



Huntington's
New South Wales

Annual Report

2015 – 2016



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 2015/2016 were:

President:	Brian Rumbold
Vice President:	Deborah Cockrell
Secretary:	Therese Alting
Treasurer:	Richard Bobbitt
Board members:	Katy Clymo
	Amanda Dickey (<i>resigned 12 October 2015</i>)
	Felicity O'Neil

Association Staff

The members of staff employed by the Association during the 2015/2016 financial year were:

Executive Officer:	Robyn Kapp OAM
Administration Officer:	Stewart Swales
Rural Family Support Worker:	Mark Bevan (<i>resigned 21 October 2015</i>)
	Julie Leto (<i>commenced 31 May 2016</i>)
Programs Officer	Amanda Dickey (<i>commenced 20th October 2015</i>)
Activities Assistant:	Karen Bevan (<i>resigned 21 October 2015</i>)

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

The last year has been a period of consolidation for the Association. Fundraising in September 2015 included a new Walk4Hope in Canberra, where members and supporters of the HD community walked a circuit around the Lake—so, with Speers Point and Parramatta Park, it meant three walks on the annual calendar in just the second year. The Canberra walk reinforced the role Walk4Hope is taking on, becoming a focal point each year for people to meet others across the HD community, often for the first time, and to bring HD awareness to the wider community.

We farewelled Mark Bevan at the end of last year after many years serving the community across NSW, particularly in his role as Rural Support Worker. We want to thank Mark and Karen again for the amazing service and commitment they have given to the Association and the HD community.

On behalf of the Board I want to thank our Executive Officer, Robyn Kapp, for her continued commitment to the Association. She has done an amazing job representing the interests of the Association to the wider community—health professionals, the HD community across Australia and beyond, and other related charities. Again, we thank our other staff—Amanda, Julie and Stewart—for their commitment to the Association and its clients and members. Staff have often gone beyond what might be reasonably expected to ensure events have run smoothly and individual clients' needs have been met. We truly appreciate this dedication.

Pauline Keyvar's drive to develop awareness opportunities bore fruit in winning for the Association free awareness advertising on SBS. The powerful advertisement created by Ben Weir, Luke Smith and Looper Films produced lots of feedback and has provided a platform for developing awareness in the coming years. Thank you to Holly Faulkner for being willing to be our Youth Ambassador and for appearing in the TV advertisement.

In the coming year we will be working hard to enrich the range of activities we are providing for the HD community—particularly so we can help improve the quality of life for people impacted by HD. We are particularly excited about adding a Youth Worker to the team to help better support younger people.

Finally, the Board thanks members for their ongoing support of the Association. Your membership is a sign that you care about, and support, the HD community. Together we can achieve more than individually, so we look forward to working with you all through the coming year.



Brian Rumbold
President

From the Executive Officer

In thinking about the past year, I began reflecting on what we have achieved in the past five years and then my mind wandered back remembering how we have progressed over the last four decades. Suffice to say that we have grown and developed from a small organisation, relying purely on volunteers to one that now has a team of five people (soon to be six with the engagement of a Youth Worker) who undertake a variety of responsibilities including administration, advocacy, programs for people with Huntington's disease, family support, rural outreach and fundraising throughout NSW and the ACT.

However, although we have a staff team, we are still very much dependent on volunteers to keep the wheels turning. Volunteers play a vital role in the sustainability of our organisation in a variety of roles – board membership; social club; holiday program; administration and fundraising. We are, indeed, indebted to all our volunteers for their valuable contribution throughout the past year.

As you read through this Annual Report you will see that we have been quite active throughout the year. Nevertheless, 2015-2016 has not been without its incidents and changes. In June our services were disrupted due to flooding of the offices and the need to undertake minor repairs and replace the carpet. Fortunately, we were fully covered by insurance.

Mark and Karen Bevan decided to retire after many years of devoted service to the Association both as members of staff and as volunteers. We will be forever grateful for their contribution. However, endeavouring to replace Mark was not easy and it wasn't until Julie Leto joined us at the end of May, that we were able to bring our Rural Support Service back up to speed. We were delighted that Amanda Dickey joined us to take on the new role of Programs Officer and we are all grateful to Stewart Swales for his administration skills and particularly his knowledge around IT issues. Pauline Keyvar continues to amaze us with her enthusiasm for fundraising and creating awareness of Huntington's disease and the Association.

