



Gateway

News from Huntington's New South Wales

Volume 17 No 3

Spring 2014



Thank you so much!

September Awareness month was an amazing success with a number of activities creating awareness of HD and raising much needed funds. The SALVO STORES partnership was a fantastic opportunity for us to promote HD and the Association in the wider community as well as giving us access to good media exposure. Not only that, they also collected donations for Huntington's NSW and Huntington's Queensland.



Our inaugural Walk 4 Hope was fantastic—two walks were held—one in Speer's Point on Lake Macquarie with around 300 people taking part and in Parramatta Park on a beautiful sunny Sunday with 30 kg of sausages consumed! It was a sea of pink and green with people travelling from the Central Coast, Coffs Harbour, Wagga, the ACT and Trangie to take part. We are planning on making Walk 4 Hope an annual event so can I encourage you to come on board next year when we'll be celebrating our 40th anniversary.



I would like to take this opportunity to say a very special thank you to our Fundraising & Marketing Consultant, Pauline Keyvar. Although Pauline has only been with us a short time, she was the driving force

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Annual General Meeting

The Annual General Meeting will be held on Saturday 8th November 2014 at 1.30pm at Camp Breakaway, 80 Highview Ave, San Remo

The Business of the Meeting is to

1. To accept the Minutes of the 2013 AGM
2. To accept the Annual Report of the Association
3. To accepted the audited Annual Financial Statements of the Association
4. To appoint the Auditor for 2014/2015
8. To elect the Office Bearers and Board Members

Nomination forms for the Office Bearers and Board elections are available upon request. Please contact the office if you would like one sent to you. Completed forms should be returned to Huntington's NSW no later than Friday 31st October 2014. Nominations may also be made at the meeting.

Note: You need to be a financial member to be able to nominate or vote. However non-members are very welcome to attend.

you decide where it goes!
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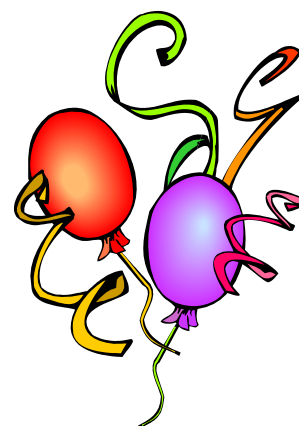
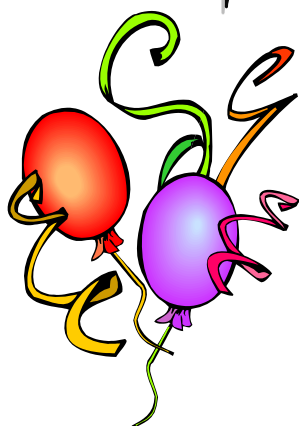


Please keep sending in your photos of families and friends with Dick Smith Foods. As we go to print we are currently in 14th position and well placed to receive a donation of \$10,000.

For more information go to <http://www.dicksmithfoods.com.au/charity-breakthrough>.

Thanks to all those who have submitted photos—we still have two months so keep up the good work!

Family Fun Day & AGM



Saturday 8th November 2014

10.30am—3pm

**Camp Breakaway
80 Highview Avenue, San Remo**

Program:

10.30am	Morning Tea
11am— 12.30pm	Fun for everyone Putt Putt Golf Bocchi Croquet (HNSW rules!) Kids' Playground Face Painting
12.30pm—1.30pm	BBQ Lunch
1.30pm—3pm	Guest Speaker— <i>The Face behind W4H</i> —Meet <i>Pauline Keyvar</i> AGM

