

# STAND BY



**Parkinson's NSW  
celebrates our carers**

Parkinson's NSW Inc Newsletter. Issue 115, Autumn  
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## Cover Image

Sue and Phil Rance in their garden. Phil was diagnosed with Parkinson's at 46.

Sue volunteers one day a week at the Parkinson's NSW office.

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**For your local Support Group  
please call 1800 644 189**

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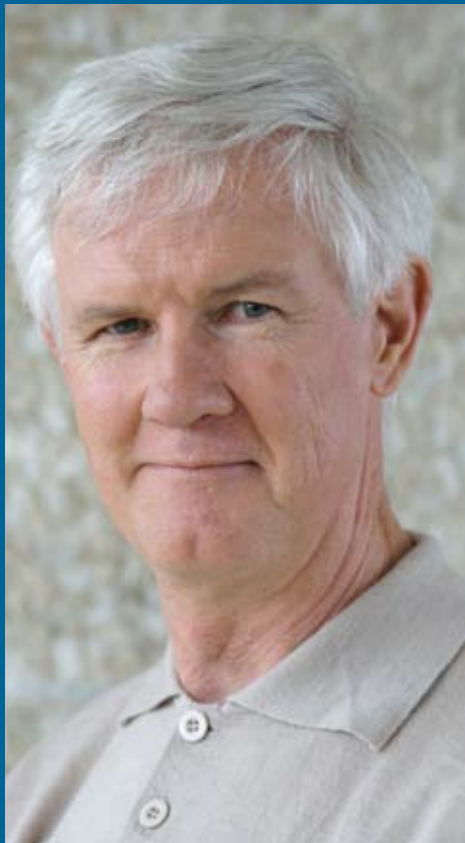
The team at Parkinson's NSW welcome your input. Please call us on the InfoLine 1800 644 189 email us, or send us a letter.

We hope to publish some of your thoughts and letters in the next issue of Stand by Me.

# Stand by me



# Spotlight on carers



## From the President

I am glad this issue of Stand By Me is dedicated to carers, since it is they who carry so much of the burden of Parkinson's disease (PD). On one hand, we must celebrate the fact that so many carers willingly take up the burden of long-term, unpaid, and sometimes thankless, work for PD sufferers.

On the other hand, my own impression is that the Person with Parkinson's (PWP) gradually focuses more and more on coping with the condition, to the exclusion of other facets of life. This leads to the carer (often a partner) having to provide all the needed support then, on top of that, to be pushed into the background to a degree by their PWP partner's preoccupation. That is not to lay blame on the PWP, since it does seem to be a factor for many diseases. The later stages of PD throw up many challenges, so it must soak up most of the PWPs' emotional and physical energy just to get through each day. I imagine the situation is worst for immediately life-threatening conditions, but the long-term nature of PD means an unrelenting pressure over many years; leading to the same sort of outcome. Having drawn attention to one of the problems facing carers, I wonder if we offer enough specifically for them. In my round of visits to Support Groups I have noticed that quite a few participants bring their carers along and that those carers are often very active in the Group. Each Group has its own

character, though, and my own, in Ultimo, has very few carers attending. Considering carers' needs, though, I am not sure that that everyone knows about respite services: these are available across NSW and can be a real lifesaver for all concerned. Our Infoline people, 1800 644 189, can advise on what's available. For carers who find the burden hard to shoulder, our Counsellors (same phone number) are available to talk through issues, over the phone; at our North Ryde office (and soon, once a week, at War Memorial Hospital in the Eastern Suburbs) or even on the internet. It would be very useful for us to know what particular needs or problems are top of mind for carers; what activities, facilities or services we should either be offering or advocating for. An email or a call to 1800 644 189 will help us redirect our efforts, if necessary, or even just to share an understanding about the carer experience. Our work of enabling people to live better with Parkinson's definitely includes carers, without whom most of us would be a lot worse off.

**Chris Davis**



# FROM THE CEO

Welcome to the first edition of Stand by Me for 2012. In this issue we focus on carers. The term “carer” normally refers to unpaid relatives or friends of a disabled or ill individual who help that person with some of their normal daily activities.

