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# GATEWAY

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Volume 11 No 2 Australian Huntington's Disease Association (NSW) Inc

Spring 2008

Australian Huntington's Disease Association (NSW) Inc

## 2008 ANNUAL GENERAL MEETING

**SATURDAY 29 NOVEMBER 2008**

**2.00PM — 4.00PM**

**West Ryde Hall - 1A Station Street, West Ryde**

**Refreshments will be served**

Non members welcome

**Guest Speaker: Dr Elizabeth McCusker**  
**Speaking on '20 years of Change and Progress'**

Please RSVP (for catering purposes only)  
Phone (02) 9874 9777 or 1800 244 735 (NSW STD Freecall) or  
e-mail [hdassoc@ahdansw.asn.au](mailto:hdassoc@ahdansw.asn.au)

### **AGENDA**

- Apologies
- Minutes of Previous AGM
- Business Arising from Minutes
- Annual Report
- Annual Financial Report
- Annual Statement
- Appointment of Auditor
- Election of Office Bearers and Committee Members
- General Business

**Note:** You must be a financial member to be able to vote.

Nomination forms for the Office Bearers and Board elections are available upon request.

Please contact the office if you need some sent to you.

Nominations may also be made at the meeting.

Completed forms should be returned to AHDA (NSW) no later than Thursday 20 November 2008.

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# From the Executive Officer

## Making a Difference

Is life more about success or is it about making a difference? By the way many live their lives in our society, one would think that success is all that matters. While success has its place, it can be a very "inward-focused me-only" endeavour if it is not balanced by significance as relates to others. In fact, to me personally, the very purpose of success is in its significance in impacting the lives of others.

Recently I attended a seminar at Lottie Stewart Hospital put on by the Outreach team there. Being new to the Huntington's community, it was a valuable learning experience and networking opportunity. I met quite a few professionals who are all doing their important part, whether neurologists, nurses, social workers, psychologists or other community workers and professionals. But the thing that impressed me the most is the fact that they all had in common the commitment and dedication to *make a difference* in the lives of those who suffer from Huntington's disease, their carers, and families.

We all know that at present, there is no cure for Huntington's disease. And when we consider the toll the disease takes on all fronts on both a person's health as well as his or her carer(s) and family members, we are left wondering at times whether any effort, no matter how valiant and committed, can really make a difference, which reminds me of this powerful story that you may have heard... It goes something like this...

As a man walked a desolate beach one cold grey morning, he began to see another figure, far in the distance. Vaguely he could make out the shape of a boy who kept leaning down, picking something up and throwing it into the water. Time and again he hurled things into the ocean. As the distance between them narrowed, the man could see that the boy was picking up starfish that had been washed up onto the beach and, one at a time, he was throwing them back into the water. Puzzled, the man approached the boy and asked what he was doing. "I'm throwing these starfish into the ocean. You see it's low tide right now and all these starfish have been washed up onto the shore. If I don't throw them back, they'll die up here for lack of oxygen in the scorching heat of the sun."

The man thought of the futility of the boy's efforts and seriously questioned: "But, there must be thousands of starfish on this beach and you can't possibly get to all of them. Moreover, this same thing is probably happening on hundreds of beaches all up and down this coast. Don't you see that you can't possibly make a difference?!" The boy politely listened, paused to think a little, smiled, then bent back down, picked up another starfish, and as he threw it back into the sea, he replied: **'Made a difference to that one!'**



In August I attended Maria Mackell's funeral. And although I never really knew Maria and only saw her once when I was being interviewed for this role and said "hello" in passing that day, I feel like I knew her indeed by the marked difference she made in the lives of others. This came through loud and clear in her funeral service where there were probably just as many people (if not more) standing in the back of that church as there were seated. Even some members of our social club made what must have been an extraordinary effort to be there to say their goodbyes to someone they knew who *made a difference*...

*Continued on Page 4*

## Farewell Maria Mackell



By Robert Curran

It is with great sadness that we report the death in hospital on 7 August 2008 of Maria Mackell, the Association's Carer Support Coordinator, following a short illness. In the two or so months prior to being diagnosed with abdominal mesothelioma in late May 2008, she had also dealt with the illness and death of her brother, and took on caring responsibility for her brother's children.