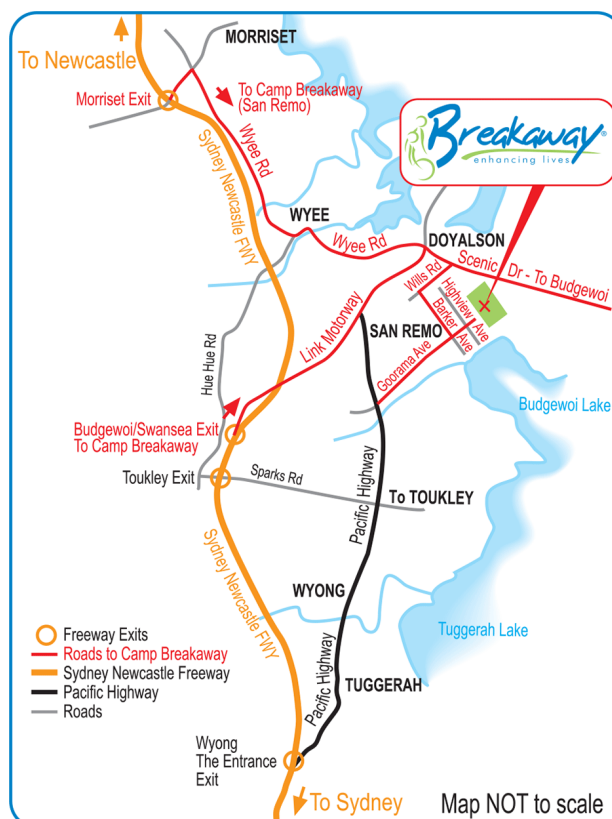
This will be a great day for all the family with lots of fun for everyone.

Come along and check out where we hold our Holiday Camp, meet other families and catch up with friends.

Our guest speaker is Pauline Keyvar, our Fundraising & Marketing Consultant. Pauline will give us a glimpse of what is involved in fundraising and the importance of marketing for organisations such as ours.

It would be most helpful for catering purposes, if you would let us know if you're coming by telephoning 9874 9777 or emailing info@huntingtonsnsw.org.au.

We do hope you can make !!



Twelve Years of the PREDICT HD Study

At the end of August 2014 the last visit for the PREDICT-HD study, which has run for over 12 years, took place.

The research study followed participants with the gene expansion for Huntington Disease who were not affected when enrolled in the study and compared them with those without the gene expansion, over 12 years or until the time of early diagnosis.

Some participants have continued with the study over the 12 years in the two components of the study PREDICT and PREDICT-HD 2. This has been a landmark study lead by Principal Investigator Dr Jane Paulsen from the University of Iowa in the United States of America and funded by the National Institutes of Health (NIH) as well as the philanthropic HD research funding organisation, CHDI, Inc. (Cure Huntington Disease Initiative). Investigators from 32 sites from around the world, including Westmead Hospital, participated. Hundreds to thousands of research visits were conducted each year. The collected information has been used in over 90 research publications about this early "prodromal" phase of the disease (i.e., the time leading up to HD diagnosis). In addition the information has been combined in some studies to learn more about the nature of the genetic changes related to the expansion in the gene and how it produces the disease. The information has also contributed to the hunt to find other factors that may influence the course of HD.

Dr Paulsen and her team in Iowa have shown exemplary leadership. The statistical back up team who manage the collected data need to be acknowledged. More than anyone however the dedicated participants and their families who have been involved in this important study need to be acknowledged, for without them this would never have been possible. We now know that subtle changes are taking place in the lead up to diagnosis. The hope now is that many of these subtle changes will be sufficient to allow for reliable measurement at this earliest phase of the disease so that clinical trials could be possible, with the aim of slowing or preventing HD. Many factors will influence this, including the safety of any trial medication as well as the pattern of changes in a particular person (e.g., early motor effects, or cognitive, or behavioural, or a combination) and the likely time from diagnosis.

While the data collection phase for Predict HD has ended the plan will be to continue to use the data collected for ongoing studies and research publications. We need participants to keep in touch as our hope is that there will be more studies in the future.

On behalf of the research team at Westmead Hospital we thank all those who were able to participate and contribute to this important research. With your involvement our Australian Westmead site had a considerable input to this landmark study that has increased our understanding of the very earliest phases of HD and will lead to future studies including the possibility of very early prevention trials.

Elizabeth McCusker Clement Loy
Jillian McMillan Jane Griffith Emily Hayes

HDYO Australia Tour 2014: Taking a stand against HD



Join us for an evening of inspirational speakers on how they face HD and how you personally can do your bit towards overcoming HD and life's obstacles in general.

To celebrate the merger of HDYO and the Australian HD Youth Alliance, HDYO is doing a two week tour of Australia in November to spread awareness of HDYO, what we do, youth support and to inspire HD family members through a wonderful series of educational events. The first of which will be held in Sydney on **Sunday November 23rd at 4pm until 6:30pm** at:

West Ryde Hall
1A Station St, West Ryde

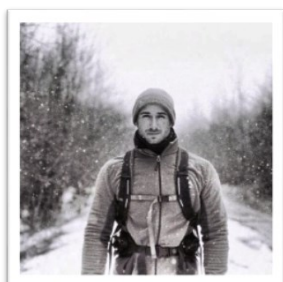
West Ryde is well serviced by both buses and trains. There is parking available in nearby streets.

