

TULIP TALKS

Parkinson's Wellington's Local Newsletter

A message to you from Peter Garelja Chairperson of Northland Action Group about UPBEAT 2019

Kia ora

In Northland, we are feeling very upbeat about our experience in hosting the recent UPBEAT weekend. We have sent this letter out to all other action groups to encourage them to seriously consider the benefits of hosting an UPBEAT weekend. We wanted an opportunity to test out our capability as an action group; to challenge the assumption that being part of a national organisation meant that power was now centrally based in Wellington. We very much hold the view that the relationship between the action groups and national office is one of partnership and collaboration. I had attended the previous UPBEAT weekend held in Hamilton in 2017. I enjoyed the experience and, following discussion with fellow Northland members, we believed that we should lobby for Northland to host the next UPBEAT weekend. We did so for several reasons:

To improve access for our members, to energise us as an Action Group, to attract and recruit new members, to raise the awareness of the latest research findings into Parkinson's in the local community and to showcase our place and share what it means to us.

We interpreted our core value as being manaakitanga (hospitality). This manifested itself in the following ways:

SELECTION OF VENUE

We were approached by Parkinson's NZ to select the most suitable accommodation venue.

WELCOME: Reflecting the bi-cultural foundation of NZ, the welcome took place in the form of a mihi whakatau (shorter version of a powhiri). The welcoming group consisted of representatives from the Pehiaweri Marae, the Mayor and the Action Group. Members of the Action Group put together a "goodies" bag for each participant. They also wore brightly coloured Parkinson's NZ t-shirts identifying them as guides who could be approached for assistance.

EXCURSIONS: We used local knowledge to offer the choice of any one of three different walks to cater for the range of interests and capabilities. Action group members acted as guides.

PROGRAMME OF SPEAKERS: This was largely arranged through national office, but input was sought concerning any interesting locally-based research.

ADMINISTRATION: All done by National Office.

E TANGATA, E TANGATA, E TANGATA

While the speakers and their presentations were all highly informative, the reality is that someone could stay at home and watch similar presentations on youtube. The real strength of the UPBEAT weekend was the opportunity it provided for those with early-onset Parkinson's (and their carers) to share their experiences, face to face, with others in similarly challenging situations.

Overall, the action group has the responsibility for creating and fostering an UPBEAT experience, unique to that location, yet still with, at its heart, a growing sense of humanity based on understanding, empowerment, hope, compassion and resiliency.

Before, this starts to read too much like an infomercial (complete with a set of steak knives to be thrown in), I should conclude by stating that the UPBEAT weekend provides the very heartbeat necessary for this organisation to thrive; local and national interest working together for the common good.

In Northland, we found hosting the UPBEAT weekend to be an invigorating experience; one which, over the years, we hope will be shared by other action groups.

Warm wishes, Peter



A word from your Action Group Chair

As I write this we are gearing up for a movie fundraiser to be held at the Penthouse cinema in Brooklyn, which we hope will attract lots of people, especially members and friends in the city.

In July I attended the mid-winter lunch at 'Zealandia' in Karori with members from the city group. It was good to see two new faces in this group. We encourage people to check their newsletter for dates of meetings and exercise classes and other activities, and to come and try them out if you haven't been before. 'Soundswell', the singing group held at St John's in Johnsonville is a great way to exercise your voice, and most enjoyable.

Meantime, our main focus now is to prepare for the annual appeal in November. We are working to establish co-ordinators for each venue and to gather as many collectors as possible to give an hour or two to collect. We know some members may not be able to collect themselves, but what about asking family and friends? No harm in asking. Then put them in touch. You will receive contact details for co-ordinators in your area.

Philippa Barker.

WOULD YOU LIKE TO TAKE PART IN PARKINSON'S RESEARCH?

IF YOU EXPERIENCE A LOSS OF FACIAL MOVEMENT WE INVITE YOU TO TAKE PART. WE ALSO INVITE SIGNIFICANT OTHERS TO BE INVOLVED (SPOUSE, FRIENDS OR WHĀNAU).

Study Details: Hypomimia, also known as 'facial masking', refers to a loss of facial movement and expression. It can make a person look cross, sad, blank, or as if they are staring. People with this symptom may also find it more difficult to smile.

Facial masking is a characteristic sign of Parkinson's disease, yet is not always well-known to people with the condition and their families. We aim to develop resources to help people better understand and manage facial masking. This is important because very few resources exist to help people with this symptom, or to guide health professionals in helping those people and their families.

What will I have to do?

Complete a series of short questionnaires. Have a short conversation with the researcher. This is video recorded (optional).

When and where?

The study takes 1-2 hours in total. The researcher will travel to you (e.g. your home or workplace).

Appointments available in Wellington & the Kāptiti Coast over July- September 2019.

For more information:

Please contact Adrienne Wootton on: aw107@students.waikato.ac.nz or phone: 0204 727 546

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This study has received approval from The University of Waikato Human Research Ethics Committee (ref 2018#46).



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A word from your Community Educators

Hello everyone

Time is racing by with Diane and I as busy as ever. We have just had our Community Educator Conference held over three days in August in Wellington. Both Diane and I enjoyed spending time with our wonderful team as well as being able to increase our knowledge about Parkinson's, which will help us in our work. Our Lower Hutt Members Support meetings are coming to a close at the end of September (no meeting Labour Day) and we have already emailed our Xmas lunch menu for your reading pleasure.

Looking back for a moment we have had some awesome meetings at Knox Church

In April

We watched Professor Simon Lewis speak about "What's in the Pipeline for Parkinsons" ...this proved a hot topic with 43 folk in attendance. If you missed this talk you can find it on UTUBE if you search Professor Simon Lewis all his presentations will come up. The talk is around 45 mins.

