Gateway

News from Huntington's New South Wales

Volume 16 No 3 **Spring 2013**

Annual General Meeting

The Annual General Meeting will be held on Saturday 23rd November 2013 at 12 noon 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 2012 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 2013/2014
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 8th November 2013. 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.

Join us a for a Sausage Sizzle Lunch!

In conjunction with our Annual General Meeting we're having a Sausage Sizzle Lunch at 12 noon at our offices.

As well as sizzling sausages, there'll be fried onions (of course) and tasty salads, culminating with delicious desserts. A donation of $5 per person would be appreciated.

Our local State Member, Victor Dominello, is hoping to join us at 12 noon. Put the date in your diary—the Board and Staff would very much welcome your presence at both lunch and the AGM.

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

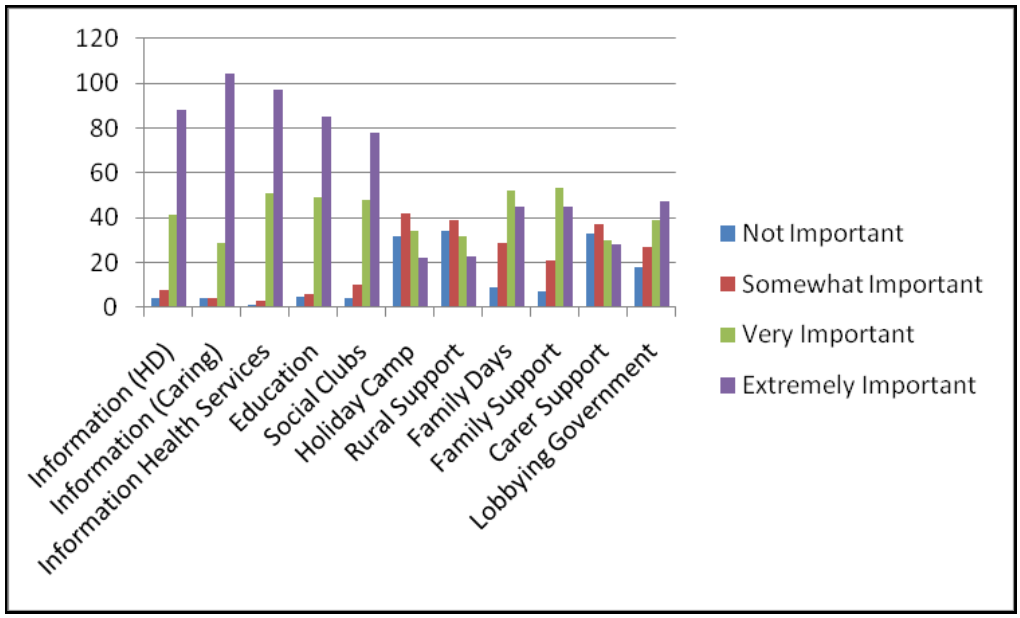
Membership Renewal!!

Thank you to everyone who has renewed their membership for this year. We are also very grateful to those who were able to make a donation—your generosity is much appreciated.

For those who haven't ye renewed, it's not too late. A strong membership will ensure that the Association continues to be representative of, and relevant to, people affected by HD in NSW and Australia.
A membership form can be downloaded from our website www.huntingtonsnsw.org.au Donations are always appreciated and are also tax deductible.

Survey Results

Thank you everyone for completing our membership survey. The survey results will guide the Board in setting priorities in how we might allocate resources in the coming year.
Below is a summary of the responses received.



Age Range of Responders		
18 to 24	0	0%
25 to 34	3	1.8%
35 to 44	13	8.0%
45 to 54	22	13.6%
55 to 64	44	27.2%
65 to 74	52	32.1%
75 +	28	17.3%
TOTAL	**162**	**100%**

Gender Breakdown		
Male	59	36.9%
Female	101	63.1%
TOTAL	**160**	**100%**

Carers' Week 2013 — Celebrating Carers

Carers Week is a national celebration of the 2.6 million unpaid carers in our community who care for a loved one. Carers are the cornerstone of Australia's mental health, aged, disability and palliative care systems. Without the support of unpaid family carers these systems would simply collapse. This year Carers Week runs from 13th to 19th October and to celebrate those who care for people with HD we have received funding from Carers NSW to hold two special functions—one in West Ryde and one on the Central Coast.