During the wonderful event you will hear inspirational and positive talks from:

Matt Ellison, Founder of the Huntington's Disease Youth Organisation (HDYO), who will share his inspiring journey from being impacted by HD to setting up a global non-profit organisation. Matt will also talk about the exciting merger happening in Australia between the HD Youth Alliance and HDYO to create HDYO Australia.



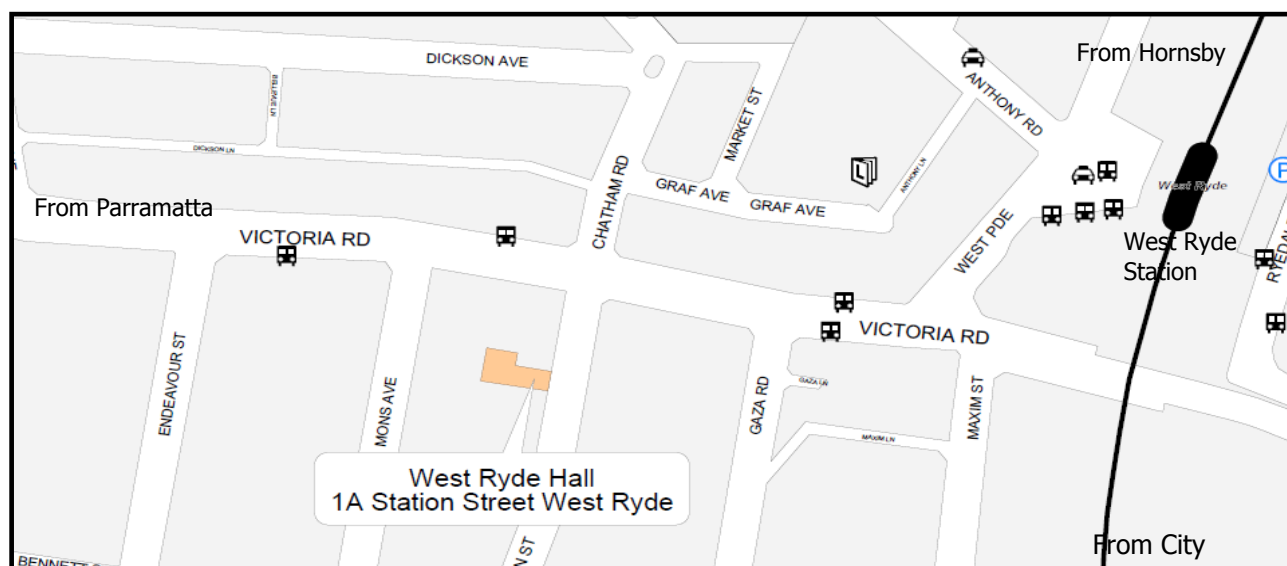
Lysle Turner, Founder of Turner Together, from South Africa. A young man who has participated in several adventures to raise awareness of HD in South Africa and is now taking on Everest in 2015 to raise global awareness of HD.



Kris King, from the UK, who inspired a nation and beyond this year with his phenomenal challenge to run and cycle his way around the coast of the UK.



To RSVP or if you have any questions regarding the event, you can contact Matt Ellison (matt@hdyo.org) or HNSW (info@huntingtonsnsw.org.au).



'It's a Neuro Thing' – Life with Huntington's Disease

We all learn to adapt to the change in our lives. A new job takes our career in a different direction, a new home helps us downsize the clutter. Life is filled with constant change. But when you find out you have Huntington's Disease (HD), the threads of life begin to unravel. Change becomes survival. Adapting becomes as vital as the air you breathe.

HD strips away the brain one function at a time. We could talk about genes, and repeats and DNA markers, but this is what it boils down to: your thinking is slower, keeping focus is more difficult, you stumble, you fall, it is harder to plan and organize. The people around you don't seem to be answering your questions fast enough, yet when they listen to you they must allow extra time for your delayed response. Jimmy Pollard calls this, "*hurry up and wait.*"

Everyday life is a struggle. As the disease progresses you lose the ability to care for yourself and become dependent on others. Trapped inside a body that once was strong and vibrant, life is now frustrating and fragile. It's hard not to be depressed about the direction things are headed. You savor the moments when others drive you to your favorite gas station to grab a soda; or to the lake just to feel the breeze and see the water; or take you to the ballpark to watch your favorite team win – things most people take for granted.

