

STAND *by* ME

Parkinson's NSW Inc
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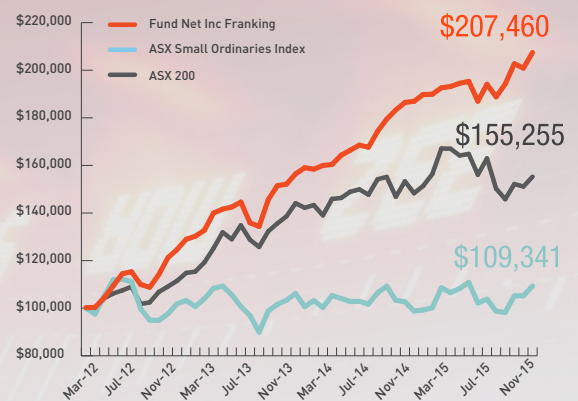
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COVER STORY

Life is full of times when we need someone to stand with us. Weddings are just one.

This issue's front cover photo is of Catherine standing by her grandfather John Dent on her wedding day.

John is my dad and the oldest member of Parkinson's NSW.

Quite an achievement. But John has always been a quiet achiever.

Diagnosed late in life, John was fortunate to be well and able to stand by my mum during her lifetime. When she died it was our turn as a family to stand close to our dad.

But John has another support, a small folded card that goes with him everywhere. When he had a bad fall, it was his Parkinson's card that alerted the hospital staff to his medication needs. When his speech is hard to understand, his 'card' stands with him as a reminder to others of the importance of taking his medication on time, despite the circumstances.

In emergency departments, slurred speech is often seen as an indicator of stroke – his Parkinson's card reminds medical staff there may be another reason.

Living with Parkinson's takes determination. It is a frustrating and fickle disease. It takes courage to see it through, more to ask for help and just some more to accept it.

To stand by someone with Parkinson's disease is not easy, but it is a privilege and one I am proud to do.

Linda Davies

(cover image by Rob Henderson)

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FROM THE PRESIDENT

Andrew Whitton

Welcome to another year, a bit belated but this is the first opportunity I have had to correspond with everyone. My first duty is to sincerely thank the outgoing board members and to welcome in the new board.

Welcome to OUR NEW BOARD

PRESIDENT

Andrew Whitton (PD)

VICE PRESIDENT

Malcolm Irving (PD)

TREASURER

Jaimee Thompson*

SECRETARY

Laurie Gray (PD)

BOARD MEMBERS

Lloyd Rothwell

Colin Hall

Bryce Vissel*

Chris Davis** (PD)

Vera Heil

Kay Double

David Veness*

Rod Chaplin*

Ramy Soussou*

* New to the board this year

** New to the board this year although is a past President

(PD) Has been diagnosed with PD

Parkinson's NSW could not survive without the skills, time and effort put in by all volunteers – particularly the board members who set the strategic path for the organisation. There is no doubting that PNSW would not be in the position it is without the following outgoing long serving board members:

John Silk (PD)	11 years
Rebecca Silk	10 years
Phillip Maundrell	9 years
John Hassett (PD)	8 years
Graham Dawkins (PD)	6 years
Sam Chu	9 years

With a combined 53 years of service, it is going to take some very hard work to compensate for this loss of experience. On behalf of the new board, and I am sure it goes for the whole membership, thank you for everything you have done over the years to make PNSW the organisation it is today.

The primary goal of the board is to ensure that PNSW provides a range of services that improve the quality of life for all PD sufferers and their carers and families. A large number of you would have experienced these services first hand – maybe calling up the Infoline for some general advice or perhaps speaking with one of our counsellors for some support and guidance. We are committed to providing these services to everyone at no cost. What you may not be aware is that PNSW is basically self-funded, we get very little government support. Two things I would ask you to consider, firstly is to join PNSW (although if you are reading this there is better than an even chance you are a member!). The more members the louder our voice is when lobbying the government or negotiating with business and the better the chance they will hear us and listen to our message.

The second thing, raising more money, is always a difficult conversation to initiate, particularly asking someone to provide for PNSW in their will. But that is exactly what I am going to do. Bequests to PNSW, have, over the years, helped us to become more financially secure. However, as we would like to embark on a program of providing more neurological nurses to the PD community in NSW we have to dramatically increase our income. To this end, if you are not able to donate through any of our existing appeals, I would like to ask you to consider joining myself and many others and provide for PNSW by way of a bequest in your will.

