world, from having a possible causative role to maintaining a healthy intake of nutrients during the later stages of the disease. One such factor is iron, the second most abundant metal on Earth and an essential nutrient for almost every living organism on the planet. We usually think of blood when we consider iron in the body, particularly the bright-red colour of haemoglobin that supplies oxygen to our cells. In the brain, iron is responsible for much more than just an oxygen delivery service, and especially in the developing brain, where the chemical reactivity of iron is harnessed to help build nerve fibres and support the rapid growth of our most complex organ.

Just like having too little, too much iron can be a bad thing. The brain is designed to use iron only when it's needed, otherwise the very nature of iron chemistry that is so desirable might get out of hand – after all, an iron atom is not a sentient being and will happily react with whatever is nearby. In Parkinson's disease we've known that something isn't right with iron metabolism for nearly a century, though nailing down exactly why has been eluding us for some time. Put iron and dopamine together in a test tube and they'll make some pretty toxic stuff that we can only assume isn't good for the brain, though we're still unable to explain why this happens later in life, considering iron and dopamine normally coexist without much fuss in the healthy brain.

To keep iron and dopamine separate from one another, the brain makes sure iron locked away when it's not being used. The storage capacity for iron in the brain is huge – aside from the liver you won't find a higher concentration of iron anywhere in the body. The brain is also generally closed off, with stringently managed 'checkpoints' allowing a steady stream of only small amounts of iron in and out. The exception to this is early in life, when the rapidly growing brain has an enormous appetite for iron and the expanding web of neural connections it builds. Soon after the brain is locked down and the iron inside becomes trapped, like a sink full of water emptying through a small drain. Add to this the constant trickle in of more iron at a rate greater than that leaving, and you can understand how the brain's iron warehouse fills up over time. Experimentally we see this in a general increase in brain iron levels with age, and this increase is further exacerbated in Parkinson's disease.

So, if the amount of iron in our ageing brain is dictated by how much iron our growing brain uses, it's entirely possible that this is an effect of our early life iron intake.

That's where the teeth come in. Our team at the University of Technology, Sydney and the Florey Institute of Neuroscience and Mental Health, in conjunction with the Icahn School of Medicine at Mount Sinai Hospital in New York City has discovered that teeth provide a timeline of past chemical exposure. Much like rings in a tree trunk, tooth morphology can be directly related to specific developmental periods, to a point where we can pinpoint precise developmental milestones to within a few days. Importantly, teeth also retain a record of iron intake in line with these growth lines, which we can directly relate to dietary habits, such as whether the subject was breast-fed or had a supplemented diet.

Dr Dominic Hare, MRSC, MRACI
Chancellor's Postdoctoral Research Fellow / Senior Research Officer
University of Technology, Sydney /
Florey Institute of Neuroscience and Mental Health
Ph. +61 3 9035 9549
Mob. +61 4 1177 6614

Photo by CARMEN-LEE-SPIERS

This is where our research is focused right now. Infant formula, although often a necessary alternative to breast milk, often contains up to 40 times the amount of iron in a chemical state that poorly reflects how it is delivered to an infant. Additionally, the perceived nutritional benefits of a diet rich in iron has given rise a number of formula brands further supplementing products with additional iron. We've found that developing mice fed a diet mirroring this high dose of iron accumulate iron in their brains faster and are more at risk of developing Parkinson-like symptoms. By no means do we intend to suggest that formula feeding directly causes Parkinson's disease, and recognise that formula feeding is often essential to new mothers and babies. However, our newly discovered findings that relate tooth iron concentration to dietary iron intake provide us with a new way to study why brain iron is elevated in Parkinson's disease, and our initial experiments identify iron-fortified infant formula as a possible culprit.

This project is still in its infancy (pardon the pun), though we'll soon begin examining the teeth of Parkinson's patients to see if early life iron exposure is indeed a contributing factor to development of the disease, and if brain iron concentration reflects what we see in teeth. Long-term there's the potential that tooth iron content might be a useful indicator of Parkinson's risk, though in the immediate future we're hoping to provide more evidence of the involvement of iron in the disease, and help push the research community into seriously targeting iron as a viable candidate for new therapies.

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Sunday 31 August 2014 | Sydney Olympic Park

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In Australia someone is diagnosed with Parkinson's disease every hour of every day.

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We also have fantastic raffle prizes to be won!

