

# GATEWAY

Volume 10 No 4 Australian Huntington's Disease Association (NSW) Inc

Summer 2007/08

## A Time For Change

### New Housing in the Newcastle Area

In our last issue we advised you that the Association was intending to close Camellia Cottage and surrender the lease of the property. A meeting was held between the Association, Office of Community Housing, Hunter Genetics and Compass Housing Services in mid-September to organise this.

In accepting early surrender of the lease the Office of Community Housing agreed to make available two 1-bedroom units in the Newcastle area, to be used for housing people with Huntington's Disease. A further 2 units may be made available in the 2008-09 funding year.

These properties will be managed by Compass Housing Services, a community housing organisation who have been managing Camellia Cottage on our behalf and who have demonstrated a very professional and caring attitude to the residents of the Cottage. The social worker at Hunter Genetics will continue to be able to nominate tenants for these properties. Hunter Genetics and Compass Housing Services will enter into what is known as a Support Agreement to govern these arrangements.

Existing tenants were relocated in late 2007, with the remaining furnishings being distributed between the occupants of the new units. The Association also paid for relocation costs.

The Association is grateful to the other parties involved for an outcome which preserves the availability of dedicated housing for people with Huntington's Disease in the Hunter region.

### Social Clubs

Due to the staffing difficulties mentioned elsewhere in this issue the fortnightly Lunch Club, which catered mainly for residents of Huntington's Lodge at Lottie Stewart Hospital, has been suspended. This decision will be reviewed later in the year.

The Social Club, which caters for those still living in the community will continue, although with some restrictions initially on what can be offered in terms of off-site excursions.

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### From the Editor

There were several changes to the Association's staffing towards the end of 2007. In December we regretfully farewelled Karen Bevan, our much-loved Activities Coordinator, who elected to retire after six and a half years with the Association.

Karen, who had foreshadowed her retirement at the beginning of 2007, had been running the lunch and social clubs, as well as organising the activities component of the holiday camps.

Earlier, Robert Curran resigned at the end of October, after almost 7 years as our Administration Officer.

Robert also filled in as the Executive Officer for most of the period between Robyn Kapp's departure on extended leave in January 2006 and the arrival of Ms Jacqueline-Marie Bohm in July 2007.

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### Inside this issue

- Camp Breakaway 2008
- Finding Facts on the Internet
- Clinical Trial Update
- Get Ready To Yell Your Story!

## **From the Editor (cont.)**

Subsequent to Robert submitting his resignation Ms Bohm also resigned. This left the Association in a somewhat difficult staffing situation, which is yet to be fully remedied although recruitment action will commence shortly.

Robert has returned to the position of Administration Officer on a casual basis to help tide things over until permanent arrangements can be made. Helen Bobbitt has also generously volunteered to help with the bookkeeping aspects of the Association. Lily Ma has been recruited to assist with administration tasks. So, for the next month or two the Association's paid staff comprises:

Administration Officer	Robert Curran (Monday, Tuesday, Friday)
Carer Support Coordinator	Maria Mackell (Tuesday to Friday)
Administration Assistant	Lily Ma (Monday to Wednesday)

## **A Time For Change (cont.)**

Subject to demand, we also plan to introduce a new Club, tentatively called the Coffee Club, which will meet monthly. This is intended for people in the very early stage of Huntington's Disease (for example, those who have had to give up work or switch to part-time work).

It will meet away from Elsie Court Cottage at various locations in the Sydney area depending upon the activity of the day. These activities will be such things as movies, visits to art galleries, museums etc and will be selected by the members of the club. Coffee or a light meal before or after the activity will provide an opportunity for social networking.

To be eligible to join you must be able to travel independently on public transport such as trains and buses and not need a modified diet.

For all enquiries about the Social or Coffee Clubs contact either Maria or Robert at the Association's office.

## **Our Thanks to the Macquarie Group Foundation**



The Association gratefully acknowledges a donation of \$1000 from the Macquarie Group Foundation.

Staff of the Macquarie Group who have attained a length of service of 10 years are able to nominate a charity to receive a donation of \$1000. We are most appreciative of the kindness of the staff member who was responsible for nominating us.

# Huntington Happenings

## Camp Breakaway 2008

The next Holiday Camp for people with Huntington's Disease will be held at Camp Breakaway at San Remo on the Central Coast between Tuesday the 1<sup>st</sup> and Friday the 4<sup>th</sup> of April.

