



Gateway

News from Huntington's New South Wales

Volume 19 No 4

Summer 2016

The Year in Review...

At the Annual General Meeting held in November, the following were elected to the Board -

President: Brian Rumbold

Vice President: Deborah Cockrell

Secretary: Therese Alting

Treasurer: Stephen Guthrie

Members: Richard Bobbitt, Katy Clymo, Felicity O'Neil

Excerpts from the 2015-2016 Annual Report presented at the AGM. The full report can be found on our website www.huntingtonsnsw.org.au. If you would like a printed copy, please contact us.

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

*The Board & Staff of
Huntington's NSW
would like to wish
you and your families
a very happy
Christmas and a peaceful 2017.*



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.

(Continued on page 2)

(Continued from page 1)

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."



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."



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.



(Continued on page 4)

Update from Westmead's HD Research Team

2016 has been a busy year for HD research, worldwide and locally for us at Westmead. Here is a brief summary of some of the highlights of the year.

Firstly, for all who don't know us, we'd like to introduce the team. In the photograph are some of us in the foyer of Westmead Hospital where we held a fundraising/awareness raising event for Walk4Hope and Huntington's NSW.

We are currently collaborating with two treatment trials and one observational study. ARC-HD and Pride-HD started a couple of years ago and are investigating medications to help chorea (movement). We are no longer recruiting to these two studies.

We are pleased with the progress of Enroll-HD - this is an international study and we are one of three Australian study sites (<https://www.enroll-hd.org>). This is not a drug trial. However, it will be used as a platform for future research. Because HD is not common, a worldwide study provides strength in numbers, and around 12,000 people around the world have participated so far. Enroll-HD is a study for all HD family members regardless of gene status. The first visit takes 2-3 hours, and the visits are then once per year. We would like to thank those who have been able to take time to be part of Enroll-HD in Westmead.

Various members of the Westmead team have attended international conferences this year –it is important for us to have an international presence, to keep up to date with the latest news, and to maximise the likelihood that we will be considered a reliable study site for any clinical trials coming up in the future. We would like to thank Huntington's NSW for their support this year.

The international HD community remains active, and there were several conferences in 2016, including the European Huntington's Disease Network conference which was held in The Hague. The last major conference for the year was the annual Huntington Study Group (HSG) meeting which took place in Nashville, Tennessee in early November. HD staff presented two posters which were well-received. We were given updates on current studies and future directions were outlined, some involving promising cutting-edge technologies.



R-L Dr Elizabeth McCusker, Dr Clement Loy, Shanthi Graham, Nickie Vukasin, Rachael Birch and Therese Alting. Other members not in the photo are Dr Florence Chang, Dr Samuel Kim and Jillian McMillan.

In the tradition of other HD conferences, one of the days was specifically designed for HD families, and this was once again a very special time, when families shared their challenges and their victories.

One speaker talked about the importance of the long history of collaboration between HD professionals/researchers and HD family members. Neither group can work alone if we want to find treatments that make a difference for HD families, and this history is one of the happier stories of HD's recent past. Families and professionals working together helped to find the gene, and although there have been no major breakthroughs just yet, there are many studies underway and in the pipeline.

We would like to take the opportunity to wish the Huntington's community a very happy holiday season. We look forward with cautious optimism to the years ahead, and thank you all for your support.

To contact the Westmead Research Team:
Landline 9845-6310 (Any day – leave voicemail if not answered)
Mobile: 0438 604 719 (Best on Mondays and Thursdays)
If you have enquiries about Enroll-HD, you can email therese.alting@health.nsw.gov.au.

Neurologists: Dr Clement Loy, Dr Elizabeth McCusker, Dr Florence Chang, Dr Samuel Kim.
Study Coordinators: Nickie Vukasin, Jilly McMillan, Therese Alting, Shanthi Graham.

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.

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.



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 2017-2018 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.