Andrew Whitton

President

PS: Should you wish to find out more about our Bequest Program, please do not hesitate to pick up the phone and call our Bequests Officer Melanie Browning 02 8015 1912 or our CEO Miriam Dixon 02 8051 1901.



FROM THE CEO

I am happy to announce that we are settling in nicely to the new offices of Parkinson's NSW. Our new address is Macquarie Hospital, Building 17, 51 Wicks Road, North Ryde. The building is on the ground floor and has disabled access along with one disabled parking space.

Parking is available near by on the hospital grounds. If you are thinking of visiting please give the InfoLine a call and they will direct you to parking areas.

I would like to take this opportunity to publicly thank the Hon Jillian Skinner MP, Minister for Health and NSW Health for their assistance in obtaining a new home for us on Macquarie Hospital campus. They also provided financial assistance allowing us to make the building accessible.

I would also like to thank Stephen Taylor (a member of the young Men's Network living with Parkinson's) who provided pro-bono architectural advice; Taubman's who generously donated all of the paint for our renovation; and Winnings Appliances who supplied the white goods for our kitchen at cost price and also for their donation to Parkinson's NSW.

While our old office was open plan we now have separate offices, some of which are shared e.g. accounts, which makes for a much quieter and more private working environment. We have a large room which is used for Board and staff meetings and in addition we have a large meeting room which will be used for education groups and house our library resources.

Parkinson's NSW would also like to thank Philip Jacobson for the generous donation of a beautiful carved wooden table for our boardroom/meeting room.

However there was a downside with the move.

We have experienced and continue to experience significant telecommunications difficulties. If you have sent an email and have not received a response, could you please resend your email and contact the office to confirm receipt. For our full list of new contact details please see page 19 of this edition of *Stand By Me*.

Staff Changes

After many years of service with Parkinson's NSW, Deb England has retired. Deb worked as a specialist counsellor and educator for Parkinson's NSW for nine years. We wish her well. Amber Abbott, Clinical Psychologist, joined us last year. Amber attends Concord Clinic as well as providing counselling at North Ryde.

I am delighted to announce the expansion of our Counselling Service with the appointment of two new team members. Juan Pedraza, originally from Chile where he held a senior position in neuro psychology. Juan will attend Westmead Clinic and counsel two days a week at North Ryde. Kirstin

Robertson-Gillam has worked as a counsellor for many years and is currently a lecturer at Western Sydney University. She also has a keen interest in music therapy. Kirstin will work four days a week with one day dedicated to education. We hope to be able to create a calendar of education events to share with you. Kirstin will fill in for Amber who starts maternity leave in May.

Many of you may have already met Melanie Browning, Community and Support Group Relations. With the departure of Antoinette Riley, Mel has eagerly taken up the reins and is working to forge strong relationships with support groups. Mel will also be responsible for our bequest program.

World Parkinson's Day Awareness Campaign

World Parkinson's Day on 11th April saw the launch of our awareness campaign featuring Andy O'Shea undergoing deep brain stimulation at Westmead Hospital. While this campaign could be seen as confronting, we hope it has raised significant awareness and encourage donations to support research and support services. Andy, his wife Denise and their three children have been extremely generous in allowing us to film and record the impact of Parkinson's has on their lives. For more information please visit our website.

Yours in Parkinson's Friendship

Miriam Dixon

NEW BOARD MEMBERS



DR BRYCE VISSEL

Dr. Bryce Vissel serves as the Head of the Neurodegenerative Diseases research group at the Garvan Institute of Medical Research as well as Conjoint Senior Lecturer at St Vincent's Clinical School, Faculty of Medicine, University of NSW.

Dr. Vissel has been Chairman of Scientific Advisory Board at Cellmid Limited since July 07, 2015. Prior to that, Dr. Vissel worked for a decade at the highly prestigious Salk Institute (La Jolla, California, USA), in the world's leading neuroscience laboratory. Dr. Vissel was recruited by the Garvan Institute to Australia from California's Salk Institute to establish and lead research in brain and spinal cord disorders and repair.

Dr. Vissel's research has been widely recognised internationally, and he has received a number of awards, including the prestigious Fulbright award, a Liebermann award and a BIOFIRST award. Dr. Vissel has published more than 50 peer-reviewed papers, many in top tier journals.



JAIMEE THOMPSON: Treasurer

Jaimee has over 17 years audit and risk management experience and is the Chief Risk and Assurance Officer for Downer EDI a mining, rail and construction company. In this capacity she oversees the risk management framework, helps drive improvement in business processes and oversees fraud investigations. Prior to joining Downer, Jaimee spent her career predominantly in Professional Services. She was a Partner at Deloitte in the Risk Services Division. In her spare time she enjoys travelling, beach days and spending time with friends.

