

# STAND BY ME

Parkinson's NSW Inc Newsletter. Issue 114, Summer 2011  
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## LEMONADE & CUPCAKES



Mary and Savannah

**In the last school holidays two budding young entrepreneurs, Mary Argy age 9, and her cousin, Savannah Lambrou age 8, set up a small shop in front of Mary's house.**

It was an old-fashioned style stall, selling homemade lemonade and cupcakes and also books that they no longer wanted to keep. Mary's motivation was to raise money for Parkinson's NSW as her mother, Paula Argy, has been living with Parkinson's for the last 17 years. They set up the shop, decorated it, made posters and decided to price everything for \$1.

Mary and Savannah also arranged entertainment: singing and dancing in the street.

This was all done with little assistance. The girls managed to raise over \$70 which has been donated to Parkinson's NSW.

Thanks, Mary and Savannah, for your stellar fundraising efforts!

## TULIP TIME

The weather was awful, but the resilience of Parkinson's NSW, the charity of choice for the 51st Tulip Time Festival in the Southern Highlands was never doubted. Our volunteers constant presence in Corbett Gardens meant that the Parkinson's cause was never without an ambassador.

Marty Rhone, our fundraising consultant was this year's Tulip Time Ambassador. Along with his ambassadorial duties he also organised during Countdown to Tulip Time a 70s themed dinner dance at Mittagong RSL featuring some of Marty's old mates from the Countdown television days: John Paul Young, Ray Burgess, Dinah Lee and Donnie Sutherland, the host of Channel 7's music show 'Sounds' in the 70's and 80's.

This was the decade that fashion forgot and the dance floor rocked with baby boomers reliving those halcyon days of flared trousers, hideously colourful shirts, mullet hairstyles and great music as the artists belted out hit after hit.

Artists Leone Harris and Michelle Roach each donated a painting for auction with the biggest bid of the night from Donnie Sutherland who paid \$2,000 for the Mohammed Ali signed boxing gloves. Our president, Chris Davis rode the whole Bowral Bike Ride, organised by the Sydney Cycling Club and supporting Parkinson's. It was a remarkable achievement by Chris who rode the entire distance including the climb up the mountain from Wollongong. Chris still managed to attend the Tulips after Dark event in Corbett Gardens in the evening.

The street parade attracted good crowds, with Marty and our CEO Miriam Dixon sharing the back seat of a big Ford Customline with Jerry Lee Lewis blaring on the radio.

Our special thanks goes to Southern Highlands Tourism, Radio 2ST, Southern Highlands News, the Mittagong RSL and the Sydney Cycling Club.



Corbett Gardens in full bloom

# From the PRESIDENT



Another year has raced by and it's almost Christmas time – I wish all our members and friends well for the festive season. I hope you all eat heartily, relax and, most of all, celebrate with your family and friends; it's the social network and support which is so important for people with Parkinson's.

I will be visiting the Coalfields and St George/Sutherland Support Groups before Christmas and I hope to visit many more in the New Year, to meet their members and to learn about their needs and concerns. While it was marvellous to participate in our Support Group Leaders' conference in September, there's no substitute for meeting people on their home ground and with time to chat. While I can't promise to get around quickly to all of our current 65 Groups, I am happy to hear from those who would like to meet soon and will develop an ongoing program of visits.

Two possible projects that I hope to initiate for 2012, depending on feasibility studies and the level of interest, are exercise opportunities, in general, and, starting in a central Sydney venue, but potentially elsewhere later, a choral group. There's a large body of evidence that exercise is beneficial for people with Parkinson's but, of course, each activity has to be tailored to the needs of the individual, so thought must go into whatever is to be offered. On the music front, a smaller, but positive case to be made for the benefits of music therapy, especially active therapy, where the participants sing with a group: the combination of voice exercise; social interaction; breathing and the sheer emotional engagement with the music makes for a powerful potential for improving one's quality of life. Of course, a choral activity would be open to carers and friends too, to embrace the wider Parkinson's family.

We'll be studying the options and viability of these projects and I would value comments and suggestions from members:

Just drop me a line to [chris.davis@people.net.au](mailto:chris.davis@people.net.au) or

Put in a call to the Infoline 1800 644 189 or

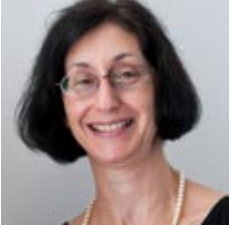
Write to PO Box 71, North Ryde BC 1670.

