

Australian
Huntington's
Disease
Association
(NSW) Inc.

Annual Report

2010 – 2011

Australian Huntington's Disease Association (NSW) Inc.

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

Auditor: Thomas GLC Chartered Accountants
PO Box 1563 Hornsby NSW 1635

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, 1993 Registered No. Y16575-09
Authority to Fundraise in NSW Number CFN13153
Licence for Conducting Charitable Collections in the ACT Number 19000322

Public Officer: Robyn Kapp

Board Members

The board members of the Association who held a position during the financial year 2010/2011 were:

President:	Robyn Kapp OAM
Vice President:	Anne Low
Secretary:	Viki Moraitis (resigned 2 nd May 2011) John Conaghan (elected 2 nd May 2011)
Treasurer:	Richard Bobbitt
Committee:	Don Ayres Karen Bevan Keith Dingeldei Jim Finn

Association Staff

Executive Officer:	Ingrid van Tongeren (resigned 21 st April 2011) Vacant (21 st April 2011 – 30 th June 2011)
Administration Officer:	Ling (Toni) Zhang
Family Support Co-ordinator:	Ramona Watts
Family Support Officer:	Mark Bevan
Administrative & Activities Assistant:	Shu Yue (Lily) Ma

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.

From the President

Huntington's NSW is a well established professional organisation providing support to families and professionals throughout New South Wales and the Australian Capital Territory.

Although this year has not been without its difficulties with the resignation of the Executive Officer in April, I have no doubt that the current staff, the Board, volunteers and members will continue to be the reason we can make progress in supporting people with Huntington's Disease and their families.

I would like to particularly pay tribute to our staff members. To Lily, Toni, Ramona and Mark thank you so much for your dedication and commitment this past year. They have stepped up to the plate above and beyond the call of duty and for this we are truly grateful.

Appreciation is also extended to the members of the Board for giving so willingly of their time and expertise throughout the year.

We will continue to face challenges in the year ahead, specifically we need to

- Identify and obtain new sources of funding;
- Update our written materials and website;
- Review our overall management and staffing structure;
- To continue and enhance our services to people with Huntington's Disease and their families.

I am confident that we will be able to meet these challenges and that the Association will achieve its mission and vision for the future.

Robyn Kapp OAM
President

Highlights of 2010 – 2011

Education

- The Association continued to publish a wide range of publications, distributing a total of 1,224 during the past year. This represents an overall increase of 7% compared with the previous year. Although there was a decrease of 32% in distribution to other agencies there was an increase of 59% in the distribution to individual requests.
- Four editions of our newsletter, *Gateway*, were produced with a production run of 500. Another 100 were sent electronically which is more than double in the previous year. The newsletter is also posted on the website. It is anticipated that the number of printed copies will decrease as more people elect to receive the newsletter electronically.
- Our website was updated regularly on a voluntary basis by Robert Curran, our former Administration Officer. The website had an average of 3,825 unique visitors per month. This compares to an average of 3,515 unique visitors per month for the past year. Accreditation by HealthInsite, the Commonwealth Government's consumer health information portal and the Health on the Net Foundation was maintained. A priority for 2011/12 is the development of a new web site to reflect the current changes in technology and to make it more 'user friendly'.
- Staff members provided 10 presentations to a range of professionals in 2010/2011 and the number of attendees at each event ranged from 5 to 20. Evaluation of these events by attendees and participants was overwhelmingly positive.
- Quarterly Liaison meetings were held with staff from the NSW HD Service; Children's Hospital, Westmead; Lottie Stewart Hospital and Hunter Genetics to network and provide updates.
- Research updates were emailed to professionals on a monthly basis. There are currently 25 recipients. However this service has not been widely advertised and also needs to be evaluated in light of wider access to the internet.

