



# Gateway

News from Huntington's New South Wales

Volume 16 No 4

Summer 2013

## The Year in Review ...

At the Annual General Meeting held in November, the following were elected to the Board -

President: Brian Rumbold

Vice President: Deborah Cockrell

Secretary: Don Ayres

Treasurer: Richard Bobbitt

Members: Amanda Dickey and Jenny Coutts

*In the Annual Report presented at the AGM, Brian Rumbold wrote*

"Earlier this week our Executive Officer Robyn Kapp and I were excited to be at the opening of the new Huntington's unit at St Joseph's Hospital Auburn. As you know this represents a very happy conclusion to all the work that has been put in to resolving the closure of Lottie Stewart Hospital including its Huntington's unit. We were very impressed with the design and quality of the new facility, the obvious commitment of the management and staff to the residents and the sheer enthusiasm of the staff in their work.



*The Board & Staff  
of Huntington's  
NSW would like to  
wish you and your families a  
very Happy Christmas and a  
Peaceful 2014.*

On behalf of the Board of Huntington's NSW I particularly want to thank Dr Clement Loy for all the input he has had to getting this project to a successful conclusion. Seeing his commitment to the people in his care is inspiring.

Of course, at any one time there may be between 100 and 150 people in residential care in NSW and the ACT because of Huntington's; the new unit at St Joseph's provides 14 permanent places. So we are also grateful to the residential care organisations that, from time to time, have committed to taking Huntington's residents. However, overall, the way residential care for younger people works is not really satisfactory, especially if you are in a regional or rural location – the options are often very limited and not ideal. We want to see a more consistent and holistic approach to this problem: have the problem recognised by providers and governments and see better, longer term solutions put in place. As a Board we will work at developing the Association's advocacy in this area.

In our strategic planning a year ago we recognised that, especially for regional and remote families, accessing timely information and suitable health services can be really difficult. Our rural support worker, Mark Bevan, has no shortage of families and individuals to visit across the state. We believe the Family Support Service is providing a vital link for families into health and other

*(Continued on page 5)*

## Office Facelift continues .....



In September, "Elsie Court Cottage" received an external facelift with a new coat of paint. This was achievable because of a grant we received from the NSW Government's Community Building Partnership program. We are also gradually working on the gardens to complement the fresh, clean appearance of the cottage.



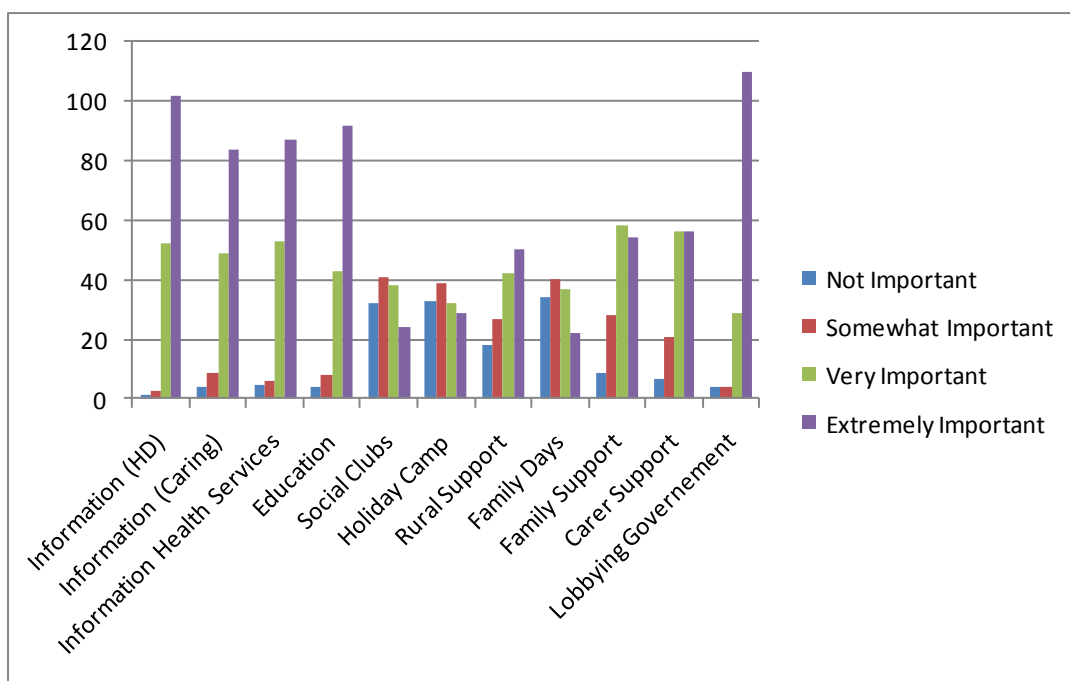
We have just received the good news that our application for funding to purchase new blinds for the office has been successful.

