Gateway

News from Huntington's New South Wales

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From the Manager

It has indeed been a pleasure and an honour to return to Huntington's NSW in the role of Manager. When I re-joined the staff last November 2011 it became obvious that we had been marking time for the past five years. However I am pleased to report that since the last Annual General Meeting we have made significant progress in a number of ways and these are highlighted in the Annual Report. If you would like a copy of the report sent to you, please contact us at the office. It can also be found on our website www.huntingtonsnsw.org.au.

Such progress has been achieved because of the dedication and commitment of both the Staff and the Board.

Once again I would like to pay tribute to all our staff members – they have continued to undertake their duties responsibly and enthusiastically. They are to be commended for their concern for families impacted by Huntington's Disease.

I am truly indebted to the Members of the Board who have given so readily of their time and expertise. Their guidance and ideas have been crucial to setting and achieving the Association's goals for the past twelve months. Special thanks go to Karen Bevan and John Conaghan who did not stand for re-election this year and we welcome Amanda Dickey to the Board.

I am confident that we will continue to make even more progress in the year ahead. Of course, we will continue to face challenges – we are facing times when governments are trying to save money and charity funding is getting harder to attract. However, we are confident that, with your support, involvement and input we can continue to have a positive impact on the lives of members of the HD community.

As we take time to reflect on the Association's achievements over the past year we should also keep in mind our vision for the future. It is only with your help that we can make that vision a reality – a reality which, it is hoped, will have wide and far reaching impacts for families and all other people affected by Huntington's Disease in NSW and the ACT.

On behalf of the Board and Staff I would like to wish you all a very Happy Christmas and a peaceful 2013.

Robyn Kapp
Manager

Annual General Meeting

The Annual General Meeting of the Association was held on Saturday the 27th of October 2012 at Elsie Court Cottage, 21 Chatham Road West Ryde.

The Chairman, our outgoing President, Don Ayres opened the meeting with a "Thank You" to the Manager Robyn Kapp and the staff of the Association, for their tireless work above and beyond the call of duty during the year.

A warm welcome was also extended to all who have attended the meeting, including the staff from the Huntington's Disease (HD) Service.

The general business of the meeting, included the presentation of the minutes from the previous AGM, which had been printed and distributed and were carried unanimously.

The Annual Report was given by the Manager, Robyn Kapp and the Annual Financial report by Richard Bobbitt followed by the Annual Statement as required by the Office of Fair Trading.

Then followed the election of office bearers and committee members with the following outcome: Brain Rumbold was elected President, Don Ayres as Vice President, Judy Rough as Secretary, Richard Bobbitt as the Treasurer and the following members elected to the committee, Amanda Dickey, Ann Low and Keith Dingeldei. Congratulations to all those elected and thank you for making yourselves available.

Dr. Clement Loy, our guest speaker was introduced and gave a passionate talk on HD and its history in Australia and elsewhere in the world and then a thorough update on the progress with clinical trials and medication being used to help patients with HD.

Doctor Loy also showed us, by way of a power-point presentation, the new HD unit at St. Joseph's at Auburn and the benefits that this facility will have for the HD community.

There were several questions from the floor and answered with great skill by Doctor Loy. I'm sure all those who attended, would have been comforted to know that we have Dr. Loy heading up the HD service.

The meeting closed with an afternoon tea and plenty of time to mix with other members and more discussions with our guest speaker.

Don Ayres
Vice-President

Huntington Study Group (HSG) 2012

The Huntington Study Group (HSG) meeting was held in Seattle USA this year. Since the discovery of the HD gene mutation nearly 20 years ago, the HSG has undertaken over 20 research studies, including trials of medications. Some of these trials are ongoing. These include the 2CARE study, a trial of high dose Coenzyme Q10 versus placebo with over 600 participants worldwide, the CRESTE trial of high dose creatine versus placebo and the Reach2HD trial of a medication called PBT2 versus placebo. While the doses currently used in these trials will not be regarded as safe until they have been thoroughly monitored in a completed trial, no serious adverse events related to a trial drug have occurred. Australian research sites are currently participating in these studies and the CRESTE (Dr Clement Loy Site Investigator) and Predict-HD studies are still open. Anyone wishing to join these studies can contact the NSW research site at Westmead Hospital (email: hsgtrials@gmail.com).