Of course a carer is often a husband, wife, parent or child of the person cared for, and it is important this relationship, such as a life time partner, continue to be recognised despite the addition of the new role of carer. I would love to hear your thoughts on carers, so please write or email me and I will try and include some of these in the next issue.

I am pleased the National Prescribing Service is producing a Parkinson's ‘passport’. A vital resource people diagnosed with Parkinson's can take with them when they go to hospital or other care facilities. The ‘passport’ will contain information about Parkinson's disease and relevant nursing best practice, specifically

the importance for medication to be always given at the correct dose and time. It will also provide details of medications to avoid. We hope it will be available by the middle of the year, and we will provide further information in Stand by Me.

I would like to welcome to the Board of Parkinson's NSW, Andrew Whitton and Colleen Canning. Andrew is a businessman who, with his team, has been the top fundraiser in recent Unity Walks. Colleen is an Associate Professor at Sydney University with a particular interest in exercise and falls prevention in Parkinson's disease.

A special mention and congratulations goes to board members Simon Lewis and Colleen Canning who are now Associate Professors.

I would also like to welcome two new staff members to our small team: Karina Traill, our new part time fundraising manager and Therese Carew assisting with our accounts and membership records.

Yours in Parkinson's Friendship

Miriam Dixon CEO

# On the groupvine

In this issue we acknowledge carers. Carers run half of our support groups and bring years of knowledge and skill from their experience with partners and family members. This gives them special understanding of the needs of new carers.

Many people with Parkinson's are also carers—for their partners, parents and children. As their Parkinson's progresses, the people they care for become their carers. Mutual carers: someone to remind you when tablets are due or to drive you to appointments.

Tamworth Support Group celebrated 20 years in December last year with visitors from Armidale, Bingara, Glen Innes, Gunnedah, Narrabri and Quirindi support groups. Congratulations to Tamworth Support Group on an amazing milestone! Pat and Allan Johnson from Tamworth Support Group are typical of mutual carers in our support groups.

In February, Parkinson's NSW staff visited support groups in Casino, Grafton and Ballina. Leaders from these groups with members of Coffs Harbour, Lismore, Tweed and Yama

gathered to hear Miriam Dixon talk about the Deloitte Access Economics Report and initiatives being pursued by PNSW. In Ballina, Deborah England outlined the counseling services. Four northern rivers groups are planning a social event as a result of this meeting. Deborah also ran training for two nursing homes and to HACC workers in the Lismore region. All groups appreciated the visit.

**“Visits provide us with a very real link to PNSW—it is easy to feel isolated by distance”.**

Gerri White, Leader of Ballina Support Group

continued over

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# THE MEDUSA CLUB

**T**he Medusa Club started late in 2010 as a social group for people diagnosed under 60 living on the Central Coast.

They may be small in numbers but they are big in imagination. Outings have included bistro pub lunches at East Gosford and Ourimbah, ten pin bowling at Bateau Bay, a ferry cruise to Palm Beach, country lunch at Jilliby and beach fishing at Ettalong.

Please contact Andy O'Shea on 0423 358 916 or Sharon Dale [spd2251@hotmail.com](mailto:spd2251@hotmail.com) for more information.

Good news for Deniliquin/Finley members. Cath McLean from Intereach Respite Care Program, has been coordinating a meeting for residents from Deniliquin, Finley, Moama and Echuca. Transport is supplied and the group meets on the 4th Wednesday of the month at 1pm at Deniliquin Neighbourhood Centre. A light snack, tea and coffee are provided. Contact Cath McLean: 03 5890 5200

**T**wo of our carers and support group leaders, in March, received awards for their services to people with Parkinson's.

Congratulations to Diana Rynkiewicz from Hornsby/Ku-ring-gai Support Group who was presented with 'A Gem of Ku-ring-gai' Award and Hazel Tolhurst, a 'Blue Mountains City Council 2012 Seniors Week Recognition Award' for her dedication and work with the Blue Mountains Support Group.

# PARKINSONG!

Every Tuesday evening, the Abraham Mott Hall in Millers Point, near The Rocks in Sydney, echoes to a mixture of choral singing and vocal exercises.

The group of 10 to 15 people with Parkinson's, including some of their carers, raises the roof—most unlike a typical, soft-spoken Parkinson's group.

