



WALK4 HOPE

HUNTINGTON'S NEW SOUTH WALES

**Be Seen Wear Pink and Green
in Huntington's Awareness Month
in September**

REGISTER TODAY



SPEER'S POINT
Saturday 10 September



CANBERRA
Sunday 11 September



PARRAMATTA PARK
Sunday 18 September

Register at Huntingtonsnsw.org.au
or call for a registration form 02 9874 9777.

Membership Renewal

Thank you to everyone who has renewed their membership for 2016/2017. We are also very grateful for the many donations we have received to date.

It is now possible to renew your membership, join the Association and give donations on-line by visiting our website www.huntingtonsnsw.org.au.

If you still prefer to fill out a membership form and post it with your payment, you can either download one from the website or contact us on 9874 9777 and we will send one out to you.

Membership fee is still only \$22 (incl GST per annum).

A strong membership will ensure that the Association continues to be representative of, and relevant to, people affected by HD in NSW and the ACT. So why not encourage another family member or friend to join?

Meet Julie ...

Hi my name is Julie Leto and I am the new Regional Social Worker. I heard about the position when I worked with John Conaghan, the Huntington's Social Worker at John Hunter Hospital, Newcastle, last year for six months.



I'm looking forward to meeting and working with families impacted by HD throughout NSW and the ACT and building strong relationships based on trust and the belief that at one time or another in our lives we all need support from a friend.

I have a family of six children, three boys and three girls. I am very hands on with my family as I am with my work—I like to be involved and useful. I'm also doing my Masters in Family Studies through Newcastle University.

I'll be located at West Ryde, Monday to Wednesday and in Jesmond, Thursday & Friday. I'm looking forward to meeting many of you when I begin my travels throughout rural NSW and the ACT. In the meantime please feel free to contact me on 9874 9777 (M-W); or 0456 115 122 (Th-F) or you can email me julie@huntingtonsnsw.org.au



When: Thursday 25 & Friday 26 August 2016
Where: NAB, 700 Bourke Street, Melbourne

This event is free of charge

Community conference days for the benefit of researchers, clinicians, service providers, Huntington's community members and the general public.
Sessions will include information on being young with HD, managing the impact of HD, the current policy environment and latest research.
Register at tiny.cc/nationalconference

You're Invited



"Come Out Swinging"
in the fight against

MND & HD
MOTOR NEURONE DISEASE HUNTINGTON'S DISEASE



mnd
New South Wales

See you @ Saints
at 7

Huntington's
New South Wales



St Marys Rugby League Club Cnr Forrester Rd & Boronia Rd St Marys

Friday, 2nd September 2016

The Terry Rae Big Swing Band
featuring Ed Wilson & MC Pat Drummond
\$50p.p.

Fabulous
finger
food,
drinks
from
the bar



Fund
raising
auction
Top shelf
prizes

For full details and to book go to www.eventbrite.com.au

Proudly supported by Upper Blue Mountains Sunrise, Rotary
ubmrotary@gmail.com

Silent Auction

Prelude to Bob Montgomery's  Darwin2Perth4MND&HD

From the EO's Desk

September is Huntington's Awareness Month and it is certainly shaping up to be a very busy and exciting time for Huntington's NSW. We're kick starting the month with a fabulous evening of entertainment at St Mary's Rugby League Club on Friday 2nd September. We are partnering with Rotary and MND NSW. For details and to book go to www.eventbrite.com.au

The first of our three Walks 4 Hope takes place on Saturday 10th September at Speers Point, followed by the ACT Walk at Lake Burly Griffin on Sunday 11th and Parramatta Park on the 18th. We're hoping for fantastic weather and large turnouts at all events.

If you missed seeing "The Inheritance" back in March last year, there's an opportunity to see it at the Riverside Theatre, cnr Market and Church Streets, Parramatta on Thursday 15th September, 7.30pm.

We are thrilled that SBS TV will be showing our ads for another twelve months and extend our congratulations to Huntington's Victoria who have been selected as an SBS Partner for 2016-2017—this means even more awareness of Huntington's in the year ahead.