You can come for morning tea or come for lunch
Why not come for morning tea and stay for lunch?

Special Morning Tea and Lunch
Wednesday 16th October
from 10.30am
21 Chatham Road, West Ryde

Special Morning Tea and Lunch
Saturday 19th October
from 10am
LooLoo's Coffee Warehouse
Unit 12/11 Cochrone Street, Kincumber

If you would like to come along to either of these events, please let us know by telephoning the office on 9874 9777 or emailing info@huntingtonsnsw.org.au.
We would love for you to join us

Making Huntington's Their Cause

A "High Tea" was held at "Wow Designer Jewellery", Caves Beach on Saturday, 21st September. The day dawned to picture perfect weather and a pleasant 21° in this magnificent waterfront gallery where almost 80 women and one brave man attended a fundraiser for Huntington's NSW.

From left: Terry Ayres, Robyn Kapp & Karen Bevan

Champagne flowed and delicious food was a plenty, as well as many beautiful gifts available for purchase by mums and daughters alike as well as some well intentioned grandmothers.

Throughout the afternoon there were lucky door prizes, raffles, including 2 nights accommodation at the Caves Beach Resort and one night at the Crowne Plaza Terrigal. A wide variety of over 22 prizes were donated by very kind supporters. A very special *"Thank You"* is extended to all from the bottom of our hearts for their generosity.

As we go to print, in excess of $3,000 was raised on the day and these funds will assist with the provision of services to our many clients throughout NSW.

The organizing team worked tirelessly for nearly six months, planning, sourcing donors, organizing food and drinks, liaising with the venue and pre-selling raffle tickets for the major prizes. The team was ably assisted by a long list of helpers, (too many to name individually), whom they could not have run the event without.

Many other helpers were rallied to prepare food and the military-like operation all came together like clockwork on the day thanks to a beautiful day and lots of generous and hopefully happy guests.

Our sincere thanks to Lee, her family and the team at "Wow Designer Jewellery" for preparing the venue and stocking it with all the necessary items for the guests to browse and buy.

Terry Ayres

Editor's Note: A very special thank you is extended to Terry and her team for organising a most enjoyable and successful day. Terry's enthusiasm and commitment to Huntington's NSW is very much appreciated.

The Sun-Herald CITY2SURF PRESENTED BY Westpac

We are most grateful to those who ran in the City to Surf in August. This is a great way to not only raise much needed funds for Huntington's NSW but a wonderful opportunity to increase awareness of Huntington's Disease.

Why not get a team together now and start training for next year?!!

On the Road again ... Mark Bevan

A frantic couple of months on the road, but very rewardsing. Let me tell you a little about my recent travels.

Since the publication of the last Gateway, I have been every direction other than East....

Bathurst, Orange and beyond

Goulburn, Wagga Wagga, Albury and surrounds

Tamworth, Dubbo and surrounds

Mid North Coast Port Macquarie and surrounds

North Coast – Kempsey to the Queensland border

I have also visited clients 'closer to home' in the Central Coast and surrounding areas.

It is such a privilege to be invited to share part of people's lives. So many people I visit are doing it tough in a variety of ways, yet they are so resilient, so strong, it is truly inspiring to spend time with them.

My meetings are not limited to people. While visiting a lovely family recently, when I came out of their house to return to my car, I found Kevin (a cow) rubbing up against my car, licking the windows, and trying to get his head in through the partly open window. The young boy in the family quickly ran at him waving him away, telling him to get away from the car. Fortunately no damage done to the car – it just needed a good wash to get the lick marks off.

An interesting development in client contact for me has been trialling the use of Skype with a couple of clients. Skype is an online service that allows you to talk with other Skype users free (anywhere in the world). It provides voice only connection (like a phone) but also allows you to view one another 'live' as you talk. If you would like to use Skype let me know – it is not quite the same as sharing a cup of coffee but it can be way better than a regular phone call.....and it is FREE! My Skype ID is Mark.Bevan49. If you are having trouble getting Skype up and going on your computer, give me a call and I will help you.

