



# Gateway

**News from Huntington's New South Wales  
Volume 14 No 4  
Summer 2011**

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## ***From the President ...***

Dear Friends

Firstly I would like to give thanks to our outgoing President, Robyn Kapp, for her willingness to return to the Association and to wish her well in her new role as Manager of Huntington's NSW.

Robyn's experience and expertise will be used to re-focus the Association back to its core roles and to ensure that the funding packages and grants from the state government continue to assist us in running support programs for NSW.

At the AGM, we saw Angela Lownie awarded a Life Membership to the NSW Huntington's Association for her work with the Huntington's community over many years. We wish her well in her retirement and trust that she will have a well earned rest from what would have been a very tough yet rewarding job .

Also at the AGM, Jim Finn was acknowledged for his contributions to the Board since 1998 and the great voluntary work he has done around "Elsie Cottage" over many years.

A précis of their inspirations from the World Congress by Robyn Kapp, Karen Bevan, Ramona Watts and Mark Bevan, delivered at the AGM has been added to this volume of Gateway. I am sure that if you were unable to attend either of these meetings, that their comments will be welcome news to the Huntington's family.

I have reviewed the new internet site that Ramona outlined in her talk, HDBuzz.net and would encourage everyone with internet access to have a look at this down to earth, easy to read site that has enormous interest for all involved in the Huntington's community.

Finally on behalf of the Board and Staff and I would like to take this opportunity to wish you and your families peace and joy for Christmas and a happy and healthy New Year.

Kindest regards,

*Don Ayres*  
President

## Meet the Board ...

**President: Don Ayres** is a Sydney born member, who now resides in Swansea NSW with his wife Terry. They have three children. Don's background is in real estate and only recently sold his last business after a career of nearly 30 years. Don is passionate about helping families affected by HD and is hoping to enlist the services of more people for the cause. With Huntington's affecting such a small percentage of the population, we need to raise awareness of the severity of this disease, so that more funding may become available for support services and research.



**Vice President: John Conaghan**, who joined the Board in 2008, lives in Newcastle and has worked as a social worker for 26 years with the local area health service. For the past 21 years he has been at Hunter Genetics in Waratah working with families

affected by HD. John's work spreads over a large geographical area including the Hunter and mid north coast regions and he has a special interest in the needs of this group. John is married to Suzanne and has one child, Tomas. John's interests include swimming, test cricket, renovating the family home and spending time with family.

**Secretary: Anne Low** is a family member who has been on the Board for the past twenty one years. She has previously served in the positions of President and Vice-President. Anne who is an English-History High School Teacher is married to Stephen and they have five children.



**Treasurer: Richard Bobbitt** first joined the Board in 1994 and has also served as Vice President. He is married to Helen and he has a degree in Chemical Engineering. Richard is a Supply Chain Manager for a chemical company. He is a keen farmer, camper, 4wd'er and enjoys travelling overseas.

**Board Member: Karen Bevan** is a family member and has been a board member for two years. She previously worked with the Association for six years as Activities Co-ordinator, facilitating the lunch club program, holiday camps and undertaking various clerical tasks in the office. Karen is married to Mark and they have two children and ten grandchildren. Karen is very keen to serve the Huntington's community in whatever way she can.



**Board Member: Keith Dingeldei** is a family member and has been a keen Board member since November 2005. Keith is an advocate for quality services for people affected by HD.

**Board Member: Judy Rough** is a speech pathologist working at St Vincent's Hospital, and a freelance classical singer. In her work in health, she has seen the value of support organisations like Huntington's NSW in providing emotional and practical support, and in empowering people through providing up to date information. In the United States she was on the board of the Philadelphia Chapter of the Lupus Foundation and in Sydney she has been involved with the Lupus Association of NSW as committee member, vice president and as president for three years. She is looking forward to using her skills to contribute to the Huntington's Association.



**Board Member: Brian Rumbold** has recently joined the Board. He is a management consultant working with organisations that include not-for-profits in the health and aged care sectors. His work encompasses business strategy, facilitation, project design, information management, and electronic publishing. Brian has a primary degree in Electrical Engineering and a Master of Business Administration. He is married to Margaret and they have two married sons and three grandchildren.

