PARKINSON'S NEW SOUTH WALES INC. NEWSLETTER – Issue 101, Summer 2007

Ease the Burden and Find a Cure

Stand By Me

Official Office Opening by Deputy Premier

The Hon John Watkins, Deputy Premier, Minister for Transport, Member for Ryde officially opened our premises on 5 November, in his capacity as our new local member. We were delighted that Angela D'Amore, Member for Drummoyne and our previous local member, was also able to attend. Their on going support for Parkinson's NSW is greatly appreciated.

Andrew McKenzie represented the John T Reid Charitable Trusts whose generous donation allowed us to build our new internal offices and furnish them comfortably. A plaque has been mounted on the entrance wall acknowledging the substantial contribution of the Trust.

Parkinson's NSW artist community have provided paintings, prints and tapestries to decorate our offices. Many of the artists were present at our opening. We hope that visitors to our office will be inspired by the personal stories of our artists and perhaps take up an artistic pursuit.

New Groups! New Groups!

Narrabri has its own Support Group which was conceived and achieved in only two weeks! Janice Holmes, Sue Stewart and Anna Thomson held a meeting on 8 October, and 19 people came - including Pat and Allan Johnson from Tamworth Support Group. They made posters, and secured radio and newspaper publicity. They arranged a guest speaker to talk about items available through Program of Aids for Disabled People, and signed up new members to PNSW. The Support Group had a second meeting on 12 November, with 20 members present and a presentation by a local pharmacist. They have decided to pay for regular advertisements in the Courier. WOW is the best way to describe this enterprising and energetic group. Congratulations to Narrabri Support Group!

Maroubra has a Support Group which met for the first time at Maroubra RSL Bowling Club on 18 October. Ten people came who had never before been to a Support Group They enjoyed the informal talks by Miriam Dixon, Deborah England, Lyn Smith and Trish Morgan, outlining the range of services provided by PNSW. The group met again in November. They are the nexus of a larger Support Group planned to evolve from the seminar program "Facing the Future with Parkinson's" which will be run in 2008.

FEATURES

President's Report

In January of this year, PNSW made the move to 25 Khartoum Road, North Ryde, leaving behind Concord and a host of memories (as well as the dreaded mosquitoes). Despite our optimism, the building and fit out of the offices was neither quick nor easy, as we negotiated our way through a considerable number of complexities. The words 'Red Tape' have taken on new meaning for our CEO, myself and office managers Linda Matheson (approvals) and Beulah Barker (setting up)!

On 5 November, John Watkins, Deputy Premier, was able to officially open our completed offices. The John T Reid Charitable Trusts generous grant allowed us to accomplish the move and establish the offices at little cost to PNSW—they have our most sincere Thank You. Their generosity allows us to now have work space that is both functional and comfortable.

The response of our own Parkinson's community to a request for artworks has been sensational. Your paintings and works of art have given heart and beauty to basic office space.

'Putting for Parkinson's', our inaugural Golf Day, was held at St Michael's Golf Course on 24 October. The planning committee included representatives from Sydney Markets Limited, the PNSW Council, Marty Rhone (our fund-raiser) and David Samer, with additional advice from Sean Fowler. David deserves special thanks for working so exceptionally hard on our behalf to secure prizes, auction and raffle items. Behind the scenes our staff worked to a high standard, contributing greatly to the success of the day. And a success it was! Thanks to our generous sponsors - who you will see more of in this issue - our fund raising goals were more than met, and the attendees had a wonderful time.

This year has seen our Seed Grants 'sprout'; one of last year's recipients has been awarded a $500,000 Federal Grant to expand their studies. It's the kind of outcome we were hoping for when awarding the Grants - giving a first step to new, promising ideas with a chance of further development.

In addition to our Seed Grant Program, PNSW has offered four scholarships to third-year medical students. Students who would like to experience a regional environment receive help with their accommodation and expenses for the year. They spend this time completing a non-medical subject, and writing a thesis on PD. Three of these Grants have been awarded, and students will be going to Coffs Harbour, Wagga Wagga and Port Macquarie in 2008. The students will liaise with the Support Group in their area to gain an understanding of Parkinson's - perhaps some budding neurologists?

We are also offering two 'top-up' Grants for PhD students to aid them in completing their studies - some budding Parkinson's researchers?

Our fund-raising efforts, combined with grants from charitable foundations and gifts from generous benefactors and bequests, have allowed us to support research and education, our counseling services, 1-800 info line and our ever growing network of Support Groups.

As we look ahead to 2008, a list of priorities comes to mind:

- Continued representations to both State and National Governments for substantial, recurring funding
- Obtaining funding for a program to train specialist Parkinson's nurses
- Funding for a program to extend the skills of regional and rural doctors in the diagnosis and treatment of Parkinson's
- Parkinson's Australia to become a strong force in representing PWP throughout Australia
- Parkinson's National Conference to be hosted by PNSW in October 2008

I'd like you to pause a moment, and think about your participation in all of this – and more.

This is the last edition of Stand By Me before our AGM, when we will elect the next Council. Due to the change to the financial year which was voted on at the last AGM, this Council will sit for 18 months. Please consider if you, or someone you feel would be an asset, would like to be nominated for Council. If you'd like to discuss the matter with me, please feel free to do so. We need vision, energy and hard work to reach our goals for the future. Join us!

Becky joins me in wishing 'You and Yours' a joyous Festive Season, and a happy, healthy, and productive New Year.

Let's Dream On!

This edition includes full colour advertisements of the Platinum Sponsors of the PNSW Golf Day.