Maria joined us as our first Carer Support Coordinator in April 2005. Shortly after, she addressed these words to the carers in the newsletter:

*"So, I'm starting this new job with a lot of enthusiasm and energy but.... I'm quite a novice in the carer's role relating to Huntington's disease. I'm assuming that it is a huge task.... on-going, sometimes without hope, sometimes frustrating, with new challenges as the disease progresses, and all with little or no support? ...Is that what it's like for you? "*

It was to prove a challenging task. Up until that time, the Association had not identified carers as such in its database. So her first task was just to identify and make contact with as many carers as possible. It was in this that her guile and lateral thinking showed itself. When her first ads in the newsletter produced little response, she resorted to direct mail and "give-aways" to encourage carers to contact her. The little tea-bag gift packs that she offered not only produced the desired responses, but introduced us to her love of tea. The basic Lipton's tea bags in our office kitchen were rapidly supplemented by a variety of exotic teas!

In other ways, we knew that Maria had arrived and that she was determined to make a difference. The somewhat dowdy surroundings that the office presented to our clients were an early challenge. Vases of flowers and garden pots would mysteriously appear from time to time to be just as mysteriously replaced when their time had passed. The missing dinner plate was probably to be found serving as a temporary pot saucer. Successive generations of new curtains graced the function room windows, until there was one of a shade and pattern that she was satisfied with. A refugee garden bench liberated from somewhere in inner Sydney arrived to provide seating for clients in a sunny corner.

It became clear early on that when Maria had a conflict between obeying the dictates of bureaucracy and giving personal attention to the carers, the carers would win out every time. Maria's energy overflowed the formal bounds of her role – it was not meant to be a "hands on" job, but her pedicures and facials will be long remembered by those who experienced them. If she didn't have the requisite skill, she always knew someone who did. Maria's family and friends were always at risk of being conscripted as volunteers to staff the various functions and activities that she organised. Good looking young men would arrive "out of the blue" at Elsie Court Cottage to perform waiting duties, whilst somewhat older friends would drive vast distances to spend a week as helpers at the holiday camps.



*Continued from Page 3*

## Farewell Maria Mackell

Maria always had time to stop and chat with clients, and to listen to their concerns. This was always done with good humour, and she was notorious for her sense of fun in situations such as the holiday camps.

Maria's perspective on caring was shaped and enriched by her own experience as a carer. In that same newsletter article mentioned above, Maria also said:

*"I come from a community services and aged care background, and have recently returned to work, after caring for my mother-in-law. So, from both my personal and professional background, I have a great interest in carers and the work they do.*

*On a personal level, my time as a carer was a bit of a roller-coaster, lots of ups and downs, interruptions to my career, big changes at home etc. But it also brought enormous benefits for the whole family. We all changed in some way. My children (2), cats (2) dog (1), and yes, even my husband (1) have all had a more enriched life through our experience of caring. I know I now have more insight, more patience, and a different perspective than before. It's a perspective that says that the here and now is important too, and in recognising that, it's possible and legitimate to enjoy the little steps along the way. I gained a very different insight than the one I had while working in the field prior to my experience as a carer. But I also acknowledge the difficulties, and feel very strongly that we need to support carers in their role."*

Maria's commitment to "her carers" was demonstrated on the day of her brother's death, when she carried on with a planned trip to Canberra to attend a support group meeting the following day. When it was suggested to her that she should cancel, she said simply that she had said her "goodbyes" to her brother the night before, and that she was needed in Canberra.



We will not soon forget her expertise, her generous spirit, robust humanity and her zest for life.

*Our sincere sympathy goes to Roger, who has lost a partner in the prime of her life, Hillier and Austin, Maria's children, and their extended family.*

*Continued from Page 2*

## From the Executive Officer

A difference is not all that hard to make... And although it may not always be a life and death issue, it nevertheless remains a big difference from the recipient's perspective. Caring enough to make a difference is something we can all do... Whether you are a medical or social professional, a carer, a family member, a donor, or an advocate and friend of our Association, I'd like to remind you that you are indeed making a difference...