In addition to regular client meetings, I have also conducted 7 in service sessions for nursing staff in care facilities across the Central Coast, Hunter, South West and South Coast.

What is happening through to the end of the year?

October 21 – 25	Holiday Camp
October 28 – November 1	West and North West regions (that covers Bathurst, Orange, Forbes, Dubbo, Tamworth and all surrounding areas
November 11-15	Mid North Coast and Far North Coast (Port Macquarie to the Queensland border)
November 29 – December 6	ACT, South West and South Coast (ACT, Goulburn, Wagga, Gundagai, Cooma, Batemans Bay, Nowra and surrounding areas)

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 or give me a call on 0410 629 850. I look forward to hearing from you.

Tracey — A Study of Determination

Skydiving, bungy jumping and riding a motorbike around Australia were incredible achievements for adrenalin junkie Tracey Jones but completing her PhD was the greatest feeling of all.

In 2006, Ms Jones was studying part time for her Doctorate of Education when she was diagnosed with Huntington's disease.

As Huntington's disease is a degenerative neurological condition affecting the brain and nervous system, the Claremont resident (47) said there were many times over the past six years when she almost gave up.

"As well as it being very difficult for me to type, I have trouble with my memory and forget certain words, which is very frustrating," she said. "With that in mind, it does feel like I have achieved this against all the odds."

"I'm very driven, so when I say I'm going to do something, I usually make sure I do it. Now that it's finished and sitting here on the table, it was worth every second."

Ms Jones' dissertation titled FLOTE-ing and Sinking: Teacher Participation in Online Professional Development was last month awarded the Postgraduate Researcher Award from the WA Institute for Educational Research at Murdoch University.

At her graduation last September, she also received the School of Education Prize for the best Doctorate of Education dissertation in the past two years.

"When I was first diagnosed, I created this mantra of making the most of every minute, so I started working my way through a list of crazy things," she said.

"After a while I decided that it was actually better if you do one big thing a month instead of cramming it in. It's my way of staying positive and moving forward."

She said receiving the award was August's "big thing" and this month she and her family were going to Rio for the Huntington's Disease World Congress from September

Acknowledgements: "Contact West", Huntington's WA, Spring 2013. Article, by Rosanna Candler, reproduced courtesy of Western Suburbs Weekly, September 10, 2013

Dr Tracey Jones with her Western Australian Institute for Educational Research award. Picture: Marcus Whisson d405956

Huntington's disease research... in space!

The sky's no longer the limit for HD research: HDBuzz interviews Gwen Owens, who's sending the HD protein into space!

The huntingtin protein, which in its mutant form causes Huntington's disease, is difficult to study because it forms clumps rather than neat crystals. Now, young HD researcher Gwen Owens of California Institute of Technology is reaching VERY high to try to crack the problem. In a special video interview screened at the recent HD World Congress, HDBuzz spoke to Gwen about her 'out-of-this-world' plans.

ED: Why is it important to study huntingtin, for people who want to come up with treatments for Huntington's disease?

GWEN: It's incredibly important to the disease… that we know that it's the single protein that appears to cause the disease and unfortunately we don't have any idea what it looks like.

ED: Which seems quite important. If you're going to try and fight something, you want to know what it looks like.

GWEN: Yes, indeed.

ED: We have really accurate understandings of the structure of some proteins, like insulin, or haemoglobin, or some of the more famous proteins, so why don't we… It's 2013; we've had 20 years since the gene was discovered. What have you guys been doing? Why don't we have an idea of what huntingtin looks like?

GWEN: Huntingtin has two properties that make it really difficult to study the structure. One is that it's huge, that it's one of the biggest proteins in your body. It's more than six times larger than most proteins. That makes it difficult to work with. The second is that it aggregates. That we know, that part of the problem with Huntington's disease is that this protein, huntingtin, aggregates in neurons and that also makes it very difficult to study.

ED: When you say 'aggregates', you mean it sticks together to form clumps?

GWEN: Exactly, yes.

ED: Why does the protein sticking together make it difficult to study?

Gwen Owens

GWEN: Well, our lab uses a technique called X-ray crystallography to figure out exactly where every carbon, every nitrogen, every oxygen is in a protein. For that, we need individual proteins, they can't be clumped together, in order to make a crystal of proteins.