Jaimee has a Bachelor of Business (Accounting) and a Bachelor of Computing. She is a Chartered Accountant and a member of the Institute of Chartered Accountants. She is also a Member of the Company Directors Institute.



DAVID REID VENESS

David joined the Board as a non-metropolitan representative. David was diagnosed with Parkinson's seven years ago and immediately joined his local support group in Bathurst. He strongly believes in and plays an active role in all of the group's activities. He enjoys exercise and encourages all those with Parkinson's to try and exercise regularly.

David joined the Board with a desire to represent country areas of NSW. He understands the difficulties providing direct support for those living with Parkinson's in country areas and is passionate in gaining more nurses for regional areas. As a member of the PNSW Board, David is willing to travel and meet support groups throughout NSW to help lobby our politicians for more nurses in regional areas.

David is retired and his background is in hospitality and banking.



RAMY SOUSSOU

Ramy is the General Manager of Regulatory Affairs and Stakeholder Relations for Red Energy and Lumo Energy, the retail divisions of the Snowy Hydro Group Limited. He is responsible for the coordination of policy objectives and stakeholder relations for the retail business as well as energy issues impacting on retail operations. His role also encompasses the management of emerging markets. Ramy has extensive experience and knowledge in the energy and renewable industry having led large teams in sales, marketing and operations within the retail industry.

Ramy was also the Deputy Chief Executive of the Energy Retailers Association of Australia (ERAA), where he led advocacy on energy policy that impacted its members. Prior to this he was the Acting Chief Executive for Energy Assured Limited, where he established the self-regulated industry initiative to ensure the best practice of door to door sales for energy contracts.

Having studied in Switzerland, the United Kingdom and Australia, Ramy holds a Bachelor of Arts (Economics) from Sydney University, an Executive Masters in Business Administration from the Australian Graduate School of Management and is a graduate of the Australian Institute of Company Directors.

He was formerly a director on the ERAA board (2007 – 2009 and from 2014-2015) and has sat on various committees inclusive of the Ministerial Advisory Council for Victorian Advanced Metering Infrastructure Program, member of the NSW Smart Meter Task Force, advisory member of the Commonwealth's Smart Grid Smart City initiative.



RODNEY CHAPLIN

Rodney Chaplin is the Sales & Commercial Director for Landis & Gyr's Services Business in Asia Pacific. Landis & Gyr is a subsidiary of the Toshiba Corporation, one of the world's largest technology suppliers to the Energy Industry. Based in Sydney, Rodney has spent the last 10 years working in the Energy industry in the technology sector, including leadership roles at IBM and SAP.

Rodney has recently joined PNSW as a non-executive director, following previous pro-bono strategy work for the PNSW management team. He is also a Non-Executive Director of Intech Credit Union (encompassing Telstra Credit Union) and currently serves on the Governance Sub-Committee. Rodney has a Class One Honours Degree in Telecommunications Engineering and a Diploma in Electrical technology. He has also studied business strategy at INSEAD/China Europe Business School whilst with IBM.

BRUCE EVANS IN HIS UNCLE'S STEPS

In late May/early June of 2015, I had the great privilege to participate in the 70th Anniversary Sandakan Death March. Along with other trekkers we followed the path taken by the unfortunate Australian and English POWs who perished in this tragic story from World War II.

It took place in the Malaysian province of Borneo near the end of World War II. 2434 prisoners were incarcerated at Sandakan. Six survived. My Uncle John, my dad's elder brother, was one of those killed on the march. The POWs were sent there after Singapore fell to build an airfield for the Japanese. Initially it was a reasonably good camp. Because rice rations were reasonable and food could be obtained from the locals, conditions were probably better than on the Burma Railway camps. However things deteriorated after the Japanese discovered a radio in the camp. When things started going poorly for the Japanese in the Pacific, the high command basically issued an order to get rid of the POWs at Sandakan. Rations were cut and many died at the camp through starvation or tropical illnesses. In 1944 orders were issued to send the "fittest" on a grueling trek through thick jungle into the centre of Borneo. Three such marches took place and this was the route we followed.

Our main guide for the tour was Lynette Silver who has researched the topic extensively and provided us with an in depth account of the whole story as we progressed along the track. She related horror story after horror story as we reached the places where significant atrocities and events happened. Lynette assigned each walker a POW who died on the march. When we reached the spot where our prisoner died, we read out a fact sheet telling the group about that POW.