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For more information about the prizes and to view the conditions please visit:
www.unitywalkandrun.com.au

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Parkinson's NSW

SPLASH AND SLASH

Bernard McGrath is a self-taught contemporary Australian artist based in Berry, NSW. Working primarily in acrylic, his mixed media works combine loud, vivid colours and textures creating a highly unique energy on canvas. Bernard's works are created by what he calls his "splash and slash method" where he splashes, throws and layers paint onto a canvas and then shakes it whilst the paint is wet forming different shapes and textures.

Bernard has had no formal training and attributes his growing artistic talents to a procedure he had in 2008 known as Deep Brain Stimulation for the treatment of his early onset Parkinson's Disease. Deep brain stimulation (DBS) uses an implantable medical device similar to a cardiac pacemaker, which treats the main symptoms of advanced Parkinson's disease by delivering electrical stimulation to a precisely targeted area deep within the brain. Bernard believes this procedure also stimulated the right side of his brain as prior to the operation he appreciated art but had never participated in any artistic endeavours. Bernard loves his new found creativity and finds it a great form of therapy for his Parkinson 's disease.

Bernard displayed his works at Queen Street Gallery in April to coincide with World Parkinson's Day on 11 April.

Thank you

On Sunday 30 March, Cowra Gun Club hosted a Clay Shooting event organised by Peter & Jenny Mould and their team in support of Parkinson's NSW.

The event was a great success with 58 shooters in attendance and just under $4000 raised. The local Support Group was also involved, running another raffle raising over $400.

Our sincere thanks to the Cowra Gun Club for organising this fantastic awareness and fund raising event and to the local Support Group for their involvement.

(L to R) Peter Mould (Gun Club President), Ray Heilman (President, Cowra Parkinson's Support Group), Joy Dwight (Secretary, Cowra Gun Club and Secretary/Treasurer, Cowra Parkinson's Support Group) and Noel Dwight who suffers from Parkinson's. Noel is a long-standing member and past-President of Cowra Gun Club and the inspiration for the Charity event.

DEEP BRAIN STIMULATION THERAPY UPDATE

Deep Brain Stimulation (DBS) is a well-established treatment for Parkinson's disease (PD), with over 80000 procedures performed worldwide since the therapy was first used in the early 1980's. Despite exhaustive studies and scientific analysis, many misconceptions remain as to its use, optimal timing and risks. This article seeks to clarify the current thinking about DBS for PD.

What can patients expect from initial medical treatment of Parkinson's disease?

Once the diagnosis of PD is made and treatment commenced, most patients improve significantly, usually achieving 60-80% improvement of physical symptoms. Most patients will require a 3-4 times per day dosing regime of commonly available medications to achieve this response. This is the so-called 'Honeymoon' phase of PD,(see figure 1) where patients experience consistent and reliable control of physical symptoms.

Unfortunately however, over time, all patients will develop complications of medical therapy known as motor fluctuations and dyskinesias. About 10% of patients develop this problem per year, such that by 10 years most patients have some difficulty or other in this regard.

Motor fluctuations refer to a variable response to me
The mildest form of motor fluctuations is end of dos
Here, patients experience a wearing off from the bei
medication as the time for the next dose is nearing.
goes on, this wearing off effect can become more n
the response to medication less predictable.

Dyskinesias refer to excessive involuntary movemen
to medical treatment. Most commonly they occur at
'peak' effect of the medication, and then settle later
medication dose cycle. Less commonly dyskinesias occur as medication effect is 'kicking-in' or wearing off. Dyskinesias are commonly more troublesome to observers than patients, but can become severe, painful or disabling in their own right.

When they first develop, motor fluctuations and dyskinesias can be treated by a variety of manipulations of medications, often initially with good effect. Unfortunately with time, some patients find that, irrespective of the alterations that are made to their medications, they cannot achieve good control of physical symptoms. It is usually at this point in time that patients consider advanced interventions for their PD including apomorphine, duo-dopa and DBS.

There are 3 main indications for DBS:

1. Patients who experience motor fluctuations and/ or dyskinesias that do not come under satisfactory control with optimal medication management. Medication refractory motor fluctuations and dyskinesias are by far the most common reason that patients with PD consider surgery.

2. Patients with medication refractory tremor.

Whilst stiffness, slowness and gait disturbance usually respond well to medications early in the course of PD, tremor response in some individuals can be variable, with some patients finding no matter how much medication they take, tremor does not respond well. These patients may respond well to DBS early or later in the course of their PD. Most studies report ~ 80% improvement in tremor post DBS.