The Westmead HD research team members who attended and Dr Anne Young. Dr Young serves as the Chair of the HSG scientific committee which reviews the HSG trials before they are undertaken.

It was the early 1990s when the late Dr Jack Penney and Dr Anne Young came to Australia for an HD Association meeting in Brisbane. There they encouraged Dr McCusker to become a member of the HSG and so the Lidcombe, then later Westmead site was established. Since then many people with HD, people with the mutation but not affected and family members have assisted by giving valuable time to participate.

Drug trials need to be precise to ensure that the information collected is accurate. The HSG meeting allowed the Westmead study coordinators to work face-to-face with the people they interact with everyday via email and phone. Jane Griffith, the Westmead Huntington Disease Service trials nurse coordinator was able to participate in meetings that allowed her to receive the latest trial updates and to provide feedback that improve the study visit experience of study participants. David Gunn, clinical neuropsychologist, attended the reviews of cognitive testing in HD as well as updates of current opinion about the most effective cognitive tests that measure change in thinking in HD over time. Some of this information which was presented by Prof Julie Stout from Monash University in Melbourne was the result of the CAB study. Several people in NSW helped with this study that will allow more reliable tracking of change.

One of the key points discussed at the meeting was how to ensure that people enrolled in research studies do not become lost to follow up. For the Westmead Hospital Huntington Disease Service Research group, this discussion highlighted the need to continue offering our research participants assistance with travel and accommodation arrangements, flexible appointment times when possible and plenty of time to ask questions of the research team.

There were many interesting talks at the HD research day where family members are invited to participate. Research from British Columbia indicates that the number of people living with HD is increasing and that the trend is that HD will be seen in more older people as the life span increases. Dr Tom Bird, a Neurogeneticist from Seattle, also spoke about HD in older people and the variable nature of the disease which sometimes can occur with Alzheimer Disease. Dr Rao from Columbia University, New York, reviewed the role that exercise and cardiovascular health play in the well-being of people with HD. Dr Steve Hersch, Prof Neurology at Massachusetts

Prof Steve Hersch and Dr Elizabeth McCusker after the CRESTE study meeting.

General Hospital indicated that the findings of a study of creatine versus placebo in people before definite onset of HD (the PRECREST trial) would be ready in the near future.
There were also presentations about treatments that may be trialled in humans in the future. In addition, representatives of drug companies presented their work focussing on possible HD therapies. If shown to be safe, these potential treatments should come to trial.

The North Eastern storms prevented Dr Nancy Wexler from attending but she continues to drive funding efforts for the Casa Hogar Amor y Fe (House of Love and Hope), the hospital for HD in Venezuela. It was in Venezuela that Dr Wexler and others undertook the major research effort involving large numbers of the local population living with HD that helped lead to the 1993 discovery of the HD gene mutation. At the Casa Hogar family members serve as staff to the large HD community, apart from a long term doctor and two other health professionals.

We are very lucky in Australia to have the services we have even though there is so much to improve. It is through the dedication of our research participants and the support of Huntington's NSW that we are able to continue to improve services and treatments for people living with HD. Jane and David would like to thank Huntington's NSW for their kind support and funding that allowed them to attend the HSG 2012 meeting.

Dr Elizabeth McCusker, David Gunn and Jane Griffith

Thank You!!

A very special thank you to everyone who has supported Huntington's NSW this past year.

Whether it be renewing your membership, making a donation, fundraising or comments about our services, we are truly grateful.

Love makes the world go round

I have a wonderful story about my mother-in-law, Alicia, who has Huntington's Disease, a degenerative disease of the brain affecting muscles, speech, mobility, behaviour, involuntary movements and many more issues. There is no treatment or cure for Huntington's Disease.

Alicia and Dave at the Social Club Christmas Party in 2011

My mum-in-law hasn't had much luck with relationships and decided there would be no more men in her life after three failed relationships and having also been diagnosed with Huntington's. She found herself broke and alone after her last break-up and moved into our home.

It was very difficult for all involved but she was so brave and just lived her life as best she could. She even volunteered for RDA (Riding for the Disabled). Soon after moving into our place she met a nice young man at her HD support group. His name was Dave and he was in a similar situation—broke and alone. He was very keen on Alicia but she didn't want to get involved and suggested that they just be friends.