We reached the spot where my uncle died after a very tough day's walking in steep terrain that was heavily overgrown. We were all exhausted mainly due to the heat and extreme humidity and we were all in good physical condition. As I told the group what I knew about my uncle and reported on his service record, I realised the enormity of the suffering he had endured. He died on the 16th June 1945. He would have been in appalling physical condition, starving and subjected to mistreatment that goes beyond understanding. Talking about Uncle John at that spot was one of the most difficult tasks I've ever done.

In a way he was fortunate that he died on that day, as things continued to worsen for those left. I can tell you Uncle John was a hero. All these blokes were heroes. To go through what they did, in the conditions they were in, is beyond belief.

Fortunately there are some great positives from my trek. It was so encouraging to see the younger trekkers of our group so moved by the story. This will ensure that the story is not forgotten. Lynette and her husband Neil, not only ensure they tell the real story of Sandakan, but they also do great things for the local people. It was their parents and grandparents who supported and assisted the POWs when they could, at great personal risk to themselves and their families. Lynette has established a scholarship fund to help the young local girls go on to secondary school, assisted with the rebuilding of a childcare centre in one of the villages, and is now assisting the villagers of Kiau to rebuild after the damage sustained in an earthquake that occurred while we were walking.

Finally I am very proud to report that my sponsors donated over \$5000 to Parkinson's NSW. Let's hope there is a cure not too far around the corner.

L to R

Fellow trekker Graham Felton and Bruce Evans





ASKING FOR HELP TO MAINTAIN INDEPENDENCE

This title may seem like a contradiction in terms, but sometimes asking for help with the things you can't do for yourself, actually helps you to keep doing the things you CAN do longer. And yet, I've spoken to many people lately who find asking for help very difficult or challenging, whether they're a person with Parkinson's or a carer. Finding ways to ask for and accept help is an important part of your self management, like a busy project manager who knows how to delegate tasks to make sure everything gets done and to prevent themselves becoming overwhelmed. Trying to do it all yourself can be impossible!

Benefits of asking for help

People with Parkinson's may need help with a range of day to day tasks, from minor assistance with doing up a button or cutting a steak, to more significant care needs like showering, dressing, and general mobility. Carers too may need assistance as the demands on them increase, especially if they're juggling other roles and responsibilities like work, family or other commitments. Accessing help when we need it can mean the difference between coping or becoming overwhelmed. It can also mean the difference between maintaining an optimal level of health and wellbeing for your circumstances or deteriorating due to neglect of important care needs. Examples: (a) Someone who is willing to ask a friend for help with transport can then still attend their weekly exercise class, which is important in managing their Parkinson's symptoms; (b) someone who can accept help with showering can then maintain a good level of hygiene and personal care, which is important for our physical, social and emotional wellbeing; (c) a carer who can access support for themselves or arrange some respite care can prevent themselves from becoming overwhelmed or burnt out. Asking for help can mean you can keep coping for longer, and in a better state of physical and emotional health by ensuring all your needs are being met.

Barriers to asking for help

There are many reasons why people don't ask for help when they need it. Not wanting to be a burden, shame or embarrassment, lack of assertiveness, reluctance to let go of your independence or control, feeling

useless, depression or apathy, or unhelpful self talk like "I should be able to do it myself" are just some of the barriers. These may all be perfectly normal reactions to reaching your limits or to a change in your abilities and autonomy, and yet if you can overcome the barriers and ask for help, you can help yourself stay as resilient as you can for as long as you can. Neglecting your care needs can result in quicker deterioration and actually accelerate a loss of independence. For some people who live alone, are socially isolated, or whose family are unsupportive, it may feel like there is no-one to ask for help. In these cases, access to community-based supports and services becomes even more important.

Some tips for asking for help

Firstly, identify your needs – what specific tasks and activities are becoming more difficult to manage on your own? What sort of assistance do you need, and who might be able to provide it?

Think about the pros and cons of asking for help vs not asking. What benefits would you gain if you got help? What's the cost of not getting help?

Identify your own barriers to asking for help – what stops you the most? – and make a plan to get around these barriers.

Rehearse your request – sometimes finding the words is the hardest part.

Be informed about your local community resources. Health centres, local councils, Parkinson's Support Groups, and your care providers may be good sources of information about what supports and services are available.

Finally, differentiate the things you can and can't do for yourself. Keep doing the things you CAN do (even if it takes longer) and focus on your abilities and accomplishments, not your limitations!