Last year's camp was for residents of Lottie Stewart Hospital so this camp will be for those living in the community.

To be eligible to attend the holiday camp you must be able to walk, sit, stand, dress, undress, shower, eat, drink and use the toilet without requiring assistance. However if a carer is accompanying you we will assess your eligibility on that basis and through discussion with your carer.

For all enquiries about the Holiday Camp contact either Maria or Robert at the Association's office. Applications from those who have not previously attended a camp are especially welcomed.



**APPLICATIONS CLOSE ON FRIDAY 29 FEBRUARY 2008.**

## Annual General Meeting

There was a pleasing attendance of 31 people at last year's Annual General Meeting, which was held on the evening of Friday 23 November 2007. This included a number of country carers, in Sydney to attend a Country Carer's City Holiday.

Guest speaker Nicolas Patrick, National Pro Bono Director of DLA Phillips Fox presented an entertaining talk about the legal issues faced by people with HD and how his firm has been assisting through its partnership with the Association.

A number of minor changes to the Association's constitution were approved. The revised constitution may be read on-line at [www.ahdansw.asn.au/association/constitution.pdf](http://www.ahdansw.asn.au/association/constitution.pdf) or contact us at the Association's office and we will post you a printed copy.

Elections for officers and board members resulted in the following being elected:

President:	Mark Bevan
Vice President	Anne Low
Secretary:	Keith Dingeldei
Treasurer:	Richard Bobbitt
Members:	Jim Finn
	Elaine Sammut
	Ian White

# Huntington Happenings

## Need A Cheap Computer?



Do you know anyone that would benefit from owning a computer?

Wesley E-Recycling, an activity of Wesley Mission (a non-profit organisation), specialise in refurbishing computers for individuals, families and community organisations.

They have a range of low cost computer packages to suit all needs.

Healthcare card holders and non-profit organisations receive Microsoft Windows XP software FREE of charge.

Call 02 8892 2880 for more information or visit their website [www.wesleycomputers.org](http://www.wesleycomputers.org) for details and pricing.

## Calling all Country and Western Fans

US Country & Western legends **Brooks and Dunn** will be performing in Sydney on March 10 at the Acer Arena (<http://www.acerarena.com.au>) (formerly the Sydney Superdome). Brooks and Dunn are the authors of the song "Boot Scootin Boogie" and have won the award of top Country Duo Award nearly every year from 1990-2006. (<http://www.brooks-dunn.com/site.php>) They play 80 concerts a year and generally in venues that seat 10,000-12,000.

Trey Gray, the drummer for Brooks and Dunn, is considered one of the best modern drummers in today's music scene. He is a native of Indiana but has lived in Nashville, TN since 1991. He is the father of children ages 3, 8, and 17. Trey was diagnosed approximately 3 years ago with HD and he has now come forward with that information, hoping that his celebrity would help get out the HD story. He wants to create awareness of the disease within the general community and help raise vitally needed funds. He has gone on YouTube to talk about HD: <http://www.youtube.com/watch?v=eeewPoh3Qs0>

The Association has been offered the opportunity to distribute information leaflets about HD at this concert.

(Note: In a recent paper published in *Cognitive and Behavioral Neurology*, J. M. Ringman explores the art of Woody Guthrie in relation to the development of the overt behavioral changes and chorea that characterized his illness. Woody Guthrie was the American songwriter, musician, writer, and political activist who died with Huntington's disease (HD) in 1967 at age 55. His relatively brief creative life was incredibly productive with countless songs and a tremendous volume of letters to his name. His personal life was similarly driven with Woody having had 3 wives and at least 9 children and an insatiable appetite for travelling the United States. Woody's ex-wife, Marjorie Guthrie, was instrumental in the setting up of the first organisation in the USA dedicated to finding a cure for HD. She also influenced the formation of many Huntington's Associations around the world, including ours.)

# Youngcare

Youngcare is a nationally registered charity and non-profit organisation formed to help young Australians with high care needs such as those with HD, acquired brain injury or MS. Youngcare's aim is to raise awareness of the issue and through partnerships with Community, Business and Government representation seeks to develop viable, sustainable accommodation solutions that provide the care and dignity we all deserve.

The first Youngcare Apartments in Brisbane opened on 8 December 2007. The design consists of 14 large, one-bedroom self-contained apartments with courtyards and balconies, coupled with state of the art facilities.