John Silk – President

Diary Dates

DECEMBER

21	NSW office closes for Christmas holidays InfoLine will be open on days other than public holidays

JANUARY

7	PNSW office re-opens

FEBRUARY

4	Mosman/Manly new group meeting*
12 & 15	Facing the Future with Parkinson's Seminar – Maroubra Support Group*
26	Annual General Meeting – to be held at the Dougherty Centre, Victo Street, Chatswood, at 10.00am

MARCH

4	New Member Coffee morning
7	Facing the Future with Parkinson's Seminar – Blue Mountains Support Group*
13	Awareness Seminar – Goulburn Support Group*

APRIL

4	Facing the Future with Parkinson's Seminar – Dubbo Support Group*

*Dates and venues to be confirmed

Please contact the InfoLine on 1800 644 189 for more information.

CEO's Report

New Program for 2008 for People Living with Parkinson's disease, their partners, families and carers

I am thrilled to announce the Cecilia Kilkeary Foundation Ltd has generously agreed to fund a new program, Facing the Future with Parkinson's. This program will provide information education sessions in rural and regional NSW and metropolitan Sydney. Please refer to Diary Dates in this issue and the next issue of Stand By Me for venues and dates.

For those of you who are unable to travel, but would like to take part in the program, we will be running five teleconference groups. Our teleconferencing groups allow you to be at home and listen in via your phone. We usually have ten participants linked by conference call.

If you attend either a face-to-face seminar or a teleconference group, you will be able to access practical advice and information, opportunities for sharing challenges and solutions with people in similar circumstances. Seminar and teleconferences will include guest presenters such as Doctor/Parkinson's Nurse Specialist, Psychologist, Physiotherapist, Dietician, Community services, Financial Planner, Lawyer. All groups and seminars are free of charge. If you would like to participate in the seminar programs or teleconference groups, please call our 1800 644 189 number.

Special Offer to Members

A wonderful addition to our counselling room is the electric lift chair generously donated jointly by Ambassador Products and Koala T Care. Wes May from Ambassador Products is the designer/manufacturer of this chair. Please visit their website at www.ambassadorproducts.com.au and see their complete range of products.

Gary Clarke from Koala T Care is the retail agent. Parkinson's NSW members are able to purchase all products through Koala T Care with a 10% discount. You can access their website at www.koalat.com.au to view their full range of products.

We were so pleased that both Wes and Gary were able to come to the office opening and demonstrate the chair to all those that came.

Parkinson's and Violent Behaviour?

I have received a letter from a member who brought to my attention that her husband became violent and confused on a large dose of a Parkinson's drug. Understandably, this was very disturbing to her husband and herself. Once the dose was decreased, he became gentle again.

Could you please call our InfoLine or drop us a note if you have any experiences which you would consider was caused by excessive dosage of any Parkinson's medication.

Cowra Support Group Awareness DVD

The Cowra Support Group held a seminar called Stand By Me on the 3rd September 2007. Speakers on the day included Dr Kay Double, who spoke on research into Parkinson's disease, and Mark Gillham, a physiotherapist based in Cowra. Ms Stacey Whiley spoke on carers' issues. Laraine McAnally, Parkinson's Nurse Specialist, spoke on the practical side of medications. Dr Simon Hammond spoke on the Central West Parkinson's disease study.

The DVD of the seminar can be purchased for $15, call the 1800 644 189 to order. Limited copies available.

Season's Greetings and a Happy New Year.

Yours in Parkinson's Friendship
Miriam Dixon – CEO

Putting in for Parkinson's – The inaugural Parkinson's NSW golf day

The gods were kind to us on the day, with threatening rain clouds holding off until after completion of the round. It made for ideal golf conditions at one of Sydney's most picturesque golf courses.

The day raised a marvellous $46,000 net for the Parkinson's NSW Counselling Service. Not bad for our first try, with one golfer commenting that it was the best charity corporate golf day he has attended.

Flushed with this success, we are looking forward to making this a regular event on the golfing calendar, and we invite readers of Stand By Me to consider participating next year.

Golfers, and others, started arriving as early as 7am for registration and a light breakfast, and to learn how to use the Blackberry scoring system - an innovative process designed by egolfscore that requires teams to input their scores via their Blackberries rather than using scorecards. Scores are then transmitted back to the clubhouse and displayed on giant plasma screens, providing instant updates on scores and team positions. We could have been excused for believing we were at Augusta, well, almost!

We had a hole- in-one competition where major sponsor Virgin Atlantic was offering return Upper Class tickets to London. Sadly no one landed it.

There was also a putting competition, which was strongly patronised - and we're not suggesting for a moment that it had anything to do with the attractive lady running it!

The day was very efficiently run by Parkinson's staff, along with Gary Dawson and his team of professional golfers. It was also terrific to see many 'Parkinson's' golfers out on the course, showing that nothing should prevent one from enjoying a good round of golf.

Once back in the clubhouse, the golfers enjoyed a tasty lunch and were entertained by one of Australia's premier comedians, Paul Martell, and another bloke who's also pretty good with the one liners, John Silk.

By about 3.30pm everyone headed off very contented; some with auction items, raffle prizes or prizes for having played some great golf. Unfortunately they were in the minority, but everyone seemed to have a smile on their face.

Marty Rhone

Research

HALLUCINATIONS AND DELUSIONS IN PARKINSON'S DISEASE

by Dr Mariese Hely

Hallucinations are common in Parkinson's Disease (PD). They are generally visual, and relate both to the pathology of PD itself and to the medications being used. Many people fear that they may be a sign of madness and keep them secret, but if you experience hallucinations it is important to discuss them with your doctor so that medication can be adjusted to relieve them.

The frequency of hallucinations in Parkinson's Disease increases with the duration of the disease, and also becomes more common as people age. About 25% of people experience hallucinations by between 5 and 10 years; about 50% by 15 years; and about 75% by 20 years of PD.

Definition of Terms

- **A hallucination** is defined as a sensory perception (sight, sound, touch, smell) that occurs without the actual external stimulation of the relevant sensory organ (eyes, ears, skin, nose).
- **An illusion** is a milder problem in which there is an external stimulus, but it is misinterpreted (for example, the water metre on the front lawn may appear as a small black dog; the city lights in the distance may be dancing fairies at the bottom of the garden; a high backed chair covered in black and red flock fabric may be a Spanish lady wearing a mantilla).

