

Australian
Huntington's
Disease
Association
(NSW) Inc.

Annual Report

2008

Australian Huntington's Disease Association (NSW) Inc.

Registered Office: 21 Chatham Road, West Ryde NSW 2114 Australia
Telephone: 02 9874 9777
Telephone (International): + 61 2 9874 9777
Facsimile: 02 9874 9177
Facsimile (International): + 61 2 9874 9177
Email: hdassoc@ahdansw.asn.au
Website: www.ahdansw.asn.au

Postal Address: Post Office Box 178, West Ryde NSW 1685 Australia

Bankers: Commonwealth Bank of Australia
Sydney NSW Australia
St George Bank Limited
Kogarah NSW Australia

Auditor: I G Petty FCPA
PO Box 80, St Ives NSW 2075

Other Information: * Australian Business Number (ABN) 54 571 730 306
* Endorsed as a deductible gift recipient and income tax exempt charitable entity; registered for GST
* Incorporated in NSW in 1993, Registered No. Y16575-09
* Authority to Fundraise in NSW Number CFN13153 expires 20 January 2011
* Licence for Conducting Charitable Collections in the ACT Number 90 expires 1 July 2009

Public Officer: Robert Curran

Management Committee

The committee members of the Association who held a position during the financial year 2007/08 were:

President:	Mark Bevan
Vice President:	Anne Low
Secretary:	Keith Dingeldei
Treasurer:	Richard Bobbitt
Committee:	Jim Finn Elaine Sammut Ian White Robert Curran (From 19 April to 5 Sep 2008) Viki Moraitis (From 25 June 2008)

Staff

Executive Officer:	Jacqueline-Marie Bohm (2 July to 9 November 2007) Vacant (until 17 June 2008)
Executive Officer:	Walid Nassar (17 June 2008 to 30 June 2008)
Acting Administration Officer:	Robert Curran (Until 7 April 2008)
Administration Officer:	Sharnie Mineeff (7 April to 30 June 2008) Sasa Berber (From 20 October 2008)
Carer Support Coordinator:	Maria Mackell
Carer Support Officer:	Judy Fullston (8 April to 30 June 2008)
Activities Coordinator:	Karen Bevan (to 21 December 2007)
Administrative & Activities Assistant:	Shu Yue Ma (Lily)

Our Mission

The energies and resources of the Association 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

The philosophy underlying all our services encompasses the principle that 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.

President's Report

The Association has faced another difficult year in 2007/2008. Fortunately, we are now in a rebuilding stage, and have a very solid Executive Officer, Walid Nassar, on board. Walid has had to learn about the complexities of his role quickly and has already successfully managed a lot of challenges. He has proven to be a strong and capable leader and he has the full support of the Board.

We have recently appointed Sasa (pronounced Sasha) Berber as Administration Officer and, of course, Shu Yue Ma (Lily) is our Administration and Activities Assistant.

In Walid, Lily and Sasa we have the nucleus of a solid team with which to move forward into the coming year.

Staff News

There have been many personnel upheavals and changes since I reported Robyn Kapp's resignation last year. As a result, it has taken longer than planned to stabilize the Association's staffing and organizational structure.

Jacqueline Bohm was hired in July 2007 as Executive Officer, but resigned in October.

In that time, Robert Curran also resigned from his position as Administration Officer after seven years in that role, so the Association was left with another big gap to fill. Fortunately, Robert then agreed to temporarily assume the role of Administration Officer while the Association recruited a new Executive Officer. Walid accepted that position in June 2008.

Sharnie Mineeff, who was hired as Administration Officer to replace

Robert Curran became pregnant and decided to leave rather than to take maternity leave. Sasa Berber, as mentioned before, is our new Administration Officer and is now working with the Association three days per week. Shu Yue Ma (Lily) was recruited during 2007, and has done well with managing the Social Club, and in assisting with administrative work.

Lunch Club and Activities Co-ordinator, Karen Bevan, left the Association at the end of 2007 after five years overseeing the Association's Lunch and Social clubs and assisting with Holiday Camps and clerical work as needed.

Most people would be aware of the death of our beautiful Maria Mackell in August 2008. This was extremely sad - both for her family and for the HD community, many of whom have been touched by Maria's excitement and enthusiasm for HD families and, most particularly, carers. She is, and will remain, greatly missed.

Judy Fullston who began working as a part-time Carer Support Officer with the Association soon after Maria became ill, left in October 2008 to take up full time employment.