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

## Survey Results ... Correction

In some copies of our last printed newsletter, the graph summarising the results was incorrect. Below is the correct version. As we are still receiving completed surveys we have set the cut-off date of 31st December 2013 for responses to be included in the final results and analysis.

*Thank you again to all those who have participated—it is very much appreciated.*



## Raising Funds for Huntington's NSW

### ***Book Fair***

A very big thank to Matina Moutzouris, her family and friends for organising and running the Huntington's NSW Spring Book Fair held in October. We are most grateful to everyone who supported this project by contributing books, making generous cash donations and giving of their time.

As a result, they raised almost \$5,000 and the continue sale of books left over from the fair will allow for more funds to be raised!



### ***Christmas Shopping Expedition***

A wonderful day was had by all who set out from the Central Coast on their annual Christmas Shopping expedition. It's been described as the best yet with lots of laughter and wonderful purchases in time for Christmas.



Many thanks to all who joined the trip, which resulted in raising over \$2500 for HNSW. What a great effort. Special thanks go to those who donated raffle prizes and to the organisers—Dianne, Debbie, Jen, Holly and Amanda.

## Holiday Camp

I had the privilege of being a volunteer at this years Holiday Camp in November held again at Camp Breakaway on the Central Coast

Another great time was had by all and once again the weather was great and so were our seven participants. We had two new volunteers Caleb & Abby Chavez who brought lots of youthful energy to camp and were certainly a great asset helping in all activities and in any way they could.



The feed back from the participants was that it was so nice to have young people showing such an interest and having such a good time with them. Both Caleb & Abby expressed what a great privilege it was for them to be part of the Camp and hope to be able to volunteer again next year.

The time at camp was not only relaxing and lots of fun but plenty of activities were on offer. We played games (every one is a winner), took leisurely walks each morning along the beautiful lake, had craft in the afternoons, each night we had team games, and shared in the wonderful culinary delights cooked by Robyn (our special chef). We also had our own musicians, Caleb and Mark, entertaining us on our last night.

I would like to say a big thank you to Robyn, Lily and Mark the wonderful staff who put so much into making it all happen and of course the other volunteers and those very special participants who made our time together so memorable.

Like Caleb & Abby I too look forward to camp next year and seeing the old faces and hopefully some new ones joining in this special holiday at Camp Breakaway.

*Karen Bevan*

## On the road again ... Mark Bevan



Well, I cannot believe that Christmas is nearly upon us. I have to tell you – I have had a wonderful year. In the past few months, I feel like 'I've been everywhere man' (the old Lucky Starr song for those old enough to remember). Here is a snapshot ...

On Monday after a week working on the HD Holiday, it was off to the west and north west of the state. An early morning start saw a stop in the Blue Mountains, then on to Bathurst, Orange, Grenfell, Forbes, Dubbo, Mudgee, Wellington to name just a few places. This trip involved meeting with a number of new clients, as well as some I have known for a few years now.

A couple of weeks later, it was off to the Port Macquarie area, and onto the Far North Coast, up to the Queensland border, visiting people in Bellingen, Sawtell, Coffs Harbour, Grafton, Murwillumbah, Kingscliff, Lismore, Byron Bay and a variety of other towns. There is not much time for sightseeing along the way, although a couple of sights bear mentioning. I was caught in a hailstorm on the way in to Bellingen – the wind was amazing, and the hail horizontal, forcing all cars to stop by the side of the road. While parked there, I watched the water rise around the car, branches being ripped off trees, but there was nowhere to go as I could not see past the car bonnet, and so had to wait it out. Then that night I entered storm ravaged Sawtell, trees down on houses, branches all over the road, emergency crews working to clean up. Then for the rest of the trip, I seemed to be chased by very large storms, mostly staying just ahead of them – a relief, as there were reports of significant hail in some areas.

