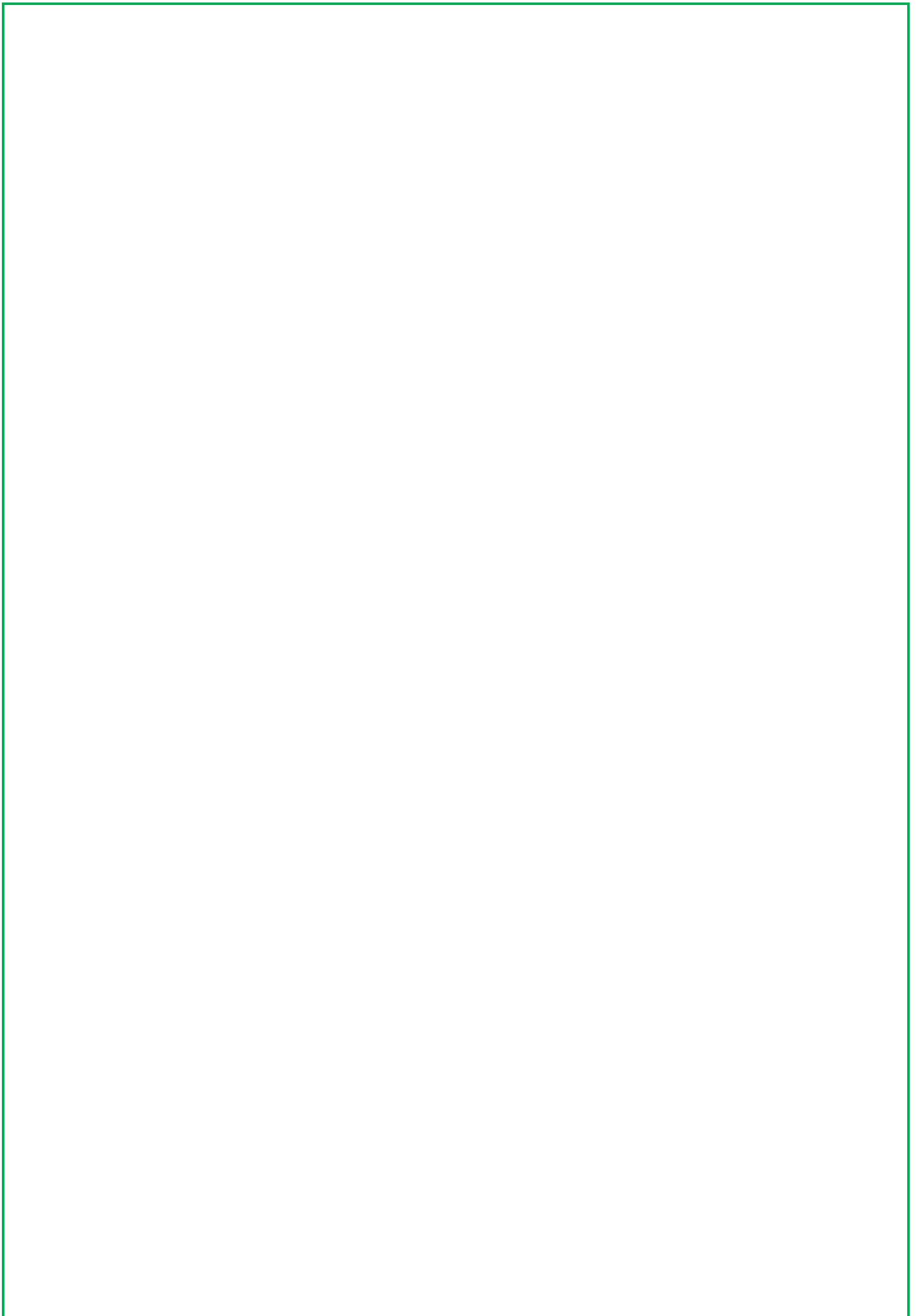




**Huntington's**  
New South Wales

# **Annual Report**

**2014 – 2015**



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

### **Trading as Huntington's NSW**

Registered Office: 21 Chatham Road, West Ryde NSW 2114 Australia  
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Postal Address: Post Office Box 178, West Ryde NSW 1685 Australia

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 OAM

## Board Members

The board members of the Association who held a position during the financial year 2014/2015 were:

President:	Brian Rumbold
Vice President:	Deborah Cockrell
Secretary:	Amanda Dickey
Treasurer:	Richard Bobbitt
Board members:	Felicity O'Neil

## Association Staff

The members of staff employed by the Association during the 2014/2015 financial year were:

