



Gateway

News from Huntington's New South Wales

Volume 15 No 3

Spring 2012

Ground Breaking News !

On Monday afternoon, 16th July 2012 at St Joseph's Hospital Auburn, the first sod was turned for the new Huntington's Unit to be built within the grounds of St Joseph's Hospital.

Among those who attended the ceremony were The Hon. Barbara Perry, Member for Auburn in the NSW Parliament; Jonathan Anderson, Chief Executive Officer, St Vincent's Health Network; Helen Miller, Director of Aged Care & Sub Acute Services, St Vincent's Public Health Services; John Geoghegan, Director of Nursing & Operations, St Joseph's Hospital; Dr Clement Loy, Director, NSW Huntington's Disease Service; Dr Elizabeth McCusker, Researcher and Neurologist; Robyn Kapp, Manager, Huntington's NSW and Don Ayres, President, Huntington's NSW.

After a solemn ceremony the first sod was symbolically turned by the Chaplain of St Joseph's, Fr Isaac Koi, and then in turn by other invited guests.

This marks the commencement of a state of the art, purpose built 14-room residential unit, all with en-suites. The facility will also have a 4-bed sub-acute neuropsychiatric unit and two beds for assessment. There will be separate lounge and dining rooms, a TV Room, an activities/multi function room, a consulting room and recreation areas, both inside and outdoors, for residents and their visitors.

The building is scheduled for completion in May 2013 and, once in operation, it will be a great step forward in patient care for the Huntington's community.

We wish to thank all those involved who have made this day a reality, from the planning stage to the architects, St Vincent's and St Joseph's staff and everyone who has had input into this magnificent development from a most grateful Huntington's community.

Don Ayres
President



Invitation

Would you like to see the plans and hear about the new purpose built unit for people wit HD at St Joseph's Hospital, Auburn?

Then come along on Saturday 27th October 2012 at 2pm to Elsie Court Cottage, 21 Chatham Road, West Ryde.

Dr Clement Loy will discuss the new unit and bring us up-to-date with its progress



St Joseph's Hospital 1903

Annual General Meeting

The Annual General Meeting will be held on Saturday 27th October 2012 at 2pm at the offices of the Association, 21 Chatham Road, West Ryde.

The Business of the Meeting is to

1. To accept the Minutes of the 2011 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 2012/2013
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 19th October 2012. Nominations may also be made at the meeting.

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

The Board and Staff would very much welcome your presence at our AGM

Please RSVP (for catering purposes only) Phone (02) 9874 9777 or 1800 244 735 (NSW STD Freecall) or e-mail lily@huntingtonsnsw.org.au

Insurance & Huntington's Disease

Firstly let me start by saying I am no lawyer and no insurance expert, I have just read around a bit and written a little on my findings navigating the insurance world and some good news I want to share.

Like most young people with HD in their families, I had basically written off life insurance. Insurances in general are a big pain and provide endless stress trying to understand the myriad of options but at least health insurance is community rated and so I have signed up with my family and put that one to the side for now.

Life, total permanent disability (TPD) and income protection insurances are all risk rated and so fall into a far more discretionary category for the insurer. As a result, with profit being far more important to an insurer than community benefit, most insurance companies will work out a way to exclude us. I am like plenty of other young people who have spent time filling out long and complex forms only to find question 42 on page 14 'do you have a family history of the following diseases/conditions'. You know what comes next....



My twisted sense of humour thinks this is all quite funny, insurers working so hard to mitigate their 'risk'. A friend of mine even had one of them turn up to his house to take his blood before signing him up to income protection insurance. I have this imaginary vision of all the insurers working so hard to exclude everyone that they end up with no one to insure. Everyone fighting over the last 10 'perfect' people in the country. Who do you know that doesn't have cancer/bad back/heart disease/mental illness or something in their family? Give me a break.

Their 'family history' wording is also really clever as it gets not only those of us who have been tested but also those who haven't. Some other companies use wording like 'have you ever been diagnosed'. Clearly they didn't hire as good a lawyer as the other company as this gave us a chance to get insurance in place prior to going through any sort of genetic testing process. For a long time we tried to leverage this and Associations and Genetic Counsellors have been recommending this approach as the best chance yet to try to secure some insurance. It was the best as it was the only option around.