# Huntington Happenings

## *Fundraising by the Lake*

Over the past few months, Terry Ayres and Karen Bevan have held two small fundraising functions to raise awareness and funds for Huntington's NSW.

The first was an in-house "high tea", with The Body Shop as the main sponsor, and product promotion event. Karen gave an overview of Huntington's to an enthralled group, most of whom had never heard about the disease.

The general consensus was that this was both a fun afternoon and a worthwhile opportunity for those attending to get some Body Shop products at a discounted price, as well as contribute to the Huntington's cause. This event raised over \$500 for the Association.

Many of the group who attended asked if Terry and Karen would run another function and so on the 29<sup>th</sup> November another fundraiser was held at "Wow Jewellery" at Caves Beach.

About 10 sponsors gave gifts ranging from accommodation for two at the Caves Beach Resort, Designer in a Box collection of bathroom accessories to champagne.

Nearly 40 people attended, including our Manager, Robyn Kapp, who gave an overview of what Huntington's NSW does for its clients and the Huntington's family. This function included a sumptuous morning tea, including champagne and the opportunity to purchase Christmas gifts, for those in the family with an eye for style.



*"Designer in a Box"  
from the Wow Factor  
Interior Design  
Newcastle, courtesy of  
Wendy Green*

Just over \$1,000 was raised with entry and raffles and once again the general opinion was "can we have another function soon?"

Our thanks to Terry and Karen for their work in organizing both these events and helping to raise much needed funds and spreading the Huntington's message.

## Do you like this Newsletter?

Tell us what you do and don't like about this newsletter so we can keep on improving it.

You can call us at the Association offices or email Robyn on [robyn.kapp@ahdansw.asn.au](mailto:robyn.kapp@ahdansw.asn.au)

## Family Support Program



It is coming to a busy year end for us at the Association. Social Club has continued to thrive and our members have been continuing to enjoy their exciting outings when we go out on excursions, and our mouth-watering home cooked meals when we stay in for lunch club. This last quarter has seen us back at the Fish Markets (our favourite!), ten pin bowling, at the movies, enjoying picnics and BBQs, as well as playing a variety of indoor games and craft activities. It has been a wonderful year for us all.

In the last few months we have had many requests for in-service talks about Huntington's Disease in care facilities as well as recreational centres. It is important to be able to impart information to nursing and casual staff as well as centre volunteers who want to learn more about HD and how they can help improve the quality of life for the people they care for. If you have a relative or friend in a facility and feel that they might benefit from a visit by a representative from the Association, please contact me on 9874 9777 or email me at [ramona@ahdansw.asn.au](mailto:ramona@ahdansw.asn.au).

We have continued to host the Carers' Support Group in conjunction with Huntington Disease Service at Elsie Cottage and have had a successful and fun-filled Christmas party at the West Ryde Hotel. Our carers have found some solace in the fact that there are others in similar positions, and share experiences and impart words of advice and friendship to one another. It is a lovely, close-knit group of wonderful people who give so much of themselves, and we would love to welcome other carers to join us in this experience of sharing.

*Ramona Watts*



## Travelling North and West ...

### Central Coast Support

Central coast meetings have been pure joy. In October, I presented some highlights from the recent World Congress in Melbourne, and we had several new people come along to that meeting.

Then we had a wonderful time at our end of year gathering at the Coffee Warehouse at Kincumber, with Mitch Faulkner kindly providing superb coffee for all. Support group meetings are usually held in The Education Room at Matthew John Nursing Home, 351 Terrigal Drive Erina on the third Monday of the month. We will be holding our first meeting for 2012 on Monday 20<sup>th</sup> February.

I would like to take this opportunity to thank all those who have attended the group during the year, and wish you all a blessed Christmas and wonderful 2012. Special thanks to a number of people who have helped facilitate our meetings – Deb Faulkner, Ian Kilpatrick of Axiom Psychological and counselling services, and of course the wonderful people at Matthew John – in particular Letitia Quirk and Eira Steane who have been a great support.

If you live in the Central Coast area, you are very welcome to attend the support group meetings – love to see you there.

