PARKINSON'S
NEW SOUTH WALES INC.
NEWSLETTER

Issue 107, Winter 2009

Stand By Me

Unity Walk 2009

Register online at www.unitywalk.com.au

Proudly presented by

Bendigo Bank

Australia's Unity Walk
for Parkinson's
Proud of my Team – Proud to help Parkinson's

We are growing and we want you to be a part of it.

On the back of the great success we had in 2008 when 1000 walked and we raised $100,000, this year's Unity Walk will be held in Australia's two largest cities on the same day – Sunday 30 August 2009.

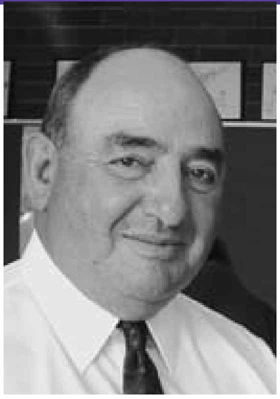
Sydney's event will once again be held at Sydney Olympic Park but the Walk itself will take a whole new route past the playing courts of the Tennis Centre, wander along beautiful Australia Avenue checking out some of the businesses located at the Park, then on past the Brick Pit Ring Walk. Get a view of the "backstage" areas of the Royal Easter Show locations and see the majestic Northern Water Feature at the base of Kronos Hill and back up spectacular Olympic Boulevard to the finish line. Melbourne's inaugural Unity Walk will start in Federation Square, in the heart of Melbourne's CBD, and run along the banks of the Yarra River in both directions.

The success of our first Unity Walk was very much due to the wonderful support we received from the Parkinson's community; our members and Support Groups. We need that support to continue because you are the rock on which this event will grow and grow to become what we hope will be one of the most significant charity events each year in this country.

The name Unity Walk was well chosen by our American colleagues some fifteen years ago. From humble beginnings the event has grown to the extent that over 11,000 attended last year in New York's Central Park and $A2.5m was raised. Wouldn't it be wonderful if we could reach those dizzy heights in this country?

The Unity Walk is all about comm**unity**; coming together in support of a common cause. A union of hearts and minds all supporting Parkinson's and a search for a cure. So please everyone put the date in your diaries and start spreading the word and organising your groups. We have assessed last year's event and come up with amendments and innovations that will make registration less challenging. We have done this with the assistance of the Everyday Hero website authors so that every dollar you raise will be there for the whole world to see. See you on 30 August at Sydney Olympic Park and to make things even easier we once again have secured free bus and rail travel to and from, thanks to the Minister for Transport's office but it is only available to those who register on-line at **www.unitywalk.com.au**.

Help us reduce our administration costs and ensure that maximum funds go towards Parkinson's research and services by registering and raising funds online at www.unitywalk.com.au.



President's Report

Remember the Unity Walk on 30th of August

Winter may have arrived and being snug by the fire an attractive option, but things are happening! Centre stage is our Unity walk. We're hoping to build on last year's success and have a wonderful event.

Some of you may have heard my interview on the ABC with Deborah Cameron, relative to living with Parkinson's. During the question and answer session I was asked by two different listeners whether a person with Parkinson's should be driving a car. We know that this is a testing issue for all PWP (including myself) and there is not a broad yes or no answer to the question. It is my feeling that as a whole, PWP are both willing and able to self-monitor their situation and drive only when confident of their ability. However, I do want to remind everyone about the change in the law since the case of the little kindergarten girl who was hit by an elderly driver. The obligation now is for the individual driver to prove his/her competency. The office has pamphlets with information from the RTA on this matter.

A few weeks later I spoke to the staff at a pharmaceutical company, again in relation to living with Parkinson's. Their reactions to my lifestyle were very interesting; Parkinson's went from being just another of the many diseases using their company medications to a 'real' problem, lived with by 'real' people. Their genuine interest was very heartening.

Two different experiences, that both highlight the need for us to communicate with as many people, in as many places as we can, just what living with Parkinson's means.

One of our most used and useful services is the Info Line. To illustrate the point, in the March quarter alone, 1220 calls were logged, reflecting both the need for this service and the calibre of our staff.

We are fortunate to have been granted a small amount of monies to do a pilot study around Dr. Simon Lewis's DASH program which will further utilize the Info Line. Those with symptoms of **D**epression, **A**nxiety, **S**leep problems, and **H**allucinations will be encouraged to **DASH** to the Info Line for more information from PNSW.

We on Council are all looking forward to the Support Group Leaders Meeting. Combined with the 30th Anniversary of PNSW, it should certainly be a forum for productive ideas that will continue to extend our important work.

Happy 30th Anniversary!

John Silk

Counselling Corner – Living alone with Parkinson's

Many people with Parkinson's live alone and manage very successfully. The single life has many benefits such as the freedom it brings and the independence that it offers. Others, however, have some worries and concerns about managing alone. Much can be done to improve the conditions and alleviate the worries of those who do live on their own.

For many, living alone is a choice bringing its own pleasures, even when PD comes onto the scene. For others, the diagnosis of PD feels catastrophic; many people thinking that their single status will make their situation ten times worse.

There can also be an assumption made that for every PD patient, there is a carer. There is a great deal of useful advice and support available to help you feel safer, more positive and less alone.

When we live alone we tend to see what we want to see. If there has been some deterioration friends tend not to challenge us the way a spouse would challenge us. The upshot of this becomes learning to challenge oneself.