Heaps of complex questions arise from this and I have endless worries about down the track. It still doesn't help people that have been tested already and what happens if later, someone who previously ticked no, decides gets tested or diagnosed? They always write somewhere about our obligation to inform them of any change in our circumstance. I worry that when they send you the 200 page terms and conditions page that their army of lawyers will have found a way in the fine print to say that they don't have to cough up. I suppose though, if I take HD out of my life, their are still plenty of ways to get sick or hurt and I hope that I still have some time before I get clinical symptoms. It could be a great meantime strategy.

I got some good news about a year ago when I heard that Virgin had released a life insurance in Australia. They had a regular product with coverage up to \$1.5M that asked questions but they also had a product up to \$750k that asked no questions. All it said is that it would exclude a pre-existing medical condition for the first 5 years. But it also defined a medical condition as something where symptoms existed that required a clinical diagnosis. So to me it looked pretty good. It also said that even if they denied your claim for a pre-existing condition that they would refund all your

premiums.

I wrote a letter to them as I am quite untrusting and asked them specifically about HD. They wrote a letter back confirming that if you only have a family history of HD but you yourself have never visited a doctor or had a test, you can even get their premium insurance but in the least, if you have been to a doctor or had a test, you will still definitely get their 'quick and easy' cover.

www.virginmoney.com.au

After getting that response I signed up and now am very happy to be able to say I have life insurance squared away and can concentrate on more important things! I keep the letter pretty handy - just in case. Please do your own research on this and make your own decisions but I would definitely recommend you take a look at Virgin's options. If you are nervous, write them a letter. I don't know of anyone else who is offering this but would love to hear about them if they do.

Some other options open to you if you need information is obviously the first contact is Huntington's NSW. You could also visit the website www.ourhdspace.org for information under the 18+ section or join our young people's group "The HD Alliance". We hold events filled with information and meeting people and we always have a lawyer on hand to do a session on insurance and legal questions. You can sign up to the alliance via the HD Space website and/or join our private facebook group by submitting a friend request to Greg Chaine (HWA).

Good luck!

Tony Mims

Editor's Note: This article outlines the experience of one person. Huntington's NSW cannot guarantee that everyone will have the same outcome as Tony. It is up to each individual to make their own enquiries with respect to insurance products.

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 office (see details on the back page) or by email to Robyn at robyn.kapp@huntingtonsnsw.org.au

Mapping the neighborhood: huntingtin's new protein partners

Study of huntingtin protein's 'neighbors' reveals dozens of new drug development targets

By Dr Jeff Carrolll, Edited by Dr Ed Wild

Why haven't we cured Huntington's disease yet? One reason is that after twenty years of study, scientists still don't understand what the huge Huntingtin protein - mutated in HD patients - does. In a new study, the group of William Yang at UCLA has mapped the 'neighborhood' of huntingtin to try and bring some clarity to this question. In the process, they've revealed dozens of new leads for drug development.

Genes, proteins and functions

Studying what other proteins are linked to it can tell us about the huntingtin protein itself. Every patient with Huntington's disease has a mutation in the same gene, which scientists call 'huntingtin'. This gene, mutated or not, needs to be turned into a **protein** before it can do things in a cell. In the case of the mutant huntingtin gene, the protein it produces causes harm in cells.

Genes serve as blueprints for cells, instructing them how to make specific proteins. These proteins are the molecular machines that carry out most of the work that makes cells function.

So, when we ask "what does this gene do?", we're usually actually talking about the function of the protein that the gene is a blueprint for. The huntingtin gene tells cells how to make a protein that's also called 'huntingtin'.

The *huntingtin protein* is somewhat mysterious; first, it is huge, nearly 6 times the size of the average protein in a human cell. Secondly, it is found in many animals — even those as distantly related to us as sea urchins and slime molds have a huntingtin gene. When proteins are found in many different species like this, scientists call them 'conserved'.

Whatever huntingtin does, it must be important to be required by so many diverse species. Finally, the protein is very unlike other proteins commonly found in a human cell. Most proteins have recognizable **domains**, or short areas that look like other proteins that help us figure out what they do. Huntingtin has none of these

features — it seems completely unique.