Family Support

- During 2010/2011 we provided information, support and referral to family members, people with HD or at risk for HD and health professionals. Many of these generated follow up contact.
- Although we maintain statistical data, what the figures cannot show is the amount of work involved in follow up. Whilst a follow up may be a single quick call or email, it equally well may involve multiple and/or lengthy emails, face to face meetings, long calls of over an hour or more, or any combination of these and may also result in an additional 4 or 5 follow up calls, emails or face to face contacts.
- Support groups continued to meet on the Central Coast (Gosford/Erina) and Mid North Coast (Port Macquarie). The Central Coast had a core attendance of 13 committed members and met on 11 occasions. The Mid North Coast met on 2 occasions with an average attendance of 15 participants.
- The existing self-managing groups in Goulburn/ACT and the Wagga areas have been supported through the provision of advice, publicity and funding the hire of venues and refreshments. The Family Support Co-ordinator made two visits to these areas.
- The Family Support Worker has made numerous trips to regional areas. During these visits he has attended and facilitated group meetings, undertaken family visits, nursing home presentations and met with health professionals. He has covered the Central Coast, Mid-North Coast, Far North Coast, Tamworth, Armidale and Gunnedah areas. visiting 5 families, the genetic counsellor and meeting with staff at a care facility
- The Family Support Worker has met with a number of carers and families who are geographically isolated from most facilities and from other HD families. He is discussing ways to more effectively support them, including electronic measures (Skype, etc) and forming loose self-support networks. Work on this will continue as his relationships with the families develop.
- The existing metropolitan Carer Support Group continued to be held monthly at the Association's office. It is co-ordinated by the Social Worker from the NSW HD Service and the Association's Family Support Co-ordinator.

Services for Clients

- One five day holiday was held in March 2011 with 11 people attending. Camp Breakaway, with its well laid out grounds and amenities continues to prove to be an ideal location for the Association's Holiday Program. The Program is one of the Association's longest running and consistently well-received services. For many years we organised two camps each year. However in recent times, for various reasons, it has been reduced to one. We will be aiming in the 2012 calendar year to conduct two holiday camps.
- Lunch Club held on a fortnightly basis at the Association's office also continues to be very popular. An average of 8-10 people attend and the highlight continues to be, as the name suggests, - lunch. The group enjoys a wide range of activities including word and card games and outings.
- The Association donated \$1,500 to the Samaritan Fund of the Huntington's Disease Service at Westmead Hospital. This assists clients such as taxi fares to the HD Clinic at Westmead Hospital.

Research Support

- Financial assistance of \$5,000 was provided to the HD Service at Westmead Hospital to enable staff to attend the Huntington Study Group meeting in the USA. They are members of the international collaborative working in HD research. Attendance by staff at these meetings is crucial in order for Dr Elizabeth McCusker and her team to continue to be members of the HSG and for the HD families of NSW to participate in research, including international drug trials.

Fundraising, Grants and Donations

- Fundraising and government grants realise the major portion of our income. The recurring NGO from NSW Health continues to increase in line with the CPI. We were advised that the Carers Grant would transfer from NSW Health to Ageing, Disability and Home Care as from 1st July 2011. We also received a grant from the NSW Community Building Partnership to repair the roof of Elsie Court Cottage.
- The telemarketing program accounted for 22% of the Association's net income for 2010-2011. The funds from this program have plateaued in the past three years to approximately \$50,000 per annum.
- The donations and fundraising of members and supporters continue to be a valuable source of funding for the Association. However to maintain and enhance our services we will need to explore further opportunities for funds.

Special Acknowledgements

The Association acknowledges the following with sincere appreciation for their contributions throughout the year: -

- NSW Health for its ongoing partnership, support and acknowledgement of the organisation's efficiency and effectiveness through its NGO and Carer's Grant Programs.
- The Department of Premier & Cabinet for its support through its Community Building Partnerships Grants Program.
- The Member for Ryde, Mr Victor Dominello, MP and the Member for Bennelong, Mr John Alexander MP, for their support.
- Our donors, those who have undertaken fundraising events or supported our telemarketing program throughout NSW and the ACT. In particular we acknowledge the wonderful efforts of Holly Faulkner and her team who conducted a very successful Dinner Dance & Auction in September 2010.
- Organisations and health professionals who have worked alongside the Association to provide services and support for people living with HD and their families.
Particular thanks go to:
 - Dr Clement Loy, Jet Aserios and the staff of the NSW Huntington Disease Service, West mead Hospital;
 - Dr Elizabeth McCusker, Westmead Hospital;
 - Angela Lownie and the Allied Health Staff, the Outreach Program;
 - Fiona Richards, Predictive Testing Program, Children's Hospital, Westmead;
 - John Conaghan, Hunter Genetics.