



Australian
Huntington's
Disease
Association
(NSW) Inc.

Annual Report

2012 – 2013



Australian Huntington's Disease Association (NSW) Inc.

Trading as Huntington's NSW

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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 OAM

Board Members

The board members of the Association who held a position during the financial year 2012/2013 were:

President:	Brian Rumbold
Vice President:	Don Ayres
Secretary:	Judith Rough
Treasurer:	Richard Bobbitt
Board members:	Deborah Cockrell (<i>joined 4th March 2013</i>)
	Amanda Dickey
	Keith Dingeldei
	Anne Low (<i>resigned 4th February 2013</i>)

Association Staff

The members of staff employed by the Association during the 2012/2013 financial year were:

Executive Officer:	Robyn Kapp OAM
Administration Officer:	Ling (Toni) Zhang (<i>resigned 10th August 2012</i>)
Family Support Worker:	Ramona Watts (<i>resigned 16th October 2012</i>)
Regional Family Support Worker:	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

Earlier this week our Executive Officer Robyn Kapp and I were excited to be at the opening of the new Huntington's unit at St Joseph's Hospital Auburn. As you know this represents a very happy conclusion to all the work that has been put in to resolving the closure of Lottie Stewart Hospital including its Huntington's unit. We were very impressed with the design and quality of the new facility, the obvious commitment of the management and staff to the residents and the sheer enthusiasm of the staff in their work.

On behalf of the Board of Huntington's NSW I particularly want to thank Dr Clement Loy for all the input he has had to getting this project to a successful conclusion. Seeing his commitment to the people in his care is inspiring.

Of course, at any one time there may be between 100 and 150 people in residential care in NSW and the ACT because of Huntington's; the new unit at St Joseph's provides 14 permanent places. So we are also grateful to the residential care organisations that, from time to time, have committed to taking Huntington's residents. However, overall, the way residential care for younger people works is not really satisfactory, especially if you are in a regional or rural location – the options are often very limited and not ideal. We want to see a more consistent and holistic approach to this problem: have the problem recognised by providers and governments and see better, longer term solutions put in place. As a Board we will work at developing the Association's advocacy in this area.

In our strategic planning a year ago we recognised that, especially for regional and remote families, accessing timely information and suitable health services can be really difficult. Our rural support worker, Mark Bevan, has no shortage of families and individuals to visit across the state. We believe the Family Support Service is providing a vital link for families into health and other community services, and it is giving families and individuals someone they can talk to who understands their situation and needs. We are working to better understand the benefits the Service delivers to families so we can look for more funding and extend its reach across NSW and the ACT.

The Board wants to thank all those who have generously given both time and money over the last year to support the Huntington's community through the Association. The resources of the Association aren't huge but the needs of the community are substantial so we are working hard to be as efficient and effective as possible, and to attract new sources of funding and donations for the benefit of the community.

I also want to thank the members of the Board for their involvement and contributions over the last year, and our staff for their hard work on behalf of the community. And thank you again to our Executive Officer, Robyn Kapp, for her ongoing commitment to HNSW—we deeply appreciate it. It's been a busy year of consolidation, but we are now better placed for the challenges of the coming year. We look forward to continuing to serve the Huntington's community through 2014.

Brian Rumbold
President

From the Executive Officer

I believe we can confidently say that Huntington's NSW has made a positive contribution to the lives of people impacted by Huntington Disease and their families in NSW and the ACT over the past twelve months. In particular our Regional Family Support Service is obviously impacting positively on the quality of life of HD families throughout rural NSW and the ACT.

The ongoing success of our core services is due to the commitment and hard work of our staff and volunteers. I acknowledge with sincere appreciation the outstanding work of Mark Bevan and Lily Ma and volunteer, Karen Bevan. Their collective energy, experience and expertise have ensured the delivery of quality programs.

Our effectiveness as an organisation is also dependent on building strong partnerships with like-minded support networks such as the NSW Huntington Disease Service at Westmead Hospitals. We have worked closely with the Service during 2012/2013 and this would not have been possible without both the Association and the Service being intent on the common goal of supporting and caring for people living with HD and their families. I extend my sincere appreciation to the committed and dedicated staff of the Service.

Our "Gateway" newsletter, our website and range of publications help us to keep members informed of research breakthroughs and assist us in raising awareness about HD and its impact on families. Consequently, the dissemination of accurate, up-to-date information to families and health professionals continues to receive priority. We have kept "Gateway" topical and informative this year by sourcing the best articles about HD worldwide.

Finally I would like to pay tribute to the Board. Our President, Brian Rumbold, has given so much of his valuable time and expertise outside the board room and for this I am truly grateful. The expertise and commitment of each Board Member have guaranteed sound governance and will ensure that the Association achieves its mission and vision for the future.

In evaluating the performance and activities of the Association, members have every reason to be proud of what has been achieved and to be confident that we will continue to make a significant contribution to the lives of people with Huntington's Disease and their families.

*Robyn Kapp OAM
Executive Officer*

Highlights of 2012-2013

Education and Information

- A total of 969 publications were distributed during 2012-2013. Although there was an increase in distribution figures compared with 2011-2012, there is evidence to suggest that more and more people are obtaining information via the internet.