The Association cannot replace either the Carer Support Co-ordinator or the Carer Support Officer roles at the moment, as we are awaiting the re-approval of our Carer Support Program funding application from the NSW Minister for Health.

As soon as approval is received, we will be seeking to recruit a new Family Support Co-ordinator and we will then be looking to hire a second part-time Family Support Officer. The re-vamped Family Support team will then work together servicing the whole of NSW in what we believe is a bold new plan to provide significantly improved

service to the wider NSW HD community. (This was a particular wish of Maria Mackell's and we are keen to see it come to pass.)

In spite of the many staff changes during 2007/2008, I believe we now have a stable and effective core team and the Association can move forward confidently.

Thank you to each of the past and present staff members for your contribution to the Association and to the wider HD community.

Board News

The Association's Board has also been through some changes in the past year. We were fortunate to see some additions to the team in Ian White, Robert Curran and Viki Moraitis. (Robert agreed to sit on the Board temporarily while a new Executive Officer and Administration Officer were recruited. He has now completed that term on the board.)

We are still keen to see new people serve on the Board, and I'd particularly like to see people with expertise or experience in marketing, finance, senior business management, law or medicine take up new positions.

It is not a prerequisite to be part of a HD family to serve on the Board. In fact, it is healthy for Boards to be comprised of a mix of family members and non-family members.

There is much to be done within the Association and to do it successfully, Board members must work together to provide the right strategic direction and support.

If you are interested in helping the Association in this way, or if you know someone else who may be interested,

please contact the Association's office for more information about what is involved in becoming a Board member.

My genuine thanks go to each and every board member who has served in the past year. Thank you so much for your efforts on behalf of people affected by HD and their families.

Finances

The Association's finances are not sufficient at present for us to do all that we would like to do, but the situation is more positive now than it has been in the recent past.

Robert Curran helped us take a close look at our financial situation and, consequently, the Board made some tough decisions in regard to staffing levels in the short term. That, along with some of the staff changes mentioned above, has resulted in the Association running close to budget in this financial year. There have also been some substantial gifts and bequests in 2007/2008, and some new fundraising initiatives are currently being reviewed.

One of the key focus areas for the Executive Officer going forward will be improving our financial position. It is hoped (and planned) that this will come through various small and large fundraising initiatives as well as seeking additional government funding. It will take Walid and the Board some time to review and implement these strategies, but they must be a priority if we are to continue to provide much-needed services to people with HD and their families.

Volunteers

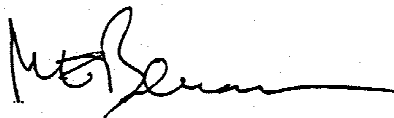
Volunteers have helped the Association in a variety of ways again

this past year. A special mention must go to Helen Bobbitt who has really provided significant help to get some key accounting issues sorted out, and, in doing so, has saved us considerable expense.

I would also like to extend a vote of thanks to all the volunteers who have contributed to the Association's work during the year.

Thank You

I cannot end the report without thanking the Association's members and supporters who have contributed financially to our activities and services over this year. Your generosity and encouragement is so important and without it, we would certainly not be able to provide the much-needed services or contribute to the research aimed at improving the lives of people affected by HD and their families in NSW. Thank you.

A handwritten signature in black ink, appearing to read 'Mark Bevan', with a long horizontal flourish extending to the right.

Mark Bevan
President

Executive Officer's Report

Education Program

Publications

The Association has a range of publications on various aspects of Huntington's Disease. Table 1 provides statistics on the distribution of publications.

Four issues of *Gateway* (Volume 10 No. 3 through Volume 11 No. 2) were published with the total circulation per issue (printed copies) between 350 and 400.

Approximately 70 copies of each issue are now distributed by email.

An email list for the distribution of research news to HD professionals has 24 subscribers.

Website

Our website continues to provide another alternative for people to learn more about our Association and to contact us. The website address is <http://www.ahdansw.asn.au>

Additionally, Accreditation by *HealthInsite*, the Commonwealth Government's consumer health information portal and the *Health on the Net Foundation* was maintained.

Visitation statistics can be found in Table 2.

Family Support Program

Information and Referral

The number of requests for information and referral is documented in Table 3.

Of about 120 calls for information, close to 58 callers identified themselves as family members, 42 as main Carers and 22 as subsidiary Carers, with the remainder being people with HD or people at risk and health care professionals. What the figures cannot show is the amount of work involved in responding to these calls.