Our fundraising goal this year is to raise enough funds to employ a youth worker. Many of you are aware of the unique challenges that young people from Huntington's families face. Huntington's associations in Western Australia, Scotland and Canada have demonstrated the benefits of having a youth worker on staff. We want the same benefits for our young people in NSW and the ACT.

I'm planning to be at all of these events—I do hope many of you will be able to join me at one or more.

In friendship

Renee Kopp

Hunter Valley Wine Experience

- *Hunter Valley Wine Tour with Hunter Hire Cars*
- *Lunch at Blaxland's Inn*
- *Accommodation for two nights at H Boutique Hotel*
- *Degustation dinner for two people at Emerson's Restaurant*
- *Winemaker tour and tasting at Piggs Peak Winery*
- *Six bottles of premium wine*

All proceeds from this fantastic raffle will go to
Huntington's NSW

Don't miss out, get your tickets today

To order tickets contact the Association
Tel: 02 9874 9777 or
Email: info@huntingtonsnsw.org.au



RAFFLE

**HUNTER VALLEY
WINE EXPERIENCE**

**FABULOUS PRIZE
FOR TWO PEOPLE
MID-WEEK IN THE
HUNTER VALLEY**

**Prize will be drawn at the
Walk 4 Hope
at
Lake Macquarie
on
10th September**

**\$5 PER TICKET
OR 3 FOR \$10**

The Inheritance Documentary

An intimate story of a courageous family



*"Truly one of the most moving and inspirational stories I
have ever witnessed on the big screen."*
Cathy Stephenson—The Dominion Post

*"Absolutely an incredible documentary—the type of
which, once you see it, you never forget it"*
ABC Radio

**Riverside Cinema,
Cnr Market and Church Streets
Parramatta**

**Thursday 15th September 2016
7.30pm**

Book on line at
<https://riversideparramatta.com.au/show/the-inheritance/>

The Centurions

Raising funds for Huntington's NSW

Like most people I had never heard of Huntington's disease.

I met my wife to be 7 years ago when I was 28 years old. As in most relationships in the early stages you are keen and eager to get to know everything about the other person. This was the first time I had ever heard of Huntington's. She explained the basics about Huntington's and the fact that it was a genetic disease that had a strong link in her family.

As my wife had not been tested yet she did not know whether she had been affected by Huntington's. In the early stages of our relationship I did not give it much thought, how bad could it really be? Since I had never heard of it I naively thought that it couldn't be as bad as it sounded, for some reason it just didn't have the same stigma and impact that say, cancer has on a person.

Our relationship continued and became serious to the point where we were engaged and entertaining the possibility of having a family in the near future. And that is when my wife decided she would be tested for HD. I still didn't give it much thought, and for some reason despite the overwhelming odds against her I thought she would still be right. We were both young, healthy, hardworking, honest people why should we be affected by HD.

As part of the decision to be tested we both underwent counselling sessions to prepare us for the potential consequences. Medical evidence would suggest a 50% chance of my wife having HD due to one parent being affected. 50% isn't bad I thought, surely we would get a break and that 50% chance, that flip of a coin would land in our favour, I decided I would be positive as we went to Bathurst hospital to be delivered the news via video conference.

Words cannot describe how utterly devastated I was when I heard the result, I was absolutely gutted, this beautiful woman who had stood by me through thick or thin, the love of my life was positive for HD. The enormity of the situation then hit me like a freight train, there was no ifs, buts or maybes. It was an absolute guarantee that my wife would get, and possibly lose her life to this horrible disease.

All the things that run through your mind when you are in love, having kids, spending the best



years of our lives together, growing old together and enjoying grandkids and much more had suddenly been torn from us both.

I have always prided myself on my ability to stay composed regardless of the situation or pressure. As soon as I heard the words HD positive I just sat there, the doctor talked for a few more minutes but I can honestly say that I didn't hear another word, I was honestly so shattered I couldn't even speak. I hated the world, I was so angry, I felt like tearing the entire room down, my heart was filled with rage. And then I looked at my wife sitting there with tears running down her face and she said "it's ok, I thought I was going to be", she took it much better than I did and to this day I still don't know how. Imagine being told that unless there are medical advancements that you are going to die from this disease, and the likelihood that it might affect you in your thirties, and you could die from it in your 40s or 50s.