A Chance Meeting in Barcelona

On a recent trip overseas with friends, my wife, Dianne, and I visited Barcelona; a fantastic city, with many wonderful things to see and do. It was made all the more wonderful by a chance meeting we had with a great guy, Gordon Shields, who has Huntington's Disease.

As luck would have it, that morning before setting out to explore the city I chose to wear a "Walk 4 Hope" tee shirt, as Dianne and I did in most cities we visited on our trip throughout Europe as it was September [Huntington's awareness month] and we had missed the opportunity to take the "Walks" at Parramatta and Speers Point before we left Australia.



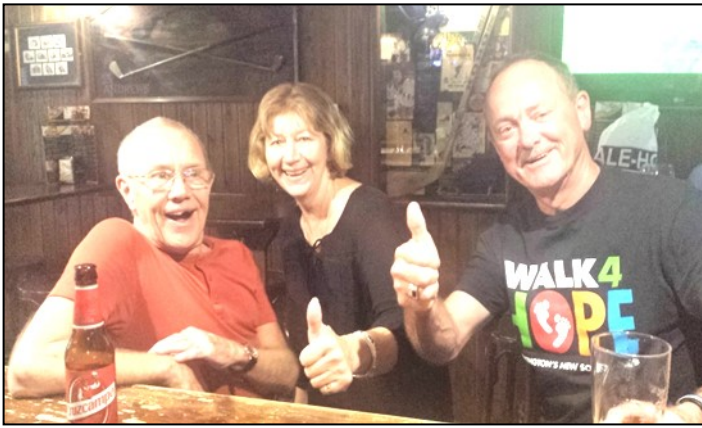
After a long day exploring Barcelona we looked for a place to sit for a while with a refreshing drink, indulging in one of our favourite pastimes, "people watching". We settled on an Irish bar called "Cheers", just off La Rambla boulevard. After a couple of drinks Dianne pointed out a guy standing at the bar who she thought had HD as he was exhibiting what we recognised were classic HD symptoms. Although we desperately wanted to, we were reluctant to talk to him in case he didn't speak English or we were wrong about his having HD and didn't want to embarrass him.

However, our reluctance soon gave way and I decided to try to strike up a conversation, thinking that I'd use the logo on my shirt as an aid if there was a language problem. I said, "G'day mate. How ya goin'?" In a broad Scottish accent he said, "I'm fine. And you?" Relieved he understood me but still not really knowing what to say next, I pointed to the Huntington's logo on my shirt and asked him whether it had any meaning for him. He replied, "Is it that obvious?" That was the beginning of a wonderful couple of hours.

Gordon told us that he is a retired engineer from Glasgow and the sole member of his family with HD. His father had HD. He travels to Barcelona from Scotland six or seven times a year to "get away" from things at home and to get lost in the hustle and bustle of Barcelona. His favourite "watering hole" is the Cheers Bar, which is just down the laneway from where he stays when he goes to Barcelona. The staff at the bar know him well and are very fond of him. None knew that he had HD, although they guessed he had some illness that over time caused a gradual deterioration of his abilities to control his movements and to walk and converse. Gordon told us that he realises the time is fast approaching when he will not be able to get around as he does now, but that he will continue to visit Barcelona as often as he can before the inevitable.



Initial shyness was soon overcome and, as the accompanying photographs show, we all became very comfortable in one another's company—sometimes crying but mostly laughing and joking, and sharing experiences. Gordon was very pleased to hear about the fundraising efforts of Huntington's NSW and its various support groups, and told us of efforts by similar groups in Glasgow. Dianne has added Gordon to her email contact list to keep in touch and to ensure that he receives all the Huntington's bulletins that she sends to others in our support group—especially those relating to recent positive and encouraging research developments and medical trials, about which he seemed not well informed.



We were very disappointed when the time came for us to say goodbye to Gordon. Our four travelling companions all said how impressed they were with Gordon's courage and how privileged they felt to have had the opportunity to sit and chat with him, listening to his story. We exchanged email addresses and invited Gordon to contact us anytime should he ever want anyone to talk to.

