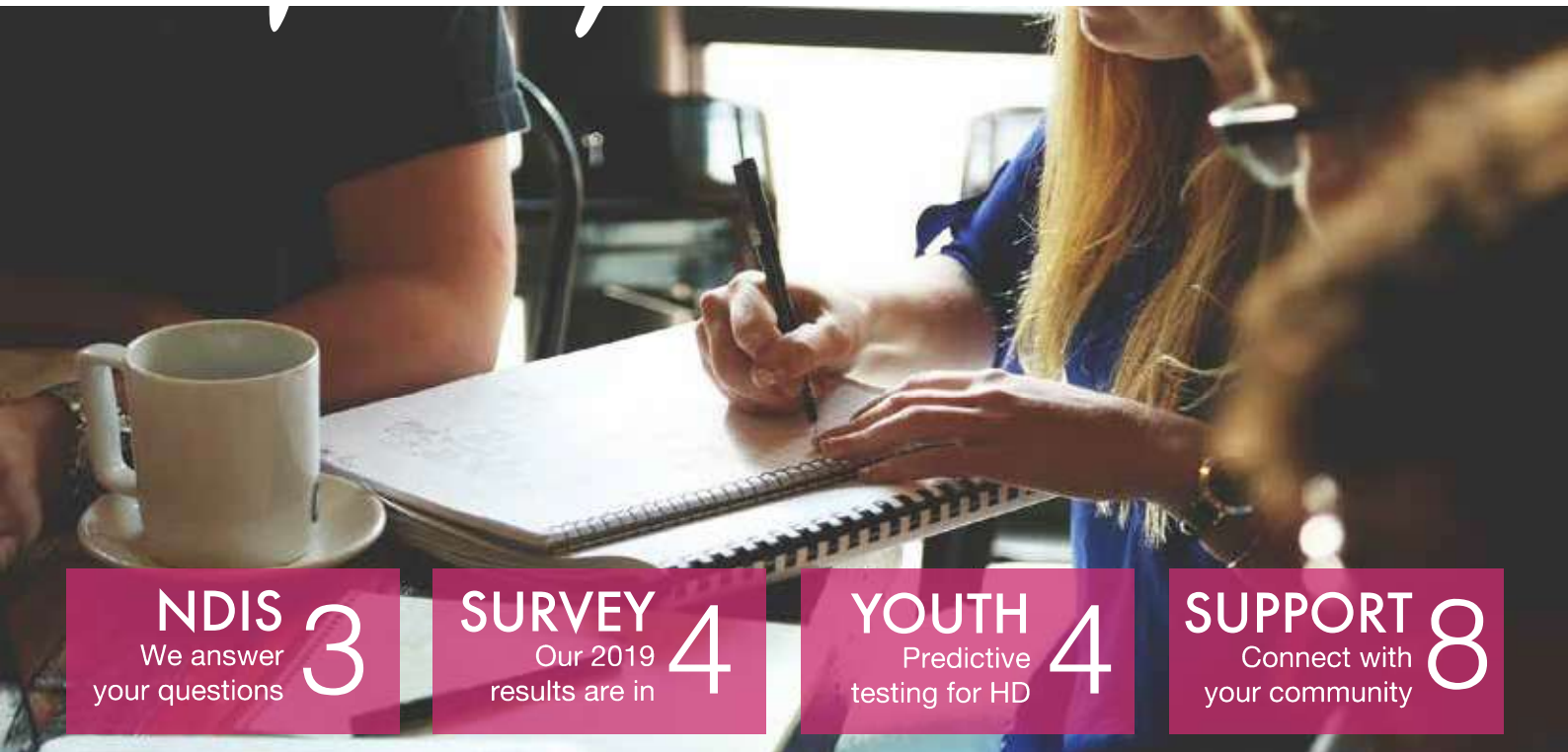


HD News

SPRING
2019



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NDIS SUPPORT COORDINATION HAS ARRIVED

Huntington's NSW ACT announces an exciting new development in NDIS support **WORDS** GISELLE BEAUMONT

AS HUNTINGTON'S NSW ACT new senior support coordinator, I am excited to be on board, and looking forward to getting to know both the Huntington's Association and community.