Despite 20 years of study, the situation today is not much improved since we discovered the gene that causes HD. We do know that the protein is really important — mice that have been genetically modified to lack the huntingtin gene die before they're born. Sharply lowering huntingtin levels seems very bad as well, multiple studies have shown bad effects in cells or tissues that lack huntingtin — particularly brain tissue.

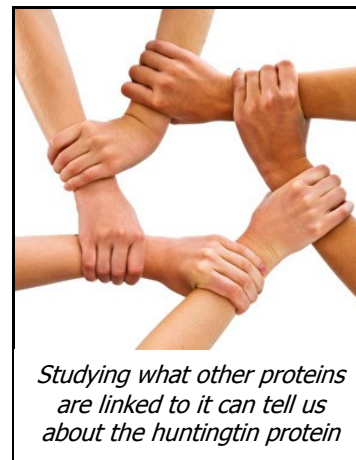
Understanding function through connections

Proteins are generally not isolated little machines, floating around in our cells doing their business. In fact, the inside of a cell is more like a thick goopy gel than a watery expanse — proteins and other parts of cells are compressed together in a dense goo in which proteins must function somehow.

Proteins normally function in partnership with other proteins — sometimes dozens or even hundreds of individual proteins work together to perform a particular task. A good example is the 'synapse' — the site of connection between two brain cells. Synapses depend on hundreds of proteins coming together in a precise manner to enable one neuron to talk to another.

Because the huntingtin protein is so unique, and yet so important, scientists have reasoned that they could better understand what it does by understanding who it interacts with. What other proteins does huntingtin stick to as it does its business in the cell? For example, if we found that all the proteins that huntingtin sticks to have a job at the synapse, that would limit our search for what goes wrong in cells with HD to that particular part of the cell.

Previous studies of this kind have been hindered by the fact that the huntingtin protein is just so



Studying what other proteins are linked to it can tell us about the huntingtin protein

enormous. The best efforts of scientists so far have relied on using small pieces of the entire huntingtin gene — slicing it into pieces and studying which proteins those little pieces stick to.

This is a bit like cutting a bit off of a large, complex, puzzle piece and finding places that the small fragment fits. Some of the spots identified by this method will be correct, but a large number will be what scientists call “false positives” — places where the little piece fits, but the whole intact huntingtin protein would not.

A new attempt at map-building

Technology for studying proteins has become more and more sensitive over time. So sensitive, in fact, that a group of scientists lead by William Yang at UCLA in California USA decided to try and build a new map of the huntingtin protein’s cellular neighbors.

Their approach was a bit audacious. Rather than chopping up the huntingtin gene into tiny pieces and sticking it in yeast cells, they decided to go to the source. They isolated huntingtin protein from mouse brains — in fact three different brain areas — and at several different ages.

Their bet paid off — they were able to identify 747 proteins that interact with the huntingtin protein in the mouse brain. 139 of these proteins had been described to interact with huntingtin before. That’s good, because it means that these results build on what was known before and are more likely to be reliable.

That leaves 608 new proteins that the huntingtin protein interacts with while doing its work in the cell. Because of the way the team looked at protein from different brain areas, they could also identify interactions that only happen in parts of the brain that are especially vulnerable in HD.

Another interesting category of interactions are those that happen in relatively old brains, but not young ones. Because HD usually affects brains after some years, these interactions might provide clues about processes that go wrong over time.

Network analysis

Imagine someone handing you a list of 608 car parts. It’s pretty hard to figure out what they all do without knowing about all the different systems in a car, and how they interact.

Unfortunately, unlike a car, no one has a complete blueprint for brain cells.

To tackle the problem of classifying this long list of huntingtin

protein partners, Yang’s team turned to a team lead by another UCLA investigator, Steve Horvath. Horvath’s team is expert in classifying these type of lists to try and understand what goes wrong in biological systems.



Any new interaction of the huntingtin protein is a potential target for drug development

In effect, Horvath’s group specializes in something very difficult — given a list of car parts, they work on trying to figure the blueprint of the car.

The two teams identified a number of systems in brain cells that they believe might go wrong in HD brains. They were able to make some very specific predictions about which proteins huntingtin will work with inside a cell. All of these predictions that were tested subsequently were found to be correct — giving us confidence that this new map is accurate.

Does this matter to HD patients?

Thanks to the effort of these scientists we now have a much more accurate map of which proteins huntingtin interacts with in the brain, which of these interactions are specific to certain brain regions and which happen only in aged brains.