The mildest forms of hallucinations noted in PD are 'presence' hallucinations. These occur when the patient may think that another person or animal is in the house with them, or is standing just behind them, but that other presence is not actually seen. The patient may think, for example, that someone is just beyond the door and they repeatedly check to be certain. Another mild form of hallucination is the 'passage' hallucination where the patient has a brief vision of someone or something moving quickly across their vision, seen out of the corner of their eye (such as a mouse or a cat running by).

Hallucinations in PD are most commonly visual hallucinations, such as animals (often a former pet, or in one case, rabbits on the kitchen benches), children and relatives. These can be quite friendly hallucinations. Patients who do not have dementia generally realise that these are hallucinations and so not real. On occasion these hallucinations can be welcomed, such as the elderly Japanese lady living in Australia who noted that the hallucinations were the only Japanese people who visited her nowadays. Hallucinations often are only present for a few minutes, but become more frequent and more prolonged with time. Visual hallucinations can also be frightening when strange people are seen in the house, frightening noises are heard outside or buildings are seen on fire. These latter hallucinations can be very disturbing for the patient and difficult for the spouse or other carer to deal with, especially when the patient cannot be convinced of their unreality. Sometimes the patient will speak to the hallucinations because they look so real, although it is unusual for the hallucination to speak back.

Auditory hallucinations are uncommon in PD. If there is sound present, it tends to be just a background sound or the hallucinations talking amongst themselves, but not directly to the patient. This differs from the auditory hallucinations that people with schizophrenia develop where voices can be ordering and threatening the patient.

- **A delusion** is a false belief that the patient cannot be induced to change by reasoning or demonstration of the facts. Delusions are far less common in Parkinson's Disease than hallucinations, and almost uniformly only develop when dementia is also present. Sometimes delusions can be mild (such as believing when a prize is announced on a television quiz show, that the patient himself has won the prize) but mostly delusions cause significant problems (such as believing that the wife or mother in law is trying to poison the patient).

It is not uncommon to have delusions of sexual infidelity, believing that an elderly spouse is having an affair with a young neighbour, or the visitors from Home Care. The delusional beliefs may lead to paranoid behaviour, which on rare occasions has led to physical violence against those who are trying to care for the patient. In a hallucinatory and delusional state the patient may not recognise the carer, or may see the carer as a foe. Carers have been hit or pushed away, and uncommonly have been hit with implements or locked in rooms.

The early mild hallucinations and illusions described involve maintained insight, but it is clearly important to treat the problem before it progresses to lack of insight, delusions and paranoia. It is frightening for the patient and very difficult for the carer to deal with, and can result in injury to the patient or others. Therefore speak up and seek help if you as a patient develop this problem.

The cause of hallucinations in PD is partly the underlying pathology of the disease. Hallucinations and other psychiatric disturbances have been described in Parkinson's Disease long before drugs for PD were first introduced. It is very important to realize, however, that medications for Parkinson's Disease can precipitate hallucinations, delusions and paranoia. Reducing the medications will often make the hallucinations disappear. Hallucinations, delusions and paranoia are more likely to occur with the anti-cholinergic medications (such as Artane and Cogentin), Symmetrel and the dopamine agonists (Cabaser, Permax, Parlodel), than with the levodopa drugs (Madopar, Sinemet, Kinson). Therefore the former drugs should be reduced first. Levodopa should be the last medication to be reduced.

Risk factors for hallucinations include increasing age and increasing duration of the disease, but they also include dementia and early cognitive impairment. This is probably due to the pathology of dementia and hallucinations being shared. There is also the factor of the lack of insight and judgment that occurs when dementia adds to the difficulty in interpreting the hallucinations as real or unreal. Depression is also thought to increase the risk of hallucinations, as it is often associated with reduced ability to inhibit irrelevant information. Another common association with hallucinations is disturbed night time sleeping patterns and daytime drowsiness. Some patients are particularly prone to hallucinate after they

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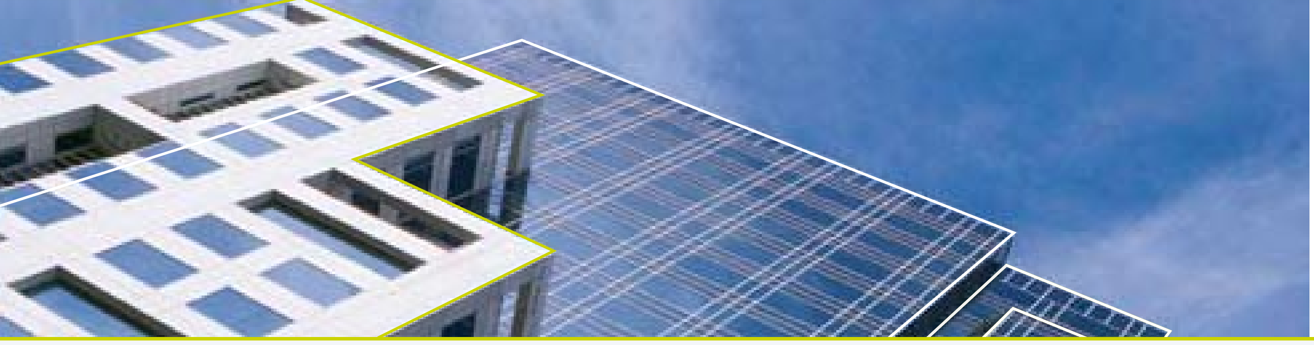

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Research

HALLUCINATIONS AND DELUSIONS IN PARKINSON'S DISEASE *continued*

have had a daytime sleep. Impaired vision also increases the risk of having hallucinations.