A new level of self-awareness will now be essential because you will have to be your own historian in medical, emotional and social matters. If you are the sort of person who is reluctant to ask for help, you may need to change this. Asking for assistance can be done in such a way as to not feel that we are overstepping the boundaries of friendship.

The main point of this particular Counselling Corner is to stress that you are not completely alone. We at Parkinson's NSW are only too happy to discuss your concerns with you and help with strategies to assist you in your journey.

Coffee Information Morning

Come and meet staff
and volunteers
at Parkinson's NSW

Talk to people living with Parkinson's

10.30am start – 11 August 2009
25 Khartoum Road, North Ryde
RSVP – 5 August 2009

Ph 1800 644 189

CEO's Report

Rural & Remote GP On-line Education Program

One of our more important projects this year has been the Rural & Remote GP On-line Education Program. This is an on-line program which allows medical practitioners and allied health professionals to easily access information on Parkinson's Disease, risk factors, protective factors, tools for diagnosis, best practice guidelines, information for treatment – decision making, information on treatment of psycho-social factors including depression and anxiety, information for patients and information on referral to community resources such as support groups and allied health professionals.

The program is designed to be free and user friendly. There is a resource section which features expert opinions and a video, highlighting aspects of Parkinson's treatment.

Medical practitioners and health professionals can also earn continuing education points by completing sections of the course.

If your health professional is interested, they can see the program via Mediserv's PrimEd education portal: www.primed.com.au/parkinsons

DASH to the Infoline

DASH stands for Depression, Anxiety, Sleep Disorders and Hallucinations. As mentioned by our President John Silk in his message, we have gained a small government grant for a pilot program as part of a joint project with Dr Simon Lewis and Dr Sharon Naismith from the Brain and Mind Research Institute.

This will assist our information officers on our Info Line (1800 644 189) to provide tips on how to deal with depression, anxiety, sleep disorders and hallucinations.

At the same time, non-identifying information gathered from this will help the researchers and medical education.

Advocacy

We have together with the MS Society been lobbying the New South Wales government for an electricity rebate for those who use air-conditioning or additional heating, based upon the particular difficulties in relation to control of body temperature faced by those living with Parkinson's or MS. We saw the raising of this issue as particularly important at a time when the privatisation of electricity retailing was being considered. We have yet to hear of any results.

Fundraising

The major fundraising and awareness raising activity over the next few months is the Unity Walk on 30 August 2009. Further details are available in this issue, from our website, or by calling our office. Apart from an entry fee and sponsorship, the Unity Walk will also feature a raffle with a beautiful quilt donated by the Cowra Support Group and featured in the *Stand by Me Summer Edition*, together with another wonderful quilt from the Gunnedah Support Group. The previous raffle of the Cowra quilt was won by the Cowra Support Group which has re-donated it for a further raffle at the Unity Walk.

New faces

I am delighted to introduce two replacement staff members who have joined our small team at North Ryde. We have as office senior, Tracy Gough. She is in the office 5 days a week. She has a bubbly personality and is always keen to assist. Isabelle Clark is our new Bequest Officer and is progressively making contact with members. See her article in this issue.

Parkinson's Artisans

As part of our 30th anniversary celebrations, we are holding an Art Show in September 2009, in the foyer of NSW Parliament House. Please contact our office on 1800 644 189 if you would like to submit any works for consideration.

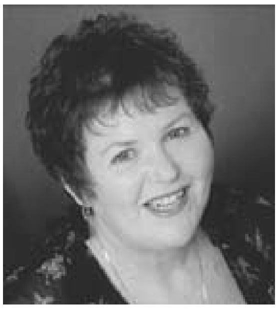
Suggestions

We are always on the lookout for suggestions, as to how we can improve our services or accessibility, and for particular circumstances calling for advocacy on behalf of people living with Parkinson's Disease. If you have any suggestions, please do not hesitate to contact us.

Yours in Parkinson's Friendship

Miriam Dixon

The James Parkinson Society … bringing hope for the future



Isabelle Clark – Bequest Officer

I would like to introduce myself. I joined Parkinson's NSW in April, coming from a background of small business and hospitality. I was the carer for many years for my Aunty who had Parkinson's, she has since passed away.

I am currently contacting members to introduce myself and to find out more about Parkinson's Disease. So, please do not be surprised to have a call from me.

I feel we all have different ways of leaving our mark on the world. A bequest is an opportunity to give back what you got out of life, and to assist others living with Parkinson's to have the benefit of a better life.

There are different sorts of bequests; if you would like more information or would like to discuss any aspect please contact me t: 8875-8900 or e: isabelle@parkinsonsnsw.org.au.

Looking forward to seeing you at our next Bequest Luncheon, which will be held on Thursday 15 October, venue to be advised.

Paula Argyropoulos – Our Unity Walk Ambassador

Paula is a very brave woman. Not just because she is living her life with Parkinson's but because she is allowing us to thrust her into the limelight and be the public face of our biggest fundraiser.

Paula is a single mother and is raising two beautiful young girls despite being diagnosed with Parkinson's at a young age. Like Nerissa Mapes, one of our previous ambassadors for the Unity Walk, Paula is one of the 10% of Australians diagnosed with the disease under the age of 40, dispelling the myth that Parkinson's is a disease of the old. Young, vivacious and attractive, Paula is very unlike the picture that is often painted, incorrectly, of people with Parkinson's.

Paula was diagnosed with Parkinson's at just 28 years of age. She had endured 2-3 years of misdiagnosis because of her symptoms; tremors, shaking, imbalance and stumbling – with everything from a heart condition to liver failure and psychological problems being suggested. At one point she had intravenous injections of vitamins, which just made things worse.