Imagine being told you are 100% going to get cancer in later life, or have a stroke or be paralysed. This was not a possibility. This was a certainty! I hated the world, I felt so pissed off that there are so many people who do nothing but hurt others, who are selfish, who lie, who steal, who murder, who rape and it was my wife who was getting the life sentence. The car trip home was the quietest it has ever been.

It took us a while to get back to our normal everyday lives and routine, I think my wife found it strangely comforting, not having the spectre of Huntington's hanging over her head, there was no doubt, Huntington's was going to forever change our lives. We still wanted to have children, but we wanted to make sure we did as much as possible to ensure that they wouldn't have to have this horrible disease in our lives.

Through a combination of IVF and PGD we found it was possible to separate the Huntington's from the non-Huntington's embryos and reimplant the

(Continued on page 6)

(Continued from page 5)

non-affected embryos through the typical IVF process. We were so happy until the process hit a few hurdles, namely financial. I am not, nor have ever been a person motivated by money. I would rather be happy and have no money than have all the money in the world and no one I loved to share it with.

The major obstacle was that Medicare did not cover the PGD aspect of the process which meant that it would cost us around \$26,000 per cycle. Through our meetings with our doctors and specialists we were told that they could reasonably accurately guarantee us a child within 4-5 cycles. This was absolutely devastating for us as Huntington's had not only had the potential to destroy our lives but was also starting to affect our ability to have the family we had so both desperately wanted.

My wife and I aren't flush with money unfortunately, nor are our parents and we had no means to attain the \$100,000-\$150,000 that we would need to have a single child. We had always spoken about having a few children, I thought 3 would be a good number (however that number may be a little small for my wife). We agonised over a decision for months, we wanted kids, but we also didn't want our kids to have to ever have to go through what we had just gone through. The only way this could happen was to sell our house and cars in order to get the money.

We had a tough decision to make, if we had kids then they would all have a 1 in 2 chance of having Huntington's, but if we went through the PGD/IVF process there was no guarantee we would ever have a child, and would financially struggle to give them anywhere near the quality of life we wanted to. For those who have been associated with IVF it is not a glamorous process, it can be a brutal, mentally draining, exhaustive and stressful process that I was not willing to put my wife through.

We made the decision to try for children without the IVF/PGD and now have 2 beautiful and healthy children, Lexie and Cheyse. But not a day goes by that we don't wonder if one or both of our children will be affected by this horrible disease, we try not to feel guilty or blame ourselves but the truth is that we do. We feel selfish for putting our want for a family in front of eliminating the HD gene forever.

The path we have chosen will enable us to give our children the lives that we feel they deserve, it will also give me the opportunity to provide my

wife with the life that she deserves. What we now have to do is wait and see, testing cannot take place until an individual is 18 years of age. And in that time I can guarantee we will look at our kids every day and ask ourselves what the answer will be? Are we going to be lucky this time and have neither of our children affected by HD?

The odds say that it might be possible, my wife's family history of HD unfortunately says it is not. So if you are me 7 years ago and you have never heard of Huntington's then do yourself a favour and get on line and spend some time having a look. This disease destroys lives and families and has NO CURE, and the most unfortunate thing is that most people have never heard of it.

So this is the story behind the Centurions, I would love to say I created the idea but truth be told it was my brothers idea, yet another example of Huntington's disease affecting the family, not just the individual.

So 100 days alcohol free is the challenge, yes it will be difficult but that pales in comparison with the difficulties for anyone associated with HD. I love a beer, especially while watching the footy or going fishing so I'm sure it will be hard. But I would give up alcohol forever if it meant that Huntington's did not exist anymore in this world, so that others didn't have to go through the pain that my wife, her family and any other family affected by HD goes through on a daily basis. Unfortunately I now know what Huntington's disease is.

Please help us by giving whatever you can using the 'Give Now' button. The more people that know about this, the greater the impact, so please also spread the word by sharing our page with your friends and family.