In July

It was an absolute pleasure to welcome Clive Cannons Pharmacist from Wainuiomata. Clive is so passionate about what most of us hate... PILLS! Importantly, he explained how pills know where to go in your body...he makes pharmacy so easy to understand...As well, he spoke about the drugs we use to treat Parkinson's and how to take medication to get maximum effect. Clive very kindly answered individual questions at the end which everyone appreciated. A hand out is available for those who couldn't make it-please ask Andrea.

In August

We hosted Samantha Read Speech Language Therapist HVDHB talking about Communication in Parkinson's and why early referral is a must!

Coming up In September

On the social front our PAG is holding a Film Fundraiser in Brooklyn. These evenings are forever popular so mark your diary NOW!- Thursday 12 September. An email will be circulated.

In October

Finally in October Diane and I will present our "Newly Diagnosed" over 5 weeks. All Newly Diagnosed clients will receive an invitation in due course. This event is always full so register your interest early.

Do enjoy the change of season...Spring is in the air!

Roll on the lambs...

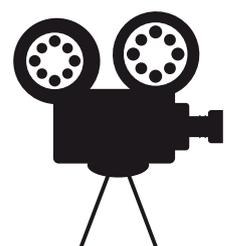
Warmest wishes, Andrea.

In May

We continued our Simon Lewis experience by viewing again, this time "Living with Parkinson's: A survivors guide" This was an easy and informative talk and resulted in a number of members requesting referrals to other services.

In June

We hosted Penny Warren Music Therapist from Soundswell Choir and it was obvious by the turnout, that singing is indeed a polarising activity much like dancing- You either love it or not!



Wellington Groups and Meetings

Wellington Support Group - Fourth Monday of the month at 10:30am

Malvina Major Retirement Village, Burma Room, 134 Burma Rd, Johnsonville, Wellington.

Dates: 23 Sept, 28 October

Northern Support Group - Second Monday bimonthly at 1:00pm

Plimmerton Croquet Club Rooms

1 Plimmerton Drive, Plimmerton

Dates: 9 September

Wellington Southern Suburbs Support Group - Second

Wed of the month at 11:00am

Rita Angus Retirement Village, Family Room ground floor, 66 Coutts St, Kilbirnie.

Dates: 11 Sept, 10 October

Wellington Carers Support Group - Second Thursday of the month at 11:00am

One Fat Bird, Marsden Village, Karori

Dates: 12 Sept, 10 October

Wellington Exercise Group - Every Wed during term time from 1:30 – 2:30pm

Room 3, Karori Community Centre, 7 Beauchamp St, Karori

Dates: Term 3 begins 16 Oct – 12 Dec

Counterpunch for Parkinson's - Starting again in 2019

Please contact Kathy McConville 021 256 1005 if you are interested and want more information

DaNZability Dance Classes - Every Friday from 10:30 – 11:30am

Main Lounge, Porirua Club, 1 Lodge Place, Porirua

Koha appreciated to cover costs

Contact Rachel physio.rachel.horwell@gmail.com

022 077 2654 or Brian 04 2323152

Sounds Well Choir - Every Friday, 10:30 – 12:00 noon

Cost \$10.00

St John's Church Hall, 18 Bassett Rd, Johnsonville. Free

Parking. Caregivers are welcome to join at no charge

New members please contact Megan 021 105 5056 or

Penny 027 471 0430

Therapeutic Tango

Please contact Cheryl Cameron 027 244 8560 or 04 233 1009

or Ian Jenkins 029 778 4728 or 04 233 1225

Newly Diagnosed Course - Every Wednesday in October

from 7pm - 9pm at Petone Community House, 6 Britannia St, Petone.

Dates: 2, 9, 16, 23, 30 October

If you have been diagnosed in the last 2 years and wish to attend, please contact either Diane or Andrea

Hutt Groups and Meetings

Members Support: 4th Monday every month (except Oct/Nov/Dec/Jan)

Knox Church 574 High Street Lower Hutt

Gold coin for tea and coffee

Time: 10:30am -11:30am

For people with Parkinson's and their care partners

All welcome - free parking with excellent access

Carer Support: Once a month on Wednesdays

Garden Lounge, Shona McFarlane Retirement Village

All welcome - free tea and coffee

Please contact Andrea for dates

Facilitated by Andrea Savage Parkinson's Community

Educator Ph: 566 0401

Exercise: Fridays each week through 2019

YMCA Somme Road, Trentham

Cost: \$3.00

Time: 11am-12 noon - please bring a drink with you

Last Friday each month there is a shared lunch. Please

bring a plate

All welcome, Partners/Carers welcome too

Nordic Walking: Urgent - do we have enough people for this group? Please contact Andrea

Mondays

Venue: Avalon Park carpark by Pavilion

Cost: \$5.00

Please bring a sunhat / sunscreen /a drink/ poles provided

All welcome - instruction on technique will be given to new walkers

If you are interested in this group please call Andrea on

566 0401

Ladies Coffee - once a month on Saturdays

Ladies with Parkinson's Coffee Group

Contact Andrea for 2019 dates

Venue: Boulcott Heritage Farm Golf Club Military Road

Lower Hutt

All welcome - bring money for tea, coffee and cake

Pls call Andrea if you are interested in this group

566 0401

Loud Crowd

By invitation for those that have completed LSVT

Every third Thursday of the month in Flo's room Hutt

Hospital.

Facilitated by Louise McHutchison SLT and Andrea Savage

Parkinson's Community Educator Hutt Valley.

Cost: FREE

**Thanks to our
recent funders**

COGS
Community Organisation
Grants Scheme