ED: Okay, so you look at a crystal and from that you can figure out the structure of the protein?

GWEN: Yes. When a crystal is formed you can actually shoot a laser through it, and based on the pattern of how light hits off of the crystal, you can actually reconstruct where everything is.

ED: From the experiment that I know you're planning, it sounds like you've kind of got to the limits of what we can do in 2013, on Earth, to get crystals of this protein, right?

GWEN: As far as we can tell, yes. We've set up more than a 100,000 different individual experiments on Earth, and we can't get anything to crystallise such that we can get a structure.

ED: I would say that does sound like you've done your background work pretty well. Okay, well let's spill the beans then. What are you planning to do to try and get crystals of huntingtin to grow, so that you can study the structure?

GWEN: We're planning on sending some of these experiments up to the International Space Station.

ED: Huntingtin in space!

GWEN: Yes, exactly. Our lab received a grant from CASIS, The Center for the Advancement of Science in Space, which is a subsidiary of NASA. They were looking for crystallisation experiments to be done on the International Space Station, and I think we made a pretty good case for why huntingtin is a really interesting protein to try to crystallise on the ISS. They realised that some of the physics in how crystals grow is really different when you don't have gravity. They found that for some of these proteins that we know crystallise well, that the crystals get much, much bigger and they form much, much better. They'll be another 10 to 20 times bigger in some cases and they actually diffract, so when you shoot a laser through it, it actually does a much better job of giving you a structure.

ED: Much bigger and much purer, it sounds like.

GWEN: In many cases. Definitely not in all cases and in some cases it did actually make it worse, as well. Huntingtin we thought would be very, very interesting to try in this situation. Because while we can get tiny, tiny little crystals, we can't get crystals that are big enough really to do our studies on Earth.

ED: How far above the Earth is the International Space Station?

GWEN: It's about 250 miles.

ED: But we can see it, sometimes. It flies overhead and you can see it like a little light in the sky, right?

GWEN: Yes, almost every night, actually. You can look it up online exactly when the ISS will be passing overhead in your location.

ED: That's cool. So, is it a zero gravity environment up there?

GWEN: No, it's technically microgravity. There is some small pull from the Earth still, even though it is very high up.

ED: Let's ask a basic question here. What happens when a crystal forms?

GWEN: So, to make a crystal you have a very high concentration of protein. Such that it starts essentially nucleating, so it forms a central core. Then it starts building more and more proteins on the outside of it, until you get something that you can see with your own eye as a crystal.

ED: So, in a solution you've got all these protein molecules, and they're all just flying around and they're spaced quite far apart from each other?

GWEN: Essentially, yes.

ED: Then when you grow a crystal, one by one the proteins stick to each other, but in an organised way. Is that right?

GWEN: Yes, indeed.

ED: It's the organisation that makes it a crystal, rather than a blob?

GWEN: Yes.

ED: How does the lack of gravity help the crystals to grow? What is it about the lack of gravity that makes the crystals grow bigger?

GWEN: So, when a crystal is growing, as I said there is this really high concentration of protein that is slowly forming this crystal. You end up with really high protein concentration, in the general solution. Right next to where the crystal is growing you have really low concentration because it's just been sucked up into the crystal, it forms a lattice. So, you have really high and really low concentration right next to each other. In the oceans, we know that if you have really high salt and really low salt, it starts mixing. Its starts having what's called convective flow. The same thing happens with crystals, is you get this flow along the surface. Apparently this flow impedes the growth of the crystal and so when this flow occurs the crystal essentially stops growing.

ED: Right, but if you take away the gravity..?

GWEN: It gets rid of most of the flow. There is some amount of flow that is good for the crystal, but having the amount of flow that is on the surface, in some crystals that are growing rapidly on Earth, clearly it impedes the growth of the crystal.

ED: What's the biggest difference that's been seen with a crystal by growing it in micro gravity?

GWEN: For lysozyme, which is one of the very

standard crystals that we actually use to test out some of our beam lines, there has been experiments that it's been 20 times the size. For our crystals, 20 times the size would be enough to start doing some interesting work on them.

ED: Oh, wow. So then you could shoot the laser beams through it and cool things would happen?

GWEN: Hopefully, yes.