If you have visited Parkinson's central recently you will have been greeted as you enter by the smiling face of the charming Paula who volunteers her services for the organisation once a week by working as our receptionist.

We will be seeing a lot more of Paula during the build up to this year's Unity Walk as she will be out and about on the media circuit encouraging Australians to get out and support the Unity Walk thus helping others with Parkinson's. She is also committed to line up with her daughters and make the Unity Walk with us on August 30.

Two heroes of the first Unity Walk

There were many great stories to come out of the first Unity Walk, and two of them for vastly different reasons.

Neil Sligar was diagnosed with Parkinson's in 1998. In more recent times he has taken on a challenging fitness regime that includes a gym program that would test those most fit and healthy. Neil has conscientiously kept up a healthy lifestyle because whilst Parkinson's was out of his control, general health was within and he could do something about that, and not use his illness as an excuse for not exercising. His training routine is not tailored as Parkinson's therapy. It's undertaken for general health. He enjoys it, and setting targets provides a continuing challenge.

Last year's Unity Walk was an afternoon stroll by comparison but it was Neil's fundraising effort that really caught our eye. He was one of the leading fundraisers, and for quite some time held a lead over the others, but as so often happens with any sporting race Neil was pipped at the post. Knowing him, he will be back this year to again walk the talk.

Another notable participant in 2008 was Herman Soenario from Kuranda in Queensland (near Cairns). It is fair to say Herman was the marathon entrant because of the distance travelled and time it took. It would have made the Walk itself seem like a blink of the eye, but there he was on the day full of enthusiasm and keen to spread the word about Australia's Unity Walk to all and sundry in North Queensland. We hope he does because there is a very good chance that in 2010 our neighbours up north will be joining the Unity Walk.

Herman Soenario and Neil Sligar we salute you.

Maureen Morrison and young Hannah

Faces of the Unity Walk

One of the most striking aspects of the first Unity Walk work was the diversity of the people who took part. Footy fans wore their team colours with pride, others wore their free Unity Walk T shirts with pride; even the canine variety got into the act.

One of the most moving observations of the day was how the Unity Walk meant so much to so many people. Some walked for their own enjoyment but many walked because it was important to do so – for them and, in many cases, for those who couldn't make it, and for those looking down from above.

There were generations of the same family walking for gran and granddad and in some cases for Mum or Dad. There were some determined to make it round the course even if it meant hitching a ride. Two such people were at opposite ends of the age spectrum. Maureen Morrison and young Hannah were 'driven' round the course side by side each enjoying the experience as we can see.

Unity Walk frequently asked questions

1. What is Australia’s Unity Walk for Parkinson’s?

   The Parkinson’s Unity Walk started in New York’s Central Park in 1994 to raise awareness and funds for research to find a cure for Parkinson’s Disease. We invite everyone, including people with Parkinson’s, their families and friends to participate in this great family day out.

2. What day will it be held?

   Sunday, 30th August, 2009.

3. Who can enter the event?

   Everyone can enter! People with Parkinson’s, their families and friends, children, neighbours or people who know someone with Parkinson’s Disease.

4. How do I register to walk?

   You can register online at www.unitywalk.com.au or contact the NSW office. Register before 23rd August for just $20 and be in the running to win a great prize. Registrations from 24th August will be $25.

5. How do I pay for my registration?

   We accept Visa and Mastercard both online and on mailed registration forms. We also accept money orders and cheques if you choose to register via mail.

6. How can I get sponsored?

   Register online at www.unitywalk.com.au and create your own Fundraising Page which you can email to family and friends to have them sponsor your efforts. The highest fundraising individual will win a 5 day/4 night holiday for 2 in beautiful Hawaii.

7. When and where will I go to register on the day?

   Registrations will begin at 10am at The Overflow on Olympic Boulevarde at Sydney Olympic Park. This is located near the railway station.

8. What time will the walk begin?

   The walk will begin at 12 noon.

9. How long will it take to get around the course?

   The 4km should take around 1 hour at a leisurely pace. There will be shortcuts if you feel that you can’t make it around the whole route.

10. Is the route wheelchair accessible?

    Yes, the entire route is wheelchair accessible.

11. What should I wear?

    Wear your favourite sporting team colours to show Pride in your Team, as well as comfortable walking shoes. BRING WATER FOR THE WALK AS WELL.

12. Are there toilets at the event?

    Yes, there are public toilets available.

13. Is there parking at the event?

    Go to www.sydneyolympicpark.com.au

14. How will the money raised be used?

    For every dollar raised, 50% will go towards research into this debilitating disease. The other 50% will fund support services for people with Parkinson’s.

15. If I can’t participate in the walk but would like to make a donation, how can I do that?

    You can donate by going to the Donations page on the Parkinson’s NSW website at www.parkinsonsnsw.org.au or call the office on (02) 8875 8900.

16. Can I obtain a refund if I cannot attend on the day?

    No.

17. What does my entry fee provide me?

    Most importantly an opportunity to help people with Parkinson’s and have a great family day out. In addition, every person who registers will receive a free t-shirt.

18. What happens if it rains?

    Australia’s Unity Walk for Parkinson’s will proceed rain or shine.

19. Can I volunteer to help?

    Yes please! Call us to find out more (02) 8875 8900.

20. Who can I contact for more information?

    Email unitywalk@parkinsonsnsw.org.au or call (02) 8875 8900.