At HDBuzz we’re always excited about the latest therapeutic advances — but fundamental studies like this are still very important. The development of the next generation of therapies relies on a much better understanding of what, precisely, the huntingtin protein does, and how this goes wrong because of the mutation that causes HD. This study brings us closer to that understanding and adds new targets to the drug discovery pipeline.

Acknowledgement: By Dr Jeff Carroll, Edited by Dr Ed Wild; HD Buzz, <http://hdbuzz.net>



HDYO is pleased to announce that one of its talking as a family about HD projects is now available to view and use as a resource.

They interviewed five families in England (parents and children) focusing on how they discuss HD as a family and whether being open has been beneficial for them. This is a wonderful opportunity to hear personal experiences on a difficult topic not just from parents, but from children and young people too. The videos are all available from HDYO's youtube channel

<https://www.youtube.com/user/HDYOFeed?feature=g-all-u>

where they can easily be shared with families and amongst staff and volunteers.

The project produced six videos in total, five being individual family interviews and then the other combining all five interviews into one short video.

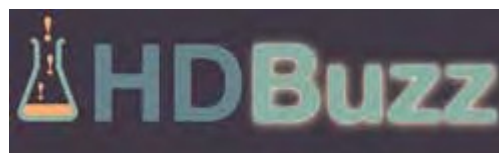
You can also access the videos on the HDYO website **www.hdyo.org**

It is hoped that these videos are of use to both families and professionals. These videos may be just the encouragement needed by those families struggling to make that brave step of talking openly about HD within the family... as these videos show, it can be a beneficial approach for all.

Special thanks go to all five families for taking part and being so open and honest.

In other updates... the HDYO website is now available in three languages (English, German and Spanish) and they are now receiving over 30,000 website views per month (2 months ago it was 20,000).

**Huntington's NSW
is a proud sponsor of**



Huntington's disease research news.

In plain language.

Written by scientists for the global HD community.

Go to www.HDBuzz.net to see what the Buzz is all about.

Changes Around the Office

In early August we said goodbye to our Admin Officer, Toni Zhang. Toni, having completed her CPA exams now has a full-time position which will enable her to gain more experience as an accountant. We thank Toni most sincerely for her time with us and wish her well in her future endeavours.

This month we shall also farewell Ramona Watts, our Family Support Worker. Ramona has decided to widen her experience in working with families. Our thanks go to Ramona for her enthusiasm for and commitment to our families and carers and we wish her all the best in her new position.

As a result of these changes Mark Bevan will now come on board full-time as our Regional Family Support Worker. We are delighted that Mark is able to do this as this will provide an improved service to our families who reside in regional and rural NSW.

Our Manager, Robyn Kapp, is now in the office three days per week (Tue, Wed and Fri) and her role will now include dealing with enquiries, information and referral with respect to any aspect of HD.

Although our staff numbers have decreased, we believe that we shall continue to provide a beneficial and worthwhile service to people impacted by HD in NSW and the ACT.

Save Money on Your Medicines

It seems there is more and more pressure on household budgets every day. When things get tight, it might be tempting to consider cutting down on your medicines.

Before making any changes to your medicines, it's important to talk to your doctor or pharmacist. Be open about your situation. Together, you may be able to come up with some solutions that will save you money. Some of the things you might be able to do are outlined below.

Ask about medicine brand choices

Some medicines with the same active ingredient (the chemical in the medicine that makes it work) are sold under different brand names. These different brands are often referred to as 'generic medicines'. Sometimes they are slightly cheaper, so buying a different brand could save you money.

Ask your pharmacist if there is a cheaper version of your medicine. The cheaper brand will always have the same active ingredient as the medicine on your prescription or the one you usually take.

Ask about a different strength medicine

A lot of medicines come in different strengths. You may be able to save money by using a different strength of medicine. For example, if you normally take two 100 mg tablets and a 200 mg tablet is available, you might be able to take one 200 mg tablet instead. This may mean that you use fewer prescriptions, saving you money.

Ask about medicines on prescription

In some cases, you can save money by obtaining medicines on a prescription rather than over the counter. This situation is more likely to apply to you if you are a concession card holder.

For example, people using paracetamol for chronic pain may save money by buying it on a prescription rather than over the counter.