Hallucinations can also occur in the presence of delirium (a temporary disorder of one's mental state due to disorders such as urinary or chest infections, drug intoxication or surgery requiring anaesthetics). In these cases hallucinations, delusions or paranoia are temporary, and resolve once the underlying problem is treated. It may be necessary to at least temporarily reduce the Parkinson's medication.

If a patient is going for a major operation (such as a hip or knee replacement), is elderly, has had their PD for some time, or has any degree of cognitive decline, I often advise them to reduce medication by about 25% of total dose the day before surgery. I also advise that they continue this reduction for the first couple of days after surgery to try and reduce the risk of this occurring post operatively. It is certainly worth discussing the possibility of hallucinations and of delirium developing post operatively with your surgeon and your neurologist to reduce the likelihood of the problem developing.

The impact of hallucinations

While mild visual hallucinations such as presence, passage, illusions and maintained insight do not appear to be a major problem to most patients, it is worth discussing them with your neurologist. This will allow the adjustment of medication to reduce the likelihood of the progression to more severe problems. The treating doctor also needs to be aware that they are present so that they do not introduce new drugs or higher doses that might worsen the problem.

More severe hallucinations, where the patient lacks insight, can cause problems for the patient. This occurs particularly if they develop delusions, and can be particularly distressing for the carer, who can become worn out explaining the unreality of the problem. The presence of hallucinations is one of the main factors that precipitate patients moving into nursing homes, because of the difficulty that carers have in managing the problem.

The presence of hallucinations also limits the use of drugs, and may lead to more slowness, stiffness and tremor. It is, however, much better for a patient to be mentally alert and a little slower than to be physically very active, but very confused. Although uncommon, severe hallucinations with paranoia and delusions have on occasion led to violence.

Management of Hallucinations

Usually this involves reducing the PD medication, especially removing or lowering the more risky drugs (as mentioned above). If the patient is already on a very low dose, drugs used for Alzheimer's disease, which increase acetylcholine in the brain, can be used such as Reminyl, Aricept and Exelon.

In severe cases antipsychotic medication may be used (drugs such as Seroquel, Zyprexa, Risperdal). These drugs deplete dopamine and can worsen the physical symptoms of PD. They are only used in more severe cases. People with severe hallucinations should be hospitalised so that their Parkinsonian medication can be adjusted quickly, antipsychotic medications can be introduced and a search for underlying problems (such as infections that may have worsened the condition) can be undertaken and, if found, treated. Preferably have a neurologist or geriatrician look after you, but if none is available, make sure your carer explains about the role of your medication in potentially worsening the problem.

In milder hallucinations it is also worth looking at the other associated factors and trying to modify them. Hallucinations often occur as the light becomes dim in the evening and therefore in the main rooms of the house bright lights are helpful in reducing the shadowing corners of the room where hallucinations may be seen. At night, if hallucinations are occurring, certainly turn on the bedroom lights brightly to reassure the patient that nothing is there.

If there is a visual impairment, it is worth discussing with your ophthalmologist whether anything further can be done to improve vision. If there is daytime drowsiness, it can be worthwhile looking at what is occurring at night to disturb sleep (such as is sleep apnoea or restless legs). Sometimes daytime drowsiness is just due to the severity and duration of PD. It is often better to try and avoid frequent cat naps in the morning by trying to keep active when possible, and having a proper hour or so nap in bed after lunch.

It is definitely worth treating depression in PD, and this possibility should be raised with your doctor. In general the presence of depression in PD is under-recognised and has implications for both the patient and the carer as regards their quality of life.

In Conclusion

Hallucinations are common in PD, but can be controlled and need not be frightening. You need to speak up and tell your doctor that they are present, so that adjustments to medication can be made, and any other associated precipitating factors can be treated.

Do you have Parkinson's Disease?

We are looking for people who have Parkinson's Disease who may be interested in participating in a clinical trial using a 24 hour patch to deliver the investigational drug. This trial is being performed by Dr Michael Hayes and his research team at the Neurosciences Department, Level 5 West, Concord Repatriation General Hospital, Hospital Road, Concord NSW 2139.

The study will be targeted primarily to those subjects who have difficulty mobilising in the early morning as a result of Parkinson's Disease.

If you are interested in finding out more please contact: Rosie Portley, Study Coordinator on (02) 9767 5184 or (02) 9767 6416 to discuss the trial.

‘Caring’– from the Montefiore Home Seminar ‘Living with Parkinson’s’ on 24th June

I’m Rebecca Silk—John’s other half. When John acted as Secretary of PNSW, I was his ‘scribe’. The year he became President, I also was elected to the Council. We are in the trenches together, fighting a rear guard action against Parkinson’s. And I speak about living with Parkinson’s from this partnership perspective.

CARERS – unique and individual

Living with Parkinson’s has an impact that spreads to family and friends as the PWP begins to require care, and all carers are not created equal. Just as Parkinson’s affects it’s sufferers in an individual way, so is it for their carers.

A carer may be a spouse or partner, parent, child or sibling, or a paid career person. They may be living together or providing back up for a person living alone or in a ‘home’ situation (such as the Monte). All bring differing skills to the role and all are affected by a unique set of circumstances. An older spouse or parent may have physical restrictions but marvellous communication and nurturing skills, a younger partner may have to balance the need for income and child care with the needs of their PWP, and a child may have to juggle family responsibilities and a difficult role reversal. Each may have limited experience with Parkinson’s. All will have new challenges.

OMIGOD! – planing, practicalities and emotions

Omigod—not yet appearing in most standard dictionaries--Omigod is probably the definitive word description of life with Parkinson’s. Most ‘Parkinson’s’ days will contain at least one Omigod situation be it serious, exasperating or possibly even funny.

Let me tell you a story:

At the beginning of the year John and I jetted off with our frequent flyer points on a 5 hour flight. The outbound flight experienced difficulties and lasted fourteen hours but we survived–Somehow.