21. How will my credit card payments be reflected on my statement?

    Parkinson’s NSW.

22. Will there be other activities on the day?

    Stay at Olympic Park to enjoy entertainment, amusements and food or bring a picnic lunch.

23. Can I get some friends together to enter as a team or corporate team?

    Most definitely. The highest fundraising corporate team will win a catered corporate box for 8 people at a major sporting event at ANZ Stadium.

24. Should I notify you if a friend or family member has Parkinson’s?

    Yes, we would like to know this valuable piece of information for the Walk and also so we can help your family in whatever way we can in the future.

25. Can we register to walk as a family?

    Yes. It is a family day out and we are offering discounted registration fees if 2 adults and 2 children walk together.

Research

DUODOPA®

Laraine McAnally, Clinical Nurse Consultant, Epilepsy/Parkinson's disease
Jane Griffith, Clinical Nurse Consultant, Neuroscience Trials

People with Parkinson's disease (PD) lack the important chemical messenger called dopamine in the brain. Levodopa therapy, a replacement for dopamine, remains the *Gold Standard* in the treatment of PD. However, with disease progression, achieving satisfactory control of PD symptoms and side effects such as disabling involuntary movements (dyskinesias) is very challenging. Complicated combined therapies are trialled, with varying degrees of success.

Long term therapy with multiple doses of levodopa in tablet form leads to a pulsatile delivery and is associated with:

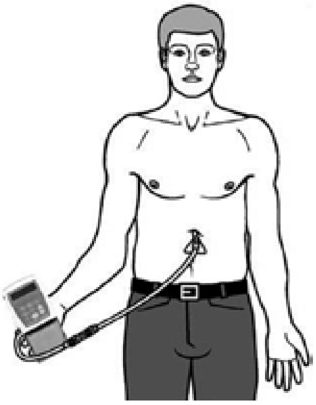
- motor fluctuations – changes in motor ability throughout the day
- wearing off – awareness of the return of symptoms before the next medication takes effect
- dyskinesias
- non-motor fluctuations e.g. off-period anxiety

Many of these issues are caused or made worse by delayed emptying of the stomach, protein interaction and erratic absorption of the drug. Continuous stimulation of the brain with levodopa, such as Duodopa®, or by other means is now accepted as the optimal treatment for people with moderate to severe PD.

Duodopa® is a new, advanced treatment in Australia for mid-late stage Parkinson's disease, while still retaining the *Gold Standard*. It has been used successfully in Scandinavia since 1991 and in the last decade has been approved as treatment in many European countries.

Duodopa® is levodopa / carbidopa, similar to Sinemet®, Kinson®, and Madopar® (levodopa/benzeraside), but in a gel form. The medication is administered directly into the small bowel through a tube passing directly into the stomach (PEG-J tube), which has an inner tube leading to the small bowel where levodopa is best absorbed. Delivering the gel directly into the small bowel controls PD symptoms more consistently than oral medications, by allowing reliable absorption of levodopa. This maintains a constant medication level and therefore stable control of symptoms.

There are two phases in the establishment of Duodopa® therapy. Firstly a small tube is inserted temporarily through the nose and stomach into the small intestine to assess the effectiveness of the treatment and determine the dose needed for the individual. In most cases all other daytime treatment is ceased as Duodopa® runs generally for around sixteen hours per day. This test phase of the treatment lasts around one week. During this time the neurologist and nursing staff who specialise in this treatment will closely monitor the person's progress, adjusting the doses as required and completing education of the patient/carer. If the person responds well to Duodopa® and the treating team and the patient are happy to proceed the patient moves into the second phase.



In the second phase under sedation or anaesthesia a small incision is made through the abdominal wall to the stomach and a PEG/J is inserted. The Duodopa® is recommenced and titration completed. Patients report varying degrees of post-operative pain which is managed with appropriate pain relief.

If there are no post-operative complications and the patient/carer is comfortable with the management of the pump and tube, the patient is discharged in 2-4 days after surgery.

The potential side effects of Duodopa are mainly related to the risks and complications of PEG surgery, which can potentially be serious but are very uncommon. In the long term, problems with tubing can occur but are usually corrected relatively easily.

Duodopa® is useful for a limited population of PD patients with a clear response to levodopa who have disabling motor or non-motor fluctuations/dyskinesias, not responding satisfactorily to individually optimised oral medication. Those selected should be in a stable mental and physical condition. Under clinical trial conditions there are also other inclusion/exclusion criteria.

At present in Australia there is limited access to this specialised treatment. Treatment with Duodopa® is approved by the TGA but not subsidised by the government. Duodopa treatment is initiated only at centres of excellence who specialize in PD and the use of Duodopa as part of an international clinical trial.

As with all medications there are advantages and disadvantages of treatment.

Duodopa® Advantages

- Smoothing out of motor fluctuations
- More "on" time
- Less dyskinesia
- Simplified medication regimen
- Able to be titrated to tiny amounts
- Rescue from sudden 'OFF" periods using extra dose function

Duodopa® Disadvantages

- PEG/J surgery is an invasive procedure with possible complications
- Tube problems
- Cosmetic issues
- Management of the pump and tube system
- Duodopa® gel must be stored in a refrigerator prior to use
- Significant cost

In our limited experience Duodopa® has a viable place in the treatment of advanced PD for carefully selected patients.

Narrabri Seminar and Cotton Farming

A visit to Narrabri on 13 May 2008 for a seminar on the program “Facing the Future with PD” brought some surprises for the staff team Margaret Byron, Deborah England and Trish Morgan.