Parkinsong! began late last year when Parkinson's NSW [PNSW] President Chris Davis was introduced to singer, teacher and choir leader Nadia Piave. Although she'd had no prior experience with Parkinson's, Nadia was quick to see the potential benefits of regular, vigorous exercising of the voice. Her energy and humour ensures maximum enjoyment for all.

The principles behind Parkinsong! are:

- The breathing associated with singing and declamation (speaking with a musical emphasis) provides valuable exercise for lungs

- The vocal activities strengthen the voice (through the improved respiratory effort)—important for people with Parkinson's.
- Singing gives a sense of wellbeing
- Getting out and mixing with other people is always good.

Although this first group only works for people who can get to Millers Point, there is nothing to prevent other Parkinsong! groups from emerging anywhere else across NSW. There are no auditions or attendance rules and the focus is on having fun.

Anyone interested in establishing a local group, please contact Chris Davis on [chris.davis@people.net.au](mailto:chris.davis@people.net.au) or phone PNSW's on 1800 644 189.

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**A** Happy New Year to all involved in working to improve the quality of life of people living with Parkinson's, their families and carers.

**FROM THE DESK OF THE NATIONAL CEO**

Parkinson's Australia has held its Annual General Meeting and elected a new National Board, including a new President, John Bird from Queensland. New Board members are Peter Raymond from Victoria and Paul Davies from South Australia.

The PA Annual Report for 2010/2011 is available on the website, [www.parkinsons.org.au](http://www.parkinsons.org.au) During December, we put a lot of work into developing and submitting a number of applications for Federal funding from the new flexible funding arrangements. We are now waiting for these applications to be considered.

The New Year sees us preparing advice for the

Medicare Locals about the benefits of employing Parkinson's Nurse Specialists as an integral part of their primary health care services.

Medicare Locals are the Federal Government's primary health care providers across Australia. There is clear evidence in Australia, and around the world, that specialist nursing provides significant benefits to people with Parkinson's, and to the health care system through more focussed services and reduced costs.

Daryl Smeaton  
CEO Parkinson's Australia

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Architect's impression of the Ipswich City Heart Building

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# UNITY WALK & FUN RUN

## Sunday 26 August 2012

This year marks the 5th Anniversary of Unity Walk and we are determined to make it our biggest and best.

Once again, we need you to help spread the word to family, friends and colleges, to help make it the success it has been in previous years. You can walk, run or both and again we have fabulous prizes for the top fundraisers and participants. While the event is about having fun, there is a more serious component—to raise funds for research and help support those affected by Parkinson's. This year we have added another exciting element:

a 4km run as well as the existing 8km run. There will be two websites this year. For walkers, [www.unitywalk.com.au](http://www.unitywalk.com.au) and runners, [www.unityrun.com.au](http://www.unityrun.com.au). The websites are linked, so hopefully we'll see you at the starting line for both events. The run website was launched on the 14 March and the walk site launches soon. This year we wanted to thank you for your generosity in fundraising, with additional prizes for individuals and teams. Participants of this year's run can expect some of the best prizes in the country for an event of this kind. We are hoping

to see every support group at the event in full numbers, and we will provide additional information and assistance so you can participate in the celebrations. So start spreading the news, Parkinson's Unity Walk and Run are on Sunday 26th August.



# The SHOALHAVEN PROJECT



Marilia Pereira

In February 2010, the Shoalhaven Project set out to assess the feasibility and impact of a community-based specialist nurse serving the needs of people living with Parkinson's.

Having polled their membership in 2008, Parkinson's NSW recognised that having 'help at hand' was the most important issue facing patients and their loved ones, who often take on the role of an informal (unpaid) carer. PNSW was inspired by the UK model operating for over twenty years and currently employing over 300 specialist Parkinson's nurses who conduct community visits, run hospital-based clinics and provide telephone advice.

In partnership with Parkinson's Australia and PNSW, the Commonwealth Government agreed to fund a two-year pilot project investigating the role of a Neurological Nurse Educator for the Shoalhaven region of NSW. This study was coordinated by Simon Lewis, Director of the PD Research Clinic at the University of Sydney's, Brain & Mind Research Institute. Simon had previously trained as a neurologist in the UK and was keen to see whether a specialist nurse could improve the lives of those people dealing daily with PD.