A little about me: I am a qualified social worker passionate about social justice and equality. I have been working in the community sector for

ten years. Since the NDIS started in Western Sydney in 2016, I have been providing support coordination to people with complex needs including mental health, homelessness, and people with neurodegenerative disease. Being able to support individuals with a disability to enable them to live the best possible life is without doubt an incentive for me. My role at Huntington's NSW ACT will be working with NDIS participants, along with their family and carers. Support coordination is a very important part of a Huntington's person's NDIS plan. Why? Because support coordinators are there to listen, walk alongside you to achieve your goals,

assisting you to navigate the NDIS system and to implement your plan.

Some of the things I will do for you as a support coordinator:

- Help with navigating and understanding the NDIS system
- Pre-planning for NDIS planning meetings
- Plan reviews
- Coordinating funded supports, as well as mainstream and community supports.

My job will be to ensure that you are central to all decision-making process-

“One great thing about our support coordination service is that we are exclusive to people with Huntington's disease...”

...CONTINUED PAGE 3



FROM THE DESK

Lewis Kaplan

LEWIS KAPLAN, CEO Huntington's NSW & ACT

IT FEELS AS though the last newsletter has only just been printed and yet here we are writing the next one.

ASSOCIATION FUNDING

As you will see from our annual report to be released in November, we ran a substantial deficit of over \$100,000 in 2018-19 and, while this was largely planned, we must do all we can to turn that around this year. Fundraising is a never-ending (but certainly not a thankless) task, and I give heartfelt thanks to all of you who contribute in any way to the Association's financial well-being.

Our advocacy campaign for more funding for Huntington's disease support services is building up. We have made a formal submission to ACT Health and hope our members there will write/phone/email/meet their local parliamentarians to support our

pitch with their stories.

We have also decided to apply to NSW Health for funding for our regional Support Group Program and our Youth Connection Program as well as seeking an increase in our basic grant (currently \$62,000 p.a. and much less than most of our interstate counterparts).

ADVOCACY

We have a growing list of advocacy issues:

Aged Care – submission to the Royal Commission
Disability Care – submission to the Royal Commission
Specialist Disability Accommodation for people with HD
People with HD in the correctional services system
Genetic testing waiting times in NSW

The best government advocacy involves people in the community contacting their local member of parliament to tell their personal stories, while the Association provides facts and figures in more formal submissions. Ideally, we will get media interest as well to help promote our cause.

If you are interested in contributing stories or engaging with us in advo-

cating on any of these issues, or you have other issues you want us to consider, please contact me (see back page for details).

COMMUNITY SURVEY

Surveys were completed by 155 people. Many thanks to all who contributed. See the report on page 4.

GOVERNANCE

The Board has recently appointed two new members, Craig Dalli and Stephen Garrard. They both have a family history of Huntington's disease, and by chance both work in local government. They along with the other Board Directors will be up for re-election at the AGM. If you wish to nominate for the Board, please contact me for a nomination form which must be returned before 14 November.

Enclosed with this newsletter is the Notice of Annual General Meeting to Members. We are aiming to run this by videoconference (as well as in person of course) so that regional and country members can attend without having to travel to Sydney.

Best wishes and happy walking in the forthcoming Walks 4 Hope.

Email Lewis on:

lewis.kaplan@huntingtonsnsw.org.au

NEW CARER REGIONAL SUPPORT PROGRAMME



ON 21 AUGUST, Senator Anne Ruston launched (<https://ministers.dss.gov.au/media-releases/5096>) the new Regional Carer

Gateway initiative. This is the policy change that forced an end to our ability to employ a Regional Support worker.

Regional Carer Gateway was designed in collaboration with carers and aims to:

'get the support [carers] need early, before reaching crisis points'
increase funding for respite
'deliver a suite of support services on a more geo-

graphically equitable basis which will be easier to navigate and less fragmented'

Carers now have access to free phone counselling, self-guided coaching and online skills courses, through the Carer Gateway - <https://www.carergateway.gov.au/>.

Does this programme meet the needs of our regional carers? Tell us what you think by emailing info@huntingtonsnsw.org.au. ■

...CONTINUED FROM PAGE 1

es so that you can exercise your rights about choice and control.

Huntington's NSW ACT understands that not everyone will wish to receive support coordination from us. However, if you are unhappy with your existing service provider and would like to receive support coordination from us, I will assist you with this process.

One great thing about our support coordination service is that we are exclusive to people with Huntington's disease. This means our support coordinators understand the impact of Huntington's disease on individuals and families.