### West of the Divide

October saw me make two trips out west. The first trip involved visiting 11 towns/cities, and the second was focused only on Bathurst and Orange. Most visits were with people I had met previously, but there were also some new people and places too. I must say that I feel so welcome in every place I visit. I continue to be inspired by the resilience and resourcefulness of so many families. My next trip out west will be around March or April.

### Far North Coast

What a great trip to this area in November – Kempsey, Grafton, Tweed Heads and Ballina. Loved meeting some new people and catching up with some more familiar faces. I travelled a bit under 2,000 kilometres, met with about 12

families, and visited 2 nursing homes. Christine Fox and Lesley Fraser from the Queensland Association arranged a support group meeting at Tweed Heads so that I could connect with some people in far north NSW to whom they provide support. While the numbers at the meeting were not as large as they had hoped, I was able to make contact with some new people. Thanks Christine and Lesley – really appreciate the way you seek to serve those in northern NSW.

A bonus was catching up with Lorraine Hodgson, the genetic counsellor based in Kingscliff who is providing a quality caring service to the area.

My next visit to the area is likely to be around May 2012.

### Mid North Coast

John Conaghan and I visited the mid north coast area in November, visiting families, including some people quite new to us, and we arranged a 'support group' lunch at the Westport Bowling Club which was attended by 17 people. Our thanks to the club for making us so welcome.

***If you would like to contact Mark or catch up with him on his next visit to your area you can do so by emailing him at [mark@ahdansw.asn.au](mailto:mark@ahdansw.asn.au) or calling him on 0410 629 850 – he would love to hear from you.***

Everyone was so open and welcoming, showing courage in difficult times, including grief and loss – thank you for your example.

My next trip to the area will be in May 2012.

### North West

Tamworth and Gunnedah beckoned in September, immediately after the World Congress, and I was able to meet with people from the surrounding area, including one person with whom I had only had phone contact previously. In addition to that, I was able to catch up with Melissa Buckman as we discussed some of the highlights of the World Congress

Plans are to visit again in March, 2012.

*Mark Bevan*

# Huntington Study Group

*From Dr Elizabeth McCusker*

The annual meeting of the Huntington Study Group ([www.Huntington-Study-Group.org](http://www.Huntington-Study-Group.org)), a non profit group of researchers from centres including North America, New Zealand and Australia with experience in the care of Huntington disease and interest in developing a cure, took place in Indianapolis in November.



The first Huntington Study Group (HSG) research site in Australia was set up in 1994 at Lidcombe Hospital and was transferred to Westmead Hospital with the move of the Huntington Disease Clinic to Westmead. Through the Westmead HSG site many people have joined HSG studies which have helped to better understand this complex disease. The first study was the data base of people with HD that was very helpful in looking at how the disease progresses and how to measure that progression so that the information could be used in trials of medication.

Huntington's NSW previously funded Dr Neil Mahant to look at the HSG information and that study was a valuable contribution to understanding progression of HD. Other projects followed including the PREDICT HD study, and to date, four drug trials. These include the current trials : 2CARE, the trial of very high dose CoEnzyme Q10 versus placebo in very early HD and the CRESTE trial of high dose creatine. These trials are still open.

The Association supports non medical staff to attend and this year supported Ms Jane Griffith, Research Nurse Co-ordinator, and Mr David Gunn, Research Neuropsychologist. At the meeting, training in assessment for the research studies takes place, review of trials to date including any problems as well as practical advice re data entry and recruitment to trials.

The HSG is also an opportunity to learn about likely new trials and to demonstrate our site's commitment to HSG trials.

The HSG meeting is linked to a HD Clinical research meeting on the last day where further updates are given as well as presentation of papers.

The review of medications used in treatment of various aspects of HD behaviours by experts in the field initiated by Lavonne Goodman and published online in PLOS Currents Huntington Disease was presented.

Data from the PREDICT HD study demonstrating that the lead into HD includes changes in thinking and behaviour as well as or instead of motor changes only was presented and a case made for a diagnosis based on non motor features. Another study from PREDICT HD demonstrated that the person's companion's opinion of changes taking place may differ from the person near to and after HD onset and people may under report. These studies are important for determining the accuracy of effect of drugs when drug trials eventually occur in this group.