Executive Officer:	Robyn Kapp OAM
Administration Officer:	Margaret Lind ( <i>resigned 15 July 2014</i> ) Stewart Swales ( <i>commenced 21 July 2014</i> )
Rural Family Support Worker:	Mark Bevan
Activities Assistant:	Karen Bevan

## 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*

September 2014 was the kick-off of Walk 4 Hope, our reinvigorated annual fundraising program. It received enormous support and is becoming an annual point of focus not only for raising funds for supporting the HD community but also for people to meet others across the community. Coupled with the creative and hugely successful Mad Hatters fundraiser in May, it has given us lots of confidence as we pursue activities in support of the HD community. Thank you to all those who contributed to the success of these events.

We remain extremely grateful to the NSW Government for its ongoing funding that allows us to provide a base of information and education services and to provide carer support, particularly for regional and rural families. Our improved fundraising will now allow us to develop our program of activities and events for people affected by HD, and to add some youth-oriented programs.

On behalf of the Board, I want to thank the staff for their commitment over the last year. Let me add my voice to those thanking Mark for his dedication to the clients in the Rural Carer and Family Support program. Thank you also to Karen for her commitment to the social club here at West Ryde.

I want to thank Stewart for his work here in the office, keeping the "back room" operating. His task has been made more complex as we have changed the way we manage our fundraising activity and our communication with our supporters and the HD community. He has been involved in setting up and testing new software while still needing to do the normal day-to-day tasks. We've really appreciated his work in all this.

Thank you again to Pauline for the amazing energy she has put into fundraising and for her commitment to the HD community. And to Robyn, we again thank you for the leadership you have given Huntington's NSW through the year. Your wisdom coupled with your depth of knowledge and understanding of the HD community has kept us on course as we've navigated the changes and grasped the opportunities that have presented themselves.

As we look ahead, we have some immediate projects we are working on:

- We welcome Amanda to the team as she transitions from Board to staff. In the coming year she will be working on adding to, and improving, the activities and events we offer to the HD community.
- Robyn's involvement with a national working group of the HD Associations across the country will, we believe, shed more light on the NDIS and its likely impacts on the HD community.
- We hope to have some initial youth-related support activities starting in the first half of 2016.
- We are exploring ways to provide more support to the HD community in the ACT.

On behalf of the Board, I again want to thank all who have generously supported the Association throughout the year. I also want to thank the members of the Board for their involvement and contributions over the last year and we look forward to serving the HD community in the coming year.



*Brian Rumbold, President*

## *From the Executive Officer*

This year we recognise that it is forty years since Huntington's NSW was established and it is only through the dedication and service by many people that we have been able to provide meaningful support and encouragement for families who are impacted by Huntington's disease throughout NSW and the ACT.

At the present time there is no cure but there is hope. We certainly know much more about Huntington's than what we did in 1975 and as I think back over the past four decades, I cannot help but remember what it was like in those early days.

We had no written information – in fact we initially purchased the Victoria newsletter for 10 cents per copy. We had no funds and there was no such thing as an HD Clinic or specialised residential unit.

However, we did have a dedicated group of people who were determined to make a difference, who had hope. They held small fundraising events such as raffles and trash and treasure stalls. They turned up at Family Support Meetings at Lidcombe Hospital every second month and they craved any new information that came their way. They are to be congratulated and not forgotten for their enthusiasm and commitment to improving the lives of those affected by Huntington's.

Over the past forty years, there has been a reluctance for young people to become involved with Association. This is completely understandable – they want to get on with their lives, they don't want to be reminded of Huntington's all the time, could there be repercussions in the work place if it was known they that were from a Huntington's family. All perfectly legitimate reasons.

However over the past few years there has been an explosion of young people keen to support the Association, particularly with its fundraising ventures. They are enthusiastic and committed; they are creative and imaginative. They are the future of Huntington's NSW and I'm sure that they will take up the cause in the same way as those who pioneered Huntington's NSW back in 1975.