Months passed and Dave would not give up. Alicia really liked him too, but stuck by her guns! Dave invited her to his place and Alicia couldn't believe how much they had in common considering there was a large age gap—Dave is 21 years her junior!

Time moved on and Dave was becoming more impatient and told Alicia if she didn't want him, he would go out with another lady in the group—He was quite popular with the ladies!

Alicia discussed her situation with me and her hesitation to go ahead with Dave. But she also told me how good he was to her and that no man ever cared for her like Dave. I told her it was okay and to follow her heart.

Now, eight years on, Alicia (now 70) and Dave live in the same aged care facility and earlier this year had a lovely commitment ceremony surrounded by family and friends.

They are so very happy, even though they are both deteriorating due to HD. I do hope this letter is published to let others know not to give up on love and life due to illness or age! Their family and friends wish them all the very best.

Leonie Edwards

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

Interview: Alice and Nancy Wexler

HDBuzz interviews Alice and Nancy Wexler, the sisters at the heart of the Hereditary Disease Foundation

The Hereditary Disease Foundation, or HDF, is a key player in the world of Huntington's disease research. At the HDF's recent biennial scientific meeting in Cambridge, Massachusetts - 'The Milton Wexler Celebration of Life and Creativity' - HDBuzz met Nancy and Alice Wexler, the remarkable sisters at the heart of the HDF's work.

The Wexlers

The story of the HDF is intertwined with the story of Nancy and Alice Wexler's lives.

Alice and Nancy Wexler
Image credit: Alice Wexler

Nancy was 23, and Alice 26, when their father Milton, a prominent psychoanalyst, told them their mother Leonore had been diagnosed with Huntington's disease in 1968. As it always is, the news was a bombshell.

Milton was not one to take such news lying down, however. He approached Marjorie Guthrie, wife of folk singer Woody Guthrie. Marjorie had established the Committee to Combat Huntington's Disease after Woody had died of HD the previous year.

"Dad was always interested in research, and wanted to recruit scientists to get interested in doing research on Huntington's," recalls Alice.

It was a daunting task: the scientific landscape was dramatically different back then, says Nancy. "In 1968 nobody had even heard of Huntington's disease, and very few people did research on it. And when we started to look for people to interest in research, it was extremely difficult to get people interested".

Alice, a historian and writer, whose books on Huntington's disease include 'The Woman Who Walked into the Sea' and 'Mapping Fate', adds, "There was actually a fair amount of research going on earlier, but one problem was that much of it was aimed at identifying people who were going to get it, in order to stop them from having children."

HDF's workshops

Undeterred, Milton established the Hereditary Disease Foundation as a non-profit organization, and set out to produce a significant shift in how Huntington's disease was viewed and studied. That remains the mission of his daughters and the HDF's expert Scientific Advisory Board.

Where to begin? Get people talking. Drawing on his background as a psychotherapist, Milton organized a series of workshops — small meetings of scientists from different fields, discussing HD and exchanging ideas freely.

The HDF's workshops — which continue to this day — always began with an introductory talk to the scientists from an HD family member. "Huntington's is a very obscure disease in a lot of ways," explains Nancy. "Even doctors who treat HD patients don't actually have a conversation with them one to one as a human being. And we felt that that was critical. People would get motivated, people would get passionate."

HDF workshops have unique rules to encourage creative thinking by scientists. "They had to be small," says Nancy. "Fifteen to twenty people," adds Alice. Slides and Powerpoint presentations are banned, too, drawing the participants out of their comfort zones. "Everybody is freaked out about that, but it gets people to focus on what actually matters in the research, and what matters about the data," says Nancy.

The HDF was instrumental in bringing some big names into the Huntington's disease field, including several Nobel Prize winners. But the sisters agree that attracting and supporting young researchers has always been key. "That was a big focus — to find young people, people who were just starting their careers, and to get them to be interested in Huntington's," recalls Alice. Recruiting young researchers goes beyond the number of years ahead of them — they are free from prejudices and preconceived notions about how to approach problems, too.

