



Gateway

News from Huntington's New South Wales

Volume 16 No 2

Winter 2013



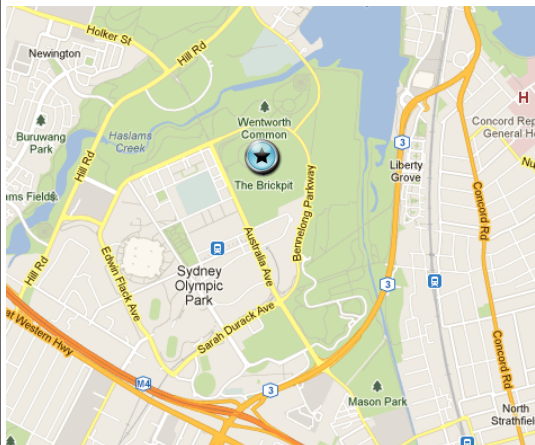
**Sunday 28th July
10am-2pm**

Location

**Wentworth Park, Banquet Tables
Marjorie Jackson Parkway via
Bennelong Parkway
Sydney Olympic Park
Homebush**

RSVP

**Tel: 9874 9777
info@huntingtonsnsw.org.au
Please include number of
adults and kids' ages**



**Entry
Gold coin donation
Sausage Sizzle lunch
will be provided**

**Activities and Games for
the Kids**

**Sponsored by Huntington's NSW and the HD Youth Alliance
www.huntingtonsnsw.org.au
www.hdalliance.com.au**

From the Executive Officer

We are very excited about the upcoming Family Fun Day and to be working alongside the HD Youth Alliance in this joint venture.

We do hope you and your family are able to come for what promises to be a fun-filled day with lots of activities for the kids and a delicious sausage sizzle lunch.

The day is not only for the kids—it will also be a wonderful opportunity for the adults to chat with one another and to make new friendships.

For catering purposes please let us know if you are coming. We'd love to see you there.

There is lots of other news in this edition of Gateway—I do hope you enjoy it.

In friendship

Robyn Kapp

Office Facelift



The Association has once again been successful in obtaining a grant from the NSW Government Community Building Partnership Program. We have received a grant for \$7,500 to paint the exterior of our office at West Ryde, *Elsie Court Cottage*. We purchased the property eighteen years ago and since that time little has been done to maintain its appearance.

Last year we received a grant to purchase new chairs for the meeting room which is used for Lunch Club, Carers' Meetings and Board Meetings. Our previous chairs had come with us from Lidcombe Hospital in 1995 and were well past their use by date!!

We are most grateful to Victor Dominello, the Member for Ryde in the NSW Government for recommending our applications.



Before



After

Volunteer Gardener

Through Volunteering Australia we have been very fortunate to have the services of a volunteer gardener, Kitae, who has spent many hours cleaning up the gardens of *Elsie Court Cottage*.

Kitae is very keen to improve the appearance of our premises and we are very grateful for his enthusiasm and commitment.

Watch this space for more 'before' and 'after' photos!!

Holiday Camp

Our Holiday Camp scheduled for March had to be postponed due to unforeseen circumstances. However we have re-scheduled it and it will now be held from Monday 21st to Friday 25th October at *Camp Breakaway*, San Remo.



Lunch Club

Our Lunch Club Program continues on Tuesdays, twice per month, from 10.30am to 2.30pm. We would love to have more people come along—it's designed for those people with HD who are still living in the community and are mobile and independent with activities of daily living. There's time to catch up, have a chat, discuss the football results and join in other fun activities. The highlight of the day is, as the name suggests, a delicious lunch.



Recently we had students, who are undertaking their Masters in Genetic Counselling, visit for their community placement program which is a part of their course. They helped out in a variety of ways including talking with our participants, serving tea and coffee and even helping in the garden!!

If you or someone you know would like to come to Lunch Club please contact Robyn on 9874 9777.