The visit was hosted by Narrabri Support Group President Anna Thomson and Secretary Jan Holmes. When the seminar was over, Anna took us to meet her husband Norm who has had Parkinson’s for 17 years. We did not know that we were meeting with a celebrity.

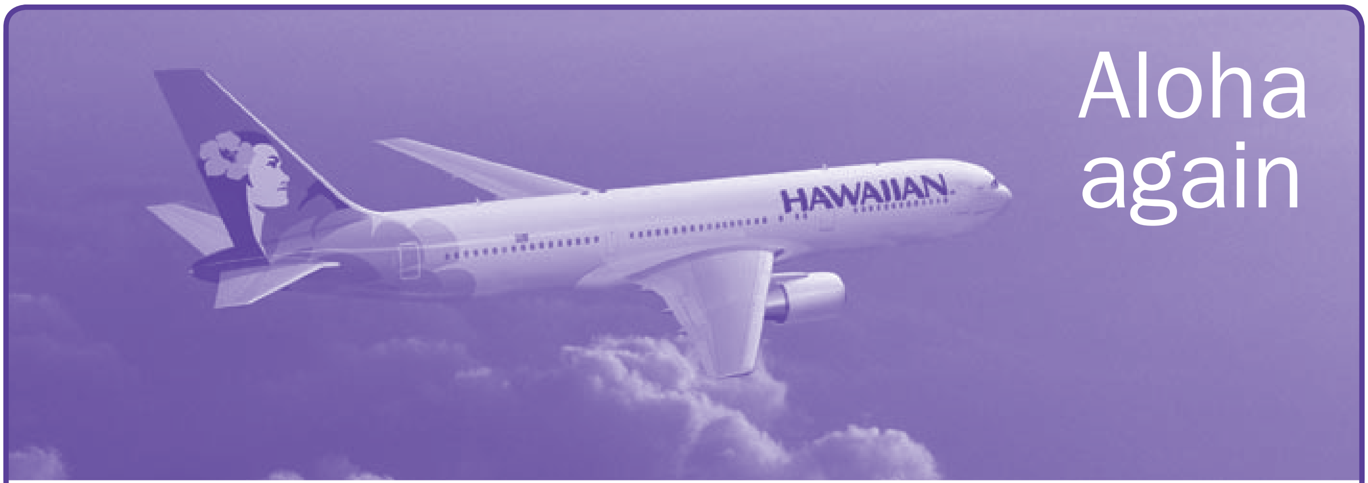
Dr Norm Thomson, PhD was awarded an Australia Medal (AM) for services to the cotton industry in the 1989 Australia Day Honours.

Dr Thomson was the leader of the CSIRO’s cotton research group at Narrabri. He visited China as scientific advisor to a delegation of Namoi cotton growers who were invited by the Chinese to assist in the establishment of a one hundred acre cotton farm in the far north west of China.

In 1988 Norm received his second Australian Cotton Growers Researcher Award for successfully breeding the first commercially successful OKRA leaf cotton which combined high yield and quality along with resistance to Bacterial Blight.

Anna took us to see where these strains of cotton were being harvested. Sunset over the cotton fields was a magical experience. Anna had arranged for us to see the cotton machinery at work.

Norm surrounded by his wife Anna, standing, Jan Holmes, kneeling, Deborah England and Margaret Byron.
See website for more photos.



Aloha again

Thanks to Hawaiian Airlines, Hawaii Tourism, and the Outrigger Reef on the Beach hotel, our top Unity Walk fundraiser and partner will be flying off to Hawaii on a 5 days and 4 nights holiday to one of the most exotic locations in the world.

This is a truly magnificent prize that is being replicated for our colleagues in Victoria who are holding their walk on the same day and at the same time so it’s going to be Aloha Sydney and Melbourne.

Outrigger Reef on the Beach’s $110 million makeover has created a delightfully unexpected and truly unforgettable new vacation experience in Hawaii. Ideally situated between famed Waikiki Beach and the entertainment centre of Waikiki, the new Outrigger Reef is a stunning new oceanfront haven of elegance, comfort, gracious hospitality, and unparalleled commitment to Hawaiian culture. For more information on the Outrigger Reef on the Beach please visit www.outriggerreef.com.

Hawaiian Airlines operates three weekly nonstop flights from Sydney to Honolulu, with onward connections to the islands of Hawaii and 10 US mainland cities including Las Vegas, Los Angeles and San Francisco. Hawaiian’s fares from Australia include complimentary meals, snacks, drinks, main screen entertainment and a generous baggage allowance of two 32kg items per passenger – no hidden extras! For more information on Hawaiian Airlines please contact www.hawaiianairlines.com.au or phone 1300 669 106

Thanks to Hawaiian Airlines, Hawaii Tourism and the Outrigger Reef on the Beach hotel it is our way of saying thank you to all for helping to make the Unity Walk the great success it is.

To learn more about Hawaii and what wonders it has to offer you visit www.hawaiitourism.com.au

HAWAI'I
Hawai'i Tourism Oceania

On the groupvine

by Trish Morgan

What's happening out there?

Macarthur support group hosted a meeting with Dr Simon Lewis and Dr Sharon Naismith from the Brain and Mind Research Institute(BMRI) at Royal Prince Alfred Hospital as guest speakers

The large audience heard Simon and Sharon describe clinical and research activities being conducted by the BMRI into cognitive and physical aspects of Parkinson's Disease. Whilst Parkinson's Disease has long been painted as a movement disorder, its impact on the psychological wellbeing and thinking skills of those living with the condition has been underplayed. Drs Lewis and Naismith and their team are seeking to redress this shortcoming.