The Huntington Disease Service gratefully acknowledges the support of Huntington's NSW and in particular those people who are able to participate in HSG studies.

## Highlights from the World Congress

*At the World Congress on Huntington's Disease held in Melbourne in September, Huntington's NSW was represented by the then President, Robyn Kapp; Board member, Karen Bevan and Staff members Ramona Watts and Mark Bevan. Each presented a highlight from the Congress at our Annual general Meeting in November. Here are some excerpts ...*

### Robyn ...

At the opening session **Peter Harper**, from Cardiff University in Wales, spoke of "*Looking back on Huntington's Disease. How can the past help us understand the present and contribute to the future.*"

There are three lessons from the past

- Shared Community—scientists and families working together.
- Pioneers—the influence of the lay organizations and people such as Marjorie Guthrie, Nancy Wexler & Ralph Walker. HD is a pioneer in genetic research and a model for wider fields of study. The predictive test guidelines are an example.
- Spirit of co-operation—between the lay groups and the researchers and between the researchers themselves.

In looking to the future

- HD is no longer to be regarded as untreatable.
- HD is part of a 'family' of brain disorders.
- There is a highly skilled community of researchers and family groups working for a cure.
- Co-operation and sharing are the way forward.
- Everyone can play a part in helping to bring a cure for HD closer.



The title of **Sarah Tabrizi's** presentation was "*Huntington's Disease: Yes we can!*". Sarah is from the UCL Institute of Neurology, London.

She said that novel therapeutic agents specifically targeting HD pathology are now on the horizon and our understanding of the clinical manifestations and underlying pathobiology of HD in the earliest phase of the disease process has advanced considerably. We are reaching a critical turning point in the history of HD and we are now better equipped to design real disease modifying clinical trials. Much has

been learnt and we are still making progress. The key questions now are how the global HD community—patients, people at risk, carers, scientists and clinicians—can translate these findings to hasten the development of effective therapies to benefit families and patients affected by HD throughout the world.

**Michael Hayden** from the University of British Columbia in Vancouver, Canada, reported that increased longevity is significantly altering the demographics of many societies. The proportion of persons over 65 is around 7% and this will double in the next thirty years to 14%, with close to 75% in developed countries such as the USA, Canada and Australia. He believes that with increasing longevity there will be an increase in persons with late onset HD and the demographics of persons affected with HD will shift from a rare disease of midlife to a more common disease of the elderly.



On the final day **Robi Blumenstein** from the CHDI Foundation in New York spoke of a strategy for finding therapies for HD and the link back to families. At CHDI they imagine the successful trial of a

neuroprotective therapy for HD and ask: What must be in place for that to happen? Three things are necessary: First, a therapeutic agent that works; second, practical designs for well-powered, informative clinical trials and third, the active participation of people with expanded CAGs in their huntingtin gene. Although efforts to develop each of these elements are underway, we need to be more explicit about the essential role of patients and families in efforts to find therapies for HD as quickly as possible. He left us with a conundrum—deciding to have the predictive test is a very personal, private decision and yet we want people who are gene positive for research?

## **Karen ...**

This was my first international conference and it was a wonderful experience. I came away very encouraged by what is happening with HD all over the world.

I would like to share briefly a story that really touched me and it was a beautiful illustration of the hope and life there is to live in HD families.

The story was told by **Martha Nance** from Struthers Parkinson's Centre USA. She was a joy and an inspiration to listen to. The work and care given to people with HD and their families in the centre where she works in Minnesota showed such care and encouragement to families with HD.



She told of a gentleman she was seeing at the clinic, his family had asked Martha if she would assess him and his driving ability, knowing he should not be driving anymore. They were having trouble handling the situation. I related to this with my own Dad, it is such a hard thing to tell someone you love, who also loves driving.

Anyway she broached the subject with him and they decided that they would make a decision based on what I guess is their equivalent of our RTA test, which he was to have in 30 days time. He had said previously he would rather be dead than not drive. As you can imagine, he was not a happy camper. So it turned out that the day before the test date he took a gun and shot himself!! However, instead of killing himself he blew his shoulder apart and as Martha put it..... 'that solved the problem of his driving.'

The gentleman was so upset with Martha that he did not talk to her for a year.