Nancy, an irrepressible storyteller, slips into an affectionate parody of a senior researcher holding forth at an early workshop: "Well, this meeting's going to go on for half an hour, after which we're going to get the revealed truth, and then — nothing's going to happen!" But the younger researchers had no such fatalism — "no sense of what was impossible," as Nancy puts it.

The marker, the gene and beyond

The emphasis on unfettered thinking and using the brightest minds to strive towards the seemingly impossible has created an impressive array of HDF-supported scientific progress.

The discovery of a DNA marker for Huntington's disease in 1983, and the HD gene itself in 1993, were accelerated by the Foundation's workshops, organization and funding. "Finding the marker was radical; that absolutely changed the planet," Nancy jokes — but it's not far from the truth: the DNA marker focused the search for the HD gene. And from the HD gene we get our entire understanding of how HD causes damage, and the large repertoire of treatment targets we now have.

Beyond HD, the efforts of the "gene hunters" were central to the revolution in genetics that we hope will eventually yield treatments for many diseases including Huntington's. "The gene hunters invented about fourteen technologies en route," says Nancy.

Nancy is also behind the Venezuela Project — a 32-year study based in an area of that country where HD happens to be many times more common than elsewhere. Hundreds of related volunteers from those villages participated in the research that led to finding the marker and the gene. DNA from the Venezuela Project was also used to discover that CAG repeat length — the number of 'stutters' in a person's HD gene — can affect the age when a person is likely to develop HD symptoms.

Since the gene was found, HDF-supported work has led to some big advances. In 1996, Gill Bates of King's College London developed the first HD mouse model. Called the 'R6/2', Bates' mice have taught us lots about how the HD mutation causes damage, and are still used today to study the disease and test possible treatments. Bates unexpectedly found clumps of protein, called 'aggregates', in the brains of her mice. "Nobody thought that Huntington's had aggregates," recalls Nancy, but spurred on by the mouse discovery, these aggregates were soon shown to be an important change found in HD patient brains, too.

Another game-changing moment was the 2000 study by Ai Yamamoto, who bred an HD mouse in which the abnormal gene could be artificially 'switched off'. To everyone's surprise, switching off the gene allowed mice that had already developed symptoms to get better. Nancy is particularly pleased to recall that breakthrough, because the HDF had nurtured Yamamoto from early in her career. "We funded her to do her graduate work. She didn't even have a doctorate!" she laughs.

Yamamoto's work paved the way for the gene silencing or huntingtin lowering treatments that are now close to being tested in Huntington's disease. In 2002, the HDF held the first workshop on using RNA-based drugs to 'switch off' the HD gene, and HDF-supported researchers like Beverly Davidson — whom we recently interviewed for our 'EuroBuzz' feature — remain central to advancing those treatments to clinical trials as quickly and safely as possible.

Today and tomorrow

After the discovery of the gene, why has Huntington's disease proven such a tough nut to crack? "Biology is really complicated; we're really complicated, our cells are really complicated," explains Nancy. "Every time you look under a rock for what the Huntington gene's doing, you find something fascinating and interesting, maybe relevant and maybe not. And so even figuring out what's relevant is tricky."

Nancy challenges an oft-mentioned piece of conventional wisdom in the HD field — the idea that we've 'cured the mice' in many different ways, and the problem now is 'translating' those successes into human patients. "I think that we haven't had very much success in models, frankly. One thing that did work was gene silencing in mice."

One success Nancy considers convincing is a drug called SAHA, which Gill Bates first tested on HD mice in an HDF-supported study in 2002. The SAHA story is a good example of why progress in science can feel so painfully slow to the people waiting for the big breakthroughs.

SAHA was thought to restore normal gene switching, which goes wrong in HD. "The mice got better. And they improved their grip strength and they improved survival a little bit. But SAHA's toxic. Gill dedicated years of her life to studying how it worked."

Ten years later, Bates presented the latest results of her work at the HDF meeting where we met the Wexlers. "She just figured out it works by doing something in the cell — not in the nucleus where the DNA is. And she just presented that at our meeting, ten years later. And Gill does more work than anyone I've ever met in my life!" It's a vivid example of how long it can take from a discovery, to a fuller understanding of the mechanisms behind it.

So, bearing in mind the amount of work to be done, and the optimism surrounding recent progress towards effective treatments for Huntington's disease, what's the HDF's focus for the near future? "Push the envelope," volunteers Nancy with characteristic enthusiasm.