Raising Funds for Huntington's NSW

Invitation

You're invited to Morning High Tea at



WOW! Designer Jewellery

WATERFRONT GALLERY



181 Northcote Avenue, Swansea

Saturday 21st September, 11am - 2.30pm

There will be raffles, prizes and a delicious High Tea

Fabulous Christmas Shopping Opportunities

Entry Fee: \$15

10% of sales to

Huntington's NSW

RSVP Terry Ayres

0402 143 776 or

terry.ayres@bigpond.com



Running for Huntington's NSW

We are delighted that once again a number of people are running in the City2Surf on Sunday 11th August to raise funds for the Association. Sincere thanks to all those who have registered so far.

***If you and your friends are planning to run this year,
why not make Huntington's NSW your cause?
Visit Everyday Hero at www.everydayhero.com.au
to set up your Supporter's page.***

Donations to the Association can be made on-line at Everyday Hero at any time. Just visit our web site www.huntingtonsnsw.org.au and click on 'Make a Donation'. You can even elect to donate on a regular basis!!



Landmark study puts Huntington's disease trials on TRACK

Final results from the TRACK-HD study show very specific changes in HD. We're ready for trials: bring on the drugs! By Dr Faye Begeti, Edited by Dr Jeff Carroll

If we find a therapy that we hope can slow down Huntington's disease, how can we prove that it works in patients? What tests should we do and how long should we follow people up after treatment in order to see any real benefits? A major new paper from Sarah Tabrizi and colleagues, reporting the final outcomes of the TRACK-HD study, provides information that will help us better design trials of new therapies in HD as well as understand how the disease progresses.

Why do we need TRACK-HD?

Many Huntington's disease families will have become a little tired of hearing about drugs that are effective in animal models of HD - surely we want to cure people, not mice or rats or worms? But before we can successfully run more effective clinical trials in HD patients, we have to understand exactly what happens in people as they become sick.

Which signs of HD do we want to try and fix as part of a therapeutic trial? These kinds of questions are particularly challenging because, unlike diseases affecting other organs, it is hard to know whether drugs can really slow down disease process in the brain, hidden as it is within the skull.

That's where 'observational' studies come in. Observational studies are those in which patients are studied without giving them any treatments, simply to understand the disease process in great detail.

Led by Prof Sarah Tabrizi of University College London, the TRACK-HD study was designed to run like a mock drug trial. People carrying the HD mutation would be studied for a defined period of time (36 months), using a large array of measurements including brain scans, specialized motor measurements and examination by a physician.

What's just happened?

In a fourth successive paper published in top journal *Lancet Neurology*, the TRACK-HD team has just reported its final data, describing what they saw in

people carrying the mutation after 3 years of observation. This timing is important, because it's a reasonable time frame for a real therapeutic trial. It lets us answer the question, 'if we had an effective treatment, could we test it in Huntington's disease mutation carriers in 3 years?'



Careful measurement of brain shrinkage, detected using MRI scanning, was one of the most powerful ways of measuring progression in Huntington's disease according to TRACK-HD

There is a simple, hopeful, message that comes from this study, and that is that we now have better ways of doing clinical trials in HD. We know which specific tests are most sensitive to change at different stages of the disease process. As a consequence of this, we know how many individuals we would need to confidently see those changes as part of any trial of a therapy in HD patients.

How'd they do it?

TRACK-HD involved annual follow up of groups of people who've inherited the Huntington's disease mutation. Using well-established mathematical calculations that help predict when someone with the mutation will have symptoms of HD, people without symptoms of HD were divided into two groups: those who are estimated to be close to, or far from, disease onset.

The team also followed a group of patients in the early stages of HD and, for comparison, a control population who did not carry the HD

mutation. Many of the control group are family members of the HD mutation carriers.

Of the 366 individuals enrolled, 298 completed the 36-month follow up. Not surprisingly, many participants that dropped out were in the more advanced stages of HD.

What'd they find?

Remember, the main goal of the TRACK-HD study was to determine which measurements best predict the onset of HD, and track its course after onset of symptoms. So what did the team observe for each of the groups in the study?