3. Patients who are intolerant of PD medication

Appreciation of the extent and frequency of medication side effects in PD has improved over recent years (see later). Many patients will experience side effects from Parkinson's medication including nausea, leg swelling and mental clouding. With slow introduction and careful management early in the course of PD, most patients will achieve good control of physical symptoms with minimal side effects. A small proportion of patients, however, cannot tolerate sufficient doses to achieve good control of physical symptoms or simply cannot tolerate PD medication. Fortunately this situation is relatively uncommon, however these patients may consider surgery within the first few years of diagnosis.

What are the benefits of surgery?

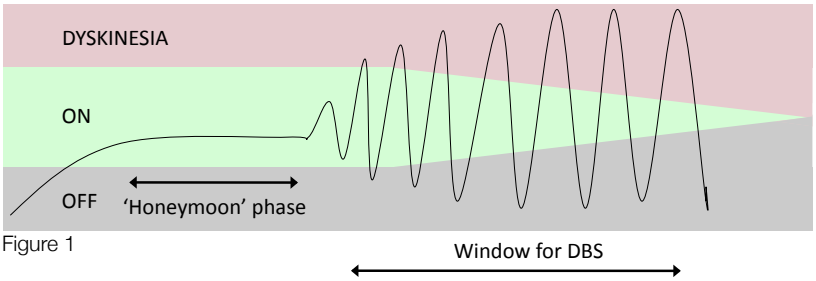

Figure 1

In patients with the symptom profiles mentioned above, the major benefit of surgery is to achieve consistency of physical performance when this can no longer be achieved with tablet therapy.

Ironically, the benefits of surgery in any one individual are determined by their medication response – not how long or reliable the benefit from an individual dose is, but rather the difference in physical performance between when medication is working and when it is not.

Patients who undergo surgery achieve approximately 75% of the benefit of their best medication effect most of the time. What does this mean in real terms? Over the years I have found the best way to conceptualise this is to ask patients to think about what they are like at their worst, then to think about what they are like at their best. Once they have these reference points in mind, most patients can conceptualise being at 75% of their best physical performance.

Whilst patients can still experience minor fluctuations and dyskinesia, most patients achieve consistent physical performance at approximately 75% of their best.

Because DBS provides consistent control, this allows us to reduce medication dose, usually by 30-100%. Most patients do prefer to be on some medication after surgery (they feel generally better on some medication rather than none), but the reduction in medication is often associated with an improvement in medication side effects.

Dyskinesias usually reduce by ~75% once the stimulation and new medication regime is established approximately 6 months after surgery.

How long do the benefits of surgery last?

Studies examining the long term effects of DBS suggest that benefits on stiffness and tremor last at least 5 years. Benefits in slowness and walking disturbance are not as marked at 5 years as they were at 1 year but patients still perform better in these domains 5 years after surgery than before surgery.

More recent studies (Zibetti et al, *Mov Disord* 2011) suggest that the benefits on activities of daily living are lost by 9 years post surgery. Of note however, these studies examining longer term effects were performed on patients who had relatively long duration of PD at the time of their surgery. For example, the average disease duration at the timing of surgery in the Zibetti study above was 16.5 years, much longer than the average disease duration in most surgical centres.

In late stage PD, patients retain a degree of both medication and DBS benefit, but also may develop symptoms that do not respond well to either of these therapies. Whilst other treatments can be very helpful in these later stages, these findings do mean that the window for surgical benefit is not open ended.

These clinical observations have focussed attention on the possibility that it may be better to consider surgery earlier in the disease course rather than as the treatment of last resort.

What is the optimal timing for DBS?

A major study published last year (Schuepbach et al, *NEJM* 2013), examined what the effects of surgery might be on patients earlier in their disease course, as soon as they experienced motor fluctuations and/or dyskinesias. This "EARLYSTIM" study followed 251 patients over 2 years to examine how patients fared with best medical management vs DBS. Patients were allocated randomly to receive surgery or best medical therapy. Here, as opposed to many of the earlier studies examining DBS, the average disease duration in both medical and surgical groups was only 7.5 years.

The results were striking. Not only did the surgically treated group perform better from a physical point of view, but they experienced a 20% improvement in quality of life compared to the patients treated with medication alone. These results clearly demonstrate the benefits of surgery at an earlier stage of PD than many patients would previously have considered.