"We try not to put all of our eggs in one basket," adds Alice, "but also to not be all over the place. Gene silencing has been one approach we feel is worthwhile. Then there's the issue of biomarkers — how do you measure whether a potential treatment is actually working in humans — that's another big question. I also think because clinical trials are so expensive and so hard to do, that we really need to insist that the work is done properly in the mice"

Helping to move the best possible treatments into the best-designed clinical trials is a major focus, too. "We hold a lot of workshops looking at designing clinical trials," says Nancy.

The 'blue sky thinking' tradition of the HDF remains apparent in its work, too. The Foundation's biennial scientific meeting, where we met the Wexlers, is renowned among scientists as a place where exciting new ideas are presented and discussed. As well as big-ticket items like gene silencing techniques and the chemical tagging of the huntingtin protein, HDF-supported projects presented at the meeting included studies as diverse as what bacteria live in the gut of HD mice; new ways of rapidly measuring gene switching problems; studying the HD gene in fruit flies; and genetically engineering cells to produce antibodies to protect against the harmful mutant protein.

We finish the interview by asking what the next few years may bring for HD research. "It does feel to me like an historic moment," admits Alice. "But we don't know. I think we still face the balance between optimism and realism, in a way. Maintaining that balance to me is a big challenge."

When we ask what the next decade of HD research may bring, Nancy's answer is shorter, and rather beautiful. "I'll go to heaven and dance," she says, and smiles.

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

National Disability Insurance Scheme

Agreement for Full Roll out of National Disability Insurance Scheme in NSW by July 2018

Most of you would have heard that the Australian and New South Wales governments have reached an historic agreement that will allow for the full roll out of a National Disability Insurance Scheme (NDIS) in New South Wales by July 2018.

Following is the press statement released

"The agreement will provide care and support to around 140,000 NSW residents with significant disability, and provide coverage in the event of disability to around one third of the Australian population.

It will provide peace of mind to people with a disability, their families and carers, and to the Australians who will unexpectedly face misfortune in the future.

It will give people with disability choice and control over the care and support they receive, rather than exposing them to the cruel lottery that currently exists, where care depends on a range of unpredictable factors.

Under the agreement reached:

- The Commonwealth will provide funding of $3.32 billion in 2018 – 51.4 per cent of the funding needed. This will cover the administration of the scheme and contribute to the cost of individual care and support packages and other supports for people with disability, their carers and their families.

- New South Wales will provide more than $3.13 billion in 2018 – 48.6 per cent of the funding needed. This will contribute to the cost of individual packages and other supports for people with disability, their carers and their families.

- The full scheme costs will be reviewed by the Productivity Commission in 2018-19 to inform COAG agreement on final scheme funding arrangements.

Today's agreement builds on the agreement to launch in the Hunter region of NSW from the middle of next-year. Other eligible New South Wales residents will start entering the scheme in 2016, and by July 2018, all eligible residents will be covered by the NDIS.

The implementation of the NDIS in NSW provides a framework for a national scheme to be rolled out in all states and territories.

An NDIS will also be launched in South Australia, Tasmania, the Barwon region of Victoria and the ACT and final bi-lateral agreements for these launches were reached at the December COAG meeting.

Editor's Comment: You can be assured that the Association will keep up-to-date with information about the NDIS and how it will affect people with Huntington's Disease.
You can also receive updates regarding the scheme at http://www.ndis.gov.au/

Carers: looking after yourself

Caring can be demanding and stressful. Finding the time to take care of your own health may be hard, but you'll reap the benefits in terms of improved wellbeing and you'll be better able to perform your caring role. Here are some tips to help you keep on top of your own health.

Stay healthy

Look after your long-term health by doing your best to eat regular meals, exercise regularly, and get enough relaxation and sleep.

Even though it may seem daunting, some moderate exercise such as walking each day can improve your overall wellbeing and boost your energy levels. Start with as much as you can manage, and gradually build up until you're doing 20–30 minutes each day.

Tiredness and exhaustion make caring more difficult. Getting enough rest and sleep can increase your energy levels and help to make you more resilient to the stresses of caring.