Thank you for that.  
Walid Nassar



# Huntington Happenings

## Staff Update

Sharnie Mineeff, our Administration Officer, is expecting her second baby and is no longer with us. We appreciate her service the past few months and wish her and her family the best. We have advertised the position and we will be going through the application/interview process in order to fill that role soon.

Our hours of operation are Monday through Thursday from 9.00am to 5.00pm and we close on Friday.

## Social Club

Our social club goes from strength to strength!

It meets here at Elsie Court Cottage every other Tuesday (fortnightly) and we currently have around six clients attending. With themes such as Aboriginal culture and the Olympics, it is always a great time of good food, entertaining activities, social catch-up and lots of fun.

Contact Judy or Lily if interested.

## Sydney Carers Support Group



Judy Fullston, our Carer Support Officer will be starting a Carer Support group for Sydney area carers.

Read all about it in the Carers News section and contact Judy if this interests you.

## Introducing Viki Moraitis

In June this year I was elected onto the board of the Association. I am glad to have the opportunity to contribute to the work that the Association does for people living with and their families affected by this disease.

At the age of 32 (1984) my mother was diagnosed with Huntington's Disease, over many years our family shared the daily struggles that are caused by Huntington's. This personal experience has opened my eyes to the impacts of the disease not only on the person living with Huntington's, but also close family and friends.

Along with my personal experience, I also bring 10 years experience in working in the Disability Sector. I have worked with people with a range of disabilities, including physical, intellectual, complex health conditions and mental illness. I am currently employed in a not for profit organisation, managing group homes in the community for people with Disabilities.

Last year I attended the International Huntington's Disease Congress in Germany. I was inspired by the current research and development and the determination all over the world to improve the lifestyles of people with HD. As a new board member I commit myself to ensuring that AHDA (NSW) continues to provide and improve much needed support services to people and their families.

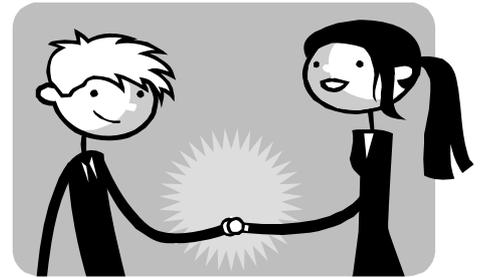
Yours Truly,

Viki Moraitis

# Care and Share

## New Quarterly Fundraising Event

Do you want a chance to make a real difference? Well here it is. We are announcing the launch of a new event which will take place once a quarter at Elsie Court Cottage for the time being. As you can appreciate, being a community organization we are dependent on grants, bequests and donations from our friends and members in order to maintain and improve our ability to provide services. While we are thankful for grants, it is one of my goals as the Executive Officer to decrease our percentage dependence on those and to increase our percentage income from donations.



This will give us so much more freedom and capacity not only to maintain our services at the current level, but to do much more.

### The aim of this quarterly 'Care and Share' event is to show we care by...

- Helping spread awareness of HD to others in our community.
- Providing information about HD and our Association.
- Facilitating a growth of awareness about HD and the Association by bringing others.

### We also want to share by...

- Encouraging generous donation towards our cause.
- Awareness, Information, Donation and Multiplication thus define our 'Care and Share' event.

### Who can join us at 'Care and Share'?

- Donors—are those who give generously to worthy causes. Those could be current donors to our Association who would like to have the chance to do more.
- Potential Donors—any and all community professionals who may or may not be aware of our Association and its work and who are open to supporting worthy causes.
- Advocates—are those whose primary gift is connecting/linking/motivating and influencing others. Those would always bring potential donors with them to the event.

Since this is a fund raising event, it is open to all members and friends of the Association who would classify themselves as donors, potential donors or advocates.

### You can benefit from being part of this 'Care and Share' event



- Become a powerful catalyst in facilitating support for our worthy work. Add significance to your professional success.
- Get tax deductions for your giving.
- Enjoy the satisfaction that comes out of being involved in such a cause.
- Have a part in our sense of shared mission.
- Meet Board members, the Executive Officer, the staff and strengthen existing relationships and form new ones.
- Meet and network with other community professionals.

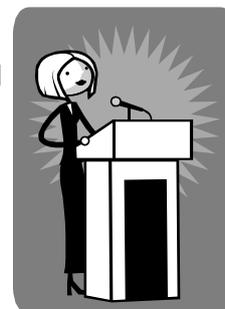
# Care and Share

## How can I get involved?

By RSVP only and is initially limited to the first 25-30 who respond.