At this stage Huntington's NSW ACT is taking small steps to provide support coordination. We are currently working with clients in the Sydney metropolitan area. We plan to hire further support coordinators soon, to increase our reach to the Blue Mountains, Illawarra and Central Coast.

FOR REFERRALS

Simply call Huntington's NSW ACT or ask your local NDIS planner or Local Area Coordinator (LAC) to request Huntington's NSW ACT for coordination of support. ■



NDIS Questions

I HAVE BEEN ASKED
TO ANSWER YOUR
QUESTIONS. THIS IS A
COMMON ONE. **WORDS**
GIZELLE BEAUMONT

Q I'm a carer and I need a break. Carer respite is not covered in the NDIS. What words do I need to use when talking to the NDIS planner so that I can get some respite to help me to continue my caring role.

A THE RIGHT WORDING Ensure respite support is built into the first NDIS plan. If respite was in place before the NDIS, it is important to document who was providing respite, for how long, and the reason it was needed. This will ensure respite continues.

Most people know the word 'respite'. In the NDIS world, using other words like 'short term accommodation and assistance', 'assist with self-care overnight' and assistance in living arrangements, will make the request more specific.

IT'S ALL ABOUT EVIDENCE

You can ask your NDIS support coordinator to attend the planning meeting. It is most important to have evidence why you are requiring respite. This can come from an occupational therapist, GP, specialist etc. Also, attaching a personal statement from you will assist. The 2018 NDIS price guide states that participants can receive 24-hour care for up to 14 days at a time. The key for respite is the supporting evidence from the doctor; does it fit with the NDIS as being reasonable and necessary? Also, it depends on

your caring role and the level of care you provide as an informal support.

Another important aspect of your caring role is to attend a range of activities to assist you to maintain your caring role that relate to you as a carer. These forms of support are "capacity building" activities.

When writing your carer's statement, ensure you highlight that you are caring for someone full-time and require support because of behaviours, on-going medical support supervision, poor sleep patterns etc. Please refer to My Life with HD NDIS series – Pre-planning workbook page Carer statement.

Please contact me at Huntington's NSW ACT for a copy or download it from here: https://www.huntingtonsnsw.org.au/sites/default/files/NDIS%20Planning_updated.pdf

WHO CAN ASSIST YOU

My advice is to start seeing your GP on a regular basis if not doing so already. The NDIS will look at your role as the informal support person, and they need to know what that looks like from your perspective. You can ask your doctor to write a letter to support your claim for the need for respite and the reasons why.

If the needs of the participant have changed, then it is important to submit a change of circumstance form along with a request for an unscheduled plan review. Your support coordinator can assist with these two forms. ■



Many thanks to the 155 people who completed our recent community survey, either from the last newsletter or from our Facebook page. **WORDS** LEWIS KAPLAN

THE MAJORITY OF YOU are a family member of and/or caring for someone with Huntington's, but we also had responses from younger people at risk, or who have tested positive, with slightly more from people who have tested negative, and from some people who are currently symptomatic. Plus a few friends, health professionals

extremely important). The other two information activities: providing information about HD and providing information about caring for someone with HD were also extremely important for around 65% of you.

These responses will help guide our new strategic plan which we should be able to outline in our next newsletter.

There was a solid mix of views about how we should communicate with you, which means that we will continue to use multiple channels, and the hard copy newsletter will not be retired (as many organisations are doing).

Many people were interested in our newly launched NDIS support coordination service. If you provided your contact details, we will be in touch.

Your comments, criticisms and compliments have been carefully read and shared across the Association's Board and staff.

Thank you so much to all who took the trouble to fill out the survey. It's important that we continue seek and respond to your views and concerns. Please don't hesitate to contact me or other staff members with your issues and we'll do our best to respond to them. ■

Your comments, criticisms and compliments have been carefully read and shared across the Association's Board and staff.

and four people with no immediate involvement or contact.

You were consistent in your desires for what your Association should be doing: most important to over 80% of you was lobbying governments for better health, disability and aged care services (advocacy). The second most important was educating health care professionals about HD. Third was providing information about accessing health services for HD (over 70% of you marked this as

YOUTH SPACE *Testing*



Predictive testing for Huntington's disease: a big decision for young people. **WORDS** AMY HALE

AT HUNTINGTON'S YOUTH Connection we help kids, young people, and their families discuss HD. We also support and educate kids and young people about what having HD in their lives means for them as individuals.