A couple of days later I received the following email from Gordon:

"Hi guys, it was lovely to meet you in Barcelona. It was nice to be treated as a person and not as a leper. At the airport I was pulled up by the police who asked if I was dancing. I answered that I had Huntington's Disease. They said o.k. and told me to enjoy my flight. Keep up the good work and fund raising. Bye for now, Gordon."

Because of my family's connection with Huntington's Disease, I know exactly how Gordon must feel on such occasions. People who are ignorant of HD and its symptoms can be very cruel. I hope that our meeting was a positive experience for him and that we were able to lift his spirits.....even if only a little.

I will never forget Gordon or the brief time we had with him. He was an absolute delight and a true gentleman. Our love and best wishes go out to him always.

Mark Faulkner
Central Coast Huntington's Disease Support Group



Huntington's NSW Holiday Break

Our office will close on
Wednesday 21st December 2016
and re-open on
Tuesday 3rd January 2017.

Blackheath Golf Day

The date for the Golf Day has been
changed to
19th February 2017

**Huntington's New South Wales
and
Huntington Disease Service – Westmead Hospital**

*invite you to
come along to our*

CARERS SUPPORT GROUP

for a get together with other carers who, like yourself, are caring for a partner, a family member or a friend with HD. Come along and join us as we share our chatter, laughter, tears and experiences.



2017 Sessions

18 January, Wednesday, 10.30am*

15 February, Wednesday, 10.30am

29 March, Wednesday, 10.30am

26 April, Wednesday, 10.30am*

7th June, Wednesday, 10.30am

5th July, Wednesday, 10.30am

16th August, Wednesday, 10.30am

13th September, Wednesday 10.30am

11th October, Wednesday, 10.30am

1st or 8th Dec(TBC), Fri, Year-end Get-Together

Sessions will be held

at

Huntington's NSW Offices

Elsie Court Cottage

21 Chatham Road

West Ryde NSW 2114

For RSVP and further information, please contact any:

Robyn Kapp, Huntington's NSW- 98749777

Jet Aserios, SW Dept Westmead Hospital – 98456699

Cecelia Lincoln, SW Dept Westmead Hospital – 98456699

***School holidays**



Huntington's New South Wales

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Email: info@huntingtonsnsw.org.au
Web Site: www.huntingtonsnsw.org.au

AHDA (NSW) Inc

The Australian Huntington's Disease Association (NSW) Inc is a not-for-profit organisation established in 1975.

Our Mission

The energies and resources of the Australian Huntington's Disease Association (NSW) Inc 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

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.

Our Services

These include education and information; advocacy; counselling and referral; holiday programs; family support; rural outreach and client services.

Our Board

President: Brian Rumbold
Vice President: Deb Cockrell
Treasurer: Stephen Guthrie
Secretary: Therese Alting
Members: Richard Bobbitt
Katy Clymo
Felicity O'Neil

Association and Other Useful Contacts

Huntington's NSW

Robyn Kapp OAM
Executive Officer

Pauline Keyvar
Fundraising & Marketing

Stewart Swales
Administration Co-ordinator

Amanda Dickey
Programs Officer

Julie Leto
Rural Social Worker
0456 013 612

Huntington Disease Service

Dr Clement Loy
Director
Westmead Hospital
(02) 9845 6793

Dr Sam Kim
Neurologist
Westmead Hospital
(02) 9845 6793

Research Queries
Dr Elizabeth McCusker
(02) 9845 6793

HD Clinic Appointments
Outpatients Department
Westmead Hospital
(02) 9845 6544

Jet Aserios
Social Worker
Westmead Hospital
(02) 9845 6699

Cecelia Lincoln
Social Worker
Westmead Hospital
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Outreach Service
Colleen McKinnon
Westmead Hospital
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Huntington's Unit
St Joseph's Hospital
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Predictive Testing

Fiona Richards
Social Worker
The Children's Hospital
Westmead
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Hunter HD Service

John Conaghan
Social Worker
John Hunter Hospital
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