A question and answer session enabled the many attendees to raise questions ranging from medication timing to dealing with awkward situations that can arise for people with Parkinson's when meeting those unaware of its symptoms.

Newcastle support group received a grant of $3,000 from the Federal Government Volunteer Grants Program. The group had a library cupboard built and installed at the Charlestown Multi Purpose Centre. The cupboard cost $1,500 and was built so that it can be moved to another venue if necessary and will not damage the centre wall. Not many groups are fortunate to have cupboard space at their venue.

The Secretary/Treasurer, Karen Begley, does a wonderful job managing these grants. She has purchased 6 Pedalex bikes with rubber safety mats (to prevent them sliding across the floor) for members to borrow. There was money left over to purchase library books and to allow $1,000 for petrol vouchers to be used by volunteers when transporting members and for fuel expenses for Parkinson's Specialist Nurse, Evelyn Collins, who attends meetings that are held on the first Saturday of the month at 2pm.

Grafton support group are having a morning tea in June with their State Member, Steve Cansdell, and hopefully the Clarence Valley Mayor, Richie Williamson, to commemorate World Parkinson's Day. This is an important opportunity to raise Awareness with the State and Local representatives about Parkinson's and the work of support groups. It is an idea other groups might adopt once a year – even if it cannot be held on 11 April.

Shoalhaven Ulladulla support group had a combined meeting with the local Arthritis Foundation members. Charles Long, President of the Milton-Ulladulla Arthritis Foundation Support Group, and Barry Mitchell were able to provide members of both groups with information regarding Arthritis and Parkinson's Disease, as well as the objectives of each support group and the role that each organisation has in finding a cure for these debilitating diseases. Both groups have agreed to convene further meetings to include other local support groups, such as the MU Stroke Club, later this year. This is a wonderful initiative other groups, especially in small country areas, may consider to increase awareness within their communities.

Leadership changes!

Tweed Heads support group is changing leaders and removing "Heads" from its name. Shirley Rushton has managed this group almost single-handedly since 2005. Other leaders understand that this can mean arranging speakers and provisions for morning tea, carrying books and resources and picking up fellow members. Shirley has also arranged two Awareness Seminars a year.

Well done, Shirley and thank you from Parkinson's New South Wales.

Helen Boddington and Jill Pope are working together as co-leaders to steer the group and are looking forward to coming to the Support Group Leaders meeting in July. Groups find that sharing the roles in a group allows for back-up in the case of emergencies and holidays. Leaders are giving their time and need to feel that they can have 'time off'.

Some other groups are undergoing leadership changes, as people move elsewhere to live or are needing to hand over the reins, and they are awaiting their AGM to decide the outcome. Change is good as new leaders bring fresh ideas and energy to the role.

The freecall number **1800 644 189** will be the contact for these groups in the interim. The office will be able to put people in touch with a representative for the group in their area.

Young Women's Group

If you are a young woman living with a diagnosis of Parkinson Disease and are under the age of 60, you might like to join our Young Women's Group.

The group meets the 3rd Wednesday of the month 10:30am – 12:00noon at our North Ryde office.
We welcome newcomers and their female family members or carers.

The next group will meet on the 15th of July.

For details contact our InfoLine 1800 644 189

Incontinence – it doesn't have to change your life

Incontinence is a problem many Australians live with. The loss of control over bladder or bowel function is estimated to affect nearly four million Australians of all ages.

Incontinence can be treated and managed; in some cases it can be cured. Assessment and advice can improve the lifestyle and wellbeing of people affected by incontinence, yet it is a taboo subject and people are often afraid or embarrassed to seek help.

Carmen Riley, CEO of Intouch, says incontinence is an important health issue confronting Australians, and Intouch Direct is a popular service because of its discretion, convenience and product range.

"Intouch Direct is a discreet service, people can shop online from the privacy of their own home or call us to place an order or request free samples. We offer over 1,400 products for men, women and children and maintain the highest levels of privacy and discretion," Carmen said.

"Intouch Direct is popular because we provide a wide range of quality products that are not available in supermarkets and pharmacies, and deliver them direct to your door, discreetly wrapped on request to avoid embarrassment.

"We can provide free samples and product advice, greatly reducing the stress of managing incontinence," Carmen said.

Choosing the right product can help maintain or improve your lifestyle. There are so many continence products available, you don't have to accept products that perform poorly or are humiliating to use.

For more information about products call Intouch Direct on **1300 134 260** or visit **www.smartshopper.intouchdirect.com.au**

Health professionals can also discuss your needs and provide advice on treatment options. The National Continence Helpline **1800 33 00 66** can provide information about local continence clinics, and the name of your nearest continence nurse advisor, or continence and women's health or pelvic floor physiotherapist.

If you or someone you care for lives with incontinence, you may be eligible for State or Federal Government subsidy schemes for continence products. Intouch administers the national Continence Aids Assistance Scheme (CAAS) on behalf of the Commonwealth Government Department of Health and Ageing.

The CAAS assists eligible people who have permanent and severe incontinence to meet some of the costs of continence products. CAAS clients receive a subsidy of up to $479.40 per year on continence products ordered through Intouch. For more information visit **www.intouchdirect.com.au** or call the CAAS Helpline on **1300 366 455**.