As the youth social worker, one topic I encounter all the time is genetic testing and the decision a lot of young people face – should I test or not?

In 1993 scientists discovered the gene that causes Huntington's disease. This discovery led to a 'predictive test' being developed. In most cases, this simple blood test can tell someone at risk of HD whether or not they themselves have the gene that causes Huntington's.

Once someone becomes aware that their mum or dad carries the gene for Huntington's disease, they often start thinking about whether they want to know if they carry the gene too. Each person with a mum or dad with HD has a 50/50 chance that they too might get HD when they are older (it is really important to remember that there is the exact same chance that they won't get it at all).

A lot of youth work time at Huntington's Youth Connection is spent sitting with young people and exploring their

feelings around whether they are going to test or not. This is great, as it is often a big, complex topic that needs a lot of thinking and talking about and we know that speaking to a professional about this can be really useful.

Taking a predictive test to find out whether or not you will get HD is a big decision and can be really hard to deal with emotionally. What if a person gets a positive result? Will they be able to live well knowing they will develop HD? What if a person thinks they'll get a positive result and then gets a negative result? How does this change things? There is no right or wrong decision when it comes to testing. Everyone is different. Some will decide to test and others will not. It is important to remember that testing is a personal choice. This means it's a choice that only the person thinking about taking the test has the right to make. Mum, Dad, friends or other family members can be great to talk to about testing and whether or not it is a good idea, but ultimately, it's the person's sole decision and they should only get tested if they are sure this is what they want to do. For this reason, genetic counselling is a part of the testing process. This helps the person making the decision really be sure they are prepared for what the results may bring.

This small article is only an introduction to some of the issues faced by people in deciding whether or not to test. HDYO has a fantastic page on this that covers all you need to know. If you're interested in learning more, have a read at <https://en.hdyo.org/tee/articles/53> or contact us here at Huntington's Youth Connection and I would be happy to have a chat with you and/or help you find out more.

If you are a child, parent, young adult or teacher and would like more information on our youth program, please call Amy at Huntington's NSW&ACT on 9874 9777 or 0499 031 231 or email amy@huntingtonsnsw.org.au ■



Research news comes thick and fast, so it's important to filter it for the best and most relevant. **WORDS** LEWIS KAPLAN

IONIS/ROCHE DRUG TRIAL

THE MOST SIGNIFICANT news is the announcement on 1 July that the Huntington Disease Service at Westmead Hospital has been approved to participate in a new drug trial, called Generation HD1. This study tests a Huntingtin-lowering (also known as gene silencing) agent developed by IONIS, and the trial will be run by a company called Roche. The study involves lumbar punctures, MRI scans, assessments and questionnaires.

The main goal of Generation HD1 is to compare the effects, good and/or bad, of RO7234292 against placebo, in study participants with HD. Participants must be between the ages of 25-65, have early stage Huntington Disease, and meet additional criteria. It is expected the study will involve 660 people with HD worldwide.

If you would like more information, you can call Westmead on 0456 740 612. The phone will be monitored on Mondays and Thursdays. Please leave a message if your call is not answered.

Huntington's NSW & ACT, and the Huntington Disease Service at Westmead will continue to provide

updates on HD research through the Huntington's NSW ACT website.

Remember that the participation criteria are there for a reason, so if you don't meet them, please don't feel too frustrated.

HUNTINGTON'S DISEASE TRIGGERED BY GENETIC INSTABILITY IN BRAIN CELLS

(adapted from an article by Medical Express)

Huntington's disease is triggered by genetic instability of a particular DNA sequence in brain cells, according to a new study of the neu-

If confirmed, the study could lead to new methods to prevent disease onset.

rodegenerative disorder. If confirmed, the study could lead to new methods to prevent disease onset. It could also result in more accurate prediction of when healthy carriers begin to show symptoms.

The age of onset of HD symp-

Moreover, researchers found the age of onset is affected by at least six genes that maintain and repair DNA

toms varies. It's previously been linked to the mutation's severity.

This mutation was assumed to be static, making an altered huntingtin gene that gradually causes damage. However, the study found evidence that an increase in the length of mutation during the lifetime of the patient determines the time of onset. When a threshold of consecutive CAGs is crossed, the disease begins to manifest. Moreover, researchers found the age of onset is affected by at least six genes that maintain and repair DNA. These genes provide new targets for therapies.