For further assistance, you can access free information and specialist counselling by calling the Parkinson's NSW InfoLine on 1800 644 189.

Article by Amber Abbot, Clinical Psychologist, Parkinson's NSW specialist counselling service.



John and Mary Marshall supporting each other.
Putting on rock climbing gear is something not easily done alone.



DEEP BRAIN STIMULATION MICK'S STORY

Mick is a 47 year old father, husband and ex-sailor who experienced a challenging and painful journey in the lead up to his diagnosis, and subsequent therapy, with PD. He is an advocate for Deep Brain Stimulation (DBS) and says he "would climb the highest tree and yell about the difference DBS makes in the hope it would change someone's life".

At age 32, Royal Australian Navy Chief Petty Officer Mick Sharp started to experience symptoms of PD. But, as a young father and not fitting the typical stereotype for PD, his difficulties in manoeuvring around the ship were attributed to an ankle injury. Missing these first vital signs of PD sparked a tumultuous 10 year journey toward diagnosis and treatment for Mick. A journey that simply should not be that hard.

According to Mick, "despite having some very dark times, I wouldn't change a thing because through my experience I hope others will benefit". It took time and persistence for me to be diagnosed with PD. It shouldn't be that hard. Parkinson's continues to affect younger people and it is important the signs and symptoms are understood."

During a posting on-board the Navy Destroyer HMAS Brisbane Mick found it increasingly difficult to get around the ship; bumping into walls and having trouble climbing up and down ladders. After months of looking forward to the posting, Mick was reluctant to raise alarm, however, his team were concerned. He recalls, "I thought it might be a result of an ankle injury or pinched nerve I sustained a few years earlier. I tried to compensate for it; however it was unfair to my team. I spoke with the Captain and we agreed I would head to Canberra for a week or so to get it checked out."

Mick never returned to the ship.

When Mick arrived in Canberra he visited the medical team. "I had visited the clinic about my ankle in the past. The GP I saw did some tests and said she didn't think the problem was orthopaedic and may be neurological." Mick was referred to a range of different specialists for further assessment. "It had been weeks since I left the ship and felt like I had every test under the sun, but doctors couldn't detect the answer. I was told I needed to learn to live with it, yet I couldn't return to duty. I tried, but I didn't know how I could overcome the symptoms."

In the weeks following, Mick was diagnosed with hysterical conversion disorder. "They said it wasn't physical, it was psychiatric. I spent the next 12-18 months on medication that began to not only mask my symptoms, but amplified them. "I started to flop around like an untrained seal. Being told this was 'all in my head' destroyed me."

Mick soon fell into a deep depression, and with a five year old daughter about to start school, the loving father removed himself from the home. "I didn't want her to see me like that. My health had taken such a huge toll on my life, and my wife's life already. I went to stay with my mum in Brisbane, but it was

then too much for her and I was moved to a hospital and then a psychiatric clinic."

During Mick's time in the clinic, he received electro convulsive therapy (ECT) in the hope that would treat his depression and disorder. After nine episodes, he returned to Canberra to be with his family. A short time after, Mick was medically discharged from the defence force. "My diagnosis had taken years of my life, and affected all of my family. Now my career was over too so we went home."

Once settled back in Brisbane, Mick searched for a local psychiatrist. "I would have been in his office for only five or ten minutes when he turned to me and asked why I was there. He basically said my symptoms didn't fit the basic parameters of a conversion disorder and referred me to one of the top neurologists in Brisbane for ongoing management. I still felt hopeless. I visited the neurologist and we spent time going through my history. He suggested that we stop my medication for three – six months so he could properly assess my symptoms. When I returned he performed further tests and said it looked like PD. I was shocked but had a huge sense of relief. I knew it wasn't my head. I remembered back to that first GP who said my symptoms were neurological and thought at last I have an answer."

Within days, Mick started on medication to alleviate symptoms of PD. "In the early days the medication worked quite well. Over time, my 'on window' (time free of symptoms) became shorter." Mick continued on medication for seven years. "Towards the end, everything was a fine balancing act. I was taking medication to coincide with my plans for the day. I didn't go out too much and always needed to be with someone when I did."

"I first heard about deep brain stimulation around 2007. The thought of people operating on my head wasn't great, particularly while I was awake. Initially I discounted it as a radical option. As time went on and medication was less effective I thought 'what do I have to lose'."

Mick received Medtronic Deep Brain Stimulation (DBS) therapy in January, 2010 at age 43.