Preliminary results of this study, presented at the National Parkinson's Nurses' Conference on the Gold Coast in March 2012, revealed that family members perceived significant improvements in the health of their loved ones after they had enjoyed the services of the specialist nurse. In addition, informal carers — most frequently a spouse — reported they had noticed an improvement in their own health, with a significant reduction in their level of depression.

"These results are clearly very important," said Simon Lewis. "Often a patient's informal carer is the only

thing standing between them and the need for nursing home care. Nobody wants to be institutionalised, and improving the health of these guardian angels will hopefully keep patients in their own homes."

Unfortunately, the Federal Government has now discontinued its financial support in the Shoalhaven. However, through charitable donations and notably support from, Hospira, a private benefactor, and Bendigo Bank providing a car, the specialist nurse is still serving this community. Stephen Dennett, a patient receiving care from the nurse, explained "Our Parkinson's community nurse is now an indispensable part of my ongoing care and support. Particularly as my disease progresses, I need more and more support from medical professionals."

The Shoalhaven Project has been proudly championed in Canberra by Sen. Carol Brown who is the Convenor for the Parliamentary Friends of Parkinson's. In a speech to the Senate she said, "This model of innovation and personalised care embedded in the rural and regional communities is proving to be the way forward for dealing with these diseases in Australia". Indeed, over the course of the Shoalhaven Project, much effort has been made to expand the specialist nurse program and both Tasmania and the ACT have appointed nurses and social workers to meet this need. PNSW continues to lobby the state and Federal Governments and it is hoped that specialist PD nurses may one day be embedded in the primary health care model throughout Australia.



When beginning to write something for this edition of Stand By Me which has caring and carers as its focus, I am reminded of the many truly inspirational people I have met or spoken with during my time working as a counsellor for Parkinson's NSW.

Deborah England

I have had many conversations with folk who say they place their personal needs a poor second to the needs of the person for whom they care. As selfless and admirable as this is, it has a shadow side.

When a person is a carer for another they effectively become the 'lynchpin'. The well-being of the recipient of the care is very much tied to the carer being able to 'do' or facilitate what is necessary to ensure an optimal outcome for the person with Parkinson's. In this context self-care for the carer is not an act of selfishness but a necessary enterprise to keep things ticking along without anybody becoming depleted.

The art of nurturing oneself is seldom, if ever, taught in workplaces or in families. Yet it becomes absolutely essential for survival in an increasingly complex role. Nurturing oneself is often just allowing some time to stop, and in stopping being open to what is necessary for us at that time, be it a bit of respite or a cup of tea and a half hour relax. Recognising what would be helpful and then having a solution focus to achieve it can be a vital first step.

Please consider taking that step.

# Sue's story

Sue Rance

“When my husband Phil was diagnosed with Parkinson's at the age of 46, it was a tremendous shock. Our lives have changed in the past 15 years and are now different from what we had planned for our future.

We had envisioned a very active retirement with trips overseas, camping and bushwalking. As Phil's Parkinson's progressed, as his carer I had to make most of the decisions, trying to work out what were the best options for both of us. I also had to take on the more physical jobs at home, such as lawn mowing, gardening and dragging the bins up the front steps. It is also strenuous to assist your husband with washing, and

dressing needing bending and twisting. I have made it a practice to keep myself as healthy as possible, by going to the gym, doing Pilates and visiting the osteopath. I'm also aware I need to make time to do my own things, coffee or shopping with girlfriends, visiting the hairdresser and regular sessions with my counsellor. These outings keep me balanced and a much nicer person to be with. A sense of humour is a must for carers!!

Parkinson's NSW support has been extremely valuable and has assisted us in having a better quality of life, as well as hope for the future. The InfoLine was invaluable during stressful times with Phil. I was able to chat, get information, and touch base. It was a relief to know support was a phone call away. I don't know how I would have coped without this support. I enjoy volunteering in the Parkinson's Office every Tuesday. Its one day a week for a



few hours when I am not a carer. I'd like to thank the staff at Parkinson's NSW for the huge positive impact they have had on my life. It gives me a great sense of what selfless giving is to know that Parkinson's NSW services are funded by donations and bequests from wonderful people who I will most probably never meet. It is this sense of kindness and the support that I've received that lead me to leave a bequest to Parkinson's NSW when I made my will. As I want to make sure others have the same opportunities and support that I have had.