A short one hour session (or so) comprised mainly of:

- 5-10 minute presentation of what HD is and its impact on people and families.
- 10-15 minute presentation of who we are and what we do.
- 10-15 minute educational video about HD relevant topics.
- 5-10 minutes talk about making a difference, asking for donations and related information about giving.
- 15-20 minutes "meet and mingle" time around refreshments.



We may also add other informative and entertaining elements in the future as this gains momentum.

## You CAN make a difference!

Remember, if you cannot give much, you can always bring others who may want to give to our cause and be the link in that chain. All of us can do this easily. I strongly encourage you to begin to make a list of people you know (relatives, friends, friends of friends, co-workers, community professionals and businesses) and extend invitations to them *every quarter*.

I have a feeling a few will surprise you and come along! In my many years of work with non-profits and fundraising I have found that *owned passion can only be transferred if shared*.

## Here's Your Invitation to 'Care and Share'!

When: Saturday 15 November 2008.  
 What time: 4.00pm (till 5:30pm).  
 Where: Elsie Court Cottage at 21 Chatham Road, West Ryde NSW 2114  
 Parking: Shopping Centre nearby.  
 RSVP: No later than Wed 12 November, 2008.  
 Call or email and let us know how many will be coming.  
 Telephone: (02) 9874 9777. E-mail: [hdassoc@ahdansw.asn.au](mailto:hdassoc@ahdansw.asn.au)



[Please put "Huntington's" in the subject as we do get a large volume of e-mail and do not want to miss yours!] We look forward to seeing you there!

## Special Thanks to Our Donors

We want to express our appreciation to all those who continue to support the Association. It is the generosity of donors like you that enables us to continue providing services to HD families.  
 Thank you!

# Research News

## Scan Could Limit Huntington's Damage

Research using newly developed Magnetic Resonance Imaging technology could soon allow clinicians to confirm Huntington's disease before symptoms appear in people who have the gene for the fatal brain disease.

An early confirmation of Huntington's disease in people who have tested gene positive for the disease could enable treatment to commence early, even before motor, cognitive and psychiatric symptoms arise. Using Diffusion Magnetic Resonance Imaging (dMR), researchers from the Howard Florey Institute and Monash University in Melbourne have identified extensive white matter degeneration in patients recently diagnosed with Huntington's disease.

White matter forms the connections between brain regions, allowing one region to communicate with another. A breakdown of these structural connections in the brain could help to explain the complex motor and cognitive problems experienced by Huntington's disease patients in the early stages of the disease.

Scientists have recently shown that this white matter degeneration starts before patients are officially diagnosed however, the extent of white matter degeneration in Huntington's disease was previously unknown. The early symptoms of Huntington's disease can be easily missed, as they are usually minor problems such as clumsiness, memory loss and loss of cognitive function. These symptoms gradually become more severe over the years, inevitably leading to death within 15 to 20 years of diagnosis.

Working on this research was Florey PhD student Ms India Bohanna, who said this discovery could also assist in the future testing of new therapeutic strategies to treat the disease.

"Currently, the effectiveness of any new treatment is determined by its ability to reduce symptoms, but we know that changes in the brain occur a long time before symptoms arise," Ms Bohanna said

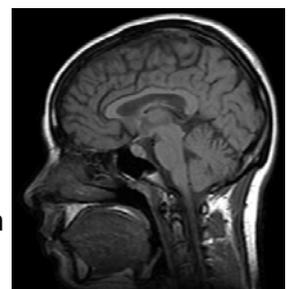
"Our discovery could allow researchers to test therapies even before symptoms appear.

"Not only does this research tell us more about how the brain degenerates early in Huntington's disease, but it also opens up new avenues in drug research and development.

Co-principal investigator, A/Prof Nellie Georgiou-Karistianis from Monash University explained: "By using diffusion MR to examine white matter degeneration early on, we can now test the ability of new therapeutics that may possibly reverse underlying degeneration in brain connections, which ultimately leads to the development of symptoms."