During March 2008 a small team will be walking the 300 kms from Canberra to Sydney to raise both funds and public awareness of young people in nursing homes and specifically Youngcare. The walk will conclude at the televised NRL match at Parramatta Stadium between the Eels & Knights and the walk will be followed by a Gala Dinner the following weekend at Hilton Sydney.

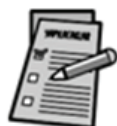
The walk will start on the 18<sup>th</sup> of March and finish on the 28<sup>th</sup> of March with the teams walking approximately 30 kilometres each day. With celebrities, sportspeople and politicians joining the walk on some days, it's sure to attract a lot of attention so look for publicity in your local area and give them a hand as they go by.

More information is available on-line at [www.youngcarewalk.com.au](http://www.youngcarewalk.com.au) , by email to: [info@youngcarewalk.com.au](mailto:info@youngcarewalk.com.au) or telephone:

- David & Katrina Sexton 0439 962 964 or (02) 9629 6406
- Troy & Sonya McPhee 0400 662 770 or (02) 8824 3853
- Andy Kirk 0411 300 366.



## Research Surveys



From time to time the Association is asked by researchers to facilitate the distribution of surveys or "invitations to participate" to our members. You may have received one or more of these surveys in the last year.

As a service to the research community we do attempt to meet these requests. However before we do so we ensure that the specific research project has been approved by the Research Ethics Committee of the sponsoring institution.

To protect your privacy we don't provide members name and addresses to the researchers. We ask for the material to be provided to us in unaddressed and unsealed envelopes and we address them ourselves. We also include a letter from the Association explaining that you are receiving the material under these arrangements.

Members are under no obligation to respond to these requests although we encourage you to do so.

# Finding Facts on the Net

Surfing the Internet for information about health has become a common online activity. In fact, the Internet has become a primary source of health information for many Americans. The Pew Internet & American Life Project recently reported that people with disabilities and chronic conditions such as HD are some of the most avid users of Internet health sites and that their online searches affected treatment decisions, their interactions with their doctors, their ability to cope with their condition, even their diet and fitness routines. People are taking what they find on the Internet very seriously.

Unfortunately, when it comes to information on the Internet it falls entirely on the user to determine the value and truth of what they read. Anyone can publish on the Internet and there is plenty of information that is untested, inaccurate, even dangerous. Because there is such a vast amount of information (and mis-information) to be found online, it is extremely important to use safeguards when surfing the web.

When you use a search engine, such as Yahoo or Google, to research a medical topic, you may be confronted with a list of thousands of websites, with no guidance on their quality or accuracy. Some websites are commercial, designed to sell things. Some are filled with unsupported information and conjecture. Some websites want you to believe that there are miracle cures that are being withheld from the public. To find reliable information, it is wise to start your search on the websites of reputable organizations: government agencies, not-for-profits and entities known for their integrity. As an example, Healthfinder.gov is a website sponsored by the Office of Disease Prevention and Health Promotion for the U.S. Department of Health and Human Services. It is a solid starting point for finding legitimate, up to date health information from a variety of sources. (In Australia, Health Insite ([www.healthinsite.gov.au](http://www.healthinsite.gov.au)), operated by the Commonwealth Department of Health and Ageing, performs a similar function.)

HDSA's own website ([www.hdsa.org](http://www.hdsa.org)) has links to resources, current research and a wide variety of publications you can download.

Other good sources of information are the National Institutes of Health ([www.nih.gov](http://www.nih.gov)), the National Institute of Neurological Disorders and Stroke ([www.ninds.nih.gov](http://www.ninds.nih.gov)), the HD Lighthouse ([www.hdlighthouse.org](http://www.hdlighthouse.org)) and the Huntington's Disease Advocacy Center ([www.hdac.org](http://www.hdac.org)).

When you find interesting research on the Internet and want to share it with your doctor, try to narrow the information down to the most important points you wish to share and show the doctor that you have garnered the information from a reputable source. While more and more doctors are accepting their patients' internet research and will gladly discuss what you have found, your doctor may not have time to look through a mass of website printouts.