The aim of treatment in PD is to maximise quality of life. Given, the progressive nature of PD one needs to accept that it may not be possible to achieve the same level of symptom control after many years of disease as can be achieved early on; but we should strive to achieve the best symptom control each step of the way.

Well-timed surgery can allow patients to maintain independence, continue working and enjoying improved quality of life for much longer than they might have otherwise.

Considering surgery is a frightening thought for most. The slow progressive nature of PD allows patients to make major compensations to deal with their difficulties and the alternative of a brain operation is difficult to consider. Understandably most patients try to put off the decision as long as possible, but the evidence tells us that patients are often waiting much longer than might be optimal for improving control of their PD. So when should patients start thinking about surgery?

Patients with medication resistant tremor or medication intolerance may consider surgery within the first few years of diagnosis, given the absence of an alternate satisfactory treatment option.

Patients with motor fluctuations and dyskinesias should consider surgery when optimal medical therapy does not provide satisfactory control of physical symptoms. Here there is a trap for both clinicians and patients as there is a seemingly endless array of tablets that can now be tried for PD. Usually however, if satisfactory control of physical symptoms has not been achieved after 6-12 months of medication trials, and other major contributors such as alternate illness or depression have been excluded, it is unlikely that tablet therapy will be effective. This is the optimal time for a discussion about the potential benefits and risks of surgery.

Parkinson's Disease Treatment Update

Dr Raymond Cook, Neurosurgeon &

Dr Paul Silberstein, Neurologist

Experience on 360 DBS patients with Parkinson's disease

A/Professor Simon Lewis, Neurologist

The Challenge on non-motor symptoms in Parkinson's disease

Friday 25 July, 2014

North Ryde RSL

Cnr. Pittwater and Magdala Roads

NORTH RYDE NSW 2113

Registration: 9:30am

Morning Tea provided

RSVP: By 11th July 2014 to Parkinson's NSW Infoline 1800 644 189 or infoline@parkinsonsnsw.org.au

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STEPPING TRAINING IN PARKINSON'S DISEASE

Volunteers with Parkinson's disease needed for a research study aimed at improving balance and leg muscle power. The study will determine the effect of home-based stepping training versus usual care on balance and mobility. A videogame will be provided to enhance stepping practice.

If you have Parkinson's disease, are aged 40 years or above and can walk unassisted (without a walking aid), you may be eligible.

This study is being conducted by a team of researchers at the University of Sydney, led by A/Professor Colleen Canning.

If you would like to be involved or would like further information, please contact:

Dr Jooeun Song
P: 9351 9436 or 0430 376 078
E: jooeun.song@sydney.edu.au

Dr Natalie Allen
P: 9351 9016 or 0468 322 724
E: natalie.allen@sydney.edu.au

Notably DBS has other beneficial effects in the long term. A recent British study (Ngoga et al JNNP 2013), which followed surgically and medically treated patients over 10 years, demonstrated that DBS delays the need to be admitted to a nursing home and is associated with greater longevity. Long term effects on mobility, swallowing and breathing likely underscore this.

What are the risks?

With any intervention there is always the risk side of the equation to consider. Ultimately a patients decision whether or not to proceed to surgery comes down to a risk/benefit equation which will depend on the nature of Parkinsonian symptoms and the presence or absence of other illnesses.

Overall the quoted risk of a major complication from surgery (bleeding in the brain, stroke, epilepsy or death) is 2-3%. In our experience, the long term risk of hardware infection is 2% and the long term risk of breakdown of the DBS system is approximately 2%.

A deterioration in speech volume and articulation is experienced by many patients within 2 years of surgery. Careful evaluation is required in patients with significant speech disturbance who are considering surgery.

The commonest difficulties we see in the peri-operative period are in the emotional and behavioural domains. Understandably, many patients report anxiety. Older patients in particular may experience confusion for a day or two after surgery. Some patients experience mood elevation, others report apathy or depression. These psychiatric symptoms are generally mild and resolve spontaneously although some do require manipulation of Parkinson's medications or anti-depressant therapy.

Whilst thinking about the risk of surgery, it is important to remember that not intervening is not necessarily without risk. In evaluating complications in the 'EARLYSTIM' study, the rate of complications was equal in the surgery group to those treated with tablets alone. Notably, psychiatric complications were more common in the group treated with tablets alone!

In the medication treatment group, medication side effects may have played a major role in cognitive and psychiatric side effects. Dopamine agonists (eg Sifrol, Rotigotine patch) in particular have been associated with a variety of behavioural disorders from impulsiveness to hypersexuality and pathological gambling (if you are experiencing these things talk to your doctor). They may not ask you about these things specifically. Side effects such as low grade nausea and mental fogginess can be problematic too.