The Department of Veterans' Affairs (DVA) Rehabilitation Appliances Program (RAP) is another Australian Government program providing continence aids for eligible clients nationally. For more information visit **www.intouchdirect.com.au** or call the Intouch DVA Helpline on **1300 134 606**.

For more information about state schemes contact the National Continence Helpline.

My husband Martin

by Martin & Jan Farrell

My husband Martin was diagnosed with Parkinson's Disease in November 2006. In July 2008 he was told he came under the Parkie Plus group. Martin has MSA (Multi System Atrophy).

We always thought he was different to the average Parkie person. The hard thing was we didn't know anyone that had Parkie Plus.

So when we were asked through *"Stand By Me"* magazine to register for a Parkie Plus teleconference we jumped at the opportunity. A chance to hear how others were coping and if they had similar problems to those of Martin.

The good news was there were other Parkie Plus people and their carers who were just as keen as we were to hook up and get that much needed knowledge, help and support for coping with Parkie Plus on a daily basis.

Our group was from the South Coast, North Coast, Central Coast, Sydney, and outer lying regional areas. About twelve of us phoned in each week, and it was just wonderful the help and advice passed on through professional people in specialised fields, and also by each other, the ones who live each day with a debilitating disorder and those of us who love them, watch and help where we can, the best way we can.

To anyone who maybe thinking "Is a teleconference for me or not"? We say dive right in, it is very easy. Miriam and Claerwen are just the best leaders. They are caring, compassionate leaders and have lots of knowledge as well. It was a lovely six weekly event, and we are now in contact with each other if the need is there. We are to have three monthly catch-ups on a teleconference; organised through Parkinson's NSW.

We would like to thank all the members of our group for their friendship and for sharing their talents and tribulations with us. And thank you Parkinson's NSW.

Sea Terror

Geoffrey Nash's short novel **Sea Terror** tells the story of the search for a submarine reported to have attacked shipping channels north of Australia. Under instructions from the UN, the navy moves in and uncovers piracy, drug dealers, terrorism and hostage taking.

Geoffrey has suffered from Parkinson's for many years and any proceeds from the sale of the book – $7 plus $1.65 p&p will be donated to Parkinson's NSW.

To buy a copy, contact Geoffrey Nash, 27/4320 Nelson Bay Road, Anna Bay, NSW 2316, Telephone: (02) 4981 9259 or Email: nash59@iprimus.com.au

Daphne Jean Fahey and John Samuel Walsh

Parkinson's NSW has benefited from a substantial bequest left by Daphne Fahey and John Walsh.

Barry Leader, joint executor of the estate with Terence Patrick, said: "I met Daphne in 1980 when she came to me asking for financial advice. At the time she was nursing her terminally ill husband, Christopher, who died in 1986."

Some years later, Daphne met John, a widower, and they discovered that they had many common interests such as collecting art, paintings and furniture. They bought a house in Hollywell, Queensland, which became their home.

Then John's health deteriorated, partly due to injuries sustained during the war, and Daphne again became a fulltime carer and nursed John until he was admitted to hospital.

"About this time, they both requested I look after their estates. They'd decided they wanted the bulk of their combined assets to go to medical research," said Mr Leader.

"John was diagnosed with Parkinson's and they decided Parkinson's NSW would be the beneficiary."

After John's death, Daphne remained at their Hollywell home until just prior to her own death in 2007.

"Daphne lived simply to ensure Parkinson's NSW would benefit from the combined assets of her own and John's estates. Although John suffered from other serious illnesses, the onset of Parkinson's seemed to have the most traumatic effect on their lives reinforcing their desire to help with Parkinson's research," said Mr Leader.

Parkinson's NSW is most grateful to the following for their support of the 2009 Australia's Unity Walk

Bendigo Bank

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CONTINUOUS CALL.

NRL

ANZ STADIUM

World Parkinson's Day celebrated in Bingara – 600kms north west of Sydney

by Trish Morgan

Bingara support group under the helm of Joan and Sonny Bush arranged the showing of the movie 'The Buddy Holly Story' at the newly renovated Roxy Theatre.

This theatre was closed in the late 1950's at the time Buddy Holly was starting his career. It was renovated by Bingara Council and a community group and reopened in 2004 by Neville Wran.

Word of the film showing to celebrate World Parkinson's Day was featured in all the local newspapers including the Bingara Advocate and Joan was interviewed on local radio. It was the original 1979 version which won many awards for the actor, Gary Busey, who played "Buddy" and an Oscar for the best music.

Well known local musicians, Helen and Tony Cornish, gave their time for free to perform a live concert before the film. Members of Bingara and Glen Innes support groups were there as well as friends from Barraba, Inverell and one couple from Rockhampton.

84 people came and there was a buzz of excitement as they bought tickets. Many knew the words to the songs and clapped and tapped their feet. They demanded an encore from Helen and Tony who were due to perform later that day in Narrabri. The movie was very entertaining and the audience stayed for a delightful country style afternoon tea. There was a Parkinson's information table in the foyer and key rings and T-shirts for sale.

Thanks to Sandy McNaughton, Manager of the Roxy, Merv and Judy Hall, and Jenni Reddy from the Roxy committee who welcomed people and ushered them to their seats. The Roxy is fully wheelchair accessible with ramps and no internal steps.

Special thanks to Bingara Support Group, President Judy Abra, Joan and Sonny Bush for arranging the day and to all the good cooks in Bingara – a very friendly town.

Trish Morgan and her friend, Margaret Dunn,a Parkinson's volunteer, enjoyed the drive via the Hunter Valley and Tamworth to join in a most memorable celebration of World Parkinson's Day.