Buying medicines on prescription will also help you to reach the Safety Net threshold (see below) sooner. If you need to use an over-the-counter medicine regularly, ask your doctor if it's available on prescription.

Ask about an authority prescription

Doctors can sometimes prescribe more medicine than is normally allowed under a Pharmaceutical Benefits Scheme (PBS) prescription by using a special prescription known as an authority prescription. For example, if you've been prescribed double the normal dose of a medicine, your doctor may be able to obtain permission to prescribe that dose for you on a single prescription by using an authority prescription. This would mean that you can buy twice the amount normally allowed for the cost of a single prescription. This would save you money, because you will use fewer prescriptions, and you may not have to visit the doctor as often to obtain repeat prescriptions.

If this situation applies to you, ask your doctor if an authority prescription might be appropriate.



Ask about a medicines review

Regular reviews of your medicines are good for your health as well as your budget. Ask your doctor or pharmacist to review your medicines, including all your prescription and non-prescription medicines. You may find that changes can be made that save you money.

Ask about non-medicine options

In some cases, there may be different ways to manage your health, in addition to or instead of using medicines.

Depending on your condition and the type of medicines you take, strategies such as eating well, keeping physically active, quitting smoking and using therapies like physiotherapy, acupuncture or massage may mean the medicines you use could be reduced or even stopped.

Get a concession card

Some concession cards allow you to get Pharmaceutical Benefits Scheme (PBS) prescriptions at a lower price.

In most cases, if you receive a pension or similar allowance from Centrelink or Department of Veterans Affairs, you will also receive a Pensioner Concession Card or Repatriation Health Card, which entitles you to medicines at the concession rate.

However, these are not the only types of eligible concession cards. For example, people on low incomes or Austudy and people caring for a foster child may be eligible for a Health Care Card. Similarly, older people who don't receive an age pension may be eligible for a Commonwealth Seniors Health Card. To find out more, contact Centrelink on 132 300, or visit the Concession Card section of the Centrelink website.

Ask about the Safety Net

The Government subsidises the cost of prescription medicines through the Pharmaceutical Benefits Scheme (PBS). If you or your family use a lot of medicines, the PBS Safety Net may help to reduce the cost of your medicines. Under the Scheme, once you or your family have spent a certain amount — known as the Safety Net threshold — on prescription medicines in a calendar year, you can apply for a PBS Safety Net card.

With this card, your PBS medicines will be less expensive or free for the rest of the calendar year. To receive a PBS Safety Net card, you need to keep a record of your PBS medicines on a Prescription Record Form, which is available from your pharmacy. Each time you have PBS medicine dispensed, give the form to your pharmacist so the medicine can be recorded. Your pharmacist can keep the record on their computer, but if you visit different pharmacies, it's best to keep your own record.

Acknowledgement: Medicines Talk No. 40 March 2012; www.nps.org.au



It's All About Caring

By Julie Stauffer

Coping with Huntington disease (HD) is devastating enough, as thousands of Canadian (and Australian) families can testify. But what happens when the caregiver becomes seriously ill as well?

Back in the late 90s, Sarah Mulcahy felt depressed, anxious and out of control. She thought she was going crazy, and her doctors couldn't offer any explanation.

Then her husband, Jim, was diagnosed with cancer. Sarah ignored her own disturbing symptoms while he battled non-Hodgkin's lymphoma. It was only after his treatment proved successful that Sarah finally got her own diagnosis. She had Huntington disease, a disease she did not know was in her family.

A year after that bombshell, Jim's cancer returned — this time in an incurable form.

Jim found himself simultaneously a caregiver and a patient. He spent sleepless nights coming to terms with his fatal disease and worrying about what would happen to Sarah and their four children when he died. Meanwhile, Huntington's had blunted Sarah's emotions, leaving her unable to support her husband through that dark period.

Experimental stem cell treatment five years ago bought Jim some time, but today everyone recognizes that his grace period could end at any moment.

For daughter Caitlin, it has meant not thinking more than a few months down the line, always ready to drop everything and move home to help when that phone call comes. But, she adds, there have been blessings as well.

"You very quickly learn what's important in your life and what's really not important," she says. "You so appreciate the good times that you do have."