Conclusions:

The decision to proceed to surgery is an intensely individual one which needs to carefully take into an account the profile of Parkinsonian symptoms and other medical conditions, but we should talk about surgery (and other advance therapies) early, when they have the greatest impact and durability.

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Adrian Unger is not just a retired pharmacist; he is a PNSW member who has lived with PD since 2004.

Bored by the monotonous and solitary nature of exercise at regular gyms, at age 48, Adrian took up non-competitive boxing training and from the first moment, he was hooked. His PD diagnosis did not deter him and the training has resulted in a high level of general fitness and a reduction in the severity of many of his PD symptoms. His experience mirrors research that highlights the importance of exercise and social interaction in helping People with Parkinson's (PwP's) to live better, more comfortable lives.

Adrian's interest in how boxing could be useful to PwP's lead him and his wife, Judy, to the USA to investigate an activity based on boxing movements (not boxing) tailored to the needs of PwP's. The exercises are vital in building and maintaining strength, endurance and balance. A most important component is the sheer fun experienced during the sessions. Adrian and Judy were fascinated to see PwP's ranging in age from late 20's to early 90's participating with enthusiasm—their collective attitude being "the best tablet I take is my boxing exercises".

On his return, Adrian has worked with two highly qualified and experienced health and exercise coaches to develop a program for our use in Sydney. Lucas Finch, MA in Applied Science (Coaching Psychology) The University of Sydney, whose background in clinical practice focused on injury management and preventive health, has worked closely with Adrian for 7 years. Jordan Wehrman, Muay Thai Coach and Special Needs Coach, is currently undertaking a MA in Speech Pathology at Macquarie University.

Being community minded, Dylan and Liam Resnekov, the owners of VT1 Mixed Martial Arts Academy where Adrian trains, are excited and proud to host the Punchin' Parko's Program. Dylan, a World Champion kick-boxer, will also assist with coaching when the program begins in July.

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

An Information Day will be held on Sunday, June 29, at 11am, at the VT1 Martial Arts Academy, 390 Eastern Valley Way, Chatswood.

Fight Parkinson's—YES REALLY!

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SEE a Demonstration of the Punchin' Parko's Program
PARTICIPATE in a Q and A session
Register on the day and receive 6 weeks training FREE!

Venue: VT1 Mixed Martial Arts Academy
19b/390 Eastern Valley Way, Chatswood

Booking Essential: Contact the InfoLine 1800 644 189 to book your place.
Access and parking : Behind the building via Lower Gibbes Street.
Turn into Smith Street off Eastern Valley Way, then right into Lower Gibbes Street
Follow the signs

FROM MOLECULE TO MEDICINE

...it takes time: 15 years in development

Everyone knows their Parkinson's medications are manufactured and supplied to them by one of the many pharmaceutical companies in the world. But have you ever stopped to think about the journey from the first discovery of a molecule to the medicine being available in your pharmacy?

Amazingly, it can take up to fifteen years to develop one new medicine from the earliest stages of discovery to the time it is available to patients. Many of the new drugs available this year were in the early stages of discovery fifteen years ago, in 1999!

Let's rewind the calendar to 1999 and take a look at what else was happening fifteen years ago.

1999 was the year that Australian voters decided to keep the queen and not become a republic, and in Europe they introduced the Euro. In cinema, we were watching The Sixth Sense, The Matrix and American Beauty, while over on TV we were watching The X-Files, Friends and Ally McBeal. In politics, John Howard was PM of Australia, Helen Clark became first female PM of New Zealand and in the U.S. President Bill Clinton was acquitted in impeachment proceedings. The world prepared for new millennium parties and computers were tested for the YK2 millennium bug!

As you can see you, a lot of time passes between drug discovery and drug availability. In fact, for every 10,000 compounds that are discovered, only 1 will make it to market 15 years later. All that comes at a cost and in 2010 the global industry invested in excess of US$100 billion in medicines R&D.

FROM DISCOVERY TO MARKET

Let's have a look at the various stages of development, from discovery to market. The journey begins with working to understand diseases and only ends when a medicine is available for patients

Pre-discovery – Understanding the disease: Researchers from government, academia and industry all contribute to disease understanding which can take many years and often leads to frustrating dead ends. In Parkinson's Disease there were major breakthroughs in the 1960s with the identification of dopamine pathways which led to the subsequent development of oral levodopa therapies such as SINEMET® (levodopa/carbidopa) and MADOPAR® (levodopa/benserazide) and later SINEMET® CR (levodopa/carbidopa) and STALEVO® (levodopa/carbidopa/entacapone). However, since that time it has proved a challenge to further develop our understanding of Parkinson's.