First, sensitive MRI brain scans, that are able to very accurately measure the shape and size of people's brain, could measure differences amongst every group in the study. Even the people predicted to be far from onset had specific areas of brain change during the 3-year duration of the study. Hopefully, all new studies of therapies in HD will include brain scans, so scientists can see whether this loss of brain tissue is prevented.

In the group of participants predicted to be far from onset, there was very little change in behavioral or other clinical measures during the 3-year follow up. These people seem to be coping fairly well with the changes in their brains observed by scanning.

"One hopeful message from this study is that people who've inherited the mutation that causes HD seem to be able to cope with it for quite some time"

However, over 36 months, participants predicted to be close to onset behaved rather differently. They started to show changes in a number of clinical tests, including a range of motor and memory tasks. As in the group predicted to be farther

from onset, these behavioral changes were accompanied by changes in brain scans that reveal shrinkage.

Over the 3-year duration of the study, some of the participants who hadn't been diagnosed with Huntington's disease at the beginning of the study have now developed symptoms of the disease. This enabled the scientists to try and

figure out which measurements predicted the transition from 'pre-manifest' to 'manifest'.

Several behaviors were useful in predicting onset of disease symptoms, including motor tasks such as finger tapping. Consistent with the idea that people with Huntington's disease have a hard time with empathy and emotional regulation, people who developed disease also demonstrated problems on an emotion recognition task.

What can we do with this information?

This study will help us to better pick tests to assess carriers of the Huntington's disease mutation who are closest to disease onset and in the early stages of disease. This will be important, as these are the groups most likely to be targeted for therapeutic trials.

It's important to note that the measurements described can't be used to predict disease onset for individual people - they only make sense when applied to groups of people, like in a clinical trial.

By using a combination of measures, from simple clinical tests to fancy imaging techniques, the authors ensured that in the future, the use of these tests could be rolled out across a large number of sites, which will make participation in any future trials logistically much easier.

We can now start to plan trials using the measures described. However, it is important to note that 'preventative' trials that aim to test treatments before symptoms onset will have to last quite long in order to see an effect: probably in the region of 36 months, if TRACK-HD is anything to go by.

Now, the crucial questions are what those therapies will be and how we can ensure that they actually do in humans what they do in cells or animal models of HD. For example, if we block mutant huntingtin production in cells or



Studying volunteers over 3 years was crucial in developing measurements that could enable 'preventative' clinical trials in 'pre-manifest' carriers of the HD mutation

animals with 'gene silencing' techniques, how can we confirm that this treatment actually does what it's supposed to do in the brains of patients with HD?

One hopeful message from this study is that people who've inherited the mutation that causes Huntington's disease seem to be able to cope with it for quite some time. If we can develop therapies that help them fight off the negative effects of the mutation, we're hopeful that people could expect more healthy years, thanks to the remarkable ability of the brain to cope with damage.

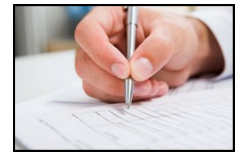
Finally the investigators, patients and control subjects should be congratulated on their dedication to this intense study. Without their continued determination to see it through to three years, the study would not have been able to make such significant claims.

Dr Ed Wild, editor-in-chief of HDBuzz works closely with Sarah Tabrizi, the global head of the TRACK-HD study. Dr Wild had no input into the decision to feature this research on HDBuzz, or the drafting or editing of the piece.



Membership Renewal

Membership renewal is coming up very soon! Over the next two weeks you will receive a letter from the Board inviting you to renew your membership for 2013/2014. We do hope you will take the time to renew your membership this year. If you're not a member, perhaps you may care to consider joining the Association.



Awareness Week



At a recent Business Meeting of the state HD Associations it was agreed to hold a National Awareness Week for Huntington's Disease. This year it will run from **Monday 2nd September to Sunday 8th September**. However, if other opportunities arise to raise the awareness of HD during the month, we won't hesitate to take them up.

Here in NSW we will be putting an awareness package together and we're hoping that our families and members will come on board and help us with this venture.