The study was published recently in the journal *Cell*. It's based on information from more than 9,000 people with Huntington's disease.

The study suggests that if the lon-is/Roche drug trial works, it should be given as early as possible before symptoms manifest, said Prof. James Gusella, a study leader. He also said that other diseases are caused by these CAG repeats in other genes. So, if the mutant huntingtin gene could be stabilised with a drug, such an approach might provide a universal treatment for all these diseases.

Huntington's carriers with enough CAG repeats to trigger the disease go through life knowing they will eventually fall ill. But estimates based on repeats are sometimes inaccurate, leading people to develop symptoms either earlier or later than expected.

Improving these estimates would be of great use to both doctors and patients.

But to be effective, those potential treatments would probably need to be applied prior to disease onset. ■



THE HD SPOTLIGHT ON...

Therese Alting

DR THERESE ALTING, PhD Huntington's NSW ACT Board Secretary

Q How did you get involved in the HD world?

A I had my first real experience of HD in 1993 when as a newly qualified neuropsychologist I worked in the HD predictive testing program at Lidcombe Hospital. Not long after that I saw a documentary on TV about Nancy Wexler and the team finding the gene through the help of the Venezuelan families. It was very moving.

Q Why did you become a HNSW & ACT board member?

A The Association had gone through a difficult time, and I wanted to go beyond my part-time role in HD research to support families in NSW another way. My kids had grown up enough for me to volunteer some spare time, and it's been a great experience (though note-taking at meetings is not my strong point).

Q What excites you about HD research?

A Like everybody, the idea that we might be close to slowing the progression of this terrible disease. Scientists around the world are approaching treatment in so many different ways. I love that some HD researchers are

at risk or from HD families, a symbol of the close connections between the two. At the end of our Enroll visits, as the blood sample is shipped off overseas, I think of it as another tiny piece in solving the HD jigsaw.

Q What has been your favourite HD moment?

A Sorry I'm going to be like a politician here and not answer the question, but a related one. The best thing will be when we have successful treatments for HD that people all over the world can access. But already there have been improvements. People used to engage in victim-blaming, forcing families to keep terrible secrets. So my favourite moment is really an era, from the 1970s, when people started to emerge from decades of social isolation and stigma to bring HD out into the open, advocate for their needs and support each other.

Q What makes you laugh?

A Our stupid dogs. British comedies, like *Black Books*. Often my own idiocy (might as well be the first one). US politics (sorry did you say laugh or cry). Socialising with friends and family. ■



IN MEMORY OF *Russell*

WE WERE NOTIFIED that our dear friend Russell Goodwin sadly passed away in June.

Russell was always a bit of a larrikin who loved to be in the thick of things whether playing UNO, bowls, footy tipping competitions or telling us his big fishing tales. One such tale was when he chatted up two young fishermen to give him some fish. We were then left to cook it!

He loved to go to the annual Camp

Breakaway and led the charge on the daily walks. We think his favourite camp was in 2016 when we visited the Australian Reptile Park and Russell draped the snake around his neck and generally talked to the animals.

Russell had the backing of his wife Cheryl and their family to move to Queensland a couple of years ago.

The Goodwin family will be at the Walk 4 Hope this year and we know Russell will be sadly missed.

Our sincere condolences to Russell's family and wife Cheryl. ■

INSURANCE BREAKTHROUGH?

Temporary changes - so don't delay! **WORDS** LEWIS KAPLAN

FOLLOWING WORK DONE by genetic consumer organisations in the UK, the Moratorium on Genetic Tests in Life Insurance came into effect in Australia from 1 July 2019 and will end on 30 June 2024. This means that from 1 July 2019, there will be a temporary suspension on the use of genetic test results as part of an insurance application up to the value of \$500,000 (for death and total permanent disability), \$200,000 for trauma and \$4,000 a month for income protection.

While this is nowhere near as generous as in the UK, it's a breakthrough of sorts. More details can be found at <https://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-20-life-insurance-products-and-genetic-testing-in-australia>

If you don't have access to the internet, here's a summary, or contact us for the full factsheet:

Private health insurance is not based on a risk assessment of your health. -You will not be asked about genetic test results or your family history of health conditions.