Drug Discovery (years 1-5) – Finding a promising molecule to become a drug: Scientists search for a molecule or compound that may alter disease course. There are a few ways to find a compound, including nature (bacteria or plants), sophisticated computer modelling, screening thousands of compounds or using biotechnology to genetically engineer living systems.

Preclinical testing (years 6-7) – Determining if a drug is safe enough for humans: Researchers test drugs in vitro or in vivo to determine if they should be tested in humans. After starting with approximately 5,000 to 10,000 compounds, scientists are now down to between 1 and 5 molecules which will be studied in clinical trials.

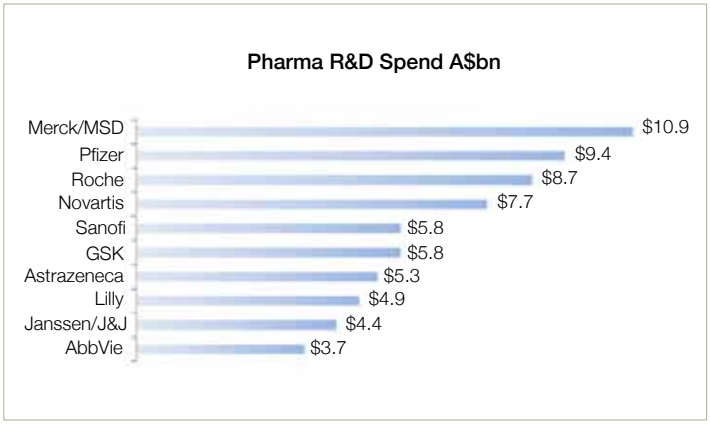
Clinical Trials (years 8-14) – To determine efficacy and safety in humans: Phase 1 Clinical Trial are in small groups of about 20 to 100 healthy volunteers to evaluate the safety of the drug in humans. Phase 2 Trials are in groups of 100 to 500 patients with the disease to examine possible side effects. Phase 3 Trials are the largest and costliest, often with 1000 to 5000 patients to test both safety and effectiveness of the drug.

TGA review (year 15) – Submit application for approval: Once all three phases of clinical trials are complete, if the findings demonstrate the experimental medicine's safety and efficacy, a company can file for registration.

Manufacturing (year 15 onwards): Large-scale manufacturing is a major undertaking. In many cases, companies must build a new manufacturing facility or reconstruct an old one. Making a drug on a large scale takes great regard for quality. Research on a new medicine still continues and as larger numbers of patients begin to use the drug, companies must monitor usage carefully.

MAJOR INVESTMENT IN R & D

All major pharmaceutical companies invest in Research and Development (R&D). The figure below shows investment in 2010 (the most recent published data). At the top of the list for that year was Merck, known as MSD in Australia, spending over $10bn.



MERCK/MSD AND PARKINSON'S DISEASE

MSD has a long history of supporting Parkinson's Disease, right back to the development of SINEMET® over 40 years ago. Alongside the original SINEMET® sits the more recently available SINEMET® CR, the controlled-release formulation.

Since their early success in bringing SINEMET® to market, MSD has committed a significant amount of time and money in pre-discovery to better understand Parkinson's and develop more treatments.

A breakthrough came in the 1990's with the discovery of selective A2A receptor antagonists and potential therapeutic usefulness in the treatment of Parkinson's disease. In the 2000's MSD identified a molecule called preladenant that passed preclinical testing and in 2007 went into Phase I and Phase II clinical trials.

There were high hopes for preladenant, as it would be the first of a new class of drugs for PD for a long time. It was hoped that combining it with L-Dopa or dopamine agonist therapy would lead to improved outcomes for patients.

Sadly, in 2013, Phase III trials of preladenant did not show it to be more effective than placebo, and so, after 15 years in the making, its development was discontinued in May 2013. After 15 years, countless researcher hours and millions of dollars invested, the journey of preladenant came to an end and it never became available to patients.