Thank you in advance for your generosity, it means a lot! – Justin

<https://give.everydayhero.com/au/centurions>

Editor's Note: As we go to print the Centurions have passed their fundraising goal of \$5,000. Congratulations guys and thanks heaps.

For current information about PGD for HD please contact your nearest genetic counsellor.

The costs for this procedure do vary so it's important to get information that is appropriate for your personal situation.

Memories are Made of This

8 tips for retaining and recalling information when you have HD

By Josh Martin

As Huntington disease (HD) progresses, it can feel as if someone has shuffled your mental filing system. Manitoba Resource Centre Director, Marla Benjamin, hears it all the time. "I've got a fog in my head," one client will tell her. "I know there's all these pieces and I just can't put them together," says another.

Everything is still there, but finding the information you want can take a frustratingly long time. Unlike Alzheimer's disease, where those mental files are actually lost, Huntington disease damages parts of the brain responsible for retrieving existing information and storing new information.

"Patients lose their ability to be able to multitask, often at the time when they are dealing with growing children, caring for their aging parents, and keeping up with daily routines such as shopping, not to mention their employment. This puts them into a very challenging, often anxiety producing situation. Making decisions as to what aspect of all of these important things in life to start to back away from is never easy," says Dr Douglas Hobson, Professor of Neurology at the University of Manitoba.

That means seemingly simple tasks like making a sandwich, remembering why you popped out to the grocery store or learning how to use the new DVD remote become increasingly difficult.

Fortunately, there are a number of strategies that can help you put the mental puzzle pieces together, like these tips from Marla and her predecessor at the Manitoba Resource Centre, Sandra Funk.

Use organizational tools. Place a large monthly calendar in a central location to organize family events and appointments, and use daily planners and to-do lists to help keep track of your schedule. Consider colour-coding your calendar entries and to-do lists: for example, one colour for appointments, another for household chores, and another for family events. Pill organizers can help you keep track of your medications. Finally, get into the habit of writing lots of notes. Even if you never look at them later, just writing them can help you remember.

Create environmental clues. Add physical reminders to your surroundings to trigger your brain. For example, put everything you need to

take with you in the morning on a table next to the door. Place post-it notes or signs around the house, such as a note on the door reminding you to lock it when you leave.

Leverage technology. There are gadgets for everything. Use them! Take advantage of tools like timers for meal preparation, kettles that shut off automatically and alarms on your watch, computer or smartphone for reminders.

Develop routines. Habits are very sticky. Whether it is placing your keys in the same spot by the door or following the same shower-shave-breakfast routine each morning, the more you can establish a predictable structure now, the easier it will be to recall down the road.

Break it down. When learning something new, break the information or instructions into bite-sized chunks. Write the steps down and give yourself lots of time to practice them. Patience and repetition are key to getting new information to stick.

Avoid distractions. Need to make dinner? Switch off the TV. Trying to listen to a phone call with other conversations going on around you? Take it to a quiet bedroom. Reducing distractions helps your brain focus on the task at hand.

Adopt a healthy lifestyle. Regular exercise isn't just good for your body, it also benefits your brain. So hit the gym, head over to the pool or just take a walk around the block. A diet rich in fruits and vegetables and lots of water can also sharpen the mind, while drugs and alcohol will dull it. Finally, treat your brain like a muscle and keep it fit with activities like reading, playing card games, doing puzzles and socializing with friends.

Go easy on yourself. When those puzzle pieces refuse to snap into place, it is easy to feel frustrated, angry or scared. Unfortunately, those feelings can further gum up the brain, making it even harder to recall information. Instead of getting wound up, take a deep breath and show your brain a little compassion. This is just a sampling of strategies on improving memory.

*Acknowledgement: Huntington Society of Canada, "Horizon", No 149, Spring 2016
www.huntingtonsociety.ca*

Nancy Wexler Receives the First Muller Award

for Contributions to the Understanding of Genes and Society Recognition for Advancing the Understanding of Huntington's Disease and Other Devastating Brain Disorders

Dr Nancy Wexler, President of the Hereditary Disease Foundation and Higgins Professor of Neuropsychology in the Departments of Neurology and Psychiatry at Columbia University, is the first recipient of the Hermann J. Muller Award for Contributions to Our Understanding of Genes and Society. The award, which was presented on April 25 at Indiana University, Bloomington, USA, recognizes luminary international geneticists whose discoveries have or are making a significant impact on the field of genetics and society.

