



WELCOME

Welcome to the second issue of the 'Park It Here' newsletter for Parkinson's support Group leaders and their members.

While contributions from our President, Mr. Chris Davis, and our CEO, Ms Miriam Dixon, are missing from this issue, they will be returning in forthcoming editions.

Mr. Davis is on annual leave and Ms Dixon is preparing an in-depth report on Parkinson's Awareness Week.

Consequently, this issue features more stories about, and reports from, the Support Groups who have responded to my request to supply details and photographs of their local initiatives and successes.

I am grateful to the featured Support Groups for their energetic and engaging contributions. I also welcome your feedback on our first issue. This enterprise is an evolutionary one and it is your responses that will serve to make it more effective as a voice for Parkinson's NSW and its Support Group Network.

Antoinette Riley
Support Group Coordinator

Snow and Ice Ball

On August 9, the Cooma Community Chest organization staged a Snow and Ice Ball; taking the initial step toward regenerating an annual ball for this region.

Some 80 people, including people with Parkinson's and their supporters attended this function at the Cooma Services Centre. I was present both to represent Parkinson's NSW and to accept a generous donation to our cause.

Sharyn Crockett, the convenor of the Snowy / Monaro Parkinson's Support Group, reported that the event was well publicized in the local press and that she was able to do further valuable promotion for Parkinson's via an interview on regional ABC radio. Sharyn, also a noted linen collector, remains a driving force for Parkinson's Support in this area.

Antoinette



L-R: Ella Stewart and Antoinette Riley



L-R: Marilynne Weston, Beaty Russell, Ella Stewart



Cooma Services Cub

Coffs Harbour Support Group

The Coffs Harbour Parkinson's Support Group has been very active of late. First, it participated by manning an information booth at the Coffs Harbour Living Well Aged Expo on Wednesday, August 20; and, second, it donated nine new Parkinson's - related books to the local library.

Jane Gow reported that the Expo involvement proved worthwhile; particularly in raising awareness of Parkinson's among the general population. She also spoke proudly of the book donation, noting that the texts concerned dealt with the multi-faceted aspects of Parkinson's care ranging from nutritional needs through to best practice in treatment and ongoing care.

Congratulations Coffs' members on your proactive contribution to the promotion of Parkinson's awareness and its latest treatment regimes.

Antoinette



L-R Library Manager Enzo Accadia, Vera Heil, Team Leader Catherine Johnston and, Jane Gow.

WALK WITH ME

Walk a little way with me
Let me guide you on the road
If the burden seem too much
Let me take the load
For here beside you I will be
No matter what may come
Let's walk forward side by side
To the sound of a distant drum
If you tire, lean on me
And we will face this thing as one
Let's just take it day by day
Until the journey's done
So let me be your guiding star
I will light your way
And every morning when we wake
I'll give thanks for another day
Let's not waste a second
Worrying about what's ahead
Each moment is a precious gift
Let us live it to the full instead
I watch the sunlight fill the world
I see a new day unfold
Let's set forth together
To see what this day may hold

Byran McAlister (Blacktown Support Group)

Unity Walk & Run

Your wonderful support has helped us to ensure that the 7th Annual Parkinson's NSW Unity Walk & Run held on Sunday August 31st was a huge success.

Total attendance was at a record 2130, with more runners and walkers participating than in previous years. To date we have raised just over \$150,000.

Thank you to all of the support groups for their hard work in the lead up to the event in raising awareness and vital funds for research and support services.



A PARKIES POEM

It is in the wee small hours of the morning
that the nagging doubts appear
in the darkest hours before the dawning
when I try to face my deepest fear
Those restless times when I toss and turn
and can't find sleep no matter what
when my strength seems to be at its lowest ebb
wondering what the hell is this thing I've got
Those thoughts that I keep to myself alone
should I just give in and to hell with it all
will my loved ones still be there
when I stumble and fall
Will I have the strength to endure,
how will I end up, why did it pick me
and I try to make sense of it all
asking for answers where none seem to be
I can keep busy during the day
Telling myself these dark thoughts should not exist
and I do my best to push them away
knowing that no matter what, I must persist
During the daylight hours I battle through
Telling my fears that I am strong enough
Doing everything that I can do
But wondering inside if it's all a bluff
It is a Parkies Battle that we fight every day
to try and keep these demons at bay
and as the sun comes up and a new day dawns
I know I'll try, come what may.