ED: So, how do you get huntingtin into space? Do you FedEx it up there and there is a daily delivery? What happens?

GWEN: We're sending our samples up on SpaceX 3, which is scheduled to send a whole load of stuff up to the ISS in January of next year (2014).

ED: So, have you made the huntingtin already in your lab, or are you busy making it? Or will you do it the day before?

GWEN: We continuously make huntingtin proteins in our lab.

ED: How do you do that?

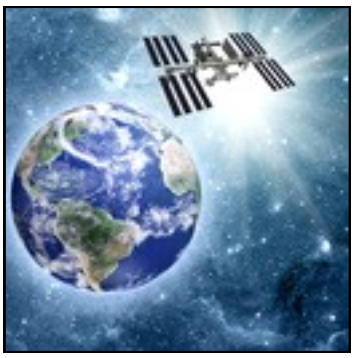
GWEN: We grow it in E. coli, which is a bacteria and we have this E. coli make the protein, the huntingtin, of different lengths. Sometimes we only use part of it, because it's such a big protein and E. coli has a lot of trouble making the whole protein.

ED: You inject extra DNA into the E. coli to turn it into a huntingtin factory?

GWEN: Exactly, yes. After we get it really, really pure then we can set up these crystallisation experiments.

ED: We know that there's a mutant protein, which is the one that does damage to cells, and there's a so-called 'wild type' or healthy protein which doesn't do damage to cells. Are you just sending up the wild type, or are you sending up any mutant protein?

GWEN: We're planning on sending up some mutant protein as well. The mutant protein aggregates more than the wild type protein, which is part of the cause of Huntington's disease. So, it's a lot harder for it to crystallise. We expect better results from the wild type but we think getting a structure of some of the mutant protein would be really interesting too, so we'll send some up as well.



ED: So, the very, very best result would be big crystals, of normal or wild type protein and big crystals of the mutant protein. You shine your laser, and we get to look at the differences?

GWEN: Absolutely, yes.

ED: Maybe even some clues as to where we could stick a drug, or what we might be able to do to turn the mutant crystal into something that looks a bit more like the wild type crystal?

GWEN: We would hope so, yes.

ED: How delicate is this specimen of huntingtin protein and how is it packaged?

GWEN: It's packaged in… Actually, I have it here. We have these little devices. This is six different little experiments. So, the trip up is … they should be fairly stable, because the experiment doesn't start until they get into micro gravity. The astronauts actually have to flip a couple of levers for us to start the experiment going. Otherwise, the huntingtin protein is not crystallising, before it's in micro gravity.

ED: So, they take out these little containers up there; flip the levers and then the whole experiment runs itself?

GWEN: Yes, exactly.

ED: Wow. That sounds good, because astronauts … they're not exactly rocket scientists, let's be honest.

GWEN: (Laughter) Yes.

ED: How long do the crystals grow then, once they flip the switches?

GWEN: It will be somewhere around four months, but it also depends on when the different SpaceX vehicles can come up and down.

ED: When does the SpaceX 3 rocket go up?

GWEN: January 15th.

ED: January 15th? Roughly when will the huntingtin come back down to Earth?

GWEN: Roughly, April. We're hoping.

ED: It's growing the whole time?

GWEN: Yes. Well, the astronauts flip a switch before it comes back down, so the experiment finishes before it reaches gravity again. If, say, it crystallised but then when it came down you have to deal with re-entry, and that can be a bit of a bumpy ride. That's probably the most difficult part, because we're worried about the crystals potentially breaking up.

ED: When something comes back down to Earth, doesn't it just fall into the sea?

GWEN: Yes. (Laughter) Delicately!

ED: How do you feel about that?

GWEN: The containers that the crystallisation experiments are in are very well isolated from vibration and from temperature changes. The protein should be coming down not too far away from where our lab is in Pasadena. So, we should be able to drive and be there almost when it splashes down. Get the protein and drive it as soon as we can back to our lab. Then shoot an x-ray laser through it.

ED: How quickly will you know after it arrives in the lab whether the crystals are big enough to be of any use to you?

GWEN: Within a couple of hours.

ED: So, that's going to be pretty exciting.

GWEN: Yes, yes. Absolutely.