In 1983, after many years of painstaking research, Dr Wexler and a collaboration of scientists, organized and supported by the Hereditary Disease Foundation, discovered the genetic marker for Huntington's disease. Ten years later in 1993, after launching an international collaboration of more than 100 scientists, they found the Huntington's gene itself. These discoveries played an important part in the development of the Human Genome Project, and also have implications for finding treatments and cures for other brain disorders, such as Alzheimer's, Parkinson's and Lou Gehrig's disease.

In selecting Dr Wexler for the prestigious Muller Award, the awards committee said, "Dr Nancy S. Wexler is a perfect example of the high calibre genetic research that has an enormous impact on human lives."

In addition to receiving the inaugural award, Dr Wexler presented the first Muller Lecture series. In her talk entitled, "Mendel, Muller, Morgan, Mom and Me," Dr Wexler discussed how she was influenced by gene hunters like Morgan, Muller, Mendel and her own mother, who received her master's degree in biology from Columbia University. She recounted the highs and lows of her career as a gene hunter starting in 1979, when she first travelled – in search of the HD gene – to a small village in Venezuela that is home to the world's largest family with Huntington's disease. This Venezuelan family now comprises more than 18,000 people over 10 generations. She continues her quest today to find treatments and cures for Huntington's disease and other devastating brain disorders.

Dr Wexler says, "I am humbled and extremely touched to receive the first Muller Award, and I accept it on behalf of the millions of patients and

families around the world impacted by Huntington's disease and other brain bandits. As gene hunters and scientists, we work for years toward goals that can seem elusive. But, we always have before us the human suffering of those whose lives have been shattered by disease. Bringing them hope and healing is what motivates us every day."

The annual award and lecture series was established in 2016 to honour Professor Hermann Joseph M. Muller (1890-1967), renowned geneticist, Nobel Laureate, social activist, and an esteemed member of the faculty of Indiana University, Bloomington. Dr Muller is best known for his ground breaking work on the nature of mutations, but he made many other seminal findings using the fruit fly, *Drosophila melanogaster*, a powerful genetic model that remains a major focus of research at Indiana University Bloomington.

The Hereditary Disease Foundation

The Hereditary Disease Foundation is dedicated to finding cures and treatments for Huntington's disease and other devastating brain disorders that impact millions of people in the United States and worldwide. Established in 1968, the Hereditary Disease Foundation facilitates collaborative and innovative scientific research to further the understanding of Huntington's disease, a genetic disorder that strikes in early to mid-adulthood, destroying brain cells, and bringing on severe and progressive declines in personality, cognitive ability, and mobility. It was work organized by the Foundation that led to the discovery of the genetic marker for Huntington's disease in 1983. The Foundation organized and funded a decade-long international collaboration of over 100 scientists who discovered the gene that causes Huntington's in 1993. This work played an important role in the development of the Human Genome Project. As a disease caused by a mistake in a single gene, Huntington's disease is an ideal model for other brain disorders. Progress toward treatments and cures for Huntington's disease can help in finding ways to treat other illnesses with more complex genetics, such as Parkinson's, Alzheimer's and Lou Gehrig's Disease (ALS).

Acknowledgement: Hereditary Disease Foundation
<http://hdfoundation.org/>

Planting Trees Together:

The 2016 Huntington's Disease Society of America Convention

HDBuzz summarizes the science from an unusually large and energized HDSA convention in Baltimore, By Dr Jeff Carroll

Nearly a thousand HD family members converged on Baltimore, Maryland for the 2016 Huntington's Disease Society of America's Annual Convention. We normally don't write reports from patient and family conferences, but there was something special about the atmosphere of this year's Convention that compelled us to pen a brief update.



The Convention

This was the second-biggest convention in the HDSA's history, and HDBuzz co-founders Jeff Carroll and Ed Wild were there to talk science. You can see a video of our presentation on YouTube and hear the audio in the latest edition of our podcast, HDBuzzCast. Many of the other talks are featured on the HDSA website.