But the great thing about this seemingly tragic situation is that this gentleman lived to see and hold his grandchildren and enjoyed very much the last years of his life and before he died, his last words to Martha were 'I love you'. What he was also saying was effectively 'I am glad I

lived - look what I could have missed.' He was so grateful for the love shared and the care he experienced, and the chance to enjoy more of his family.

I related so much to this story and it brought back the beautiful memories of my Dad and the joy that he had seeing two of his grandchildren marry - and attend both the weddings. He even flew with a nurse to Brisbane for one wedding. Dad also had the joy of holding five great grandchildren and watching them grow up a little. Seeing the pleasure he got from them he would not have wanted to miss those special times, as did the gentleman who thought that if he couldn't drive life wasn't worth living - how wrong he was.

Martha was an encouragement to families and professionals with her upbeat and caring approach. We can still do so much for our loved ones and friends with HD to give them enjoyment and pleasure; we just need, as one of the other wonderful speakers said, "to look at the glass half full instead of half empty - there is always hope.

I do hope this story encourages and inspires you to push on. Try and focus on how far things have progressed. Even though it's not nearly as far or as fast as we would like we have come such a long way since my Dad was first diagnosed in the late 70s and there is so much more hope and help than ever before. The conference confirmed this for me and I am very grateful for the opportunity to attend such a wonderful event.

## **Do you have a Story to Share?**

If you have a contribution that you wish to make to the Newsletter please send it to us at the Association offices (see details on the back page) or by email to Robyn at [robyn.kapp@ahdansw.asn.au](mailto:robyn.kapp@ahdansw.asn.au)



## Ramona ...

**HD Buzz** is a new internet portal that brings the latest news about Huntington's disease research to the global HD community.

There has been much discussion about the articles on HD research, either on the internet or in newsletters, being very scientific. This makes it difficult for people with HD and their families to understand the full extent of what the research and medical terms actually mean.

So with a lot of collaboration between scientists, researchers and doctors, HD Buzz was created a few months ago. Basically it is an internet site that is all about HD research and updates written in plain language. It provides easy to understand snippets of relevant scientific papers and conference reports and it's all free. It covers laboratory and clinical research, with the aim of helping people to understand the latest HD science.

The editors-in-chief are two young doctors, **Ed Wild** from London and **Jeff Carrol** from the USA. Their staff writers come from the UK, Canada and Germany, and it is also translated



Ed Wild



Jeff Carrol

to many different languages from French to Spanish and Finnish. The translation is done by volunteers from the worldwide network of HD Associations, the European Huntington's Disease Network and bilingual HD scientists. The content of HD Buzz is freely disseminated to other HD community websites, blogs and social media platforms like Facebook and Twitter, so it is obviously readily available to both the younger generation and more mature people.

HD Buzz tries its best to be impartial and not to report favourably about any particular drug company. The articles disseminate information, but they do have to be careful not to promote any one drug over the other. They don't accept advertising or allow themselves to be sold to marketers. HDBuzz does not accept funding or support from drug companies or anyone else with a vested interest in a particular therapy for



HD. They believe that taking money from any organization dedicated to a particular therapy could give the impression of bias in their reporting, which they aim to avoid.

Their aim is to engage the reader – the writers ask for comments, suggestions for other articles, people's viewpoints - it really is quite interactive with the aim of engaging people, to get them more involved. However the editors make it very clear that the website is not a substitute for medical advice and that they cannot offer any advice - it is purely information, updates and discussion.

**Scoring** - HDBuzz writers assign each reviewed article a score. First, they describe each story as either 'clinical' or 'pre-clinical'. 'Clinical' studies are done with human subjects, while 'pre-clinical' studies are done using either animals or cells in the laboratory. Each story is then scored according to its relevance to HD community members. The score is indicated by a thermometer icon – hotter stories are more likely to be relevant. Relevance is judged according to how closely related the research is to finding disease-slowing treatments for HD. For example, a brain imaging study that shows early changes in the brains of people with the HD mutation would be scored as 'clinical' research, but won't directly lead to treatments on its own. On the other hand, the results of a drug trial – whether positive or negative – would be scored highly because they are likely to be of greater interest to HD community members.