On our return all went smoothly. Tickets presented, and straight onto the aircraft, then, up the steep, winding flight of stairs to the quiet, secluded upper deck. In total panic, I turned to John and asked him how could he have booked the upper deck?—we must change seats etc., etc., etc. What was my problem?—those stairs. But I came up them just fine John replied. Yes—but after a long flight how would he get down?! In an instant all sorts of thoughts and emotions were fighting themselves—worry, fear, guilt, and plain ordinary everyday concern! Why hadn’t I thought ahead—how could I upset John—it must never happen again. So what did happen? The hostess asked to take our bag—I suspect encouraged by a helpful friend—and as you see, all was well and a hint of humour now colours the incident. The constraints of life with Parkinson’s remain—with a mental note to check all flights in the future. Omigod!

A PARTNERSHIP – similar goals, individual needs, communication and consideration

‘Caring’ is best as a partnership and working together creates the best possible situation for all concerned. My personal view is as a carer who is also a life partner, and while the physical aspects may remain constant, I am a different person than a paid carer or even another family member. People who have spent their lives together tend to view life as a ‘joint issue’ and Parkinson’s as a journey to be travelled together, which possibly makes things logistically easier, since personal care comes more naturally and general well-being is more easily assessed. The Parkinson’s sufferer remains ‘themselves’ for most, if not the entire duration of their illness, allowing communication and affection to remain and to contribute to maintaining quality of life.

But it’s not all smooth sailing. As a carer, one gradually takes on one task after another; small things such as signing cheques, paying bills, maintaining the family ‘books’. As things progress, you will add some personal care, household jobs, and perhaps driving—all previously taken for granted. A carer, conscious of preventing isolation and depression, may ensure lots of family dinners and an ‘open house’ for friends. He or she will take care to have all medications clearly listed and understood. Decision making will become a greater responsibility. The list extends over time and the determination to do as much or even more than possible to make sure your ‘Parkinsonian’ has every need met can bring both physical and emotional tiredness etc. etc. etc.

However, the greatest problem facing a carer who truly ‘cares’ isn’t taking on extra responsibility, and it isn’t exhaustion; it is wanting to be perfect 100% of the time and finding it not humanly possible. This is the area where the Person with Parkinson’s is able to “Care”. A time when communication is important and kindness can be returned by encouraging their carer to take some time to nurture themselves. It can be lunch with a friend, a few hours for a favourite activity or as simple as a kiss or a thank you to acknowledge their worth and refresh their spirit. Thus, a partnership is strengthened, and a carer able to continue to ‘care’.

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On the groupvine

by Trish Morgan

First time visit to northern support groups in October.

Trish Morgan set out to visit the groups in the north east of the state, all of whom meet in the second week of the month.

Nambucca Valley support group lead by Margaret and Bruce Butcher was formed in August 2006 and meet in the Uniting Church Hall in Macksville. There were more than 20 people present including Vera Heil and Joyce Ryder who drove down from Coffs Harbour. They were keen to hear about the activities at PNSW. Feelings of isolation had been reduced when Margaret and Vera attended the Support Group Leaders meeting in Sydney in July. There was interest in the power-point presentation used for “Coffee Mornings” with a view to holding a coffee morning themselves.

Grafton support group lead by Cathy Eggins meet in the Nurses Lounge at Grafton Hospital. This small group is preparing to host a seminar next year as part of the “Facing the Future with Parkinson’s” program. Country people make use of their community connections to assist them in organizing events. We enjoyed a delicious and convivial lunch in the hotel next door after the meeting.

Ballina support group meet in the Crowley Anglican Retirement Village and are lead by Gerri and Stuart White and Morrie and Shirley Lewis. Twenty two people were there including Physiotherapist, Dianne Hemsworth from Ballina Hospital, who offered ongoing support despite a shortage of allied health staff in the area. Dianne says she knows 5-6 younger men who would benefit from email contact with the Young Men’s Parkinson’s Network. Her email has been given to Gary Cearns, leader of the network. Members of Ballina group felt distanced from PNSW. Dianne suggested the use of videoconferencing to bridge the gap.

Tweed Heads support group hosted a seminar with Dr Geoffrey Boyce as guest speaker. Dr Boyce opened his talk emphasizing the value of support groups. 44 people attended and 6 joined PNSW. Dr Boyce suggested that the northern support groups lobby the State Government together to gain allied health services especially speech programs. He invited allied health people to come to Casino to see the level of services that Casino Parkinson’s support group receive. Dr Boyce allowed an hour for questions. Trish talked about the variety of support groups and gave out a questionnaire about what people want from their group and how they can be involved in the group. Four people volunteered their personal stories and members really enjoyed this session. Volunteers from Twin Towns RSL Ladies Bowling Club assisted group leader Shirley Rushton, by making sandwiches and cakes and serving morning tea and lunch.

Visit to Albury in November

Albury/Wodonga support group hosted a meeting where Third Year students of Speech Pathology at Charles Sturt University conducted a workshop. There were several new members and Glenis Gordon, John and Sybil Hanson from Finley support group thought the drive of 150kms was well worthwhile to take part in the workshop. Valerie Leyden and Bruce Ockenden have been working hard to provide education and an environment for mutual support for the local members. Valerie and Trish Morgan met with the Mayor and his Group Manager Community and Recreation who offered to assist the group with venues for meetings and a seminar in May 2008 This seminar will be part of the “Facing the Future with Parkinson’s” program

Trish, Bruce and Valerie at Albury Support Group meeting.

News from Wagga Wagga

Fundraising for Parkinson’s is supported by the community at large in Wagga Wagga.. Tumut Lions Club held a street stall on 26th September and raised $700 for research. Bronwyn Kosman, the daughter of members, Via and Gerald , ran in the Sydney Half Marathon and raised $3000. Support group members sold over 25 books of raffle tickets.

Thank you everyone for your energy and generosity.

Book Review

Living Well, Running Hard *by John Ball*
Indiana, Authorhouse, 2005.