Having survived the storms in the north, two weeks later, I was on the road again for a very exciting trip to the South West, ACT, and South Coast (Goulburn, Canberra, Wagga, Gundagai, Tumut, Cooma, Bateman's Bay, Nowra and Wollongong area). Why was it exciting? All my trips are exciting, but this one in particular. I attended lunch with a number of families in Canberra, and amongst those folks was a new couple, and it was just great to meet them, while catching up with others I have known for some time. Goulburn saw meetings with some

new people, and also gave me the chance to catch up with an old 'HD friend'. Then Wagga Wagga saw about 20 people attend a morning tea at the Commercial Club. This was fantastic! A new family came along, and there were people aged from 2 to 77 in attendance. Thanks so much to those who came along – I have a feeling that this will be a regular event, and a number of people expressed interest in staying in touch with one another outside of these meetings.

With families struggling in regional areas and feeling isolated, with people not understanding HD, I am very keen to try to put families in touch with one another (if they are keen to do so) as an ongoing means of providing additional support amongst people who have had similar experiences.

I have also attended some recent Central Coast support group meetings. At a recent meeting, we watched a video from HDBuzz with Dr Ed Wild giving a summary of research initiatives. The people attending found it very informative and interesting. For those who are interested in HD research, I strongly encourage you to make [www.hdbuzz.net](http://www.hdbuzz.net) your first port of call.

I am still working on the Skype initiative I mentioned previously, and would love to hear from you via Skype if you use it. Remember, it is FREE, and EASY. Call me if you need help setting it up on your computer. Then you can 'Skype' me – my Skype ID is Mark.Bevan49.

I just want to take this opportunity to wish you a blessed Christmas and 2014, and thank you to so many who have supported and encouraged me during this past year.

**And don't forget.....** If you live in regional NSW, and would like to catch up when I am in your area, please email me at [mark@huntingtonsnsw.org.au](mailto:mark@huntingtonsnsw.org.au) or give me a call on 0410 629 850. I look forward to hearing from you.

*Mark Bevan*

*(Continued from page 1)*

community services, and it is giving families and individuals someone they can talk to who understands their situation and needs. We are working to better understand the benefits the Service delivers to families so we can look for more funding and extend its reach across NSW and the ACT.

The Board wants to thank all those who have generously given both time and money over the last year to support the Huntington's community through the Association. The resources of the Association aren't huge but the needs of the community are substantial so we are working hard to be as efficient and effective as possible, and to attract new sources of funding and donations for the benefit of the community.

I also want to thank the members of the Board for their involvement and contributions over the last year, and our staff for their hard work on behalf of the community. And thank you again to our Executive Officer, Robyn Kapp, for her ongoing commitment to HNSW—we deeply appreciate it. It's been a busy year of consolidation, but we are now better placed for the challenges of the coming year. We look forward to continuing to serve the Huntington's community through 2014.

*Brian Rumbold*

*In her report to the membership, Robyn Kapp wrote*

"I believe we can confidently say that Huntington's NSW has made a positive contribution to the lives of people impacted by Huntington Disease and their families in NSW and the ACT over the past twelve months. In particular our Regional Family Support Service is obviously impacting positively on the quality of life of HD families throughout rural NSW and the ACT.

The ongoing success of our core services is due to the commitment and hard work of our staff and volunteers. I acknowledge with sincere appreciation the outstanding work of Mark Bevan and Lily Ma and volunteer, Karen Bevan. Their collective energy, experience and expertise have ensured the delivery of quality programs.

Our effectiveness as an organisation is also dependent on building strong partnerships with

like-minded support networks such as the NSW Huntington Disease Service at Westmead Hospitals. We have worked closely with the Service during 2012/2013 and this would not have been possible without both the Association and the Service being intent on the common goal of supporting and caring for people living with HD and their families. I extend my sincere appreciation to the committed and dedicated staff of the Service.

Our "Gateway" newsletter, our website and range of publications help us to keep members informed of research breakthroughs and assist us in raising awareness about HD and its impact on families. Consequently, the dissemination of accurate, up-to-date information to families and health professionals continues to receive priority. We have kept "Gateway" topical and informative this year by sourcing the best articles about HD worldwide.