It has been my pleasure to work with a Board whose members are committed and enthusiastic about the mission and the activities of our organisation and I extend my sincere appreciation to each one for their support and encouragement. In particular, I wish to express my heartfelt thanks to our President, Brian Rumbold, for his dedication and inspiration to furthering the cause of Huntington's NSW.

I firmly believe that if we continue with the same zeal, commitment and imagination as we develop our Youth Program, expand our existing social programs and enhance our support in rural and regional NSW and the ACT then augurs well for Huntington's NSW in the year ahead.



*Robyn Kapp OAM
Executive Officer*

Social and Support Programs

October this year saw us farewell Karen Bevan, our Activities Officer, after many dedicated years. Her gentleness and genuine care for our clients made the holiday camp and social club programs safe places for people to be themselves and build friendships. Karen will be sorely missed and has kindly offered to return as a volunteer at our future holiday camps.

Social club



The Social club said goodbye to two old friends and welcomed two new members. This fun loving group enjoyed a range of new board and memory games, scalextrix and paper plane competitions, birthday and Melbourne Cup celebrations, homely cooking, loads of Uno and laughter 😊.

In May, a partnership with a local Heartmoves leader was created to pilot a fortnightly exercise program tailored to people with Huntington's Disease. Who knew you could sweat so much keeping a balloon afloat!

Thanks to the HD Service for their professional input into the exercise program and to Stewart who volunteers each fortnight to make every social club a special occasion for every client who attends.

Holiday camp

Another successful camp was held at Camp Breakaway in San Remo, attended by five clients. We sadly said goodbye to a few longstanding friends and welcomed in some new faces - clients, staff and volunteers. Our clients enjoyed delicious food, daily walks along the lake, relaxing yoga, a VIP (behind the scenes) tour of the Australian Reptile Park, crochet, S.E.A.T workshops, painting and drawing, plenty of night life including: trivia, a magic show, sing-a-longs, campfire stories and most importantly they enjoyed each other's company.



A big thank you to our wonderful volunteers Karen, Mark, Amy, Mark and Tony for making this a memorable year.

'MyVoice' art fellowship



Art offers new ways to express one's thoughts and feelings.

Stephen Dernocoure, a highly experienced art facilitator, was engaged to guide a small client group in finding their voice again through the use of visual and poetic art forms. Participants enjoy the calmness of creativity, the pleasure of friendship and a renewed sense of well-being.

This initiative was piloted between March and April and due to positive client feedback we were happy to adopt the program in our service offering. Stephen will present a presentation regarding our client's growth and a display of their art collections at this year's AGM.

West Ryde Carers Support Group

This well-established support group welcomed two new members and continues to be hosted by Huntington's NSW. The group are guided through current concerns and request topical presentations to aid their carer education and is facilitated by the NSW HD Service Social Workers with some input from our Executive Officer.

Central Coast Support (self-managed)

This was a sad year for our friends on the Central Coast, attendance dropped due to the deterioration of loved ones, and the passing of the husband of one of their founding members. Our hearts go out to all members for their shared losses.

Carer's Support Group

This tight-knit group met monthly over coffee and cake. This year they have shared invaluable knowledge and drawn much needed strength from each other.

Family Support Group

Welcomed one new member. The group met monthly and used email to stay in touch and pass on valuable information and updates.

For this group, fundraising and awareness are top priorities. They hosted another energetic Christmas shopping trip and a successful Huntington's day through an affiliated social golf club; raising thousands for our cause. They are also regular faces at our Speers Point and Parramatta Walks 4 Hope. We are very grateful to Di, Deb, Jen, Holly and Mark for their unwavering support of Huntington's NSW.

Rural & Regional Support

With the departure of Mark Bevan in October 2015, the search began for a suitable replacement. This took longer than anticipated and the position was finally filled in late May 2016. Between November and May we supported families via telephone calls and emails. We are grateful to Board Member, Felicity O'Neil, who co-ordinates a bi-monthly lunch for families in Canberra.

Education/Information/Communication

With our ever changing digital world, the means by which we communicate with our members and supporters as well as those seeking information about Huntington's disease and the Association have also changed and it's important that we keep abreast of shifting developments in all aspects of social media.