"Although there isn't yet a cure for Huntington's, researchers at the Florey and Monash, and from around the world are working to develop new treatments to delay the onset and severity of this devastating disease," A/Prof Georgiou-Karistianis said.

Collaborating on this project was the Florey's A/Prof Anthony Hannan, who has shown that mental and physical exercise can delay the onset of Huntington's disease and slow the progression of symptoms in a mouse model of the disease. This is the first study to look at white matter changes across the whole brain in Huntington's disease, and importantly, to study how the breakdown of connections between brain regions might lead to the widespread deficits found in Huntington's disease patients.



# Research News

*Continued from Page 8*

The researchers hope to conduct further dMR studies to examine white matter degeneration in people who have tested gene positive to Huntington's disease but are up to 10 years away from developing symptoms. Diffusion Magnetic Resonance Imaging is a recently developed brain imaging technique that enables examination of the brain at a microstructural level and the mapping of white matter tracts by tracking the movement of water in the brain.

*This research was presented at the 14th Annual Meeting of the Organisation for Human Brain Mapping, which opened on 15 June in Melbourne and has been accepted for publication in Brain Research Reviews. Acknowledgment: Howard Florey Institute.*



## Changes in the Huntington Disease Service

By Dr Elizabeth McCusker

From 1 September 2008 I will take long service leave. Dr Clement Loy who has worked with us in the Huntington Disease service as Movement Disorders Fellow has been appointed as my locum and will be assisted by Dr Kaitlyn Parratt, the current Movement Disorders Fellow.

On my return in November, I will be stepping aside to a one day a week Huntington Disease Research position at Westmead Hospital in the Huntington Disease Service. This will enable us to take advantage of more research opportunities, especially those projects run by the Huntington Study Group including COHORT, PREDICT HD, 2 CARE and others. The HD Association supported the establishment of the position.

After over 20 years it is time to make a change to ensure the continuity of our service. My current position as Director of the HD service and Neurologist in the HD clinic and to the Outreach team and the Lottie Stewart unit has been advertised and we await the appointment of my replacement.

It has been an absolute privilege to be involved with Huntington Disease patients and their families as well as the staff of the Association our service and the people in the world wide HD community. I am determined to continue to work with our research team on projects aimed at finding the cure or a means of delaying onset. It is far too difficult to say good bye to so many extraordinary people, many that I have known for years. I heard a carer say once, 'I would never have chosen to walk this route but I have certainly met some amazing people along the way'. I couldn't agree more.

## Introducing Jet Aserios

In May this year, Jet Aserios commenced his employment with the Huntington's Disease Service as a full-time Social Worker. Prior to joining the service, Jet worked as a Defence Social Worker based at RAAF Richmond and Liverpool Military Area. He holds an undergraduate and Master's degrees in Social Work and is currently an Accredited Member of the Australian Association of Social Workers (AASW). Jet can be contacted at Westmead Hospital on (02) 9845 7528.

# Carer News

## Tidings from Judy Fullston

### We'll Miss You Maria

Since I last communicated with you, my colleague Maria Mackell (Carer Support Coordinator), passed away. It has been a sad time for all of us who knew her. Thank you for your calls and even though some of you have other stressors in your lives, you found time to express your sorrow and give us support as we tried to cope with the loss of our friend - or as some of you expressed it... "our mate". Part of a verse by Helen Keller states "Life is an exciting business and most exciting when it is lived for others..." Although I have not been with the organization for long, the feedback I received from service providers, clients, carers and other family members reflected those words of Helen Keller.....Maria was 'very caring and tried to do whatever she could for those in need'. We shall miss you Maria!

## On The Case For Carers

Over the past three months, I have been kept busy playing detective in trying to find out what services are out there. I haven't even started on those in the outer regions. I would really appreciate if those of you who are service providers could send me a brochure or a summary of your services.

I often ask myself "how do Carers or family members get through the huge 'maze' when looking for support?" Just understanding the 'jargon' can be stressful let alone trying to search through all the information which is out there. A client once disclosed to me that when she visited an agency for assistance, she received so much information and left with an array of brochures that she felt so overwhelmed she "broke down and cried". Instead of assisting her the client said that she "felt more confused and alone"! Please don't get to this point, contact me, and together we will try to achieve a positive outcome.