An ongoing issue I must stress is the need for Parkinson's NSW to have more members because: bigger constituencies get the ear of government; our knowledge of Parkinson's in the community is stronger if we have a bigger database and also membership subscriptions help us to fund our support services and research investments.

If you can encourage Parkinson's friends to join, you will help us build a stronger organisation.

Finally, I would like to share my own story about exercise, from the recent Tulip Time event, which is described elsewhere in *Stand By Me*. The Sydney Cycle Club (SCC) has, over the past four years, adopted Tulip Time by setting up a bike ride, from Centennial Park in Sydney, to Bowral, calling it Ride for a Reason. Funds raised through this event are channelled to the Tulip Time charity which, this year, was Parkinson's NSW. As a long-term cyclist, I decided that I should do my bit to support the event which supports us, so I enrolled. The ride is not a trivial one, however, since the route is 165 km long and includes the steep, winding Macquarie Pass. I had never ridden 165 km in one day, but decided it was do-able. Owing to travel commitments and the logistics of finding a suitable bicycle, I didn't ride more than 50 km in any one training session; so, when I joined the Ride for a Reason group at 6 am on 24 September, I was woefully under-prepared. It was cool and a light drizzle heralded the ride. The 80 or so cyclists were divided into six bunches and I joined the slowest one. As a long-established club, SCC has excellent organising skills, so our bunch was shadowed by a support van, which shielded us from the worst traffic threats, and was on hand to pick up anyone who 'sagged'. Needless to say, I soon realised how fit the riders were and I clung to the back of the bunch with grim determination. Climbing Macquarie Pass became a question of mind over matter, as I painfully pedalled and, I realised later, cooled down too much. Up on the Highlands, I was just able to enjoy the beautiful forested route and finally pulled into Bowral, aching and chilled. It took a long, hot shower and a large bowl of pasta to restore me. I don't know yet just how much was raised by SCC's Ride for a Reason, but I suspect it's probably the largest single source from Tulip Time. In particular, the riders in my bunch (D) cheerfully put up with my slow pace and offered companionship. I also have renewed respect for the commitment and fitness of all the SCC riders, and especially for their contribution to Parkinson's.

Chris Davis, President



# From the CEO

## Deloitte Access Economics Update

Parkinson's Australia has now released the Deloitte Access Economics Update on their previous report in relation to the financial and human impacts of Parkinson's Disease.

The update estimates 30 new people are diagnosed every day, an increase of 17% since 2005. They assess this as having a total financial cost for 2011 of \$775m, an increase of 48% due to an increase in health system costs and productivity costs.

They note that in addition to financial costs, the burden of the disease is estimated to cost an additional 46,069 Disability Adjusted Life Years or years of healthy life lost. This results in a calculation of a net value of the burden of the disease at \$7.6b in 2011, an increase of 21% in 6 years.

With the benefit of the report we will continue to lobby, along with Parkinson's Australia, for government funding for Parkinson's specialist nurses. There is significant evidence from the UK that investment in Parkinson's specialist nurses saves significant amounts in medical specialists services, avoiding hospital admissions and reduced bed delay.

We propose to make a copy of the report available via our website, and to send copies to state members of parliament. We would encourage you to contact your own MPs to see whether

they have a copy and are willing to support our efforts for funding of Parkinson's specialist nurses. We welcome updates on your communications with local MPs.

We are pleased to announce, with the assistance of Hospira, Bendigo Bank and a private benefactor, we will be continuing the neurological nurse educator position in the Shoalhaven region into 2012.

**All of us at Parkinson's NSW wish you and your families season's greetings and all the best for the year ahead.**

## Working age and young onset

One of the areas highlighted by the Deloitte Access Economics study was the number of people of working age who are affected by Parkinson's, with the consequential economic cost to them, their families and the community.

As mentioned previously, we have been working with the Sustainable Futures group at the University of Technology Sydney to conduct research into the experiences of people diagnosed with

Parkinson's under 65 years of age. We welcome further participants for that research.

For that purpose please see our website or contact us on phone 1800 644 189.

In 2012 there will also be a national young onset convention in March. This will enable people living with Parkinson's and their partners to discuss common issues and share experiences. Please contact the same website and phone number for details.