Today, Jim dedicates himself to looking after Sarah. It is because of Jim that she is living at

home, going for walks, accompanying him during his volunteer activities and enjoying visits from their grandchildren. According to Caitlin, her Mom's the happiest woman in the world.

Jim will readily admit it isn't easy, but his frankness about the bad days and his sense of humour keep him going.

The Mulcahy's would be excused for feeling bitter about the hand that fate has dealt them. However, as Caitlin points out, in some ways their experience is typical: most Canadians will either need care or end up caring for someone at some point in their lives.

Her advice? "I think all you can do is take each day at a time and try to find the value in what you're doing and also be honest with yourself about those days when it really is awful," she says. "Be kind to yourself and to each other."

"We've been lucky to see both of our parents rise to the occasion really bravely," she concludes. "We have gotten to see this wonderful example of caring for one another, which is what you end up realizing life is all about."

Caitlin is currently completing her PhD dissertation on the role that mothers play in preserving family memories, and what happens when they begin to lose their own memory.

*Acknowledgement: "Horizon", No. 138, Fall 2012, Huntington Society of Canada
www.huntingtonsociety.ca*



Redefining Independence

Excerpt from *"I Met My Father the Night He Died"*, by Elizabeth Baxter



I can remember the day my mom and I had the "talk" with my dad about giving up driving. My father's chorea had gotten worse and he was losing his ability to show good judgment and recognize spatial boundaries while driving alone. After several "close calls," my mother and I made the difficult decision to take away the keys.

I remember we were all sitting at the round table in the kitchen. My dad was very quiet as my mom pleaded her case. I can still see the look of utter disappointment and betrayal on my dad's face as she told him he would no longer be making his favorite donut runs to town. When my dad looked across the table at me, I felt as though I had betrayed him, too. I felt so guilty limiting his freedom, but deep in my heart I knew it was the right thing to do. Making that hard decision for my dad was the moment when my role changed from daughter to caregiver, even though I was only 20 years old.

Taking the keys away from my dad was extremely difficult and emotional, because driving is a universal symbol of independence. I know it "killed" my mother to say the words she had been rehearsing in her head for years, but there were too many risks involved in continuing to let dad drive. Looking back, we probably should have made the decision earlier, but my mother told me she thought it "would break his heart." I know it nearly broke mine.

Once the storm cloud cleared, however, my mom got creative and thought of a new way for my dad to feel independent. She got my father on

our farm's four-wheeler so he could help her deliver hay to the horses in all the different pastures. To keep him on track, she taught my dad to focus on her back and keep the handle bars pointed in her direction while she walked ahead. When HD finally caused my father to retire, my mother asked him to help her with more chores around the farm, morning and night. It was really cute watching the two of them putting on their barn clothes and heading out together to do the chores, mom in front and dad behind on the four-wheeler.

Chores were not the only thing they did together. My dad would also follow my mom to the riding arena where she would ride her horse while he watched from the four wheeler. My dad spent many hours each day enjoying time with his loving and patient wife. Anyone could see how happy he was to be with her, doing chores or just sitting on the porch together. Looking back, I think it may have been the happiest time of my dad's life, simply being with my mom all day.

Feeling useful and remaining mobile added so much to my father's life those last years. I think it was inspired how my mother redefined independence by getting my dad off the road and on the four-wheeler, able to help her with the chores.

Our story is just one example of how caregivers can look for activities that will keep their loved ones engaged, even as their needs and abilities change. My mom was lucky that my dad responded so well to the idea of the four wheeler and was able to drive it safely. You may have to try several different activities, because something may work one week and not the next. Try not to get too attached to one idea, because HD symptoms are always changing and evolving into new symptoms. My advice is to take a deep breath and stay flexible. New activities may not always work, but then again, they might!

Acknowledgement: "The Marker", Spring 2012, Huntington's Disease Society of America
www.hdsa.org



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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: Brian Rumbold

Treasurer: Richard Bobbitt

Secretary: Judy Rough

Karen Bevan

John Conaghan

Keith Dingeldei

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(02) 9845 6699

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Westmead Hospital
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Westmead Hospital
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Huntington's Lodge
Nursing Unit Manager
Lottie Stewart Hospital
(02) 9804 5854

Nursing Staff
(02) 9804 5803

Predictive Testing

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

Hunter HD Service

John Conaghan
Social Worker
Hunter Genetics
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