Finally I would like to pay tribute to the Board. Our President, Brian Rumbold, has given so much of his valuable time and expertise outside the board room and for this I am truly grateful. The expertise and commitment of each Board Member have guaranteed sound governance and will ensure that the Association achieves its mission and vision for the future.

In evaluating the performance and activities of the Association, members have every reason to be proud of what has been achieved and to be confident that we will continue to make a significant contribution to the lives of people with Huntington's Disease and their families.

*Robyn Kapp*

*The full Annual Report can be found on our website [www.huntingtonsnsw.org.au](http://www.huntingtonsnsw.org.au). If you would like a printed copy, please contact us.*



## Lunch Club

Our last Lunch Club for 2013 was one of mixed emotions. It was a wonderful day and included a delicious Christmas Lunch—turkey and home-made Christmas pudding. We were entertained by the very talented Chavez family with a performance of Christmas carols and songs. It was also a day of some sadness as we farewelled our Activities/Admin Assistant, Lily Ma , who has been with the Association for over six years. Lily has decided to undertake a TAFE course in aged care. We thank Lily for her commitment and enthusiasm during her time with us and wish her well in her future endeavours.



## Carers Support Groups

Our West Ryde Carers Support Group meets on **Wednesdays** each month at **10.30am**, at the Association's office, **21 Chatham Rd West Ryde**,

*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.*

*The group is facilitated by Jet Aserios and Cecelia Lincoln from the HD Service.*

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

### 2014 Sessions

22nd January	26th February	19th March	23rd April
28th May	18th June	9th July	13th August
24th September	15th October	12th November	
Friday 5th or 12th December Christmas Dinner (tbc)			

We are delighted to announce that a second group is starting in 2014 and these meetings will commence at **2pm** and will be held at the **South Penrith Neighbourhood Centre**

**3 Trent St, South Penrith.**

The dates for these sessions are

26th March	30th April	11th June	23rd July
27th August	1st October	5th November	
Friday 5th or 12th December Christmas Dinner (tbc)			

To RSVP and for further information, please contact:

Jet Aserios or Cecelia Lincoln 9845 6699, Social Work Department, Westmead Hospital or  
Robyn Kapp, Huntington's NSW, 9874 9777

# DNA shutdown proteins in Huntington's disease: More than meets the eye

Blocking HDAC4 improves Huntington's disease-related problems in cells and mice - but in a surprising way By Dr Melissa Christianson, edited by Dr Ed Wild

*DNA is the longest instruction manual on Earth. Because it's so long, cells use special helper proteins called HDACs to shut down sections of the manual they don't use very often. Now, scientists have shown that interfering with one specific HDAC improves HD-related problems in cells and mice — but does so in an unexpected way.*

## A sticky situation

Every case of Huntington's disease is caused by a mutation in the HD gene. In HD, one tiny part of this gene gets repeated a whole bunch of times. Since genes tell the cells in your body how to build proteins, this genetic change makes a protein called **huntingtin** get built incorrectly. To be specific, huntingtin protein in HD gets extra pieces of a building block called **glutamine**.

This doesn't sound so bad, until you find out that glutamine is sticky. Really sticky. We're talking bubble-gum-in-your-hair, can't-get-it-out-without-scissors sticky. Proteins with lots of glutamine stick to everything (themselves included!), making big globs in cells.

In Huntington's disease, the globs are made up of huntingtin as well as anything else that happens to get gobbled up into them. These globs gunk up healthy brain cells, making them get sick and die. Scientists think these globs might even be related to the onset of clinical symptoms in HD.

## Houston, we have a (DNA) problem

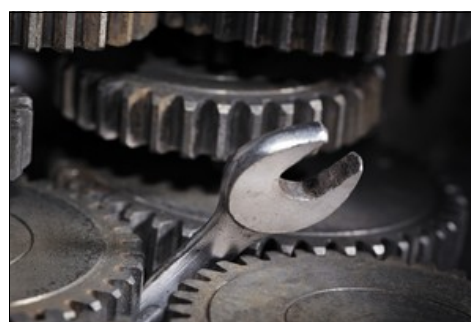
There are lots of ways that huntingtin protein can make brain cells sick in HD. One is by interfering with DNA.