In particular, we would like some personal stories similar to those on page 8 of this newsletter. Why not start thinking now about your story—we would be very happy to help you write it.

We'll let you know more in the near future.

Central Coast Youth Forum

It was early on a very wet, miserable Saturday morning as I made my way from Sydney to Gosford on the Central Coast. As I drove very, very carefully in dreadful conditions, I kept asking myself "Why am I not at home, curled up with my cat, drinking a coffee and reading the paper?"

Saturday 23rd February was the date for the Central Coast Youth Forum and it was being sponsored by Huntington's NSW. Mark Bevan and I had promised Holly Faulkner, the organiser, that we would attend.

What we didn't know was the surprise that awaited us. Twenty eight young people gathered in the library of St Philip's Christian College to hear presentations from, among others, Robin Hay, Genetic Counsellor; Dr Clement Loy from the NSW HD Service; Steve McArthur, Scientific Director, Genea (Sydney IVF). The topics covered included genetic testing, research, PGD IVF and there were also helpful hints on exercise and nutrition; coping strategies and insurance issues.

The most moving segments for me were the personal stories—young people talking about their own experiences of testing positive or negative; making the decision to have or not to have children; undergoing PGD IVF—they all spoke honestly and openly.

Over the tea breaks and lunch, there was the opportunity to talk informally with one another and to share one's thoughts and ideas; as well as enjoying the delicious food prepared by Holly's group of helpers.

It was a wonderful day and I'm sure everyone came away having learned something new from the speakers and having been inspired by those who told their stories. Congratulations to Holly and her team for their great organisation.

Robyn Kapp

On the road again... with Mark Bevan

What has happened so far this year?



Late in 2012, I took the plunge and had both knees completely replaced. As a result my travel schedule needed to be pushed back slightly to undertake the significant amount of driving involved in making regional visits.

My first venture for the year, was a trip to Canberra in March, along with Fiona Richards from the NSW HD Service, to attend a support group meeting. Sixteen people attended and everyone had an enjoyable lunch. From the amount of noise coming from our tables, I would say some great conversations were had – some with old friends, and also there was the establishment of some new connections. I am not sure of the date for the next meeting, but if you are interested in attending the ACT gatherings, please let me know and I will put you in touch with the organiser.

From Canberra, I travelled across to the beautiful south coast region where over the week before Easter, I was able to visit a dozen or so families from Wollongong area through to the far south coast. I also had the privilege of running two in-service training sessions in Batemans Bay and Port Kembla.

As this newsletter goes to print I will have been to Bathurst, Orange and beyond and to Goulburn, Wagga Wagga, Albury and surrounds.

My dates for future visits are

| | |
|------------|--|
| June 26-28 | North West – Tamworth, Dubbo and surrounds |
| July 4-5 | Mid North Coast Port Macquarie and surrounds |
| July 15-19 | North Coast – Kempsey to the Queensland border |

If you live in any of these areas, and would like to catch up when I am travelling in your area, please call me on 0410 629 850 or email mark@huntingtonsnsw.org.au. I would love to hear from you.

Meet Kristen



Huntington's disease dominated my childhood. In 2003, when I was nine years old, my mum was officially diagnosed, but my family believes she exhibited signs as early as 1999. Her disease progression was swift and brutal. Only two years after diagnosis, in 2005, she moved to a nursing

home because her emotional mood swings, outbursts, and out-of-control movements were too much for even a team of family members to handle.

It was in this nursing home that she would lose her ability to speak. A few years later, she developed difficulties swallowing. Closer to the end, her balance betrayed her. She was subsequently forced into a wheelchair, in which she developed many bruises and sores. As a teenager, I spent weekends, holidays, and summer vacations visiting her in that nursing home. Because she couldn't speak, it was very much a one-way conversation. She knew everything I was going through, yet I could not relate to anything happening to her. I never had the opportunity to ask her how she felt about her fate, which became even more devastating when I learned that her disease could one day become my own.