It is a fantastic website, not just for information on HD, but the reader knows that this information is written and summarised by scientists, doctors, researchers and it is all done in plain language and easy to understand. That makes a big difference in the accumulation of knowledge and understanding of HD. Many people feel overwhelmed by all the information out there, not knowing what is relevant and what is not. HD Buzz is like a one-stop shop where they summarise research, post updates and let you have your voice, which seems to be making a big difference to people who tend to feel quite isolated with Huntington's Disease.

## Mark ...

Talking with **young people** in a family affected by HD can be a challenge. It was recommended that where possible, telling young people about HD is best done as an ongoing conversation, being as open as possible, easing them into it a little at a time, using suitable materials to help explain things properly in a way relevant for their age

There is suitable information available to assist families with this – the website [ourhdspace.org](http://ourhdspace.org), pamphlets available from the Association and 'Talking to kids about Huntington's' by Bonnie Hennig (<http://www.talkingtokidsabouthd.com/>)

10 thoughts for young people affected in some way by HD.....

- It is hard
- You need good friends
- You need one or two grown ups you can count on
- Talking is better than not talking
- Write a paper for school on HD
- Ask questions
- Use your energy constructively
- Use your energy creatively
- Connect, connect, connect
- Remember... You are the future!!!!!!!!!!!!!!

It was awesome to hear how some young people affected in different ways by HD have taken a very positive approach and decided to DO SOMETHING. One guy was running 15 marathons, another organising a dinner dance. The effects of these and other initiatives include: allowing the young person to channel their energy constructively into something to benefit the HD community; to raise awareness of HD and in some cases, to raise money to help families affected by Huntington's.

One amazing example was a young guy in the USA whose mum had HD. He decided to raise some money to help people understand the illness his mum had. He started off with a few friends, shot basketball hoops, and ended up raising \$6000, with about 50 people participating. From that it became an annual event, attended now by over 600 people, and the total money raised is about \$750,000 over 14 years. Amazing from small beginnings, and willingness to have a go.

Matthew Ellison from the UK said that there is a lack of information available in a relevant form for young people, and so in January 2012..... HDYO ([www.hdyo.org](http://www.hdyo.org)) will be launched. This is a website designed to target young people impacted by HD – carers, children of affected people, etc – designed by and for the young, including young carers. All material will be approved by experts, and in relevant language.

## Care

The need for lifelong service to support families, including carers and extended family was reinforced, and I am very mindful of that as I visit families in regional areas.

While the following coping tips for carers may not be new and some may sound too hard, I believe the effort to act on them can pay off.

- Make hard decisions on what is important, and what your priorities really need to be – decide what is genuinely worth doing and what is not, in relation to your HDP and others in the family – don't sweat the small stuff, it is usually not worth the effort.
- What is your attitude – half empty or half full. Can you look with hope, and find joy in difficult times, or is it all doom and gloom? It is worth trying to approach life with 'the glass half full' attitude.
- De clutter – this in itself can help simplify life a little. Throw, tidy or stash some stuff. It was emphasised that carers can really benefit by taking time to get more organised, and even pursuing some sort of study or other interest... to do this successfully you need to find the time, but spending some time getting organised can potentially give you more time in the long run.
- Don't neglect the spiritual side of things – this can be extremely beneficial to you.
- Try to find time, and ways, to include some fun and spontaneity in your life.
- Give back to the HD community as opportunity provides – or perhaps look for an opportunity. You probably have more to offer to others than you imagine.
- And it is OK to have a meltdown occasionally – you cannot always be a super hero.

Finally, I loved the principle from Martha Nance that they abide by '*There is never nothing I can do*' – and I want to be able to live by that.

## Sleep right, sleep tight

Our sleep patterns change as we get older. Developing good sleep habits is a more effective way of solving sleep problems than resorting to medicines. Sleeping tablets usually make sleep problems worse, not better, in the long term. They can also cause side effects, even those bought without a prescription. If you don't sleep well, some of these strategies might help.