Yes, it is another of those “inspirational” titles designed to elevate the senses, in the pursuit of excellence, and while this is no textbook, it deals very openly with the author’s approach to major issues, controlling his journey.

Of particular interest was his very intimate handling of the role depression was playing in his life, a depression which was turning him into a social recluse. and affecting his family in every way.

With professional assistance he was able to turn his life around, and pick up on his childhood passion of running. His desire to take action and his willingness take on challenges, all contributed to the man who became Team Parkinson. He still runs each year, raising more than a million dollars for research.

An easy read. MM.

A special Thank You to our Life Members

What a splendid celebration we had on Tuesday 13th November. Those attending were John Silk and Miriam Dixon, some Council members and some members of staff and, most importantly, our Life Members who were able to come. The celebration was a small token of appreciation of the commitment the Life Members have to Parkinson’s NSW.

The celebration was a morning tea held on the patio of the Speakers dining Room at State Parliament House. Thank you, Angela d’Amore, state member for Drummoyne and our staunchest supporter in Parliament, for arranging the venue.

We were pleased that some of our honorary Life Members could come along. These are people who have made outstanding contributions to our organisation. Thank you for what you have done, and still are doing, to support Parkinson’s NSW.

Stephanie and Lyle came from Albury to join us and Randolph rode in from North Richmond on his Harley. Jean came along with a photo and some documents of her father, Don Gration. Don had Pd and placed an advert in his local paper asking for people who would be interested in forming a support organisation for people with Pd to write to him. This was how Parkinson’s NSW was conceived nearly thirty years ago. The mother of another guest, Jan, was one of seven people involved in the first trial of L-dopa in Queensland in the 1960s.

These are only a few of the forty or so guests. All our Life Members are very dear to us. Thank you to each and every one of you.

Notice of Annual General Meeting

Our Annual General Meeting will be held at
10 a.m. February 26, 2008
Dougherty Centre, Victor Street, Chatswood, NSW

InfoLine Update

We would like to advise members that Parkinson’s Australia are in the process of revising and updating Information Sheets on a variety of topics. These will gradually become available upon request through our office as they are phased in during 2008. We are also conducting a major overhaul of our own resources at PNSW so that we can give you up-to-date information on a host of services and products from hydrotherapy, massage therapy, and rehabilitation equipment to satin sheets and medication timer devices.

Those members who attended a Parkinson’s disease presentation by Dr Geoffrey Boyce, organised by Tweed Heads support group in October, will have seen a demonstration of some of the products available. We have a couple of medication timers on loan at our North Ryde office for anyone who would like to have a closer look.

Why not drop in and take a look at the publications and videos we have available for loan in our library? We now have a cosy reading corner where you can sit and browse through what we have in stock. We would welcome your recommendations as we review and upgrade our reference library.

Please contact either Lyn or Claerwen on any subject by email: infoline@parkinsonsnsw.org.au or by phone on 8875 8900 or 1800 644 189.

Lyn Smith and Claerwen Armstrong

Young Men’s Parkinson’s Network

Are you under 60? Living with Pd?

Are you looking to meet other men
who share similar experiences?

Your partners are welcome to come and enjoy a coffee
with other partners while the Men’s Network meets

Monthly Meetings
Every third Tuesday from 10.30 – 12.00noon
25 Khartoum Road, North Ryde

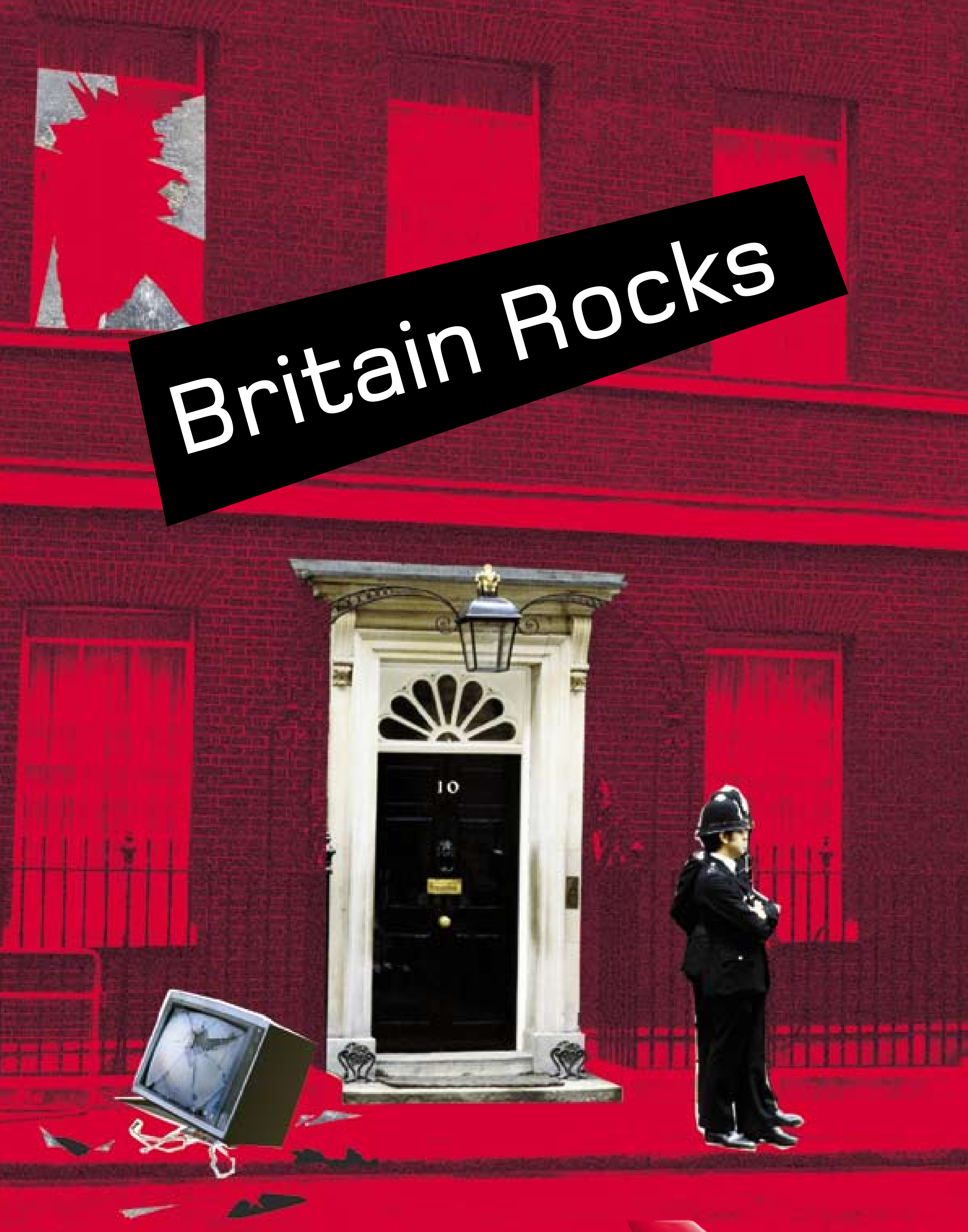
Contact: Garry Cearns
Mobile: 0418 648 835
Phone: 9871 1853
Email: Cearns@netspace.net.au