## Unity Walk and Tulip Time

We would like to thank all those who participated and volunteered for these recent events, which are intended to raise awareness of Parkinson's as well as being fundraisers.

All of us at Parkinson's NSW wish you and your families season's greetings and all the best for the year ahead.

Yours in Parkinson's Friendship

Miram Dixon, CEO



## WANTED RESEARCH PARTICIPANTS

Changes in central motor circuits in health and disease.

Neuroscience Research Australia is looking for volunteers to participate in a study of how the brain compensates for damage to areas which control movement in Parkinson's Disease. This knowledge will enable us to develop better treatment strategies in this common movement disorder.

The study will involve taking an ultrasound of your brain. We will test movement using a series of movement tests and also assess thinking and memory. Some volunteers will be asked to undergo Magnetic Resonance Imaging (MRI) and magnetic stimulation of the brain. These routine tests are safe and painless.

We are recruiting both healthy individuals and individuals with Parkinson's Disease. In order to participate you need to be:

Between 55-70 years of age;

Able to attend three appointments at Neuroscience Research Australia in Randwick;

If you have Parkinson's Disease, you need to be able to delay your medication on the day of testing until testing is completed.

To register or for further information contact Connie Severino Phone: 9399115 or email: volunteers@neura.edu.au

# RESEARCH MATTERS

## Promoting a healthy brain and mind in Parkinson's disease

Researchers at the University of Sydney are investigating whether a group-based program targeting healthy brain ageing, can improve memory and thinking skills, also known as cognition, in patients with Parkinson's Disease.

Associate Professor Sharon Naismith, a Neuropsychologist and Director of The Clinical Research Unit and Healthy Brain Ageing Team, at the Brain and Mind Research Institute, is working alongside Dr Simon Lewis, Director of the Parkinson's Disease Research Clinic in order to investigate the efficacy of this program.

Associate Professor Naismith was the proud recipient of a Parkinson's NSW Seed Grant, which will provide preliminary funding for the trial. "It is well established in many diseases of the brain and mind that ongoing and challenging brain exercise is associated with improved cognitive functioning", Associate Professor Naismith says. However, very few studies have examined this in Parkinson's Disease. "There is no reason to think that in Parkinson's Disease, the brain is not capable of neuroplasticity. This is the process whereby the brain undergoes continued growth and reorganisation in response to stimulation. Recent international literature suggests that not only is cognitive activity important, but that social activity as well as exercise is important for the health of the brain. It seems that at least moderately intense levels of aerobic exercise, as well as muscle resistance training promote levels of important protective chemicals in our brains called neurotrophins."

Associate Professor Naismith, who co-authored the *DASH (Depression, Anxiety, Sleep Disturbance and Hallucinations, 2010)* booklet with Dr Lewis, also emphasises the importance of mental health for healthy brain ageing. "Factors such as depression, anxiety



and sleep disturbance must also be managed proactively, since they have been associated with decline in memory and thinking skills overtime, and appear to trigger the release of adverse chemicals called glucocorticoids. These appear to be harmful to our brain structures, particularly those supporting memory. Sometimes medication can help, but in many instances depression and anxiety can be effectively alleviated without the use of drugs."

The research program promotes a holistic, multi-factorial approach to healthy brain ageing, by combining educational sessions targeting the 'modifiable risk factors' for cognitive decline with computer-based brain training exercises. The group program requires attendance at the Brain & Mind Research Institute in Camperdown for two-hours, twice weekly for seven weeks. Educational sessions are delivered by a variety of health professionals including Neuropsychologists, Psychologists, Neurologists, Exercise Physiologists and Nutritionists.

The computer-based brain exercises are

engaging and tailored to the individual and are therefore suitable for a wide-range of people. "The program so far has been very well received", says Associate Professor Naismith, who stated that the attendance rates and feedback from the 35 participants to date has been excellent. We hope that the program will be associated with improved memory, as well as improvements in mood and quality of life. If we can demonstrate this, such programs may be able to be delivered to the community more widely.

The next round of groups will commence in mid-October, and then again in early 2012.

**To enquire about participation in this study, please phone the Parkinson's Disease Research Clinic on: (02) 9351 0702, or email: [pd.clinic@sydney.edu.au](mailto:pd.clinic@sydney.edu.au).**

# ON the **GROUP VINE**



Dr Paul Silberstein at Awareness Seminar

## Support Group Leaders Meeting

On 15 and 16 September 79 members from 46 support groups attended a two day workshop hosted by Parkinson's NSW. Seventeen metropolitan and 29 country groups were represented at the event with most attending the Annual Awareness Seminar at Parliament House the previous day.