### Reset your body clock

We all have an internal 'body clock' that controls our daily cycle of becoming sleepy in the evening, sleeping through the night, and waking up in the morning. Being 'in sync' with your body clock makes it easier to sleep. You can help to set your body clock by consistently going to bed and getting up at the same time every day, regardless of how well you slept the previous night. If you can't get to sleep within 20 minutes, get up and do something relaxing in another room until you feel sleepy again. Persist with this routine until you develop a regular sleep pattern. It will also help your body to associate going to bed with sleep rather than sleeplessness and frustration, which, in turn, will help you to sleep better. Sunlight also helps to set your body clock, so try to get outside in the sun for a while every day.

Some people can sleep well despite having a short nap in the afternoon. However, if you're having trouble sleeping at night, avoid having a nap during the day. If you do nap, keep it to only 20 minutes before 3 pm.

### Have a bedtime routine

Doing the same things each night in the last half hour or so before going to bed helps to remind your body that it's time to go to sleep.

Your bedtime routine might include things like having a light bedtime snack or glass of warm milk, having a warm bath, reading, or listening to music, the radio or a talking book. Avoid computers.

### Be comfortable

Keep the bedroom dark while you sleep. Even dim lights, such as those from a television or computer screen, can disturb the body clock and result in poor sleep. Try to keep your bedroom and bed at a comfortable temperature. Being too warm or cold is a common reason for waking up frequently in the night.

### Relax your mind

You can't sleep well if your mind is not relaxed, so



try not to take your day-time stress, anger or work to bed with you. Also, avoid work and activities involving concentration, such as working on the computer, late in the evening. If you can't relax because of chronic worrying, stress or anger, consider learning some relaxation techniques to help you 'switch off', or seek help from a GP or counsellor.

### Avoid stimulants

Avoid caffeine drinks, such as tea, coffee, energy drinks and cola, close to bedtime and maybe even from

early afternoon. Milk contains tryptophan, which has been shown to enhance sleep, so consider a warm milk drink instead.

Alcohol before bedtime may help you to dose off. However, it also disturbs the normal sleep rhythm, so you won't tend to sleep as well.

### Get regular exercise

Being physically active during the day makes it easier to fall asleep and improves how well you sleep. However, the timing is important. Exercise too late in the day stimulates the body and raises body temperature, making it harder to sleep. Exercise in the morning or afternoon gives your body time to wind down and cool down.

### Getting back to sleep

If you wake up during the night, relax and try not to get stressed. Try some relaxation techniques or a repetitive, non-stimulating activity like counting sheep. Remind yourself that although it's not as good as sleeping, resting in bed can still refresh your body. If you've been awake for more than 20 minutes, try getting out of bed and doing a quiet activity in dim light until you feel sleepy again.

### Tackle underlying problems

Poor sleep can be a side effect of some medications and some chronic conditions, including depression, anxiety and sleep apnoea. In these situations, treating the underlying problem often alleviates the sleep problem.

If you have sleep problems, talk to your doctor or pharmacist, and tell them about any other symptoms you may be experiencing. If their suggestions don't help, consider asking for a referral to a sleep specialist or sleep clinic, so your sleep problem can be investigated.



## Huntington's New South Wales

PO Box 178, West Ryde, NSW 1685

21 Chatham Road, West Ryde, NSW 2114

Telephone: (02) 9874 9777

Facsimile: (02) 9874 9177

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

Web Site: [www.ahdansw.asn.au](http://www.ahdansw.asn.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: Don Ayres

Vice President: John Conaghan

Treasurer: Richard Bobbitt

Secretary: Anne Low

Karen Bevan

Keith Dingeldei

Judy Rough

Brian Rumbold

## Association and Other Useful Contacts

### Association Staff

**Robyn Kapp OAM**  
Manager

**Ramona Watts**  
Family Support  
Co-ordinator

**Lily Shu Yue Ma**  
Administration and  
Activities Assistant

**Mark Bevan**  
Family Support Officer

**Toni Ling Zhang**  
Administration Officer

### Huntington Disease Service

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

**Outreach Service**  
Westmead Hospital  
(02) 9845 9960

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

### Huntington's Lodge

**Anita Popovic**  
Nursing Unit Manager  
Lottie Stewart Hospital  
(02) 9804 5854

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

**Nursing Staff**  
(02) 9804 5803

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

### Predictive Testing

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

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

### Hunter HD Service

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

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