"Since having the procedure, my life has totally changed. I feel closer to the man I was on that ship, than ever. I don't require any medication, I can drive, go for a walk and I am more independent and spontaneous than ever. I have qualified as a Justice of the Peace and volunteer at the local hospital. The things most people take for granted are gifts that enrich my life.

"My advice to others with PD is get DBS as soon as you can. It has given me a second shot at life. I might be turning 47 in December this year (2013), but I have two birthdays now. In January, I have my DBS birthday when I turn four."

Photo: Mick and Judi Sharpe



This patient testimonial relates an account of an individual's response to the treatment. The account is genuine, typical and documented. However, the individual's response does not provide any indication, guide, warranty or guarantee as to the response other persons may have to the treatment. The response other persons have to the treatment could be different. Responses to the treatment discussed can and do vary and are specific to the individual patient. Please consult your healthcare professional for a full list of benefits, indications, precautions, clinical results, and other important medical information that pertains to the therapy or products discussed.

About the Therapy

Deep Brain Stimulation (DBS) usually uses a surgically implanted medical device, similar to cardiac pacemaker, to

deliver electrical stimulation to precisely targeted areas on each side of the brain.

Although the exact mechanism of action is unknown, it appears that continuous stimulation of these areas (or regions) blocks the signals that cause the disabling motor symptoms of PD, essential tremor, dystonia. As a result, many patients achieve greater control over their body movements.

Medtronic DBS Therapy is available in Australia and New Zealand for Parkinson's disease, essential tremor, dystonia, epilepsy and obsessive compulsive disorder.

Patients where medications are not maintaining quality of life are candidates for DBS therapy.

BEQUESTS A PRIVATE AFFAIR

Bequests are often a private affair, a decision that may be known only to yourself and your solicitor. Bequests allow you to give back to a group or organisation that has helped you, but you are unable to thank financially while you are alive.

But Parkinson's NSW likes to thank people, which is why we encourage those who leave bequests to join the James Parkinson Society. Joining can be private and your gift can still remain anonymous.

Recently Parkinson's NSW received a bequest from one of our members who wanted to remain anonymous. Diagnosed with Parkinson's in 2004 they contacted the InfoLine and joined their local

support group. Both played a significant role for this member to keep their quality of life while living with Parkinson's.

Their gift was celebrated in a private ceremony where they received their James Parkinson pin – a gold tulip – as a token of appreciation.

Their bequest will assist in funding our vital support services such as InfoLine. We are deeply touched by their generosity.

If you would like more information on our Bequest Program please contact our office on 1800 644 189.

SUPPORT GROUPS

contact the InfoLine for more information

Albury/Wodonga

Armidale

Avalon/Pittwater Palms

Ballina/Northern Rivers

Bankstown

Bathurst

Bega Valley

Bingara

Blue Mountains

Broken Hill

Calvary/Kogarah

Casino

Castle Hill

Central Coast

Central Coast/Medusa Club

Chinatown – City

Coalfields/ Lower Hunter Valley

Coffs Harbour

Cowra

Deniliquin

Dubbo

Dundas/Parramatta

Eastern Suburbs

Eurobodalla

Fairfield/Liverpool

Glen Innes

Goulburn

Grafton

Griffith

Gunnedah

Hawkesbury

Hornsby/Ku-ring-gai

Illawarra North

Illawarra South

Kings Langley

Lismore

Macarthur/ Campbelltown

Manly/Mosman

Manning/Great Lakes

Maroubra

Mid Western/Mudgee

Myall/Tea Gardens

Nambucca Valley

Narrabri

Nepean

Newcastle

Orange

Parkes

Pittwater/Warringah

Port Macquarie

Quirindi

San Remo

Shoalhaven/Nowra

Shoalhaven/Ulladulla

Snowy/Monaro

Southern Highlands

St George/Sutherland

Tamworth

Tomaree Peninsular

Tweed

Ultimo – City

Wagga Wagga

West Wyalong

Yamba

Yass

Working Mens' Group

Younger Womens' Group

MAKE PARKINSON'S A PRIORITY

Make Parkinson's a Priority reflects the needs of the 80,000 people living with, and the 700,000 affected by Parkinson's in Australia.

It engages the Parkinson's Community nationally to ask government to 'Make Parkinson's a Priority' through:

- Recognising Parkinson's as a National Health priority are;
- Investment in equitable access to Parkinson's Nurse Specialists and equitable access to medications and therapies;
- Investment and capacity building in Parkinson's research;
- Investment in upskilling the workforce to enable timely diagnosis, better care and support for People living with Parkinson's.