See website for photos.

Donations

IMPORTANT NOTICE regarding General Donations

All general donations will now be acknowledged in our Annual Report which will be published for the Annual General Meeting on the 29 September 2009.

There has been a significant increase in our general donations and as there is limited space in our newsletter, this decision has been made for all general donations received in this financial year. We will continue to publish in Stand By Me, donations made for In Memoriam and for Birthdays.

Thank you for your continuing support.

Donations have been received in memory of the following people between 27th February and 31 May 2009.

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.

IN MEMORIAM

J Bamford
Mr Ayton
Liselotte Birkefeld
Nancy Bugge
Roy Critcher
Lydia Eisenberg
Umberto Fabbi
Donald Fortescue
Mrs Groves
Dorothy Hearne
Margaret Lans
Joyce Leece
Leonard Mackey
Edward Mann
Chas McGilivray
Peter Michael
Ronald Northam
Rosano Parasiliti
Diana Reynolds
Leonard Sadlier
Kath Sharp
Carmel Sharpe
Darryl Smeaton
Leslie Smith
Neil Staveley
Reginald Stonestreet
Maria Vlastuin
Keith Webster

DONATIONS WERE RECEIVED IN CELEBRATION OF THE BIRTHDAY'S OF:

Norma Doyle
Mervyn Fine
Jennifer Hershon
Luma Mehmet
Pam Richardson
David Stewart

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
Bega Valley	Sue Nelson	02 6495 9932
Bingara	Joan Bush	02 6724 1976
Blacktown	Bryan McAlister	02 9674 6827
Blue Mountains	Hazel Tolhurst	02 4751 9903
Broken Hill	Colleen O'Brien	08 8087 2175
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 Rumbel	02 4931 5210
Coffs Harbour	Vera Heil	02 6652 9959
Cowra	Ray Heilman	02 6341 3692
Dubbo	Lorna White	02 6882 7778
Dundas/Parramatta		02 9876 4284
Eastern Suburbs	Marion Welch	02 9369 0250
Eurobodalla		1800 644 189
Fairfield/Liverpool	Warwick Brown	02 9602 8231
Finley	Glenis Gordon	03 5436 9293
Glen Innes		02 6732 1252
Goulburn	Mick O'Connor	02 4822 6732
Grafton	Cathy Eggins	02 6642 2156
Griffith	Angela Bortolin	02 6962 3289
Gunnedah	Lisa Hagley	02 6742 0018
Hawkesbury	Jill Sykes	02 9621 1794
Hornsby/Ku-ring-gai	Diana Rynkiewicz	02 9488 7092
Illawarra North	John Coppens	02 4283 1346
Illawarra South		02 4232 2807
Lower North Shore	Jan Cumming	02 9412 2740
Macarthur	Maree Sinclair	02 4626 4959
Manly/Mosman	Bill Lindsay	02 9949 3991
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
Pittwater/Warringah	Margaret Smith	02 9913 7745
Port Macquarie	Patricia Stephenson	02 6584 0212
Quirindi	Les Howard	02 6747 1459
Shoalhaven/Nowra	Jonathan Morgan	02 4464 3028
Shoalhaven/Ulladulla	Barry Mitchell	02 4454 0747
Southern Highlands	Marj Webb	02 4871 2615
St George/Sutherland	Myra Chalmers	02 9525 7215
Tamworth	Pat Johnson	02 6765 6948
Tomaree		1800 644 189
Tweed Heads	Helen Boddington	02 6676 2549
Ultimo	Chris Davis	0411 532 504
Wagga Wagga	John Allen	02 6925 2713
Yamba	Heather Wilson	02 6646 1369
Yass	Clarrie Schlunke	02 6226 4150
Young Onset	Trish Morgan	1800 644 189
Young Men's Network	Garry Cearns	02 9871 1853
Young Women		1800 644 189

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Governor of NSW

Sir Nicholas Shehadie AC

HON. ADVISOR

Lady Angela Carrick

Diary Dates

AUGUST

11	Coffee/Information morning – North Ryde office
30	Australia's Unity Walk for Parkinson's – Sydney Olympic Park
31	Parkinson's Artisans' Show – thru till the 25 September

SEPTEMBER

1st week	Parkinson's Awareness Week
2	Awareness Seminar – State Parliament House
29	Annual General Meeting – Vincent Fairfax Centre, North Ryde

OCTOBER

8	Cocktail Party 'Shaken not Stirred' – Paddington Town Hall

NOVEMBER

24	Coffee/Information morning – North Ryde office
29	Golf Day – Monash Golf Club

DECEMBER

5	Parkinsons' Christmas Party – venue TBA

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

Parkinson's … with personal experience

A special education seminar for those wanting to learn about Deep Brain Stimulation (DBS).

Featuring

Dr Paul Silberstein and a panel of people who have had DBS.

Venue

Northern Sydney Education Centre, Macquarie Hospital Campus
Wicks Road, North Ryde

When

Wednesday 1 July, 11.00am, Registration 10:30am

RSVP by Wednesday 24th June on 1800 644 189

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.

To become a member, visit our website:

www.parkinsonsnsw.org.au

or

Call InfoLine: 1800 644 189

At the December Council Meeting it was decided that, from 1st April, all subscriptions and joining fees will be increased as follows:

- Individual Membership: $35
- Professional Membership: $75
- Organisations: $100
- Life Membership: $350

Parkinson's NSW Inc. ABN 93 023 603 545

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