On January 27, 2011, my mother passed away from complications due to pneumonia. I was seventeen years old. Over the next year, I embraced the "freedom" I felt from the disease. My mother was at rest and no one else in the family was suffering. However, this "freedom" was short lived as I soon made the decision to undergo genetic testing at age 18. Not only that, I decided to make a documentary about it.

Almost two and a half years later, I am now only a few months away from releasing my documentary. With my genetic testing journey complete, I am re-creating a new identity as a college freshman at Stanford University in California. The past few years have been full of hope and excitement as I watch the scientific world progress closer and closer to a cure for the disease that tried to take over my family. Thankfully, my family is stronger than anything Huntington's disease tried to dish out. Today, we are using that strength to do everything in our power to make sure it never devastates another loved one again.

Meet Erika & Melissa



Many of our stories are similar, but they all seem to have a unique twist. My symptomatic father took his life when I was 11 years old.

Realizing how precious family is, my sister and I became very close. Eight years later we found out that she has the gene expansion and I don't. I never really felt guilty (as I know many people do); I knew there was nothing I could do about our gene status. When she started showing symptoms just a few short years later -10 years earlier than expected - I knew there had to be something to make this seemingly helpless situation less scary and devastating. Taking action and learning as much as I can is how I cope with knowing my sister and so many amazing friends I have met will be affected by this disease. I joined an observational trial called COHORT just like the now enrolling ENROLL-HD, got involved with my local chapter and sought information about HD. Just shy of 9 years from when we found out our gene results I am a first year medical student/ aspiring neurologist, member of the Northwest Chapter Board of the Huntington's Disease Society of America, a support group leader in Central Washington, and now serve on the ENROLL-HD care committee. My sister is participating in a clinical trial and her symptoms seem to be better. The knowledge I have gained and the people I have met who are working tirelessly to find more effective treatments give me hope. There is nothing that I want more than for my sister and other people dealing with this disease to have a better quality of life. If you or a family member is struggling with HD please know you are not alone. Even though you may feel helpless there is always something that can be done. Get involved and find out how your talents can contribute to the HD community.

Acknowledgement:
Huntington Disease Society of America
www.hdsa.org

Simple rules for a good night's sleep in Huntington's disease

In part two of our special feature on sleep problems in Huntington's disease, we bring you Prof Jenny Morton's 'simple rules for a good night's sleep', distilled from her comprehensive review of sleep research in Huntington's disease.

Simple rules for a good night's sleep

In the first part of this special feature on sleep, which appeared in our Autumn edition of *Gateway*, Prof Morton reviewed what's known about sleep problems in Huntington's disease. Problems with sleeping and loss of normal daily rhythms in HD are common but potentially manageable. Here, based on what's known about sleep disturbance in HD, as well as advice that comes from sleep research more broadly, we are pleased to present Prof Morton's simple rules for a good night's sleep.

The rules are reproduced here by kind permission of Elsevier Science, from A. J. Morton, 'Circadian and sleep disorder in Huntington's disease', *Experimental Neurology* 2012.

As ever, this extract is provided for information only, and that HDBuzz is not a source of medical advice. If you are having problems with sleeping, you should see your doctor.

Bedtime and napping

1. Set a **bedtime**, and go to bed within 30 minutes either side of this time.
2. Fix a **'wake-up' time** that is 8 h after your set bedtime. Note that you will probably need to set an alarm to wake you up. You must get out of bed when the alarm goes off, even if you still feel tired. It will probably take a couple of weeks to get used to your 'going-to-bed' and 'wake-up' times. Stick to your going-to-bed and wake-up times, even at the weekends, until your sleep patterns are consolidated.
3. Establish **going-to-bed patterns of activities** that will help you to sleep (see below, 'Getting ready for bed').
4. **Avoid taking naps during the day.** If you feel sleepy, do something else. Go for a walk, do the dishes, take a shower. If you must

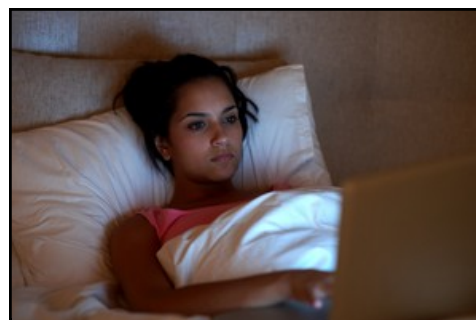
take a nap, limit it to 30-40 minutes and set your alarm clock to wake you up.