Through our members and support group, Members of Parliament can learn first-hand of the impacts of living with Parkinson's. It's your voice that counts. Parkinson's NSW will be supportive in all activities undertaken by our members and support groups.

The *Parkinson's Australia Action Framework* was launched at Parliament House, Canberra on 15 March at a Parliamentary Breakfast attended by Members of Parliament, CEO's and President's from Parkinson's Organisations around the country. Ann Sudmalis MP is the co-Chair of the Parliamentary Friends of Parliament group and remains a strong advocate for Parkinson's Nurse Specialists having had first-hand experience of the nurses value in her own Electorate where our Parkinson's Nurse Specialist, Nina Cheyne provides this service.

Please join this campaign by going to the website www.parkinsons.org.au where you can view, subscribe and support the campaign. If you would like to become an advocacy champion, please contact Miriam Dixon via miriam@parkinsonsnsw.org.au or call 1800 644 189.

We would like to encourage support from families, friends, GP's, nurses, aged care facilities, neurologists, and other health professionals with this campaign.



Living with Parkinsons?

Quest For Life is a 5 day residential retreat designed for people seeking ways to actively contribute to their own healing and wellbeing. **You will leave this retreat:**

- knowing how to optimise health & wellbeing
- understanding yourself & Parkinsons disease more deeply
- with practical tools for managing moods & expressing difficult emotions
- feeling inspired & encouraged to embrace your challenges in a more positive way
- understanding the positive impact that meditation & mindfulness can have on your brain & your life

Retreat Dates: 9-13 May, 29 Aug - 2 Sept, 2016

1300 941 488 or visit

www.questforlife.com.au



13 - 33 Ellsmore Rd, Bundanoon NSW 2578. Supported by NSW Health.

YOUNG RESEARCHER OF THE YEAR 2015



Dr Moran Gilat was announced as the inaugural winner of the Parkinson's NSW Young Researcher of Year award at a reception at Parliament House in August.

This exciting new award was open to early career researchers who are currently working on a Parkinson's related project, are 40 years old or less and are PHD students or up to five years post (relative to opportunity).

Young researchers from across NSW submitted posters that outlined their current research project. There were 3 criteria for the judging; scientific merit, design of poster that supported the information and clarity of communication to a layperson.

Dr Moran Gilat works as a member of Dr Simon Lewis' research team at the Brain & Mind Centre within the University of Sydney. Dr Gilat was inspired to research into Parkinson's disease by his mother who is a nurse in an aged care facility. During his undergraduate studies, Dr Gilat said "I became inspired when a patient with Parkinson's disease visited a lecture to talk about the daily problems he faced. One of his major problems was freezing of gait. A phenomenon he explained that most people, including his GP did not know about and therefore couldn't help him. This really struck me, because how could such a common symptom of Parkinson's disease still be so poorly understood? Trying to find an answer to this question led me towards the research team at the Brain & Mind Centre."



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“I have been extremely lucky to meet very friendly Parkinson’s patients over the years that has made me dedicated to keep trying my best to provide more knowledge to the field that can translate to better outcomes to those affected by Parkinson’s.” said Dr Gilat.

Parkinson’s NSW CEO, Miriam Dixon said “It is wonderful to see so many young people passionate about research and using their intellect and education to help us find new treatments and ultimately find a cure for Parkinson’s disease.” “We were amazed at the high standard of the submissions we received from all our applicants. Dr Gilat’s poster really stood out for easy to understand language and a very clear design that supported his scientific research.”

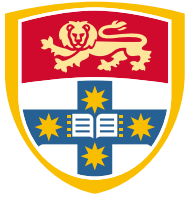
The other finalists for the award were; Dr Boris Guennewig (The Garvan Institute), Dr Brianada Koentjoro (Kolling Institute of Medical Research), Dr Sandy Stayte (The Garvan Institute) and Benjamin Trist (Brain & Mind Centre, University of Sydney).

What type of Parkinson’s do you have?

Knowing the answer to this question can slow down your Parkinson’s and help you to look, move and feel better.



Get control of your Parkinson’s and find out more today!



THE UNIVERSITY OF
SYDNEY

EXPLORATION OF WALKING IN PARKINSON'S DISEASE

Volunteers with Parkinson's disease are required for a study evaluating walking. The study aims to determine how people with Parkinson's disease rate their walking ability.

If you are aged over 40 and have Parkinson's disease you may be eligible to participate.