You probably know that cells use DNA as an instruction manual. Just like you might read an instruction manual to learn how to make and assemble the parts to a new car, cells read the pages of the DNA code to learn how to make and

assemble the proteins they need to work properly.

But, DNA is the longest instruction manual on Earth. Cells have to shut down the parts of DNA that they don't need so that they can quickly find the DNA instructions that are important for them.

You wouldn't want to read an entire thousand-page manual on how to build a car when all you needed to know was how to open the gas tank!



*In HD, huntingtin protein forms globs which gum up the machinery of cells.*

In HD, however, this DNA shutdown process gets all messed up. The wrong parts of DNA get blocked off at the wrong time, making it really hard for cells to read the information they need.

This problem is like what would happen if some mean person stapled the pages of your car instruction manual together while you were using it. Even though the instructions would all still be there, you might not be able to read a really important part (like how to attach the wheels) if that particular section were stapled shut when you needed it.

## Targeting HDACs in HD?

Because scientists think that this DNA shutdown causes problems in HD, they've tried to target the cellular helpers that actually do the business of shutting down DNA in the disease. These helpers are called HDACs (pronounced "aitch-dacks"), and they come in many different varieties.

Scientists showed a while back that a cancer drug blocking the HDACs all at once, improved HD-related problems in lab animals. However, this drug has bad side-effects, like weight loss,

that would likely make it unusable for people with HD.

But all is not lost! Scientists think that blocking different HDAC varieties one at a time might let them tease apart the good effects from the bad. They hope that the good effects – but not the bad ones – come from blocking just one special variety of HDAC.

The best candidate for this special variety is HDAC4. Like the Huntington's protein, HDAC4 has lots of those sticky glutamines we talked about earlier. It gets stuck in the very same sticky globs as the Huntington's protein. This puts it in the right place at the right time to do bad things in HD.

Therefore, scientists wanted to test whether specifically interfering with HDAC4, but not the other HDAC varieties, could improve HD-related problems in cells and mice.

### A scientific surprise

To test this idea, scientists made cells and mice that produced a very sticky huntingtin protein – just like the one in human HD. Then, they used some fancy genetics to eliminate HDAC4 in these cells and mice.

Excitingly, getting rid of HDAC4 made the cells and the mice healthier! In particular, the scientists noticed improved movement and prolonged survival in the mice – both of which would be key aims for any human HD treatment.

What was really surprising, though, was that all of these benefits happened **without correcting the DNA shutdown problem** we spent so long talking about earlier!



*Of the many DNA shut-down proteins, HDAC4 turns out to be the one most closely linked to Huntington's disease.*

Confused yet? So were the scientists! There was more to the HDAC4 story than originally met the eye. They were studying it because it works with DNA, but it turned out to be important because it was doing something else that they hadn't expected.

The scientists think that this unexpected 'something else' involves those

sticky globs we talked about earlier, the ones that gunk up brain cells. Getting rid of HDAC4 delayed those globs from forming in the scientists' experiments. Given how bad the sticky globs are for brain cells, it's really exciting that scientists may have found a way to attack the globs directly.

### So what does this mean for HD?

These findings are important for the Huntington's disease community because they cast HDAC4 in a new light. Instead of targeting HDAC4 because it affects DNA, scientists now know to target HDAC4 because it affects the sticky globs that make brain cells sick. Therefore, HDAC4 might give us a way to get at the very sticky globs we think cause big problems for people with HD.

Scientists can use this new knowledge to better develop HDAC4 as a potential drug target for future HD therapies. Of course, there's still a lot of work to be done before scientists will understand how to exploit their new discoveries for use in the realm of treatments.

Still, it's important to remember that scientific progress usually comes in small steps like this, rather than giant leaps.





## Seizing the Day: Living with a Genetically Inherited Disease

*The following article 'Living with Huntington's Disease' is one part of a three part story written by Rachel Garnett (published UK Sun Newspaper October 6th 2013) about genetically inherited diseases.*

<http://www.express.co.uk/life-style/health/434569/Seizing-the-day-Living-with-a-genetically-inherited-disease>

### Living with Huntington's Disease

Sue Cross, 35, is a driving instructor from Brighton UK. Her mother Liz, 75, has Huntington's Disease, a neurological condition that causes progressive mental and physical deterioration. The disease is inherited and Sue also carries the faulty gene. She says: "Growing up, it was my dad I'd turn to for reassurance. I love my mum but she was always emotionally remote and withdrawn. My uncle told me that she was outgoing and carefree when she was younger, but I never knew her like that.