It can be encouraging to stay abreast of current research trends using the Internet. Scientists and investigators around the world are diligently striving toward breakthroughs in understanding and treating HD and its symptoms. The Huntington's Disease Society of America (HDSA) and its partners, CHDI, Inc., and the Huntington Study Group are working to expedite the movement of basic research into effective treatments for the disease through the HDSA Research Pipeline for Drug Discovery, which you can read about elsewhere in this newsletter.



(Acknowledgement: Reprinted with minor modifications from "The Marker", November 2007 (Magazine of the Huntington's Disease Society of America))



# Research News

## Clinical Trial Update – The Huntington Study Group

At the end of the Huntington's Disease Society of America (HDSA) pipeline for drug discovery are clinical trials which bring the most promising compounds for treatment to people with HD. HD families are encouraged to participate in the many clinical and observational trials that are conducted at HDSA Centers of Excellence and other HSG sites.

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The HSG continues to be very active in the Huntington's Disease research arena. Efforts are focused on finding treatments that make a difference for HD. HSG research trials cover a wide spectrum within the Huntington's Disease community. The following overviews describe the most current HSG research trial activity.

### Trials Recently Completing Enrollment

TETRA-HD completed enrollment of 84 participants in December 2003. **Tetrabenazine** is a drug widely available in Europe and Canada. It eases one of the most disabling symptoms of Huntington's Disease, involuntary writhing movements known as chorea, according to a study published in February 2006 [Neurology 2006;66:366-372]. Prestwick Pharmaceuticals, Inc., the study sponsor, has filed a New Drug Application with the FDA to market the product for treatment of chorea in the United States. Review of the application is pending.

PHEND-HD completed enrollment of 58 study participants in January 2006. The study was designed to gather information on the safety and tolerability of the experimental drug **phenyl butyrate**.

This compound inhibits histone deacetylase (HDAC), an essential component of the body that "turns on" or stimulates genes. Phenylbutyrate may be a potential drug therapy in HD by directly helping to turn on genes that are blocked by HD. The potential benefit of phenyl butyrate in people with HD has never been established. The analysis of the data is ongoing.

DOMINO completed enrollment of 114 participants in May 2007. Participants are still undergoing study visits. Recent studies in a mouse model of HD have demonstrated that minocycline helps to slow down the clinical onset of HD and prolongs life. In a previous HSG trial, minocycline was shown to be safe and tolerable in HD patients at doses of 100 mg. and 200 mg. per day over 8 weeks of use [Neurology 2004: 63:547-549].

TREND-HD was designed to determine the effect of the experimental medication **ethyl-EPA** on the motor (movement) signs and symptoms of HD. Forty-one North American HSG research sites evaluated 316 participants with early signs of HD. Preliminary results announced in April 2007 showed no statistically significant difference between those taking the experimental drug and those on placebo over six months of study. There was no evidence in the preliminary analysis of any major safety concern. Further evaluation of the data is currently taking place.

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# Research News

## **Trials Currently Enrolling**

DIMOND B is a clinical study using a research medication, **Dimebon**, in patients who have mild to moderate Huntington's Disease. Dimebon is an investigational medication that has been shown to inhibit brain cell death in models of HD and Alzheimer's disease (AD). In a 12-month study of patients with Alzheimer's, Dimebon was well-tolerated and significantly improved cognition and memory, behavior, activities of daily living and overall function when compared to placebo. The current HSG study will assess the effects of Dimebon on cognition, memory, behavior, and motor function of HD patients, as well as the safety and tolerability of the drug when administered over a 3-month period. DIMOND B is seeking to enroll approximately 90 study participants.

PREDICT-HD began in September 2001 to study healthy persons who are known to have the CAG expansion in the HD gene. The intention of the study is to gather essential information on the early stages of HD in order to develop drugs that can slow or postpone the onset of the disease. To date 992 participants have enrolled in the study. Gene negative participants can still enroll in this important project.

COHORT is a long-term observational study taking place at 40 North American and Australian HSG sites. The goal of COHORT is to collect information from individuals who are affected by HD and those who are part of an HD family, in order to learn more about HD, potential treatments, and to plan future research studies of experimental drugs aimed at postponing the onset or slowing the progression of HD. This study is recruiting both adults and children who have clinically diagnosed HD and adults who are apart of an HD family. Individuals who choose to participate will have one study visit every year. There are currently 864 participants enrolled in COHORT.