Not deterred, Merck/MSD continues to support Parkinson's Disease research and is one of 13 industry sponsors of the Parkinson's Progression Markers Initiative (PPMI), a landmark observational clinical study comprehensively evaluating cohorts of significant interest using advanced imaging, biologic sampling and clinical and behavioural assessments to identify biomarkers of Parkinson's disease progression. PPMI is taking place at clinical sites in the United States, Europe, and Australia.

PHARMACEUTICAL COMPANIES AND PARKINSON'S DISEASE – THE FUTURE

An opportunity may still exist to develop treatments that deliver more controlled release of levodopa. Several options currently exist, including SINEMET® CR, MADOPAR® HBS and DUODOPA®. However, several small and midsized drug developers are pursuing the development of levodopa reformulations to offer yet more controlled release options.

The greatest unmet need in PD, however, remains the development of therapies that delay the progression of the disease, coupled with the need for reliable markers for earlier diagnosis of PD.

Even though the pharmaceutical industry continues to make great progress in drug discovery, as we now know, it is not a quick process and can take up to 15 years from first discovery until a new medicine is available. We just have to be patient.

Further Reading and References

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LOCAL Hero

Mrs Pereira said what she loved about her work was the ability to make a difference to people's lives.

"If I can help someone have a quality of life with a challenging condition, it's the most rewarding thing."

A NURSE who has helped improve the lives of hundreds of local sufferers of Parkinson's disease and their carers was been named the 2014 Australia Day Citizen of the Year in a ceremony at Nowra Showground on Sunday morning.

Marilia Pereira is now in her fourth year of running the neurological nurse service which originally began as a pilot program.

She has 280 clients and their carers and drives 30,000 kilometres each year to see them, helping sufferers of the degenerative disease to stay in their own homes for longer.

In addition, Mrs Pereira uses her own time to educate doctors, health care professionals and staff at aged care facilities about the disease.

Winning the award will help Mrs Pereira to further raise awareness about Parkinson's disease.

"I will be able to use it to spread the word about Parkinson's and how we as a community can get together and support those who have it and their carers," she said.

Shoalhaven Mayor Joanna Gash said Mrs Pereira was an exceptionally deserving recipient of the 2014 Australia Day Citizen of the Year Award saying her actions had provided immense comfort to the local community at a time of need.

"I would like to congratulate Mrs Pereira, on not only being named the 2014 Australia Day Citizen of the Year Award recipient but for her amazing work in the field of neurogenerative conditions," said Cr Gash.

"Through her ongoing commitment, Mrs Pereira has helped ease the isolation, concerns and burden placed on the sufferers of Parkinson's disease, their families and carers.

"Mrs Pereira has also received strong praise and thanks from local doctors, health care professionals and aged care facility staff for her continual education and community awareness programs.

"As well as giving talks to support groups and other neurogenerative disease seminars Mrs Pereira was recently invited to address a selected group of Parliamentarians at Parliament House."

Mrs Pereira said what she loved about her work was the ability to make a difference to people's lives.

"If I can help someone have a quality of life with a challenging condition, it's the most rewarding thing," she said.

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WHAT'S ON

29
June

Let's KO Parkinson's Disease
PUNCHIN' PARKO'S

25
July

Surgical Intervention for Parkinson's Disease Seminar

31
August

UNITY WALK & RUN

1–7
September

Parkinson's AWARENESS WEEK

3
September

Parkinson's AWARENESS Seminar

4
September

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22
October

Allied Health Awareness Seminar
(For Health Professionals only)

30
October

Newly Diagnosed Program

13
November

GOLF DAY

18
November

AGM

Almost flying. The Big Ride

(L to R) The Hon Don Harwin MLC, The Hon Shelley Hancock MP, Ms Miriam Dixon CEO Parkinson's NSW, The (former) Premier Barry O'Farrell, The Hon Melinda Pavey MLC, Parliamentary Secretary and The Hon Mick Veitch MLC, Shadow Minister for Trade and Investment, Shadow Minister for Regional Infrastructure and Services, and Shadow Minister for Regional and Rural Affairs.

Parkinson's NSW Inc ABN 93 023 603 545
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WHO WE ARE

Parkinson's NSW Inc is a not for profit, community-based organisation established in 1979 to provide information, counselling and support to people living with Parkinson's disease.

We work in partnership with a network of support groups throughout the state.

We encourage research into Parkinson's disease and co-operate with those undertaking it.

We advocate on behalf of the Parkinson's community and strive to increase community awareness of the disease.

We look towards taking a leadership role in representing the Parkinson's community in New South Wales and Australia-wide.