A single inquiry may be a simple request for information to be sent, but it may also be about more complex issues resulting in 5 or 6 additional/follow-up calls to secure the right information or agency to assist the person.

Services in Regional Areas

Our regional activities tended to be a combination of a social activity and information days. In some cases, we have been able to secure a local service provider e.g. Respite Care, but service providers such as Genetic Counsellors have proved difficult to engage with, due to shortages in the Regions.

We have carried out:

- Country Carers Beach Holiday- August 07 (6 Carers plus volunteers)
- Country Carers City Holiday – November 07 (6 Carers plus volunteers)
- Combined Carers and Clients Holiday Camp (2x approx 8 Clients and 3-5 Carers)
- Regional meetings in Southern NSW/ACT (2x 16 Carers each time)
- Regional Meeting in South West (1x 10 Carers)
- City Carers – Family days (2x 8 Carers per meeting)

In early 2008, prior to her passing, Maria Mackell our Family Support Coordinator began work with a group of 10 Carers to form the basis of what was to be called "Carer to Carer" support network. One of its aims was to identify key issues for Carers such as why Carers stay hidden. The plan was to determine key support needs for Carers and ways they can pass on experience and skills to other Carers. The project launch was to be mid to late June 2008, but due to the sudden illness of Maria Mackell and her subsequent death early August 2008, it was put on hold.

Should funding be granted and we are able to hire a Family Support Coordinator and an assistant Officer, we will then re-think this project and perhaps launch it with some modifications to better fit our grant proposal model of caring for Carers.

Activities with Partners and Service Providers

We attend about 3 or 4 meetings per year to network with other Carer Support services to reduce the isolation for our staff as well as to stay on top of issues and share ideas and strategies. Meetings have been held with Alzheimer's Australia and RNSH Carer Support staff.

Meetings have also been held with others about respite care issues and with the Huntington's Disease Service staff over specific issues or staff training days.

Other service providers we have engaged with include Meadowbank TAFE who have provided students for Carer Pamper Days. Over the course of the last 18 months more than 110 information packs have been sent to numerous Service providers and partners in order to provide information and maintain on-going relationships.

Holiday Camps

Two holiday camps were held, one a City-camp in September 2007 and the other a regular camp at Camp Breakaway April 2008.

Statistics for the camps are found in Table 4.

Day Care

The day care program ("social and lunch club") continued to operate at West Ryde throughout the year, although lunch clubs have been suspended until vacant positions are filled. Attendance statistics are given in Table 5.

Other Client Services

Grants totalling \$742 were made to the NSW Huntington's Disease Service to assist with the costs of running the Outreach Clubs, and \$450 was committed to the Christmas Hampers organised by Lottie Stewart Hospital for needy members.

Carers Support Program

Agreement with NSW Health

A grant proposal was submitted to the Department seeking extension for another year.

The proposal highlighted our "family support" focus rather than our previous "carer support" focus. As mentioned last year, this will be a more holistic approach that will hopefully help us identify more carers and family members.

Our proposal also outlined the need to cover as much of country NSW as our financial and staffing resources allow.

Under the initial agreement there was a requirement for the Carer Support Project to have a separate Carer Support Management Committee which was changed to an "information and planning" day format in order to involve more carers and enable representation and participation by country carers. Due to the volume of administrative work involved in such a planning day, and in light of our staffing shortage, the decision was made by the board to postpone this activity and re-visit it in Feb/March 2009 to assess our capacity to hold it then if our staffing situation improves.

Reaching Out through Activities, Events and Correspondence.

Over the last year, the events and activities for Carers have included Country meetings, City Carers Morning Teas, Lunch meetings, Gardening Workshops, and the Photo Voice project. Attendance at the activities varied. With almost 200 Carers now registered on our database (both primary and subsidiary Carers), we have made significant progress in reaching Carers or family members through activities, events and our mail outs.

Country Trips

There have been Country meetings held in Canberra, Newcastle, Taree, Port Macquarie and Coffs Harbour with a total of over 50 people attending those meetings. While each

of the meetings were relatively short (approximately, 3 hours each) they were very beneficial in alerting us to the issues of families and carers in those areas.

Carers Photo Voice

Presentations have been made to groups in the wider community – such as the Red Cross, Senior Groups, and other Carer Support groups.