This study is being conducted by a team of researchers at the University of Sydney, led by A/Professor Colleen Canning. Assessments will be carried out at Faculty of Health Sciences of the, University of Sydney, East St, Lidcombe

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

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CHANGE TO DISPENSING OF APOMORPHINE

STADA Pharmaceuticals Australia Pty Ltd would like to advise that the company has assumed responsibility for the supply of apomorphine 20 mg/2 mL and 50 mg/5 mL ampoules in Australia as PBS Section 100 items from February 2016.

The new brand name for apomorphine is MOVAPO®. It is exactly the same product previously supplied as APOMINE. Only the packaging and name have change

SUPPLY OF MOVAPO® under PBS until April 1st, APOMINE and MOVAPO® are being listed as substitutable brands of the same item and either brand can be dispensed.

After April 1st:

- If the prescription states apomorphine 20 mg/2 mL or 50 mg/5 mL, MOVAPO® will be supplied.
- If, however, the prescription states the brand APOMINE, a new prescription for MOVAPO® will be required in order for apomorphine to be supplied under the PBS.

NEW CONTACT DETAILS

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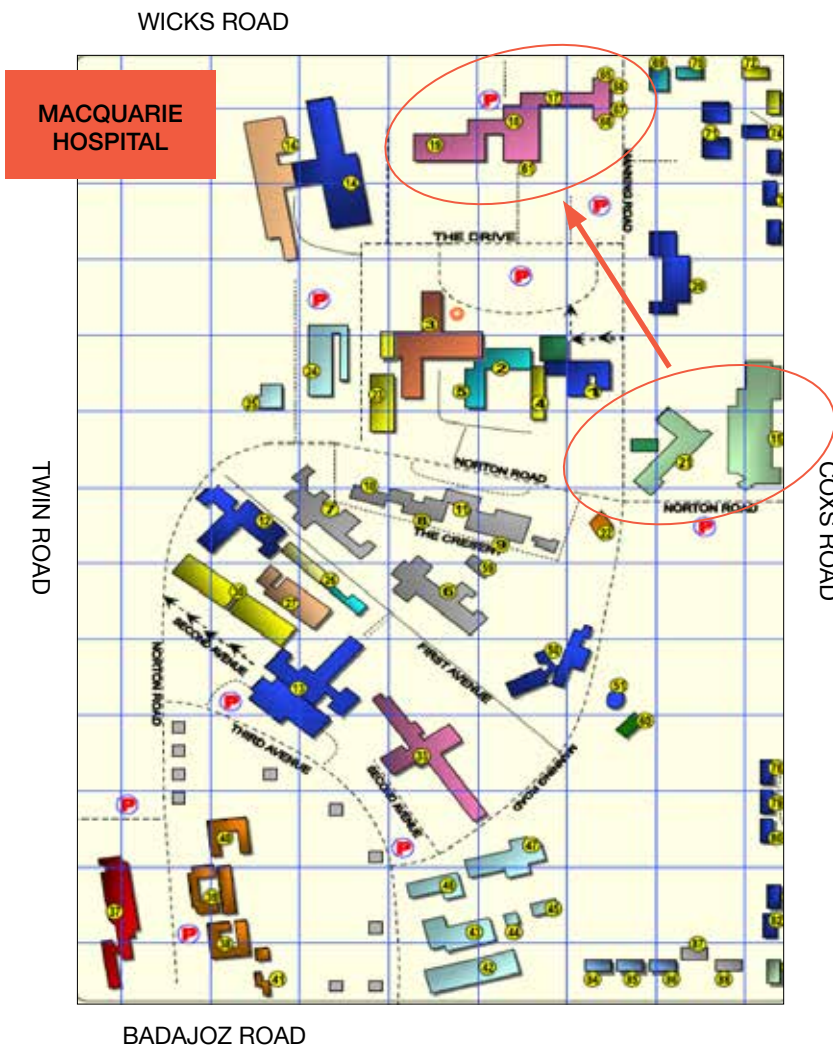
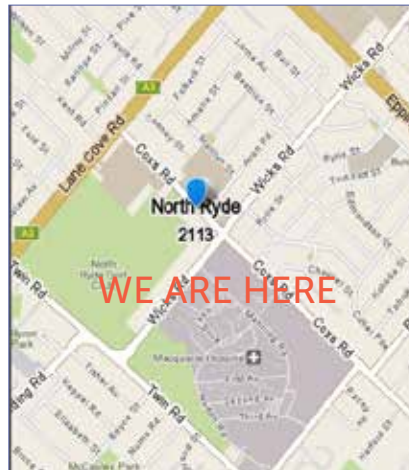
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Hospital Clinics:

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