Exercise

Take a regular bout of **exercise** during the day, but don't do strenuous exercise within 2 hours of bedtime.

Food and drink

1. **No coffee** more than 4 hours after your wake-up time. (For example, if you get up at 7 am, you should not drink coffee after 11 am.)
2. **No alcohol** within 2-3 hours of bedtime. (If you go to bed at 11 pm, ideally you should not drink alcohol after 8-9 pm.)
3. Try to eat your **last full meal** at least 4 hours before bedtime.
4. Have a **light snack** before you go to bed. Foods that are rich in tryptophan may be helpful. These include milk, yogurt, eggs, meat, nuts, beans, fish, and cheese (Cheddar, Gruyere, and Swiss cheese are particularly rich in tryptophan). Try warm milk and honey or bananas.
5. **Avoid smoking or chewing tobacco** for at least 1-2 h before bedtime. If you smoke, cut down on cigarettes/tobacco. Nicotine is a potent drug that speeds your heart rate, raises blood pressure, and stimulates brain activity. If you are addicted to nicotine, withdrawal symptoms may wake you at night. It also goes without saying that quitting smoking offers other health benefits.



*This is wrong!
Computers should be kept outside the bedroom, and backlit screens shouldn't be used for pre-bed reading.*

Your bed

1. Should be used only for **sleeping, reading and sex!**

- No working in bed;
- No watching television;
- No playing computer games.

2. Should be comfortable. This may sound obvious, but if your bed is too hard, or too soft, you will not sleep well. If you have not bought a new mattress in the past 10 years, consider whether or not it is time for a new one. If you have joint pain or get cold at night, use a mattress pad or underlay. If you get cold at night, use a duvet with a high tog rating rather than layers of blankets that can be heavy. If you get hot in the middle of the night, try using two thinner duvets so you can throw one off in the middle of the night. If you share a bed, and you both have disrupted sleep, try using separate sets of sheets and duvets, so you are not competing with your partner for your bed coverings.

Your bedroom

Should be:

1. **Cool** (18-20 C) but not cold;
2. **Well-ventilated**;
3. As **dark** as possible;
4. As **quiet** as possible.

Your bedroom should not have a television set or a computer in it. If it does, make sure they are switched off at the wall (so there is no light

showing.) Your mobile telephone must be switched off and left in another room before you go to bed.



Establish a 'pre-sleep ritual', including relaxing activities like taking a bath or reading

Getting ready for bed

1. Establish a **pre-sleep ritual**. For example: switch off your mobile phone, have a snack, put the cat out, clean your teeth, get into bed, read a book for a few minutes. Or: walk the dog, switch off your mobile phone, have a bath, clean your teeth, get into bed, read a book for a few minutes

2. Worrying

- Don't take your worries to bed. Try not to think about your job, school, daily life or illness when you are in bed. If you are naturally a worrier, try 'active worrying' whereby you use a worry period during the late afternoon or early evening. Write a list of the things that are worrying you, and decide which ones you can do something about the next day. Decide on a plan of action for those. Leave the others on the list for another day.
- Don't worry about not sleeping. Humans have amazing capacity to do without sleep, and a good night's sleep is often enough to restore the balance. Contrary to popular belief, insomnia is not lethal. It might make you grumpy, and in the long term it can be deleterious to your health, but it will not kill you. It is not clear how much sleep is essential to life, but it is much less than the average insomniac gets, so worrying about not getting to sleep is counter-productive.
- Remember if you can't sleep, you can always rest. One of the major functions of sleep is to allow your body to rest. While you are asleep, your heart slows down significantly. The simple act of lying quietly in bed achieves a decrease in heart rate. So, even if you spend 8 hours in bed, resting without sleeping, this is better for you than being up, pacing about and being anxious about not being able to sleep.