Allen’s Triple A

awareness, acceptance, activity

Have you met my friends - The Hallucinations?

They are always there, night or day including snuggling up to me when in bed. They speak amongst themselves and I can hear the sound but can’t make out the words. Hallucinations present themselves in many different ways and could be at any time or location. It is not uncommon thinking that there is some kind of small animal at the edge of my peripheral vision. When I turn to see what it is I find that it is only a leaf from a tree.


Britain Rocks
10

Counselling Corner *by Deb England*

One of the concerns that people often bring to counselling is about anxiety. Managing anxiety can be achieved but first let's have a look at what anxiety is and how it might present.

Anxiety can be defined as being stressed, worried, afraid or uncertain about the future. It can range from worry about the progression of the disease, financial matters, employment, and attractiveness to others, to matters such as 'who will look after me?'

Social anxiety is another form that anxiety can take and this condition is common amongst women. The person fears that they may act in a way that will be embarrassing or even humiliating. 'What will people think if I spill something?' or 'What if I shake too much?'

There is also anxiety that many carers face. There is the worry about leaving the person at home on their own, fear about falls and so forth and the often very pervasive fear about not being adequate carers.

Symptoms of anxiety are very often camouflaged by PD symptoms. These symptoms can include one's heart racing, breathlessness, sweating, trembling, chest pain, nausea, feelings of choking or dizziness.

Someone may have an underlying anxiety issue that is made worse when diagnosed with PD. Anxiety produces muscle spasm which inhibits movement when coupled with PD. Some medications can cause 'panic like' symptoms.

Anxiety can certainly impact people's lives. It often leads to social withdrawal as the person worries what other people may think about them. As such, the person begins to avoid social situations. This can play out as withdrawal from 'the world' on an emotional level.

When someone is anxious they are more inclined to interpret circumstances in a way that supports their particular stance thereby making themselves more anxious. An example of this could be:

Someone doesn't say 'Hello', this then being interpreted as 'He or she doesn't want to admit that they know me'. This sort of negative self talk then further exacerbates the anxiety. It also feeds back into the social anxiety that they are experiencing and produces further strain on relationships with others.

The self-talk that we all do can have an anxiety producing spin or an anxiety reducing spin eg

- 'I'm a clumsy fool' could be 'I spilt my tea'
- 'Good things never happen to me' could be 'Some good things do happen to me'
- 'I can't get over the fact that life is so unfair' can be 'I can accept that things don't always go as I wish them to'

What can be done?

- Chat with your doctor to see if there is any anxiety producing effects in the medication that you are taking
- Think about chatting to someone you trust
- Perhaps your doctor may suggest some anxiety relieving medication

Be your own 'best friend'

- Learn to recognise the symptoms of anxiety
- Learn to relax
- Re-organise
- Communicate
- Resist PD being the central issue in your life
- Confront anxiety provoking situations gradually
- Challenge unhelpful thoughts
- Seek help

Speeding Vibrations

YOUNG ON-SET NETWORK

Diagnosed under 60?

Come and join our group for a Sunday Lunch every 2 or 3 months at various locations

ALL WELCOME!

Contact: Sarah Lines 02 4627 5632
jsl022@bigpond.com

Coffee Morning

Come and meet staff and volunteers at Parkinson's NSW

Talk to people living with Parkinson's
10.30am – 11.45am, 4 March 2008
25 Khartoum Road, North Ryde

RSVP – 29 February 2008
Ph 1800 644 189

Profile: Glenda Rawlinson

Glenda Rawlinson was diagnosed with Parkinson's about four years ago. This confirmed her suspicions, as she had developed a tremor which started in her right thumb and gradually spread through her hand, and she also had been dealing with a problematic right shoulder.

Glenda manages to continue her love of craft in her good periods – sometimes at 3am. She makes cards for all occasions – some contain her own verses - and all are written in a beautiful cursive script.

Glenda also fashions table centrepieces and pendants by painting on optical lenses. She makes Christmas decorations bearing children's faces cut from photographs, and creates decoupage. Her second bedroom is a family museum. Photos taken throughout the life of each of her children, grandchildren, parents and grandparents are mounted in individual large picture frames.

Glenda supports Parkinson's New South Wales through the sale of her craft, and is a member of Canterbury and Bankstown Support Groups.

Donations

$50 and over received between 28 September and 30 November 2007

We offer our sympathies to the families who have lost their loved ones.
We also thank the friends and families who have donated to Parkinson's NSW in their memory.