If only they understood how much it meant to you, and how much they mean to you. The person with HD, deep down, knows that life goes on around them. Their caregivers go to work and have responsibilities. But the part of their brain that functioned in that capacity doesn't work right anymore. They are not the same person and that puts stress on the families who love and care for them.

Darwin once said that those most adaptable to change are the survivors, not the strongest, or the most intelligent, but those that take change in stride. A family living with HD is the prime example.

"Princess Elsa"

For personal reasons, our first HD story has

fictional names. Her love of spending time watching princess videos with her young daughters gave way to the names chosen to tell her story.

This is the story of Elsa and Christopher. They have two daughters Anna, 7, and Sofia, 2. Elsa was a runner her whole life. She participated in four, half Iron Man triathlons as well as many other athletic events. Swimming, biking and running for miles and miles were her passion. Then she started falling. "I knew something wasn't right," said Elsa, remembering crashing her bike, stumbling in the race and skinning her knee. "It wasn't normal for me."

Christopher noticed changes, too. The changes started not long after their second daughter was born, so he feared it was related to the pregnancy. Awkward movements, slurred speech, getting 'locked' on a topic. But what 30-year old woman wants to hear the love of her life tell her that something might be wrong.

A visit to see extended family brought the subject to the forefront again. They noticed the change in Elsa's behavior and mannerisms as well. Together with Christopher, their family pointed out things that Elsa couldn't deny and eventually got her to acknowledge what they were seeing, and what she was feeling.

As a tenured first grade educator, Elsa was the lead teacher for her grade level and took pride in her classroom. She tried desperately to maintain her job while searching for answers. After a battery of tests and no definitive results, her medication was adjusted to help with anxiety. Christopher continued to keep in contact with the Principal at the school who was also seeing changes in Elsa.

Elsa's family was spread out and somewhat estranged, so when talking to neurologists, she had no family history to offer. Doctors focused on curable diseases first, but as they worked through the tests, Elsa's symptoms continued to change and then they would have to do the tests again. A full genetic work-up was ordered this time around.

While the testing carried on, Elsa used social media to try and contact some of her estranged family members to ask about genetic disorders or diseases that might have run in the family. Her paternal Grandmother eventually responded and shared that Elsa's father had been diagnosed with HD just two weeks prior. Elsa's paternal Grandfather was also later diagnosed with HD. His symptoms had previously been thought to be related to years of alcohol abuse, but was tested after her father's diagnosis.

"We never knew anyone with HD before, but we were willing to learn," said Elsa.

Christopher called a well-known, and recommended, HD doctor in the area and pleaded for an appointment. It was April, and they set the appointment for early the next year, which wasn't good enough, but it was all they had available. Elsa tried to go back to teaching in August but her symptoms had worsened and she was unable to function in the classroom she so loved.

The roller coaster of change was starting to wear on the family. They just wanted confirmation and direction. Christopher kept calling the doctor's office hoping to slip in when there was a cancellation. In October they caught a break. With one look, the doctor knew Elsa was suffering from Huntington's Disease. "It took us almost two years to figure it out," said Elsa. "Our lives were turned upside down."

Elsa and Christopher, who met in high school English class, have been married 11 years. Before the diagnosis they had a typical marriage where Elsa was the organizer and kept the household going.

"It's a difficult position. We created a schedule for her while I'm at work. She follows it and checks things off," said Christopher. The routine is in 15 minute increments and helps Elsa go through the day with their two -year-old daughter, Sofia. Things like teaching Sofia her letters and numbers, potty training, fixing lunch, all things Elsa is still capable of in moderation. She just needs reminders. "The routine is helpful. (Christopher) helps me a lot. When he asks me questions, he only gives me two choices at a time now," said Elsa. "We had a lot of change in a short amount of time."

Christopher learned from HD speaker and author

Jimmy Pollard that people with HD have difficulty with too many choices. Open-ended questions require more thought and can cause frustration. Simple choices are much easier for someone with HD to handle.

The weaning away of her freedoms has been devastating as well. HD takes away all your independence – even the ability to run simple errands. "I was depressed at first," said Elsa. "To give up driving at the age of 32 is very hard. It was overwhelming. I started thinking about dying, and not seeing the girls graduate or get married."