Clinical trials

According to the Huntington Study Group's HD Insights Publication, there are currently **thirteen** clinical trials recruiting or in progress in Huntington's disease, some of which are testing treatments specifically designed with HD in mind, rather than drugs thought to be generally good for brains. This is an incredible time for HD families.

Good news from the 'gene silencing' trial

Ed Wild gave an update on the trial of Ionis-HTTRx, the first 'gene silencing' or 'huntingtin-lowering' drug that's ever been tested in human HD patients. Speaking on behalf of the sponsor, Ionis Pharmaceuticals, Ed reported that the trial began in September 2015 and that 5 clinical sites are now up and running. In an exclusive HDSA update, he announced that there have been no safety issues with the drug so far, and the trial's independent safety committee had just approved the start of the third of four dosing levels. This is the best news we could have expected at this stage in the trial, and we eagerly await further updates.

Where do I sign up?

How can HD-impacted people get into a clinical trial? In the US and Canada, the answer is HDSA's TrialFinder system. You enter a few basic details and within a minute you will see a customized list of what studies you may be eligible for in your area, with links to the research teams.

What if I'm not eligible?

Clinical trials can be hard to get into because each one has strict criteria for who's eligible and who's not. If you find there's no drug trial near you that you're able to take part in, don't lose heart. Here's our 3-step plan for finding the silver lining.

"We need to recruit all active trials as quickly as possible."

Sign up for Enroll-HD, a platform for understanding HD and a database for recruitment into future clinical trials. Virtually all HD family members are eligible, even people who haven't had a genetic test.

Be a trial wingman: spread the word about trials and research on Social Media and in person to your friends and family. Can you volunteer to help someone else be in a trial, by accompanying them to appointments or helping them complete trial activities?

Take part in observational studies – that's HD research that doesn't involve testing new treatments. These studies are essential because they help bring about the next generation of treatments and trials.

Innovation

Although the HDSA convention isn't a science meeting, we were surprised by the amount and quality of innovative new projects we heard about there. Our personal highlights were:

- **CHDI Foundation** linking up with IBM's Watson supercomputer platform to understand HD, like modeling the huntingtin protein and how it's affected by the HD mutation
- Hearing directly from Teva Pharmaceuticals' Dr David Stamler that they remain committed to getting **SD809** licensed for HD. SD809 is a slow-acting form of tetrabenazine for HD movements that the FDA recently requested

more information about. Stamler was unequivocal: "The FDA did not reject the application ... they asked for addition information and analyses ... There were no safety concerns that were raised by the Agency ... Teva is doing everything in its power to bring this medicine to the market as quickly as possible."

- Azevan Pharmaceuticals' STAIR trial, investigating whether their drug SRX246 can help with the common and very challenging symptom of **irritability** in HD.
- Wave Life Sciences, engaging early with the HD community to talk about their programs to develop new 'gene silencing' drugs to lower production of the mutant huntingtin protein. Wave's approach aims to take advantage of a quirk in chemistry. Most drugs are actually a mixture of 'regular' and 'mirror-image' versions of the same drug that have the same basic structure but can behave slightly differently. Wave hopes that by eliminating the mirror-image versions, their silencing drugs will be more powerful. If this works it'll be pretty cool.

Planting trees

In our regular research roundup, we compared Huntington's disease research to a tree, rather than the 'pipeline' you may have heard about before.

The roots of the tree are the global HD community; the trunk is the 'basic' laboratory research that happens every day and helps to keep new drugs coming; the branches are the observational research involving human volunteers that helps us understand HD and develop new drugs; and the leaves are the clinical treatment trials that let us test those drugs.

We like this image because all parts of the tree are interconnected and depend on each other to produce the fruit we all need: effective treatments for Huntington's disease.

Acknowledgement: <http://en.hdbuzz.net/>



Enrolment for the Enroll-HD study continues at Westmead Hospital. This international study presents an opportunity for all family members affected by Huntington's disease to be involved in research. The study is an international collaboration, with study sites in the USA, Europe, South America and Australia. As of June 2016, over 11,000 participants had been recruited world-wide.