RESPOND-HD is an observational trial looking at issues of potential discrimination in those affected by HD. The information gathered in this study will allow researchers to examine the experiences of persons who have undergone genetic testing for HD or those persons who are at risk for HD. Study participants from PHAROS and PREDICT research studies are being recruited for this study as are those from geographical areas where there are differing discrimination laws for employment and insurance, and also from foreign sites where health care systems may be different from domestic sites.

## **Upcoming Trials**

NIH approved funding for the 2CARE study of **coenzyme Q<sub>10</sub>** versus placebo in individuals with mild to moderate Huntington's Disease. The initiation of the study was delayed by the FDA who requested additional animal testing since the 2CARE study is investigating a much higher dose (2400 mg. /day). With the additional testing completed, the FDA has now given permission for the study to proceed. Enrollment of participants at approximately 46 sites in North America and Australia should begin in early 2008.

PREQUEL is a trial to test the tolerability and biological activity of **coenzyme Q<sub>10</sub>** in those with pre-manifest HD. A grant was submitted in July 2007 to the National Institute of Neurological Disorders and Stroke (NINDS). PREQUEL has received positive feedback and plans are being finalized with NINDS. Christopher A. Ross, M.D., Ph.D., is the principal investigator and Kevin M. Biglan, M.D., M.P.H., is the co-principal investigator.

CREST-E, a trial to test the safety, tolerability and efficacy of **creatine** in persons with HD, is scheduled to move ahead. As of November 2007, funding has been secured from the National Center for Complementary and Alternative Medicine (NCCAM) and the FDA Orphan Products Division. Steven Hersch, M.D., Ph.D. is the Principal Investigator.

For more information on these studies and how to participate, please see the HSG website: ([www.Huntington-Study-Group.org](http://www.Huntington-Study-Group.org)).

(Acknowledgement: Reprinted from "The Marker", November 2007 Magazine of the Huntington's Disease Society of America)



# Carer News

## ***Don't just sit there! Do something!***

We know there are many benefits from participating in activities with the person we care for. But sometimes its hard to think of interesting or stimulating things to do with "your" person. An activity that can be shared or enjoyed by both you and the person you care for, can turn an ordinary day into a positive experience for you both.

We have recently come across two carer resources that we feel are worth letting you know about. Both of these have been produced by Alzheimer's Australia, for carers of a person who has Alzheimer's disease, but, we have found much that would be very relevant to people with Huntington's Disease.

### **The Activity Book for Carers**

This activity booklet has been developed to assist carers to match activities with the needs, abilities and interests of the person they care for.

It presents some guidelines for helping the person you care for, perform activities. What may work for one individual will not necessarily work for another, but the booklet offers advice and guidelines on working out what the person you care for would enjoy, and the ideas on adapting activities are quite helpful.



### **The Personal Life History Booklet**

We were introduced to this booklet at an information day that was part of the Country Carers City Holiday in November, and it was such a hit with the carers. It provides a guide to writing up a simple life history for the person you care for. It includes ideas for rekindling memories and tips on presenting the information.

This would be a delightful gift for the person you care for and something you can create together.

Note: While we recommend these as useful resources, we do need to tell you that they have not been "reviewed" by HD specialists or allied health staff, so take this into consideration when adopting the ideas or planning activities.

Interested? Please phone the office and ask Maria for a copy of either of these, and we will post you one.

# Carer News

## A New Focus on Family Support

Since the Carer Support Program began in mid 2005, the Association has had contact with over 100 carers, through individual requests for information or support, activities, meetings or workshops and through the Carers holidays etc. From this contact, our awareness of the issues that impact on carers and family members has grown. However, we are also more aware of issues that carers want addressed. As we plan our activities for 2008, these are significant factors in deciding what we do. Another factor is the changes that have occurred in other programs within AHDA.



**Being pampered at the "Country Carers City Holiday", November 2007**

With the retirement of the Activities Officer Karen Bevan, late last year, we decided to look at the client activities (such as Lunch and Social Clubs and the Holiday Camps), and to see how we could best provide these services. At the same time, changes to the Administration Officer position, meant that Information and Referral tasks would also need to be re-assigned.

We have decided that all the activities provided for people with HD, or for their carers, including information/referral, Social Clubs, Holiday camps and Family meetings etc would be better described as **Family Support**.