Elsa says writing letters to the girls to be read on special occasions has helped her some, in case she's not there to share it with them. "I just want to enjoy the time I have with them." And she does. They play outside, read books, watch Disney movies and play in the pool, just like other families. Elsa just can't do it alone.

"You learn who the important people in your life are and who truly cares." Christopher's family has stepped up and become a huge support system, as well as Elsa's former colleagues at the school where she taught. Some take her to church where she says the Bible studies are helpful. And, a year ago she and Christopher found the Liberty HD Support group.

Most people, including health professionals, do not even know what Huntington's Disease is or how it affects many lives in Missouri and around the world. The Liberty Support Group is a haven where family and friends of those with HD can come together and be reminded they are not alone. Members of the group exchange ideas, resources and enjoy the camaraderie. "I am so thankful we found the support group. It's been a life-saver in a million ways."

"Alice"

Statistics show that Huntington's Disease has an average onset age of 35-45 years old. Medical journals say that symptoms can include chorea and speech trouble. Alice Swenson of Smithville is 63, and does not fit the mold, but she has Huntington's Disease.

Her first experience with HD was when she was growing up, though she didn't know that's what was. "When my Grandma started acting different, mood swings and things, they thought

it was the grief over losing a child in a fire. Sometimes Grandpa would simply lock her up," said Alice of her visits to see her grandparents. "We were all a little wary of her actions...it was scary at times because we didn't know why she acted that way."

The same grandmother attended her wedding to Wendell. But when Alice's father chose to leave the family when Alice was only 22, her grandmother was already in the nursing home where she would live out her days. Alice still had no idea what Huntington's was.

Her whole family became estranged after her father left. It wasn't until 2005 when she made contact with one of her brothers, she noticed his huge movements and that he could not sit still. They took him to a neurologist to find out what was wrong. After examining her brother, the doctor told them, "If you had Huntington's in your family, I'd swear that's what it was."

She looked up her father who was in a nursing home out of state. He told them he didn't have Huntington's before she even asked about it. He was in denial and refusing proper care. She and Wendell worked together and learned as much as they could about the genetic disease. They attended their first HD conference in Arizona and met a lot of families going through the same thing. She became consumed with research and information. She wanted to understand genetic testing and be a part of it.

In 1998, her family reunited for her grandfather's 90th birthday. It wouldn't be until seven years later that she realized there was HD in her family. She had a conversation with a sibling and found out they knew all along but didn't share the discovery with others. "He said, 'I kind of went around the room at Grandpa's party and picked out the ones with HD.'"

She was frustrated, devastated, and on a mission. A mission to find a cure. And the more people that participated in research, the more chances there were at finding one. "My goal from the beginning was to involve the kids and grandkids," said Alice. She spent nine years in the Predict HD study in Iowa City, Iowa and is now working with the Enroll HD study. She is also on the list to test "gene silencing" when they begin to test humans. "You kind of get addicted to the research part, or at least I did,"

said Alice.

All three of their children and four of their seven grandchildren travel to Iowa to be a part of the testing, in hopes their contribution to research will help find a cure. Once, when she and Wendell were shopping at an outlet mall in Iowa after a research visit, Wendell noticed a woman who was clearly showing signs of HD. Alice was inside a store, so he waited until the woman went into the store and then politely asked the man what his wife was afflicted with, he answered 'Huntington's'.

"We talked for a while, but once I sicked Alice on them about research, 10 days later they were enrolled in a study." Wendell said smiling.

For Alice HD is internal, the anxiety, restlessness, a "wobbly" day, not sure of herself. She is in her 60s and has a gene repeat of 40, but her symptoms don't show the chorea and speech troubles, like most.

Alice gets frustrated when people chock up her internal symptoms to age. "It's irritating, they don't understand." She goes onto explain. "I do not have movements, but I am sick. Sometimes the chorea doesn't show up as pronounced. For some people they can't hold a job because they can't manage the tasks, some people are exhausted and depressed, can't remember things or go off into their own little world. But it doesn't mean they don't have HD."

She has four brothers and one sister. Of the six siblings, five have Huntington's and one is living at risk. But the statistics don't stop her. She continues to do everything she can to help find a cure.

"I have a great motivator, my family. We are close. Wendell and I have been married 45 years. Our family is our life. To see any one of them develop Huntington's Disease would be devastating. That is why we work so hard to raise awareness and find a cure."