Falling asleep & staying asleep

Get into your favorite sleeping position. If you don't fall asleep within 15-30 minutes, try getting up, going into another room, and reading until you are sleepy. Some people find that listening to the radio or a talking book helps them go to sleep. Radio is a much less stimulating medium than TV, so listening to the radio is fine.

Getting up in the middle of the night

Most people wake up one or two times a night for various reasons. If you wake up and cannot get back to sleep within 15-20 minutes, you do not need to stay in bed trying to sleep. Get out of bed if you want to, but if you get up, you should leave the bedroom. You can sit quietly, read, listening to the radio, have a drink or a light snack, do a quiet activity such as a crossword puzzle, or take a bath.

- Do not do office work;
- Do not do housework;
- Do not watch television;
- Do not play computer games;
- Do not check your e-mail;
- Do not check your phone messages.

After 20 minutes or so, go back to bed.

Remember that your sleeping time starts at your chosen bedtime. If you don't sleep, **you shouldn't roll your wake-up time forward to compensate.** You should get up 8 hours after you went to bed.

This article is an extract from a recent peer-reviewed review article by Prof Morton in Experimental Neurology, which looked at all published research on sleep in HD, including that of her own group.

Family & Friends Support Group

Our family & friends support group meets on **Wednesdays** each month at **10.30am**.

The venue is the Association's office,
21 Chatham Rd West Ryde,
and we would welcome new members.

It's a great time to get together with other carers who, like yourself, are caring for a partner, a family member or a friend with HD.

Come along and join us as we share our chatter, laughter, tears and experiences.

2013 Sessions

19th June
10th July
14th August
25th September
16th October
13th November
Friday 6th or 13th December
Christmas Get Together TBC

To RSVP and for further information,
please contact:

Jet Aserios or
Cecelia Lincoln
(02) 9845 6699

Social Work Department
Westmead Hospital



Huntington's New South Wales

PO Box 178, West Ryde, NSW 1685

21 Chatham Road, West Ryde, NSW 2114

Telephone: (02) 9874 9777 Facsimile: (02) 9874 9177

STD Free Call: 1800 244 735 (Country NSW only)

Email: hdassoc@huntingtonsnsw.org.au

Web Site: www.huntingtonsnsw.org.au

AHDA (NSW) Inc

The Australian Huntington's Disease Association (NSW) Inc is a not-for-profit organisation established in 1975.

Our Mission

The energies and resources of the Australian Huntington's Disease Association (NSW) Inc are directed towards satisfying the needs of people with or at risk for Huntington's Disease and their families in NSW and the ACT by providing and/or facilitating delivery of a range of quality services.

Our Philosophy

People with Huntington's Disease and their families are individuals with equal value to all other members of Australian society, with the right to treatment and care by knowledgeable professionals and care givers, the right to appropriate support services and the right to have the best quality of life possible.

Our Services

These include education and information; advocacy; counselling and referral; holiday programs; family support; rural outreach and client services.

Our Board

President: Brian Rumbold

Vice President: Don Ayres

Treasurer: Richard Bobbitt

Secretary: Judy Rough

Deb Cockrell

Amanda Dickey

Keith Dingeldei

Association and Other Useful Contacts

Association Staff

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Activities Assistant

Mark Bevan
Regional Family Support
Worker

Huntington Disease Service

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Westmead Hospital
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Jet Aserios
Social Worker
Westmead Hospital
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Cecelia Lincoln
Social Worker
Westmead Hospital
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Outreach Service
**Colleen McKinnon &
Mark Cirillo**
Westmead Hospital
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Huntington's Lodge

Nursing Unit Manager
Lottie Stewart Hospital
(02) 9804 5854

Nursing Staff
(02) 9804 5803

Predictive Testing

Fiona Richards
Social Worker
The Children's Hospital
Westmead
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Hunter HD Service

John Conaghan
Social Worker
Hunter Genetics
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