Attendees found the two day workshop valuable for sharing ideas about group activities and personal stories. The meeting venue at Dunmore Lang College

next to their accommodation made it easy for participants. The evenings at The Ranch and North Ryde RSL were especially enjoyable.

Special thanks to bus drivers Dennis and Carlo, who ferried everyone to various destinations with a smile. North Ryde RSL arranged a Courtesy bus to provide transport from their Club.

## Senior Leaders retire

We would like to acknowledge retiring support group leaders Bruce King, from Manning/ Great Lakes and John Allen, from Wagga Wagga. During their time as leaders they have built up their respective groups membership and tirelessly worked to raise the awareness of Parkinson's in their community. Both have shown great leadership within their groups and communities.

We congratulate Bruce and John!

## Speeding Vibrations enjoy lunch at Bowral in Tulip Time

A small group of original members of the Young Onset group met on 25 September for lunch on a rainy Sunday. Log fires and delicious food ensured a pleasant time. The display of tulips in Corbett Gardens was certainly worth a visit.

## New Support Group at Kings Langley

Tuesday 27 September saw 11 people gather at 'The Lodge' in the Adventist Village at Kings Langley to form a new Parkinson's support group. Jill Sykes, well known member of the Speakers Group, convened the meeting. Attendees included several people with Parkinson's, carers and other residents of the village who came in support. The group will meet on 4th Tuesday of the month at 10am. Bryan McAlister from Blacktown support group came to wish the new group well.



L. Support Group Leaders Conference



Awareness Seminar

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# Unity Walk & FUN RUN



**On an overcast morning, 200 runners lined up on Olympic Boulevard to run 8km around Sydney Olympic Park to raise funds for Parkinson's NSW in the inaugural Fun Run.**

It was an early start for organisers and volunteers at this year's event with many coming from our major sponsor Bendigo

Bank. The run attracted some serious runners including our two winners Belinda Martin, current Sydney half marathon winner, and Earl O'Brien. Each won a five day trip to Hawaii flying Hawaiian Airlines and staying at the Courtyard Marriott Hotel on Waikiki Beach.

Then, at 11.30, under the archway on Olympic Boulevard 1,300 people lined up to walk the 4km Unity Walk, led by the Hills District Pipe Band.

Despite the comfortable 18 degrees, the halfway drink station was well patronised with Sydney Markets generously handing out fruit and a copy of the Sunday Telegraph at the finish.

There were rides, the tattoo lady and face painting for the kids, with the massages from the students and staff from Sutherland TAFE proving very popular. 2GB radio personality Chris Smith hosted the formalities and the Luke Lukess band rocked the stage with our ambassador Peter FitzSimons available to sign copies of his books.

The money raised will go in grants for research into Parkinson's disease and to help people with Parkinson's, their carers and families.

We would like to thank all our sponsors, the volunteers, and PNSW staff who ensured the day ran smoothly and efficiently.

Next years will be our 5th Anniversary. We look forward to welcoming our biggest crowd ever as we celebrate this great fundraising occasion for Parkinson's.

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# From the COUNSELLING CORNER

When asked to write something about the counselling service at Parkinson's NSW I was tempted to write something about the services we offer and the type of concerns that people bring to counselling.

The former can easily be elicited from talking to someone at a Support Group or by ringing Info Line and the latter can be as many and varied as the folk accessing the service. Instead I thought I would write about what the Counselling Service means to me.

Each time that I speak with someone about a matter that they are worrying over or struggling with, I am often humbled to be included in this sometimes, intensely personal and private information. What a privilege to be trusted with this and I am honoured to be viewed in this way.

The other thing that I am privileged to be a part of is travelling to various places in NSW either visiting Support Groups or being part of Seminars about Parkinson's or delivering education at various centres as part of our programs. I am again very grateful to be so warmly welcomed by not only our members but also by introductions to various other community organisations and groups.

For me, being able to raise awareness and de-mystify a lot of the misconceptions about Parkinson's is a mighty thing. If a person can understand the 'why' something is happening that person can often live with the 'how' it may be manifesting. To be of some assistance helping navigate this with someone is an endeavour in which I am pleased to be involved.