Byran McAlister (Blacktown Support Group)

IN MEMORIAM

Hugh McLean was a great supporter of Parkinson's NSW. Following his 1985 diagnosis, Hugh and his wife, Marie, founded the Shoalhaven Parkinson's Support (the "Shoalhaven Shakers") for people with Parkinson's and their carers.

The first meetings were held at the Shoalhaven Hospital and, later on, at the Nowra Masonic Hall. In 2006, the membership numbered 119 making it the biggest regional Parkinson's Support Group in NSW. Hugh had Deep Brain Stimulation (DBS) about 10 years ago and, over the past few years, began suffering other health issues and complications.

Hugh, a caring gentle man; was admired by many. He will be sadly missed. RIP Hugh McLean (died August 22, 2014.)

- Barry and Irene Mitchell
Shoalhaven / Ulladulla Support Group

Community Seminar at Albury - Wodonga

On July 29, some 200 people attended an information seminar staged by the Albury – Wodonga Parkinson's Support Group and supported by Parkinson's Victoria.

The Seminar, which featured presentations by Dr. Richard Peppard (Movement Disorder Neurologist) and Victor McConvey (Parkinson's Specialist Nurse Consultant) had two main objectives: first, to provide an updated overview of Parkinson's; and, second, to supply the latest information about best practice in Parkinson's treatment and care.

Alys Cummings, the Speech Pathologist with the Rural Allied Health Team's Transition Care program, reported that the Seminar's audience, which was evenly distributed between NSW and Victoria, thoroughly enjoyed the experience, including those who had journeyed from as far afield as Corryong, Wangaratta and Porepunkah.

Congratulations to all involved for the planning and implementation of this innovative event. Besides earning valuable columns in the local press, it has already led to local enquiries.

Antoinette

REMINDER



THURSDAY 13 NOVEMBER

To register call InfoLine on 1800 644 189 or visit
<http://pnswgolfclassic.gofundraise.com.au/>

EASING THE IMPACTS OF PARKINSON'S DISEASE.

On August 8, the Hawkesbury Parkinson's Support Group held an all day conference at the Windsor library; focusing on methods to ease the effects of Parkinson's. The conference was a success due primarily to its five presenters, who provided knowledgeable research data and methodology for the 66 PwP and carers who attended.

The Parkinson's NSW C.E.O., Miriam Dixon, enthusiastically opened the conference. She introduced Simon Lewis, Associate Professor in Cognitive Neuroscience, who emphasized the increasing medical cost of PD. He noted that, presently, it is second only to cancer-related spending and is projected to increase substantially in the foreseeable future. Simon went on to argue the case that the proactive provision of more qualified neurological nurses would serve to mitigate a significant amount of these costs. Following this, Associate Professor Colleen Canning spoke about the positive benefits of physical activity and exercise at all stages of PD. Her soon-to-be-released research paper provides extensive data to support this contention.

Next, Melissa McConaghy, a Parkinson's Specialist Physiotherapist, and founder of PDWarrior, demonstrated the benefits of her 12 week program for PwP: including showing a video about the reversal of limited physical mobility and how it could lead to a possible reduction in medication.

The next speaker, Speech Pathologist, Colleen Kerr, spoke about alleviating speech and swallowing problems through specific jaw and throat exercises and care education. Her Speech Pathologists' service treats sufferers at home or in care facilities and teaches nurses the correct treatment processes.

Finally, Jeannette Harvey, a Music Therapist, demonstrated how singing and humming could provide a 'feel good' adjunct to Speech Pathology. Jeannette had us all practising warm-up throat exercises prior to a spirited humming and singing session. All in all, the conference was a great success and provided a model for future initiatives in this crucial area of PD care. Congratulations to our small but valiant committee and our wonderful speakers.

Thank you
Russell Endicott. Hawkesbury Support Group.



L-R Assoc. Professor Simon Lewis, Cognitive Neuroscience Specialist; Assoc. Prof. Colleen Canning; Ms Melissa McConaghy PDWarrior Specialist Physiotherapist; Ms Colleen Kerr, Speech Pathologist; Ms Jeannette Harvey, Music Therapist

FORTHCOMING EVENTS CALENDAR

- 22nd October Allied Forces Approach – "The War on Parkinson's " a full day seminar for Health Care Professionals only
- 30th October Newly Diagnosed with Parkinson's Program 10 a.m. – 4p.m at the Vincent Fairfax Dementia House. RSVP via email or InfoLine 1800 644 189
- 13th November 8th Annual Parkinson's NSW Golf Classic at Monash Country Club, Ingleside. RSVP – InfoLine 1800 644 189 or via email pnswn@parkinsonsnsw.org.au