Now I know about Huntington's Disease I think mum was showing symptoms for years before she was diagnosed. HD damages the brain cells that control emotions and behaviour as well as movement. She was often depressed – one of the first symptoms of HD – and would drink too much because of it. She could also be socially awkward and abrupt – I cringed sometimes at how she spoke to people. Over the years she saw various doctors but they never got to the bottom it. We thought that's just the way she was." Then in 2009 her condition started to deteriorate rapidly. She became very twitchy, lost the ability to cook – which she used to be brilliant at – and stopped looking after herself.

Doctors thought she'd had a stroke but a neurologist tested her for Huntington's Disease and the result came back positive. I'd never heard of HD but it was a relief to get a diagnosis, so that at last we could get some help. Then I went on Wikipedia and saw that HD is hereditary. Worse still, it seemed that mum had actually been lucky because the disease often strikes when people are much younger. Was this going to happen to me? I knew I had to get myself tested and when my result came back positive too, I burst into tears. Images of being in a wheelchair or withdrawing from loved ones flashed through my mind.

When I told mum, she said she felt guilty because the faulty gene came from her. I don't think she really understood though, and within a few months she was asking me how I'd got it but I don't blame her – it's not her fault. Dad feels very sad but he doesn't show it in front of me. He told me before the results but he doesn't remember, that if I have HD, I should take lots of holidays. I went straight to Australia and blocked my worries out. But as soon as I got home, I went into delayed shock.

Then in January 2010 I joined my local branch of the Huntington's Disease Association. It helped to meet people who were facing the same situation. And I realised how important it is to raise funds for research, because a cure seems close.

It wasn't long after mum's diagnosis before the disease really took hold. In the space of a year she went from coming out with me for coffee to needing a wheelchair and not being able to wash herself. I bathed her, which felt like total role reversal, before it became too much and I got a carer for that. Dad took over the rest of her care. He's 77 now, but he's amazing.

*(Continued on page 10)*

## *Announcing the 2014 Australian HD conference*

### **"Embracing Opportunities with HD"**

**National Huntington's Disease Conference 2014**

**Perth, Western Australia 11th - 12th September**

The Conference will be hosted by Huntington's WA and it will bring together family members, researchers, allied health professionals, care workers and members and supporters of all Huntington's Disease Associations across Australia.

Details of key note speakers, the full programme and how to register for the Conference will be available early 2014.

Contact Huntington's WA: Phone: (08) 9346 7599 or Email: [admin@huntingtonswa.org.au](mailto:admin@huntingtonswa.org.au)



*(Continued from page 9) Living with Huntington's Disease*

The scariest thing for me is facing HD as a single person. Although I have lots of friends and my it. For me the behavioural changes are the most distressing. I can go out in a wheelchair if I have to, but if I don't want to go out, that doesn't bear thinking about.

The hardest thing is not knowing when symptoms will start and constantly imagining that they have. My memory can be bad, and when I went for my yearly check-up at the hospital and told them I sometimes forget things, they said I was fine.

This autumn I'm going travelling again to South America and New Zealand. I haven't made plans for the future – I don't even want to think about ever needing care – but HD has made me grab life with both hands. By doing that, I hope to keep the disease at bay for as long as possible."

*Acknowledgement: Huntington's Queensland, Newsletter, December 2013*

*(Continued from page 11) How to prevent heat exhaustion*

your body temperature rises to above 40°C and, if untreated, can permanently damage the brain, heart, and other organs.

The symptoms of heat stroke can be similar to heat exhaustion, but you may also stop sweating completely, become delirious or unsteady on your feet, have a fit or collapse.

#### **When should I see a health professional?**

Call an ambulance if you think you or someone else has heat stroke. Seek urgent medical attention if:

- heat exhaustion symptoms don't improve within 30 minutes of applying first aid
- someone is at high risk of developing heat stroke, such as babies and older people.

Ask your doctor for advice before exercising in hot or humid weather, especially if you have a medical condition that restricts your fluid intake. Ask your health professional if any of your medicines can increase your risk of sunburn, dehydration, or heat exhaustion.