The study is 'observational'. It is not a drug trial, but a way of gathering a large database of information to prepare for the next phase of research. Study visits are similar to usual clinic visits, comprising questionnaires, a physical examination, memory testing and blood collection. The main focus is on gene carriers, either affected or not, but the study is also open to the whole family.

The study involves a baseline visit followed by one visit annually. The first visit is the longest, and takes about two and a half hours. Studies after this should be around an hour. The Enroll-HD website is a great source of information about the study. You can find more information at the website, www.enroll-hd.org

The study organisers hope to recruit 20,000 people at risk or with HD worldwide. We are told that the study is designed with privacy concerns being paramount, and all information collected is de-identified. It is also possible to withdraw at any time.

The study involves once yearly visits and takes about 2½ hours. It is open to all HD family members.

If you are interested in participating in this exciting new study which represents the next phase of research into HD, you can contact the study coordinator, Therese Alting, at the Westmead HD Service. Telephone 9845 6310 or 0438 604 719 or email her at therese.alting@health.nsw.gov.au

Carers' Support Group

Huntington's New South Wales and
Huntington Disease Service – Westmead
Hospital

*invite you to
come along to our*

CARERS' SUPPORT GROUP

*for a 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.*

Sessions will be held at
Huntington's NSW Offices
21 Chatham Road, West Ryde NSW 2114

Dates for the remainder of 2016

17 August, Wednesday, 10.30am
5 October, Wednesday, 10.30am*
9 Dec, Fri, Year-end Get-Together (TBC)

* Denotes School Holidays

*To RSVP and for further information, please
contact either: Jet Aserios or Cecelia Lincoln, SW
Department, Westmead Hospital on 9845 6699 or
Robyn Kapp, Huntington's NSW on 9874 9777*

Central Coast Support Groups

There are two support groups for HD families on
the Central Coast.

1. The Support Group is for all members of
the HD community—carers, supporters,
people with HD, people at risk.
This group usually meets on the last
Monday each month at 7pm Niagara Park
Stadium, Washington Ave Niagara Park.
2. Carers morning coffee are for carers only
and are generally held two weeks after the
support group meeting on a Saturday
morning. Past and present carers share
their ideas and knowledge.

If you would like to know more about these
groups and details of dates, times and venues
please contact Dianne Faulkner on
04106 8604 or at
huntingtons.centralcoastnsw@gmail.com

Tips for Caregivers and Family Members

Incorporating cues into your questions
makes it easier for someone with HD to
find answers. So instead of asking "When
is your dentist appointment?" ask "Is
your dentist appointment this morning or
this afternoon?" When you need to
communicate something, break it into
chunks and wait until you're sure one
piece has sunk in before you move on to
the next.

www.huntingtonsociety.ca

Providing Hope for the Future

Over the years we have received some
wonderful donations in the form of
bequests. One enabled us to purchase our
premises in West Ryde and another
provided funds for our regional support
program. We are most grateful to those
who remember Huntington's NSW in their
wills.

Gifts like these mean that we can put more
funds into the support we are able to
provide for families impacted by
Huntington's Disease across NSW and the
ACT, particularly for people in regional
areas and young people.

Once your family is provided for,
Huntington's NSW would be most grateful
for your gift. Leaving a gift to the
Association in your will is easy and if you
are considering changing or making your
will please contact Pauline Keyvar or Robyn
Kapp (02) 9874 9777 for a confidential
discussion. For further information our 'will
wording' is on our website
www.huntingtonsnsw.org.au.

Do you have a story to share?

If you have a story that you would
like to share in "Gateway" please
contact Robyn at
robyn.kapp@huntingtonsnsw.org.au



Huntington's New South Wales

PO Box 178, West Ryde, NSW 1685
21 Chatham Road, West Ryde, NSW 2114
Telephone: (02) 9874 9777
Free Call: 1800 244 735 (Country NSW only)
Email: info@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: Deb Cockrell
Treasurer: Richard Bobbitt
Secretary: Therese Alting
Members: Felicity O'Neil & Katy Clymo

Association and Other Useful Contacts

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