We have also made presentations at the Huntington's Disease Service planning day for staff and service providers.

We have also been asked to put the Carers Photo Voice project on display at the John Hunter Hospital and other regional centres. We have not been able to do this due to lack of staff time.

Challenges Ahead

Perhaps the greatest challenge we face is securing funding for our Family Support Program. We will continue to apply for the Carers grant as well as re-think ways of securing more funding from individuals and corporate donors.

Other than funding, we continue to face three challenges in this area: 1) identifying more Carers; 2) drawing more Carers to participate in activities and 3) reaching Carers and family members we have identified who are isolated.

Involvement in activities as well as linking Carers and services together remain the two most effective catalysts to advance more active engagement from Carers. We will thus continue with an approach that supports Carers and family members to not only attend events and activities but to maintain or build relationships with other Carers, and to link them with service providers in their area.

Special Working Relationships

Networking with other professional service providers is key to the success of our own work as well as theirs. Being an interdependent community of professionals, we need the expertise of all involved in order to ensure the best service to clients, Carers

and families. We therefore place a high priority on maintaining co-operative working relationships with other service providers. A special working relationship with the Huntington's Disease Service, especially the Outreach Team, has existed for some time. Our relationships with researchers, genetic counsellors, social workers and other professionals within our network will continue and develop further.

Membership

Membership statistics are shown in Table 6.

Research Program

One grant was given to Dr. Elizabeth McCusker for \$3000 to facilitate the attendance of a researcher at the annual Huntington's Study Group meeting in the USA.

Special Acknowledgments

The Association acknowledges the following with sincere appreciation:

- The NSW Health Department for its ongoing support through its grants program
- Organisations and health professionals who have provided services and support for people with Huntington's Disease and their families, including:
 - Dr Elizabeth McCusker and staff of the NSW Huntington Disease Service;
 - Management and staff of Huntington's Lodge at Lottie Stewart Hospital;
 - Fiona Richards of the Predictive Testing program at the Children's Hospital, Westmead;
 - Management and staff of Hunter Genetics in Newcastle
- All who made donations, raised funds or purchased goods through our telemarketing program.

- All our volunteers throughout the year.
- Robert Curran for invaluable support and help throughout the year.

Sincerely,

Walid Nassar
Executive Officer

Activity Statistics

Table 1 – Publication Distribution

Measure	Publication	This Year	2006/07
Quantity sold or supplied in bulk to other agencies to distribute	All titles	539	531
Distributed in response to individual requests	All titles	233	483
Quantity sold or supplied in bulk to other agencies to distribute:	HD Book	80	115
	Physician's Guide	111	45
	Caregiver's Handbook	85	23
Distributed in response to individual requests:	HD Book	28	94
	Physician's Guide	6	9
	Caregiver's handbook	13	10

Table 2 – Website Usage

Measure	This Year *	Last Year
Unique visits (average)	2878	1847
Origin of visitors	United States (60%) Australia (27%) Unknown (2.6%) Italy (1.6%) China (1.5%) Other (7.3%)	United States (54%) Australia (30%) Canada (3%) United Kingdom (2%) Other (1%)
Most popular pages (in rank order from most popular)	1. Symptoms of HD 2. Information Index (FAQ) 3. Cause of HD 4. History of HD 5. Progression of HD 6. Association News Archive	1. Home Page 2. Symptoms of HD 3. Information Index 4. Progression of HD 5. Cause of HD 6. History of HD

* Information shown is for a sample month comparison rather than the entire year. The sample month is June 2008 and June 2007.

Table 3 – Client Contacts for Information & Referral

Type	This Year	2006/07	2005/06	2004/05
Professionals	48	32	37	49
Families	58	62	64	56
Students & Others	14	12	4	16
Total	120	106	105	121
Rolling 3-year average	110	111	116	134

Table 4 – Holiday Camps

Measure	This Year	2006/07
Number of camps	2	2
Camp days provided	6	8
Client/days provided	58	73

Table 5 – Day Care Program

Measure	This Year	2006/07
Lunch club – occasions	10 (ended Dec 2007)	19
Lunch club – client/days provided	66	95
Social club – occasions	19	17
Social club – client/days provided	95	90

Table 6 – Association Membership

This Year	2006/07	2005/06	2004/05	2003/04
291	296	286	312	327

The breakdown of the 291 total members is as such:

Renewed Members	New Members	Life Members	Fee-Exempt Members	Total
223	43	4	21	291