Acknowledgement: Becky Black, "The Leader", Plattsburg, Missouri, USA, 10th October 2014

Western Wanderings

During September I travelled out west of the state. As always, it was a great trip, meeting up with lots of people, but this one was very special for two reasons..... a morning tea in Cowra attended by 17 people, and one in Forbes where 11 people came along.

Why was this special? We had not held morning tea meetings in these towns previously, and I was not sure whether people would attend, and then how they would interact with others they had not previously met (and I had not met several of those attending either).

So on Tuesday, in the beautiful setting of the Japanese Gardens Tea Rooms at Cowra, people gathered, and talked, and talked, and cried, and talked some more. They shared HD stories with others who could relate.....it was inspiring.

I had booked a table till midday, but people were having such a good time that we continued on until the last people left at 2.15pm. Many exchanged phone numbers, and no doubt will be in touch, and all cannot wait till our next get together.

On Thursday it was Forbes. Eleven people met in the delightful Mezzanine Café. Again, this was a great time of people sharing stories and building relationships.

A big thank you to Cowra Japanese Gardens Tea Rooms and Forbes Mezzanine Café for both making us so welcome and looking after the groups.

With these morning teas being so successful, it would be great to see more such meetings around the state. Perhaps you are interested in being part of a morning tea in your area. If so, please let Mark Bevan know on 0410 629 850 or at mark@huntingtonsnsw.org.au and he will try to organise something to suit.

(Continued from page 1)

behind Walk 4 Hope and it was her commitment and enthusiasm that spurred us on to make our first Walk 4 Hope so successful.

Donations are still coming in, however we do know we have raised over \$72,000—what a wonderful achievement!

We are also very grateful to the many sponsors who supported us during September.

They included

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True Blue Quality Meats, Wyong
Free Choice Tobacconist, Wyong
West Gosford Fruit Spot
West Gosford Newsagent
Henry Kendall Family Tavern
Southern Sun Healthcare Pty Ltd

And last, but not least, a huge THANK YOU to everyone who contributed in any way to HD Awareness Month 2014.

In friendship

Robyn Kapp
Executive Officer



Melatonin alterations in HD help explain trouble with sleep

Many people with Huntington's disease have problems sleeping. Sleep-wake cycles are controlled in part by melatonin. Melatonin is a hormone produced by the pineal gland, important for regulating sleep, a hormone that makes you drowsy at bedtime. Scientists in London measured melatonin levels in HD patients, gene carriers, and unaffected individuals and found changes in the levels and timing of melatonin release. This could help to explain the sleep disruptions that occur in HD.

Sleep can be elusive

If you've ever been in bed with your mind racing, wishing for sleep, you know that slipping into dreamland is far less simple than it seems. In fact it requires a lot of complex coordination by different parts of the brain to get your body in tune with the darkening world, leaving you drowsy enough to fall asleep and restful enough to stay that way till morning.

We know that people with Huntington's disease sleep poorly: nearly 80% of Huntington's disease sufferers experience sleep disturbances. These can include an increase in the length of time it takes to fall asleep, changes in what the brain is doing during sleep, and decreases in the amount of truly restful sleep. It's not well understood why these disturbances occur in HD, but a new study highlights changes in levels of melatonin, a chemical that regulates sleep and wakefulness in relation to the rising and setting of the sun.

Brain control of sleep

Our predisposition for night-time sleep and daytime activity is just one of many circadian rhythms, a term that refers to anything that changes within our bodies on a 24-hour cycle, and can be synchronized with what's happening in our environment. Lots of human behaviors are rhythmic or change predictably over the course of a day. Not only sleep and alertness, but also digestion, body temperature, and the immune system change depending on what time it is. We've talked about sleep and circadian rhythms in Huntington's disease before.

These rhythms are overseen by a brain region called the suprachiasmatic nucleus, or SCN. The SCN acts as the brain's timekeeper, coordinating the body's activities over the 24-hour day. Neurons in the SCN are perfectly situated to communicate with cells from the eyes that describe how much light there is in the

environment. With this information, the SCN can send out a message to other brain and body areas telling them what they need to do to keep their cycles running smoothly.



Melatonin is a hormone that helps the brain decide when to sleep and wake.