We continued with our quarterly newsletter "Gateway" which is distributed both in hard copy and digitally. Similarly, with our bi-annual "Hope for HD" which is a very useful tool for communicating with our donors, supporters and potential sponsors.

Requests for information from family members, people with HD or at risk for HD and health professionals usually come via telephone or email. Where necessary the caller is referred to the HD Service at Westmead Hospital, Genetic Clinics at major hospitals or to our Regional Family Support Worker.



We continued to financially support the web sites of HDYO and HD Buzz – two excellent sites for up-to-date information about HD and HD research. Our own website is destined for a major overhaul this coming year. The biggest growth has been seen in our Facebook page with over 1600 likes. Although this has focussed mainly on fundraising events, it has also proved a valuable source for disseminating news pertinent to HD.



Fundraising and Awareness

Our fundraising and awareness programs were, once again, extremely successful over the past twelve months. This is due, in no mean feat, to Pauline Keyvar, her hard work and her commitment to our organisation. During September 2015 which is HD Awareness Month there were three Walks 4 Hope – Speers Point, Parramatta and Canberra – with each walk being very well attended.

We were most fortunate to have members and supporters organising events around the state and further afield including the Antarctic! Under the expert leadership and guidance of Pauline each event surpassed its original goal in terms of dollars raised.

Following on from our very successful SBS television advertisement, we attracted further media attention and we are very grateful to Holly Faulkner and her family who were so willing and courageous to tell their story.

Research

We were proud to support the research of Dr Govinda Poudel, Research Fellow at Monash University. Dr Poudel and his colleagues, Professor Nellie Georgiou-Karistianis, Professor Gary Egan and Associate Professor Alex Fornito are investigating how the course of cognitive and psychiatric decline in Huntington's disease might be predicted. We expect the results of this research to be published in the not too distant future.



Representation and Relationships

Our Executive Officer represents Huntington's NSW on the Neurodegenerative and Neuromuscular Working Party of the Agency for Clinical Innovation. The purpose of the working group is to provide leadership and direction in developing recommendations on how to deliver and/or enhance current and emerging models of care to improve health care performance for people living with ND & NM conditions.

We enjoy an excellent working relationship with the HD Clinic and Outreach Service at Westmead Hospital; St Joseph's Hospital and the Sister Maria Cunningham Centre, Auburn; Children's Hospital, Westmead and John Hunter Hospital, Newcastle. Quarterly Liaison meetings are held with relevant staff members of these institutions and Robyn Kapp is the Consumer Representative on the SMCC Management Committee.

Grants and Funding

We continue to receive funding from NSW Health with an increase in line with the CPI. For some time, the Ministry has been exploring the option of transferring to a tender process rather than recurrent funding which we have been receiving for the past thirty years. It is highly likely that this change will occur in the 2017-2016 financial year.



Our funding from FACS supports our work in regional and rural NSW. The grant does not cover the total cost of the program so we rely on our fundraising and donations in order to provide a comprehensive program and to also include the ACT.

Under the Community Building Partnerships Program we received \$5,845 for new signage, the erection of a fence and landscaping. We extend our sincere thanks to Victor Dominello, Member for Ryde who continues to support our applications for this funding.

Special Acknowledgements

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

- NSW Health; NSW Family & Community Services; The Department of Premier & Cabinet
- The Member for Ryde, Mr Victor Dominello, MP
- Neville Barrett and Freddy Choo from Salvation Army Stores
- HLB Mann Judd
- Our donors including those who give through our telemarketing program.
- Organisations and health professionals who have worked alongside HNSW, especially
 - Dr Clement Loy, Director, NSW HD Service, Westmead Hospital;
 - Jet Aserios, Cecelia Lincoln, Colleen McKinnon, Terry McGill and the staff of the NSW Huntington Disease Service;
 - Dr Elizabeth McCusker and the Research Team, Westmead Hospital;
 - Fiona Richards, Predictive Testing Program, Children's Hospital, Westmead;
 - John Conaghan, John Hunter Hospital;
 - John Geoghegan and the staff of the Sister Maria Cunningham Centre and St Joseph's Hospital, Auburn.