Life insurance products such as cover for death, disability, trauma and income protection are based on a risk assessment (underwritten contracts). This may impact on the cost or terms of the policy

You are not required to have a genetic test as part of the risk assessment when applying for life insurance

If you do have a genetic test, your life insurance company must not use your genetic test results (up to the financial limits set above) unless you choose to declare them.

YOU MAY BE ASKED

Your age, gender, current health and medical history, including any signs, symptoms and any diagnosed conditions you have had or continue to have, even if diagnosed through a genetic test

The results of medical tests you have had

Any health conditions that have been diagnosed in your first-degree relatives (parents, children, brothers, sisters) only and the age they were diagnosed.

You are not required to provide any other information about your first-degree relatives including their genetic test re-

sult(s) if known to you, their name or date of birth.

THE LIFE INSURANCE PRODUCTS ARE GUARANTEED RENEWABLE

As long as the premiums are paid, you do not have to notify the insurer of any change in your health or of the results of any medical or genetic test taken after your policy has started.

A genetic test undertaken after a policy has been secured that shows you have not inherited the faulty gene in the family, and you choose to declare the results, means that the impact of a family history may be removed from your risk assessment that informed the cost and terms of the contract. Contact your insurer to discuss this.

The Moratorium does not apply to existing life insurance policies.

Involve your family doctor, medical or genetics specialist if necessary, in negotiations with the insurance company. ■



Huntington's

NSW ACT

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Outpatients Department
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John Hunter Hospital

JOHN CONAGHAN

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HUNTINGTON'S UNIT

St Joseph's Hospital

(02) 9749 0215

PREDICTIVE TESTING

Find your nearest Genetics
Clinic at www.genetics.edu.au/genetic-services

EDUCATION RESOURCES

Huntington Study Group

Global HD cooperative
therapeutic research org.
<https://huntingtonstudygroup.org/education/>

HDYO

Support and education to young
people (aged up to 35) impacted
by HD around the world.
<https://en.hdyo.org/>

RESEARCH QUERIES

Dr Therese Alting

Enroll-HD Study
(Westmead Hospital)
(02) 8890 6310 or 0438 604 719

HDBuzz

Research news. In plain
language. Written by scientists.
For the global HD community.
<https://en.hdbuzz.net/>

WHAT'S HAPPENING?

Community Support Groups

SEPTEMBER, OCTOBER, NOVEMBER & DECEMBER MEETINGS

CARER SUPPORT

NEWCASTLE Jesmond
Neighbourhood Centre,
44 Mordue Parade

10:00am - 12:00pm

Thursday, 12th Sept
Thursday, 10th October
Thursday, 14th November
Thursday, 12th December

SYDNEY 21 Chatham
Road, West Ryde

10:30am - 12:30pm

Wednesday, 25th September
Wednesday, 23rd October
Wednesday, 6th December

CENTRAL COAST LooLoos
Coffee Warehouse, 12/11
Cochrane St, Kincumber

10:00am-12:00pm

Saturday, 28th September
Saturday, 19th October
Saturday, 23rd November

FAMILY SUPPORT

ACT lunch Ainslie Football Club,
52 Wakefield Avenue, Ainslie

12:30pm - 2:30pm

Tuesday 12th October
Saturday, 7th December

WOLLONGONG Wollongong
Golf club, 151-161 Corrimall St,

10:00am - 12:00pm

Monday, 2nd September
Monday, 14th October

Monday, 4th November
Monday, 2nd December

PORT MACQUARIE Westport
Club, 25 Buller Street

11:00am - 1:00pm

Friday, 6th September
Friday, 4th October
Friday, 1st November
Friday, 6th December

CENTRAL COAST Niagara
Park Stadium, 16 Washington
Ave, Niagara Park

6:30pm - 8:30pm

Wednesday, 16th October
Wednesday, 11th December

COFFS HARBOUR Joyland
Carers Retreat, 5B Breakers
Way, Korora

11:00am - 1:00pm

Friday, 20th September
Friday, 18th October
Friday, 15th November
Friday, 20th December

ORANGE & CENTRAL WEST
LiveBetter Café Connect,
107 Prince St, Orange

10:30am - 12:30pm

Saturday, 21st September
Friday, 25th October
Saturday, 23rd November
Saturday, 21st December

For further details about any of
these meetings can be found on
our website, by contacting us
on 02 9874 9777 or email:
amanda@huntingtonsnsw.com.au.