Because of the resulting circadian rhythms, levels of all kinds of substances made by the body can fluctuate normally with the amount of light outside, and melatonin is an important one. Melatonin is a hormone, a chemical messenger that circulates in the blood. It is produced by an organ deep in the center of the brain called the pineal gland. As the sun begins to go down, the SCN senses the change in light and sends a message to the pineal gland to start secreting melatonin. Melatonin helps to regulate sleep cycles by causing drowsiness and lowering the body's temperature a little in preparation for sleeping through the night. Melatonin levels are high throughout the night, but as the sun comes back up, they drop, corresponding with increased wakefulness.

Are melatonin levels altered in HD?

Since Huntington's disease patients have problems regulating the normal sleeping/waking cycle, a group of researchers in the UK led by Prof Tom Warner wanted to ask whether the rise and fall of melatonin levels in HD patients is abnormal compared to unaffected individuals. Previous studies had measured patients' melatonin at a single time point, early in the morning, but Warner's group wanted to monitor melatonin levels throughout the 24-hour cycle to get a better sense of how the rhythm of melatonin production is affected in HD.

(Continued from page 10)

They recruited 13 patients with moderate to advanced HD, and 15 people who do not have the HD gene. They also included 14 people who carry the HD gene, but had not yet shown disease symptoms. Each person involved in the study spent a day and night in a private room, under supervision by clinicians. They could walk around and do what they liked during the day, but they weren't allowed to nap, and the lights were out between 10 pm and 6 am. The researchers inserted an IV line so that they could collect a small amount of blood every hour, even in the middle of the night, with minimal interruption of the volunteers' sleep.

Melatonin in HD and gene carriers: lower levels and improper timing

Using a sensitive type of chemical analysis, the researchers determined the amount of melatonin in each person's blood, then compared the three groups with one another using a variety of statistical methods.

They found that the HD patients had much lower levels of melatonin in their blood than those without HD – around 85% lower on average. Presymptomatic carriers of the HD gene also had slightly lower melatonin levels than normal.

Another finding was that HD patients and gene carriers showed more variation in the time of day that their melatonin levels began to rise. Most of the volunteers without HD had a surge of melatonin around bedtime, while HD-affected individuals' melatonin levels rose at different times – some in the afternoon, some in the middle of the night.

An explanation for disrupted sleep in HD?

By consistently monitoring blood levels of melatonin for a full 24 hours in Huntington's disease patients, presymptomatic HD carriers, and unaffected control participants, this study showed that melatonin levels are indeed altered in HD, a finding which may help to explain why patients experience disrupted sleep.

The researchers go on to suggest that a low or poorly-timed surge of melatonin from the pineal gland could mean that there's something wrong with the timekeeper neurons in the SCN. Several different types of Huntington's disease mice have shown problems in sleep and other cyclic behaviors controlled by the SCN. Abnormalities in signalling chemicals produced by the SCN have

been found in HD brains, both human and mouse.

Back in 2011, we reported on a study in which melatonin treatment improved behavior and survival in Huntington's disease mice. It's not yet clear whether we can link that finding with the new discovery of decreased melatonin levels in HD patients. But sleep disruption can be a major source of stress and can worsen the symptoms of many diseases. Improving sleep through melatonin therapy, could be a positive change for the body and brain. However, it's not yet clear whether melatonin is effective in HD to improve sleep, let alone as a means of slowing down the progression of the disease.

A case for clinical trials of melatonin

There hasn't been a clinical trial of melatonin as a therapy for Huntington's disease patients with sleep disturbances, but this study provides good evidence of HD-related changes in melatonin levels, and suggests that a clinical trial might be warranted. Melatonin is already an approved supplement that many people buy over-the-counter or get on prescription, to adjust their sleep patterns. Some patients appear more responsive than others to melatonin and other sleep aids; perhaps this could be explained by the variable timing of melatonin production that this study found in HD patients.

Finally, these results don't provide any explanation for why changes in melatonin occur in HD. We can speculate that the SCN or its communication with the pineal gland may be disrupted, but the reasons for that are unclear. It's also fairly clear that changes in melatonin are only one of several things that can cause sleep disruption in Huntington's disease, and we're definitely not saying that every HD patient should take melatonin. However, these results make a solid case for a clinical trial, and importantly, the study provides one explanation for why it's so tough for many HD patients to catch some much-needed zzzs.

Acknowledgement: By Leora Fox , edited by Dr Ed Wild, <http://en.hdbuzz.net/>





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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: Don Ayres

Member: Jenny Coutts

Member: Amanda Dickey

Association and Other Useful Contacts

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