Deb England

## James Parkinson Society Bequest Lunch



Long time Parkinson's NSW supporter, Don Willcox, was inducted into the James Parkinson Society by Miriam Dixon.

The annual James Parkinson Society Bequest Lunch was held on 20 October at the Grand Pittwater Room, North Ryde RSL with 80 members and supporters of the James Parkinson Society joining together to enjoy a delicious lunch.

Nata Forte, entertainer, singer and songwriter provided the cabaret style entertainment with all the members joining in. Don Willcox read two poems from his book *Shaking Stanzas & Vibrating Verses* and his book and Nata's CD were given as lucky door prizes.

Council member John Silk, OAM, was instrumental in setting up the James Parkinson's Trust during his time as President. He talked of the Trust's financial performance and how, through confident management, it is continuing to grow and create a solid foundation for the future of Parkinson's NSW.

Gary Cearns gave an inspirational speech about his own journey with PD. Diagnosed at 49, he spoke about how the diagnosis affected his work and family and the importance of the Working Age Men's Network (formerly the Young Mens Group), that he chairs.

If you would like information regarding how to leave a gift to Parkinson's NSW in your will please contact Isabelle Clark - Bequest Officer. Knowing your memory will live on in the gratitude of strangers is certainly a contribution worth making.

Guardian Funerals North Ryde and Macquarie Park Cemetery and Crematorium generously sponsored this event.

Isabelle Clark - Bequest Officer  
Isabelle@parkinsonsnsw.org.au  
0403 324 486

## 2012 National Young Onset Convention



We invite people living with Young Onset Parkinson's, in NSW and throughout Australia, to be part of this important event. It will provide an opportunity to learn more about the latest developments in Parkinson's treatment and research and also focus on additional themes and topics of particular relevance to younger members of the Parkinson's community.

Presenters will include Dr Simon Lewis from the Brain and Mind Research Institute, Dr Bryce Vissel from The Garvan Institute, a legal expert from Gilbert and Tobin, and Lee Silverman Voice Treatment

and 'Big' Practitioner, Lyn Tulloch. There will also be sessions on exercise and Tai Chi.

A full program and further details is published on our Parkinson's NSW website and available from our InfoLine.

Places are limited so contact our InfoLine for more details and to register. 1800 644 189 or, if interstate, (02) 8875 8900  
infoline@parkinsonsnsw.org.au

When. 16 March - 18 March 2012  
Where. Sydney Conference & Training Centre, Ingleside, NSW.

# WHAT'S ON

## December 3 Christmas Party

Vincent Fairfax Resource Centre  
RSVP 1800 644 189

## February 16, 2012 Coffee Morning

RSVP: 1800 644 189

## March 16-18, 2012 National Young Onset Convention

RSVP: 1800 644 189

### Contributors

Chris Davis  
Miriam Dixon  
Deborah England  
Claerwen Armstrong  
Isabelle Clark  
Associate Professor Sharon Naismith  
Trish Morgan  
Paula Argy  
Marilia Pereira  
Marty Rhone

### Editorial Team

Linda Davies  
Pip K

### Parkinson's NSW Inc

1800 644 189  
PO Box 71  
North Ryde BC NSW 1670

Macquarie Hospital Building 21  
120 Cox's Rd  
North Ryde NSW 2113

### For your local Support Group

please call 1800 644 189  
pnswn@parkinsonsnsw.org.au  
www.parkinsonsnsw.org.au  
www.facebook.com/parkinsonsnsw  
www.twitter.com/parkinsonsnsw

## In Memorium Donations 25 May- 25 October 2011

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Eleferios Kasiou	Brian Woods
Lyn Keehan	Doris Yum
Alan King-Gee	

## Celebration Donations

50th Wedding Anniversary  
Pat & Lionel Kremer  
Wedding of Michel & Karen Wagner  
60th Birthday Robyn Glover  
65th Birthday Winsome Ford  
65th Birthday Darla Daniel  
70th Birthday Bill Berman  
Marilyn's birthday  
Les Brenner's birthday

## Thank you to all our Unity Walk & Fun Run sponsors



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Everyone at Parkinson's NSW thanks all of our volunteers for their ongoing help. We also wish each and everyone one of you a very happy festive season. We look forward to new and exciting challenges in 2012!



Parkinson's NSW

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

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