If you or any member of your family are considering leaving a gift to Parkinson's NSW, please feel free to contact our bequest officer for information. It would be an honour to welcome you into the James Parkinson Society. Isabelle Clark Bequest Officer.

e: [isabelle@parkinsonsnsw.org.au](mailto:isabelle@parkinsonsnsw.org.au)  
or 0403 324 486.



# In Memorium donations

26 October 2011 - 4 April, 2012

Harold Allsopp  
David Armstrong  
Roy Ashton  
Robert Beecroft  
Allan Bible  
Norman Binskin  
Elma Boyd  
Libby Boydell  
Geoffrey Bradford  
John Braid  
George Brown  
Graham Brown  
Hazel Brown  
Phyllis Byrn  
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Dorothy Crossingham  
Bernard Danks  
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Peter Hayden  
Bruce King  
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Anna Maria Landi  
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Phillip Lee  
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Dr Casimir Motyka  
Vernon Newman  
Basile Nicolis  
Janice O'Neill  
Kevin Peattie  
Ronald Pickford  
Gwen Pittard  
(Hazel) Sylvia Porter  
Lorraine Quigley  
Thelma Rice  
Kevin Rochfort  
Leonard Rynkiewicz  
John Sanderson  
Jack Sedwell  
Carmel Stapleton  
Hazel Stirling  
Patricia Stokoe

John Taylor  
Nicholi Tokmakoff  
John Vardas  
Edward Wilson  
Terry Zadro

## Celebration Donations

60th Birthday of Dorothy Elder  
60th Birthday of Tass Karios  
70th Birthday of Roger Malouf  
70th Birthday of Heather Aronson  
70th Birthday of Juan Placencia  
80th Birthday of Bruce Cook  
Wedding of Len & En-Qi Resnekov  
50th Wedding Anniversary of  
Judith & Ken Sawyer

## MUSCLE POWER TRAINING IN PARKINSON'S DISEASE

Volunteers with Parkinson's disease needed for a research study aimed at improving leg muscle power. The study will determine the effect of a fully supervised exercise program at the University versus an independent home exercise program.

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

This study is being conducted by a team of researchers at the University of Sydney, led by Associate Prof. Colleen Canning.

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

**Ms Serene Paul**

p: 9351 9435 or 0405 303 102  
e: serene.paul@sydney.edu.au

**Associate Prof. Colleen Canning**

p: 9351 9263  
e: colleen.canning@sydney.edu.au



Join our team on 12 August in Sydney's favourite 14k and make fundraising the focus of your challenge. We have ten Gold Entries available in the City2Surf and are looking for committed fundraisers to be a part of our team.

By taking one of our Gold spots you'll start ahead of the pack (just after the red start). Whether you're a novice or an experienced runner you can make every step count and help us to make a difference.

We're hoping to raise \$20,000 in vital funds for research and support services for those living with Parkinson's.

Apply now to be a part of our team.

## TELL US MORE

We want to know more about what you would like to read in Stand by Me.

Do you like to read about what we are doing, or some more about current research? More about current treatments or new research? Please fill in the enclosed survey and mail it back in the postage paid envelope. We value your feedback.

Thank you.

## Change Your Focus

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# WHAT'S ON

10

MAY  
PNSW Coffee Morning

30 &  
31

MAY  
Newly Diagnosed  
Program

13-14

JULY  
Parkinson's Australia National Conference  
Brisbane

Please call the InfoLine  
to RSVP for events.

Places are limited for some  
event, so confirm your place  
early.

9

AUGUST  
PNSW Coffee Morning

26

AUGUST  
Unity Walk & Fun Run

29

AUGUST  
Allied Forces Seminar  
(Health Professionals Only)

5

SEPTEMBER  
Parkinson's NSW  
Awareness Seminar  
(places limited)

15

NOVEMBER  
PNSW Golf Classic

13

NOVEMBER  
Parkinson's NSW  
Annual General  
Meeting

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## Disclaimer

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