This more "holistic" approach means that program staff members will have a wider area of responsibility (i.e. both people with HD and carers) and more contact with members. This will range from the initial contact or phone call through to participation in activities, meetings etc. This change in focus fits well with how members see themselves. We have often been told: "I'm a husband, (or a wife, son or daughter), rather than a "carer", so we feel there may be more people comfortable with joining an activity that comes under the umbrella term of Family Support.

There will be two Family Support Officers who will share roles and each will have responsibility for covering specific country areas as well. So the Social clubs for people with HD, or specific activities for carers, or family activities (for both groups) will be staffed by the same Family Support Officer. This will lead to a more integrated approach, and it will also be more cost effective for the Association.

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**Enjoying great company and a great location at the Aquila Beach House Holiday, August 2007**



**Members attending an info session at the "Country Carers City Holiday", November 2007**

# Carer News

*Continued From Page 10*

## **So, what would you contact a Family Support officer for?**

- Information and referral (in the office or in our "outside work" i.e. country visits, meetings etc.).
- An individual carer or family member consultation (in the office or in our "outside work" e.g. country visits, meetings etc.).
- Organisational and community level consultations and support for families and carers (from the office and in outreach work)
- Finding out about our "specific" activities such as Social Club for people with HD, or specific activities for carers only.
- Finding out about our "joint" activities such as Family meetings, Camps, etc.
- Finding out about our "Country Visits" and meetings.

We will shortly be advertising for an additional Family Support work person. For further information please contact Maria Mackell on (02) 9874 9777 or STD Freecall 1800 244 735 (Country NSW only).

## **Get Ready To Tell Your Story!**

We all know that being connected to others is good for us and good for communities. Telling our story, and sharing our experiences with others builds our identity and connects us to other generations. So we have drawn up a series of family days and workshops which we are calling: Our HD Family Stories Days.

The days will be a combination of a social activity and a special 'skill' workshop. We are planning these for Sundays (March - June) so people working weekdays can also join in, and if country members wish to join us, there is time for travel.

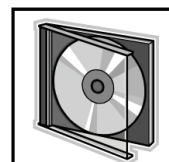
Each workshop will be a 'standalone' so you can come to one or come to all of them! Or you can come for the social part and not attend the workshop, or vice versa. It's up to you.

The focus for each day will be:

A chance to catch up with other HD families

Delicious refreshments

A special workshop presented by an expert!



Presentations will include:

Writing your story

Using art to tell our stories

Preserving family stories and memories

Digital Story Telling - Making a DVD – about you - for others

Creating a blog – develop a space to share your thoughts and experiences with others.

If you are interested in attending, or contributing in some way, please contact Maria Mackell on 9874 9777 or STD Freecall 1800 244 735 (Country NSW only).

## Gateway

'Gateway' is the newsletter of the Australian Huntington's Disease Association (NSW) Inc.

## 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.

## Committee 07/08

President: Mark Bevan  
Vice President: Anne Low  
Secretary: Keith Dingeldei  
Treasurer: Richard Bobbitt  
Members: Jim Finn  
Elaine Sammut  
Ian White

## Australian Huntington's Disease Association (NSW) Inc

PO Box 178, West Ryde, NSW 1685  
21 Chatham Road, West Ryde, NSW 2114  
Telephone: (02) 9874 9777  
Facsimile: (02) 9874 9177  
STD Free Call: 1800 244 735 (Country NSW only)  
Web Site: [www.ahdansw.asn.au](http://www.ahdansw.asn.au)

## Association and Other Useful Contacts

### Vacant

Executive Officer

### Robert Curran

Administration Officer

### Maria Mackell

Carer Support Coordinator

### Vacant

Activities Coordinator

### Huntington Disease Service

#### Dr Elizabeth McCusker

Director

Westmead Hospital

(02) 9845 6793 (leave message)

Lottie Stewart Hospital

(02) 9804 5803

(Tuesday afternoon)

### HD Clinic Appointments

Outpatients Department

Westmead Hospital

(02) 9845 6544

### Outreach Service

#### Suzie Docherty

Social Worker,

Westmead Hospital

(02) 9845 6699

### Vacant

Social Worker,

Westmead Hospital

(02) 9845 6699

### Angela Lownie

Clinical Nurse Consultant,

Lottie Stewart Hospital

(02) 9804 5863

### Jeanette Moxon

Outreach Nurse,

Lottie Stewart Hospital

(02) 9804 5863

### Huntington's Lodge

#### Joan Stewart

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,

(02) 4985 3100