*Robyn Kapp OAM  
Executive Officer*

## ***Highlights of 2014-2015***

### ***Education, Information and Communication***

- Requests for hard copies of information booklets and fact sheets have been decreasing over recent years, due in no small way to the fact that more and more people source their information via the internet, including our own website. The website maintains accreditation with external government reviewers (The HONcode standard for trustworthy health information.) in relation to its health and medical content.
- Four editions of our newsletter, *Gateway*, were published over the past twelve months, covering a range of informative and interesting subjects, including research updates and encouraging, personal stories. The newsletter is distributed in hard copy and electronically via email and it is also uploaded to our website.
- This year we introduced a biannual newsletter, *Hope for HD*, which focuses mainly on our fundraising events and personal stories. This newsletter is distributed to our donors and supporters and is also a useful tool when making contact with potential sponsors and other interested contacts.
- The Association continues to support HDBuzz, which 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.
- In the past twelve months we have made considerable use of our Facebook page for communicating with members, supporters and donors particularly in relation to events and fundraising. There are currently over 850 followers of the page.
- In November 2014, we hosted a visit from Matt Ellison, Founder of the Huntington's Disease Youth Organisation (HDYO). Matt shared his journey from being impacted by HD to setting up this global non-profit organisation which Huntington's NSW continues to support.

### ***Family Services and Advocacy***

- The annual holiday camp was held at Camp Breakaway, San Remo, in March 2015 with ten people attending. This program continues to be a very successful and well-received service.
- The Social /Lunch Club was held on twenty occasions during 2014-2015 with an average of 5 people attending on each occasion. The group enjoys a wide range of activities including card games, morning tea and lunch. The possibility of attracting funding to assist with transport will be investigated in the coming year and it is hoped this will assist others to participate.
- We made representation to the St Vincent's Hospital Network outlining the need for a Nursing Unit Manager for the Sister Maria Cunningham Centre at St Joseph's Hospital, Auburn. We are delighted to announce that funding for this position is forthcoming from the Ministry for Health.

- During 2014/2015 we provided information, support and referral to family members, people with HD or at risk for HD and health professionals. In the main we are contacted by either telephone or email and 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.
- Our Regional Family Support Worker, covers rural NSW and the ACT. Regional visits include facilitating group meetings, undertaking family visits, nursing home presentations and meeting with health professionals.

Region	Number of trips		Number of client visits		Number of clients seen		Number of client contacts Phone, email, etc	
	2013/14	2014/15	2013/14	2014/15	2013/14	2014/15	2013/14	2014/15
North West	2	2	15	26	20	36	161	309
North coast	2	2	26	26	52	54	341	399
South coast	2	1	25	13	55	24	164	182
South west	2	2	31	32	51	55	301	274
West	2	2	27	31	46	54	252	248
Mid north coast	2	2	11	18	19	37	126	183
Hunter	Ad hoc		3	3	6	5	92	84
ACT	2	2	0	3	0	9	109	147
Central Coast	Ad hoc		18	19	38	37	351	294
<b>TOTALS</b>	<b>14</b>	<b>13</b>	<b>156</b>	<b>171</b>	<b>287</b>	<b>311</b>	<b>1897</b>	<b>2120</b>

- The Central Coast Support Group and Carer's Group continue to serve the people of that area well. Both groups meet on a monthly basis and are self-managed.
- 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 8 people each month. The Association would like to be able to offer similar groups at other times, particularly to meet the needs of those who cannot attend during the day.



## ***Awareness, 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 \$19,903.40 from the NSW Community Building Partnership to paint the interior of Elsie Court Cottage and to replace the floor coverings. We are most grateful to Victor Dominello, MP, Member for Ryde who continues to support us by recommending that we receive this funding.
- Under the expert leadership of Pauline Keyvar from Fundraising and Mentoring Solutions Pty Ltd (FAMS) our fundraising and associated donations increased dramatically over the past twelve months. Our first Walks 4 Hope in Parramatta and Speer Point were a huge success in both creating awareness and raising funds. We also partnered with Salvation Army Stores who collected donations and promoted Huntington's across their ninety nine stores in Queensland, NSW and the ACT throughout September. We look forward to our continuing relationship with them.
- The Mad Hatters Tea Party at the Intercontinental Hotel proved a fun and creative way to celebrate our 40<sup>th</sup> Anniversary as well as adding to our fundraising tally for the year. Our sincere thanks are extended to the dedicated Committee who worked tirelessly to make it such a success.
- We are truly grateful to Maddison Spence who bicycled over 14,000 km around Australia to raise awareness and funds for Huntington's NSW. His tally was in excess of \$32,000.
- The screening of "The Inheritance" in Sydney and Parramatta and associated media coverage also created awareness of Huntington's disease.

## ***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 Carers Program.
  - The Department of Premier & Cabinet.
  - The Member for Ryde, Mr Victor Dominello, MP
  - Pauline Keyvar, FAMS
  - Neville Barrett, Freddy Choo and the staff of Salvation Army Stores
  - Our donors including those who give through our telemarketing program.
  - 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 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;
  - Sister Maria Cunningham Centre and St Joseph's Hospital, Auburn.