Year	Number of Publications	Percentage change from previous year
2011-2012	715	- 42%
2012-2013	969	+ 35%

Distribution Category	Number of Publications
Families	240
Professionals	244
HNSW Rural Service	221
HD Service (Westmead)	249
Hunter Genetics	15
Total	969

- Four editions of our newsletter, *Gateway*, were produced during the reporting period and we continue to print in-house. The print version still proves to be more popular than the electronic version with an average of 306 copies sent via mail and 143 sent electronically. The newsletter is uploaded to the website and is included in information packs in response to requests for information. Anecdotal feedback concerning the content has been very positive.
- We continue to evaluate our new website which went live in April 2012. From July 2012 to June 2013, there were 10,719 unique visitors to the site. There is need for a major revision of the content and it is anticipated that this will be undertaken in January/February 2014. We are most grateful to Jason Turnbull from Digiscape for his input and advice. The website maintains accreditation with external government reviewers (The HONcode standard for trustworthy health information.) in relation to its health and medical content.
- The Association continues to contribute financially to HDBuzz, a website that features up-to-date scientific research news on Huntington's Disease, written in plain language by scientists. This website also provides invaluable material for the newsletter.

Family Support

- During 2012/2013 we provided information, support and referral to family members, people with HD or at risk for HD and health professionals. Contact is made either via telephone or email. Where necessary the caller may be referred to the HD Service at Westmead Hospital or to our Regional Family Support Worker.
- Mark Bevan, our Regional Family Support Worker, became full-time in October 2012. Regional work, which covers rural NSW and the ACT, is challenging because of the spread of families affected by Huntington's. During regional visits Mark attended and facilitated group meetings, undertook family visits, nursing home presentations and met with health professionals. He had contact with 52 new clients and 7 new health professionals over the period. Contact with some clients via Skype was trialled with success and will be explored further as opportunities arise.

Region	Number of trips	Number of client visits	Number of clients seen	Other client contact Phone, email, etc
North West	2	16	33	91
North coast	1	18	54	128
South coast	2	22	55	137
South west	2	36	70	218
West	2	29	73	215
Mid north coast	1	11	26	230
Hunter	Ad hoc	3	6	66
ACT	1	0	0	99
Central Coast	Ad hoc	16	36	301
In Service		12	147	
Support meetings: Central Coast, ACT, Mid North Coast		8	92	

- The support group which meets on the Central Coast (Gosford/Erina) continues to serve the people of that area well. Attendance has been between 6 and 20, with around 10 consistent attendees. The location for meetings changed to the Central Coast youth centre at Niagara Park during the year.
- The Association hosted the metropolitan Family and Friends Support Group each month at its premises in West Ryde. This group is facilitated by the Social Workers from the NSW HD Service and the average attendance was 7-8 people each month.

Services for Clients

- Unfortunately the Holiday Camp scheduled for March 2013 had to be postponed until October 2013 due to unforeseen circumstances.
- The Social /Lunch Club was held on twenty occasions during 2012-2013. An average of 5 people attended on each occasion. The group enjoys a wide range of activities including word and card games and, of course, a delicious lunch. There is room for more participants however the major obstacle facing those who are interested is transport. Community transport providers are reluctant to travel outside their respective LGAs. Six genetic counselling students attended Lunch Club during the year as part of community service which is a requirement of their training.
- In supporting youth and young people, the Association contributed financially to HDYO, an international website for young people impacted by Huntington's Disease. The goal of HDYO is to empower youth with knowledge about HD and provide a supportive community to help each other cope with realities of the disease. Discussions were held with the HDY Australia as to how we might best support young people in NSW and the ACT. This resulted in HNSW sponsoring a very successful forum for young people on the Central Coast in February 2013 with both Mark Bevan and Robyn Kapp representing HNSW. Congratulations must go to Holly Faulkner and her team for organising such a wonderful event. Plans were also put in place for a joint Family Fun Day to be held in July 2013.

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.

Advocacy

- As stated in our Constitution, it is the aim of the Association to give families a strong single voice when making representations to governmental and other bodies. To this end we persisted in our representations to Western Sydney Local Health District and the Minister for Health regarding the two vacant nursing positions in the HD Service at Westmead Hospital. The positions were eventually advertised and in January 2013, Colleen McKinnon was appointed the Clinical Nurse Consultant and Mark Cirillo the registered nurse in the HD Service.

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 received a grant of \$8,250 from the NSW Community Building Partnership to paint the exterior of Elsie Court Cottage. We are most grateful to Victor Dominello, MP, Member for Ryde who recommended that we receive this finding.
- The donations and fundraising of members and supporters continue to be a valuable source of funding for the Association. We are indebted to those who held fundraising events and those who participated in the City to Surf and other events.
- Everyday Hero (www.everydayhero.com.au), a web site designed specifically for donating to and fundraising for charities is proving to be a valuable tool for fundraising. People can participate in major fundraising events such as the City to Surf and select Huntington's NSW as their charity for sponsorship and donations. This website can also be used by those wishing to conduct independent fund raising events for the Association.
- The Fundraising Kit was completed and is available on our website. This ensures that all fundraising events conducted on behalf of Huntington's NSW fulfil the legal requirements for fundraising in both NSW and the ACT.

Special Acknowledgements

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

- NSW Health for its ongoing partnership through its NGO Program.
- NSW Family & Community Services for its support through its AD&HC Program.
- The Department of Premier & Cabinet for its support through its Community Building Partnerships Grants Program.
- The Member for Ryde, Mr Victor Dominello, MP
- Our donors, those who have undertaken fundraising events or supported our telemarketing program throughout NSW and the ACT.
- Organisations and health professionals who have worked alongside HNSW to provide services and support for people living with HD and their families.
Particular thanks go to:
 - Dr Clement Loy, Director, NSW HD Service, Westmead Hospital;
 - Jet Aserios, Cecelia Lincoln, Colleen McKinnon, Mark Cirillo and the staff of the NSW Huntington Disease Service
 - Dr Elizabeth McCusker, Westmead Hospital;
 - Fiona Richards, Predictive Testing Program, Children's Hospital, Westmead;
 - John Conaghan, Hunter Genetics.