*Acknowledgement: Medicinewise Living, December 2013*



## How to prevent heat exhaustion

Exercising when it's hot can rapidly exhaust and overheat your body. Recognising the warning signs and acting fast could save your life.

### How can my body overheat?

Your body can overheat if you exercise strenuously in very hot or humid weather. Dehydration, sunburn, and drinking alcohol can all reduce your body's ability to sweat and cool.

Heat exhaustion can affect anyone, but very young children and older people are at greater risk. You are also at high risk if you:

- are overweight
- have diabetes
- have kidney, heart or circulation problems
- are not used to hot or humid weather.

Some medicines can affect sweating or body temperature. These include diuretics (which increase fluid loss) and some medicines for the treatment of high blood pressure and heart disease.

Certain medicines can also increase sensitivity to sunburn, including some antibiotics, medicines that suppress the immune system, treat cancer and mental health conditions.

### What are the symptoms of heat exhaustion?

Heat exhaustion can make you feel extremely hot, tired and thirsty. You may also sweat heavily and urinate less than normal.

You may experience painful muscle cramps in your legs, arms, or abdomen. Other signs of heat exhaustion include:

- pale or clammy skin
- headache
- dizziness or fainting
- nausea or vomiting
- rapid heartbeat (not from exercise).

### What can be done to treat heat exhaustion?

Heat exhaustion can be managed using first aid. Heat stroke is a medical emergency and requires urgent professional medical attention (see What are the complications of heat exhaustion? below).

### Stop, rehydrate and cool down

As soon as you notice any signs of heat exhaustion:

- move to a cool or shaded area and lie down
- apply cool water to skin or clothing
- loosen or remove clothing
- drink cool water or rehydration fluids; avoid caffeine or alcohol.

Also follow these steps if you are helping someone else who has heat exhaustion, but only give them cool fluids to drink if they are fully conscious and able to swallow.

### How can I avoid heat exhaustion?

- Stay hydrated

Drink water or non-alcoholic, non-caffeinated drinks before, during and after exercise — even if you're not thirsty.

- Exercise in cooler weather

Avoid physical activity on very hot or humid days, and between 11am–3pm. If this is not possible, take regular breaks in the shade and rehydrate.

- Avoid sunburn

Apply sunscreen with a high sun protection factor (SPF) that blocks both UVA and UVB rays. Use other sun protection measures including a brimmed hat and protective clothing.

- Wear light clothing

Loose, lightweight clothing allows sweat to evaporate and cool you.

- Slowly adjust to the heat

If you're travelling abroad or to a hotter part of the country, it can take time to get used to heat or humidity, so arrive well before you do any strenuous physical activity. Try to build up the intensity of your exercise slowly.

### What are the complications of heat exhaustion?

If heat exhaustion is not treated quickly, heat stroke may develop. Heat stroke happens when

*(Continued on page 10)*



## Huntington's New South Wales

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Web Site: [www.huntingtonsnsw.org.au](http://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

### Association Staff

**Robyn Kapp** OAM  
Executive Officer

**Mark Bevan**  
Regional Family Support  
Worker

### Huntington Disease Service

**Dr Clement Loy**  
Director  
Westmead Hospital  
(02) 9845 6793

**Dr Sam Kim**  
Neurologist  
Westmead Hospital  
(02) 9845 6793

**Research Queries**  
**Dr Elizabeth McCusker**  
(02) 9845 6793

**HD Clinic Appointments**  
Outpatients Department  
Westmead Hospital  
(02) 9845 6544

**Jet Aserios**  
Social Worker  
Westmead Hospital  
(02) 9845 6699

**Cecelia Lincoln**  
Social Worker  
Westmead Hospital  
(02) 9845 6699

**Outreach Service**  
**Colleen McKinnon &  
Mark Cirillo**  
Westmead Hospital  
(02) 9845 9960

**Huntington's Unit**  
**St Joseph's Hospital**  
(02) 9749 0215

### Predictive Testing

**Fiona Richards**  
Social Worker  
The Children's Hospital  
Westmead  
(02) 9845 3273

### Hunter HD Service

**John Conaghan**  
Social Worker  
Hunter Genetics  
(02) 4985 3100