ED: Can you give me some idea of the sorts of things that knowing the crystal structure of proteins has led to in the past?

GWEN: One example is when HIV was first discovered. Some of the HIV proteins, like the HIV protease, which is important in the function of the protein, its crystal structure was solved. Then using that, organic chemists and synthetic chemists were able to use that structure to make something that inhibited what they expected the function was. They kind of locked on to the structure and were able to make a new drug against HIV based on the crystal structure.

ED: Finally, do you have a message for the folks here in Rio and watching online?

GWEN: Sure, if you ever want to see when the ISS is passing overhead, you can always just go to the website spotthestation.nasa.gov and know that between January and April this year, huntingtin will be passing overhead.

ED: Well Gwen, this is absolutely amazing. I mean, it's so exciting that this is happening. I really appreciate you taking time to talk to me. I know that everyone here in Rio is going to be absolutely over the moon that this is happening. I guess, even if it doesn't work at all, it's totally worth trying and its really cool stuff, so thank you very much for taking the time to talk to us.

GWEN: Well, thank you very much for having me.

Acknowledgement: HD Buzz
By Dr Ed Wild, Edited by Dr Jeff Carroll
If you would like to watch this interview on Youtube go to www.hdbuzz.net

Complementary Medicines — are they effective?

Complementary medicines are popular in Australia. They can be used to 'complement' medicines prescribed by a health professional or, in some cases, may be used as an alternative to conventional treatments.

Vitamins, herbal medicines and mineral supplements are widely available through pharmacies, supermarkets, online retailers, and complementary health practitioners (e.g. naturopaths).

Some people report benefits from taking these medicines, but are they really effective? And, is there any evidence to show that they actually help you?

There is some research into certain complementary medicines that shows there may be a benefit in using them. However, there is a lack of evidence from good clinical trials to support the effects of many complementary medicines.

Here are a few points to consider when deciding whether to try a complementary medicine.

Complementary medicines are medicines too
Complementary medicines, while often less powerful than prescription medicines are medicines and still need to be used with care.

Like all medicines, they have side effects, interactions and, in the worst case scenario, they can potentially be harmful. This is why it is important that you tell your health professional about all the medicines you or anyone in your care is taking.

When you're sick with cold or flu, it may be tempting to try complementary medicines to help speed-up your recovery. Three medicines that are commonly promoted as helping treat or prevent cold and flu are echinacea, zinc, and vitamin C.

How is the medicine made and what is it made from?
There can be a large variation in how a complementary medicine is made and what it is made from. For example, echinacea preparations (often used to treat colds and flu):

- are available in various forms (tablets or liquids)
- are available in various strengths
- can be made from different parts of the echinacea plant (e.g. the stems, leaves and/or roots)
- may be made in different ways (e.g. as the dried herb, extracts of the plant juices in alcohol or fresh juice pressed from the plant)

sometimes contain other ingredients (e.g. other types of plant extract).

Less is known about the effectiveness, side effects and interactions of complementary medicine

This means that when buying a complementary medicine, it is difficult to know which form and strength to buy, how much of it to take, and what side effects might you experience.

This is not the same for prescription and pharmacy medicines, which have strict manufacturing, testing and marketing rules and regulations.

Is there evidence that the medicine works?
Prescription and pharmacy medicines sold in Australia have to undergo extensive clinical research and testing.

Complementary medicines do not have to be proven to work in the same way as prescription and pharmacy medicines do. They undergo less testing in general, so less is known about their effectiveness, side effects and interactions.

In other words, a complementary medicine might not do what it is claimed to do and, at worst, it could possibly do you harm.

Acknowledgement: *Medicinewise Living http://www.nps.org.au/*

Tell your health professional about all the medicines you — or anyone in your care — are taking, including prescription, over-the-counter and complementary medicines (herbal or natural medicines and vitamin and mineral supplements).
This is because all medicines, including herbal and natural medicines, can cause side effects and may interact with other medicines. The benefits and risks of herbal and natural medicines may not have been tested.

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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: Brian Rumbold
Vice President: Don Ayres
Treasurer: Richard Bobbitt
Secretary: Judy Rough
Deb Cockrell
Amanda Dickey
Keith Dingeldei

Association and Other Useful Contacts

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