OUR VISION

A community free of Parkinson's disease.

OUR MISSION

To enhance the quality of life to all people living with Parkinson's disease.

PARKINSON'S NSW INC.

Building 21
(Cnr Manning and Norton Rd's)
Macquarie Hospital
120 Coxs Road
NORTH RYDE NSW 2113

POSTAL ADDRESS
PO Box 71
NORTH RYDE BC NSW 1670

CONTACT NUMBERS

Reception	02 8875 8900
Fax	02 8875 8999
InfoLine	1800 644 189

WEBSITE

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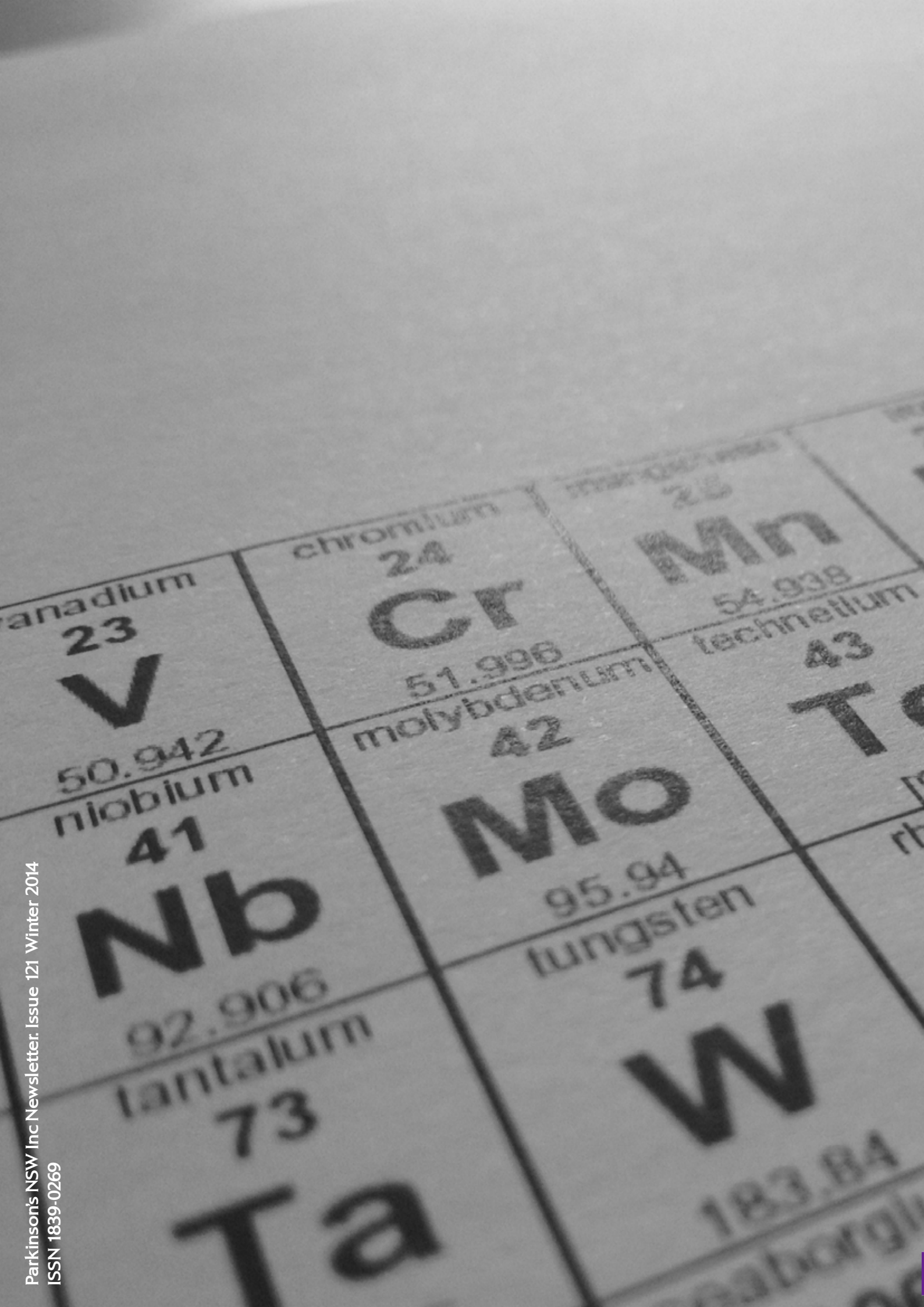

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