If you're having difficulty relaxing or getting to sleep, consider learning some relaxation techniques. Also, consider asking your doctor for advice about getting a good night's sleep without using medicines.

Keep up your own health care and medicines

If you don't have one already, find a GP that you trust, feel comfortable talking to, and who understands your caring role.

Make sure you have regular health check ups and see the doctor when you're ill.

Keep your medical appointments separate from those of the person you're caring for, so you don't push your own needs aside.

Don't neglect to take your medicines. You probably make sure that the person you're caring for takes all their medicines — do the same for yourself, particularly if you have a chronic condition.

Seek help for depression

Depression is common in carers, as are periodic feelings of bitterness and sadness about your situation.

Such feelings may or may not be a sign of depression. If you're feeling chronically miserable, anxious or stressed, you could be depressed — talk to your GP. They can advise you if it is depression and suggest ways of managing it. Treating depression can improve your sleep patterns as well as your mood.

Look after your back

Back injuries are common in carers. Prevention is better than cure. If your caring involves lifting or moving the person, ask the healthcare workers you deal with if they can arrange for someone to come and advise you how to lift safely. They may also be able to organise or recommend some aids that make the task easier.

Get the services you need

You don't have to soldier on! Make use of the services available to carers. Don't just consider them for the person you care for: take up services that will help you and improve your quality of life.

Services you might consider include meals on wheels, house cleaning, gardening, shopping, transport, cleaning gutters, installing fire alarms and essential house repairs.

If you're finding it hard to do some of the more difficult caring tasks, ask if you can have a trained carer or nurse come and do them for you. Such tasks might include showering, dressing, giving injections and changing dressings.

If you're being woken up frequently because the person you care for needs help using a urine bottle or similar, ask if a community occupational

therapist or incontinence nurse can come and offer some solutions.

Get emotional support

Caring for someone can be quite lonely and isolating, particularly if you don't have the time or energy to keep up with family, friends and social activities.

Among other things, the isolation can mean you don't have as many opportunities to talk about how you're feeling, so your feelings can start to overwhelm you.

Finding someone whom you can trust and talk openly with — be it a relative, friend or health professional — can prevent 'things getting on top of you'.

You can also consider using your State or Territory Carers Australia telephone help line. These are staffed by experienced carers who can give you support and information. Some Carers Australia branches also have individual or group counselling services.

A face-to-face or online support group or a Facebook group can give you a network of people who have a first-hand understanding of your situation and give you a way to share experiences, feelings and information with other carers.

Take respite breaks

For your long-term health and wellbeing, it's important that you allow someone else to provide temporary respite care to the person you're caring for while you have a break from caring. Taking breaks will help to restore and refresh your mind and body, so you can continue caring.

Seek help from family members or a respite service. Either way, you should not feel guilty about asking for help or taking a break. Some of the more common types of respite care include:

- in-home care
- day care programs
- residential care in an aged care home.

The sort of break you can take will depend on the opportunities available in your area.

Nevertheless, try to organise the type of break that best suits your needs and preferences. Possibilities include short weekly or fortnightly breaks of 3–4 hours, regular overnight stays once every 2–4 months, or occasional longer breaks of a week or more.

Where to get help and information
Commonwealth Respite & Carelink Centres

The network of 54 Commonwealth Respite and Carelink Centres helps carers, older people and people with disabilities by providing information about services in their local area. Services covered include:

- personal care services
- domestic help services
- accommodation in hostels
- and nursing homes
- all types of respite care
- carer support groups.

Contact your nearest centre by ringing 1800 052 222 (freecall).

Carers Australia

Carers Australia is the national organisation for carers. Its State and Territory branches run various programs to support carers including:

- information and support help lines
- support groups
- emotional and psychological
- support services
- short-term counselling.

Ring them on 1800 242 636 (freecall) or visit them at www.carersaustralia.com.au.
Carer information packs

A pack of nine fact sheets containing practical information for carers is available from the Australian Government. The pack is available in 13 languages, and has versions for young carers. Topics covered include:

- taking care of yourself
- managing health care and medications
- taking a break.

Ring the Aged Care Information Line on 1800 500 853 to order a free pack, or download it from the Department of Health and Ageing website at www.health.gov.au.

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Huntington's New South Wales

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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
Amanda Dickey
Keith Dingeldei
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