Commonwealth Carelink Centres

Because this organization covers the whole of New South Wales, I will research small areas and provide you with some information about the identified services in subsequent newsletters. The Commonwealth Carelink Centres - there is one in your area - have been extra helpful. The number to contact is 1800 052 222. This is a freecall however mobiles are charged at the usual rate. This agency even has information on recommended toilet stops. Next time you get stuck in a 'maze' do what I do..."Grrrrrr!"...then take a deep breath...count to ten....and dial the Carelink freecall number above.

If you are from a non-English speaking background there are a number of free and confidential language assistance options available to you. I am only going to give you a couple of these. Firstly, if you contact the Translating and Interpreting Service (TIS) on 131450, ask to be put through to 02 9265 9333 which is the City of Sydney translating services. Another option is the Attorney General's department for Interpreting and translating and ask the TIS operator to put you through to either 1800 684 449 or 02 9228 7484; or perhaps you would prefer to contact these numbers yourself without going through the TIS agency? Please contact me if you require further information.

# Carer News

## A Very Multicultural Social Club

Some of you may not be aware that we have a Social Club Program at our Centre every fortnight for people with Huntington's Disease (HD). The program is based on a person-centred, social model of care. Every quarter the clients and staff discuss and plan future activities and try to keep in contact with our community, as well as national and international events. For example, Lily and I went all out and developed a great program to celebrate NAIDOC week. In fact, a couple of clients enjoyed it so much they wanted the manual so that they could show the two clients who could not attend on the day what they missed. The activity in the morning looked at the history of NAIDOC; the 'Dreamtime'; the heroes of the struggle for ATSI (i.e. Aboriginal & Torres Strait Islander) rights; their art, artefacts, music, dance and other cultural aspects. We reminisced about our interaction with ATSI friends. After lunch we played ATSI games and clicked and clacked to the sounds of the didgeridoo. The recreation room was surrounded by posters; the Aboriginal, the Torres Strait Islander and Australian flags; placemats and other ATSI paraphernalia. Our most recent club celebrated the Beijing Olympic Games 2008. This included a variety of Chinese displays such as the five Chinese Luck Doll Mascots; Chinese lucky charms hung from the walls to wish all the contestants "good luck"; two Chinese racing boats brought extra colour to the area; posters and large coloured newspaper headlines with photos of various successful contestants along with flags of the various participating countries. Clients represented their heritage backgrounds such as Greece, Denmark, Australia, England, France, Scotland, China, and the Netherlands. They waved their individual flags and chanted for their team member. Lily supplied the Chinese articles for the display and dressed in her Chinese clothes for the occasion. Like Beijing the AHDA Social Club members once again exceeded themselves!



## Attention Sydney Carers!

The next project for the Carer Support Unit is the birth of our monthly Carer's Support Group meetings for Carers of people with Huntington's Disease. The Support Group will meet on the last Thursday of each month. Our first meeting is on 25 September 2008 from 10.30am to 12.30pm. Other meeting dates for 2008 are 30 October and 27 November 2008, so note these on your calendar. The meetings will be in the activities room at Elsie Court Cottage. For catering purposes, I need to know if you will be joining us on any of these dates.

**'An open ear is the only believable  
sign of an open heart'**  
- David Augsburger



This will be your support group and our first meeting will be about what you want from these meetings. As well as sharing your experiences, strategies etc, would you like education about a particular subject? Would you like to watch a movie or participate in other social events? How about learning a new hobby or finding out about 'googling' and other computer topics etc? Is the time suitable? Carers Week begins on the 19th October, would you like to have a special event for carers and family members? If you have special dietary needs please let me know. Our location is not far from the West Ryde railway station and bus stops. If you require care for the person you care for, please contact me. If you already receive regular services, contact your service provider who may be able to arrange care for you.

## 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  
               Viki Moraitis  
               Elaine Sammut  
               Ian White

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

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 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

**Walid Nassar**  
 Executive Officer

**Vacant**  
 Administration Officer

**Vacant**  
 Family and Carer Support  
 Coordinator

**Judy Fullston**  
 Family and Carer Support Officer

**Lily Ma**  
 Administration and Activities  
 Assistant

**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

**Outreach Service**  
**Jet Aserios**  
 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