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Newcastle Parkinsons Support Group
Tamworth Parkinsons Support Group

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Hints and Tips

Due to popular request, we have started a new column for Stand By Me – Helpful Hints and Tips to meet the challenges of living with Parkinson's. If you would like to share your tips and hints please drop us a note either thru the post, fax or email.

Soda water may help.
When taking medication, try using soda water instead of water. It helps to dissolve medication in the mouth and speeds up absorption.

By Janine Lavender

Used Stamps

Thanks to everyone who have been regularly sending stamps for our benefit.

Our fantastic volunteers, Kel and Jill Healy, have had a very busy year processing and trading your used stamps. So far this year they have raised in excess of $3000.

This has gone towards funding kits and other information in response to calls and enquiries through our InfoLine. Remember Kel and Jill will be very happy to receive your stamps or stamps you can collect from friends, neighbours or companies. Please ring the office if you would like their address.

The James Parkinson Society … bringing hope for the future

by Margaret Byron, Bequest Officer

Like many other charities, Parkinson's NSW relies a great deal on donations. Many of you have responded generously to our recent letters requesting donations for specific purposes such as counselling and the InfoLine.

You may be like me, "asset rich but cash poor". We give as much as we can to our favourite charities and often wish we could do more. Because we must be careful with our income and be prepared for any eventuality in the future, we may not be in the position to give more money now.

This is why bequests are an excellent form of "donation". You see, bequests do not have to be a specific sum of money – money we may need later to pay for an operation or care assistance to maintain independent living.

One of the best ways to make a bequest to Parkinson's NSW is with a percentage of the estate. My father gave 25% of his estate to each of his children and the remaining 25% went to the charities of his choice. Of course, my brother, sister and I knew about the allocation long before he died.

You may like to consider apportioning your estate to loved ones and giving a percentage to Parkinson's NSW.

For the specific wording (to help your solicitor), or to ask any other questions, please contact Margaret on (02) 9876 5351 any time between 8am and 8pm.

Support group contact details

GROUP	CONTACT	PHONE
Albury/Wodonga	Valerie Leyden	02 6040 6153
Armidale	Julie Bowden	02 6771 4346
Ballina	Gerri White	02 6628 8278
Bankstown	Trish Morgan	02 8875 8903
Bathurst	Jennifer Mannell	02 6332 8963
Blue Mountains	Hazel Tolhurst	02 4757 4214
Broken Hill	Colleen O'Brien	08 8087 2175
Canterbury	Trish Morgan	02 8875 8903
Casino	Dawn Dennis	02 6662 6141
Castle Hill	Gayle Parker	02 9634 0578
Central Coast	Les Norris	0418 607 684
Chinatown Bi-lingual		0421 224 712
Coalfields	Betty Rumble	02 4931 5210
Coffs Harbour	Vera Heil	02 6652 9959
Cowra	Ray Heilman	02 6341 3692
Deniliquin/Finley	Glenis Gordon	03 5881 3295
Dubbo	Lorna White	02 6882 7778
Dundas/Parramatta		02 9876 4284
Eastern Suburbs	Marion Welch	02 9369 0250
Eurobodalla		02 4472 2037
Fairfield/Liverpool	Warwick Brown	02 9602 8231
Glen Innes		02 6732 1252
Goulburn	Mick O'Connor	02 4822 6732
Grafton	Cathy Eggins	02 6642 2156
Griffith	Joyce Giacomelli	02 6966 9900
Gunnedah	Lisa Hagley	02 6742 0018
Hawkesbury	Jill Sykes	02 4730 4302
Hornsby/Ku-ring-gai	Diana Rynkiewicz	02 9488 7092
Illawarra North	John Coppens	02 4283 1346
Illawarra South		02 4232 2807
Lower North Shore		02 9412 2740
Macarthur	Maree Sinclair	02 4626 4959
Manning/Great Lakes	Bruce King	02 6555 9409
Maroubra	Trish/Lyn	02 8875 8900
Nambucca Valley	Margaret Butcher	02 6564 8231
Narrabri	Janice Holmes	02 6792 1468
Nepean	Joe Golding	02 9670 5093
Newcastle	Verlie Sullivan	02 4954 0338
Parkes	Con Diamond	02 6862 1925
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Port Macquarie	Patricia Stephenson	02 6584 0212
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Southern Highlands	Marj Webb	02 4871 2615
St George/Sutherland	Myra Chalmers	02 9525 7215
Tamworth	Pat Johnson	02 6765 6948
Tomaree	Ian Canham	02 4994 9276
Tweed Heads		07 5524 9417
Wagga Wagga	John Allen	02 6925 2713
Yass	Peter Wells	02 6226 2233
Young Onset	Sarah Lines	02 4627 5632

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Membership Application

Name (Mr, Mrs, Ms, Dr) ____________________

Organisation (if applicable) ____________________

Address ____________________

State ____________ Postcode ____________

Tel (H) ____________ (W) ____________ (M) ____________

Email ____________________

Have you been diagnosed with Parkinson's? Yes/No

Date of Diagnosis ____________ Date of Birth ____________

Annual Membership (incl. GST)

☐	Individual Membership	$22.00
☐	Organisational Membership	$55.00
☐	Life Membership	$220.00
☐	I would like to make a donation of (tax deductible over $2)	$____________
	TOTAL AMOUNT	**$**____________

Pay online – www.parkinsonsnsw.org.au

Joint Membership
(Each member may nominate a joint member – at no cost. Please complete)

Name ____________________

Relationship to Member ____________________

Address ____________________

State ____________ Postcode ____________

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Bequests

Please consider leaving a bequest to Parkinson's NSW in your will. It is the ultimate gift you can make; to leave a lasting legacy in perpetuity and assist those with Parkinson's. Alternatively, a living legacy will mean that you can personally experience the benefit your generous gift provides.

To make a bequest or living bequest please call 1800 644 189.

Parkinson's NSW Inc. ABN 93 023 603 545

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