



Annual Report

2017 – 2018

Huntingtons NSW & ACT 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 OAM

Board Members

The board members of the Association who held a position during the financial year 2017/2018 were:

President:	Brian Rumbold
Vice President:	Deborah Cockrell
Secretary:	Therese Alting
Treasurer:	Stephen Guthrie
Board members:	Richard Bobbitt (<i>resigned 18th November 2017</i>)
	Katy Clymo
	Alison Hill (<i>elected 18th November 2017</i>)

Association Staff

The members of staff employed by the Association during the 2017/2018 financial year were:

Executive Officer:	Robyn Kapp OAM
Administration Officer:	Stewart Swales
Programs Officer	Amanda Dickey
Rural Family Support Worker:	Julie Leto
Youth Liaison Worker:	Amy Hale

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.

Chairman's Report

Our Executive Officer is retiring

I want to begin by confirming that our Executive Officer, Robyn Kapp, will be retiring at the start of the coming year. As you may know, Robyn has been Executive Officer from 1983 to 2006, then from 2011 to the present. Robyn has represented a point of stability for the Association through times of considerable change. Her relationships with many across the HD world and the broader disabilities charities sector has enabled the Association to garner support for the HD community from the Health system itself and from the wider community.

For example, over the years, Robyn has seen the securing of the HD-specific residential care places that are now in the Sister Maria Cunningham Centre at St Joseph's; she has advocated for good genetic counselling services as part of the health system, and for all kinds of support for the HD Service now located at Westmead; she has promoted awareness of HD in the wider community, worked with other Associations around Australia to see more Federal support coming to the HD community, and internationally encouraged the flow of information to our HD community so we can be kept up-to-date with trends and progress in both care and medical research itself.

Robyn's own experience of HD in her family has given her a great understanding of what families must deal with when living with HD. It has also given her the licence to speak frankly when that has been needed—on the one hand preventing those of us without first-hand experience from trivialising the impacts; and on the other hand helping those going through dark times to deal with the seemingly insurmountable challenges. She has spent lots and lots of time on the phone just listening to people as they deal with the specifics—and the generalities—of HD.

Robyn, the HD community across NSW and the ACT will truly miss your experience and wise counsel through your role as Executive Officer. On behalf of the Board, I thank you for your commitment and dedication to the Association and to the HD community over so many years. We wish for you a productive time in the coming years as you find a little more space to devote to some of the other areas of your multifaceted life. And we look forward to your ongoing involvement as a member of the Association!

We are currently recruiting for Robyn's replacement and we will announce the results to members as soon as possible.

Board retirement

I also want to thank our Board member Deb Cockrell for her service on the Board for the last five years. Deb will not be re-standing this year for personal reasons. We will miss her involvement: we have really appreciated her commitment to the Association and her strong contributions to Board deliberations. We want to wish her the very best in her extremely busy life.

Loss of Government Funding

The general climate that the Association operates in remains one of change, and the Association continues to be impacted by those changes. Unfortunately, in June, one of the two small amounts of funding we had been receiving from the NSW Government was withdrawn as a result of a change in Government policy. We had been receiving a small annual grant from the NSW Department of Family & Community Services (FACS) to provide Carer Support. We applied this funding exclusively to HD carers in regional and rural parts of the State because we are well aware that those carers face additional challenges accessing services. We had provided a Carer Support Worker to keep contact with carers and their families, and to help them navigate the

system as they dealt with day-to-day issues. With the withdrawal of that funding, we do not have the resources to support that role.

The Association is not the only organisation to lose funding. We understand the NSW Government has stopped funding many ongoing programs to various disability communities because it believes the Commonwealth Government's NDIS now covers those areas of need.

The loss of this funding has made it extremely difficult for us to support HD families in regional areas, particularly through times of crisis. We are exploring ways to provide better support from a distance, particularly through better use of technology. In the meantime, we continue to provide phone support, and continue to encourage support groups in regional areas by funding meeting venues and finding facilitators.

However, the NSW Government continues to provide us with a small amount of funding to disseminate information into the HD Community. We really appreciate receiving this funding, which enables us to deliver information in a range of ways: via the web site, newsletters, email and Facebook. We are currently rebuilding the web site so it will be easier to navigate and use.

NDIS

As the NDIS has come online, HD clients have experienced difficulties achieving Plans that truly meet their needs. Health sector professionals and HD families are now encouraging the Association to set up an NDIS Support Coordination service so that HD clients can negotiate more effective Plans. We are currently setting up a service, which we will announce and launch in the first half of 2019. To break even, the service will initially have to be focused on the Sydney region. However, our hope is that we can use what we learn from running the service to provide input to service providers in regional areas, improving the quality of Support Coordination not just in Sydney but beyond.

The role of the Association

The Association needs to constantly assess its role in this changing world. It is clear that many families—especially remote from the main centres—still struggle to understand how to access available services and want to know how the Association can help.

As an Association, we need to go back to our members to better understand their circumstances. We need to find more ways to communicate how the Association can help members deal with HD through a time of substantial change in the way governments are funding health and disability services. This will be a major focus for us in the coming year.

Thank you again for your support of the Association. We look forward to the coming year as one where we can make a material difference to the lives of people within the HD community.



Brian Rumbold
Chairman

Executive Officer's Report

Do you sometimes think back to where you were and what you were doing when major events took place somewhere in the world? For me I remember well where I was when President John F Kennedy was assassinated; when man first walked on the moon; when Princess Diana was killed a motor accident. The latter event is still very vivid because we were hosting the International Meeting on Huntington's disease at a major hotel in Sydney with delegates from around the globe in attendance.

This set me thinking as to where I was when significant events regarding Huntington's disease occurred – the announcement in 1983 that a marker gene had been identified and of course the isolation of the gene itself in 1993. I first learned that HD was in my family some fifty years ago when my father was diagnosed. My memories of that time are now rather vague although I do remember the neurologist explaining the genetics of HD clearly and accurately to my sister and me – we were most fortunate as others did not have such a good experience.

Of course, there was no Association or Outreach Service we could turn to for assistance, support and information – only a few lines in a text book. However, by 1975 changes were afoot with the establishment of the NSW HD Association by a small group of families and the beginning of a relationship with Lidcombe Hospital. There was still limited information and of course no funds. But there was enthusiasm, commitment and dedication. From these small beginnings, over the past 43 years, the Association has grown to what it is today.

Of course, our Association didn't achieve everything in isolation but by communicating, sharing resources and ideas and by developing relationships with the associations in the other states and the global HD community, especially Canada, England and the USA, as well as health professionals, doctors and researchers we developed programs and resources that would benefit HD throughout NSW and the ACT.

I'm reminded of the meaning of our logo (which incidentally was developed by the Huntington Society Canada and adopted by most national organisations and the International Huntington Association).

"The logo represents the upper torso of an individual, since Huntington's Disease may affect both mental and physical functions. The smaller image inside reflects the reduced physical and/or mental capabilities of an affected person.

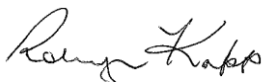
The symbol is shown as the flower of a growing, vibrant plant to recognise the growth and development of the work of Huntington's Disease Associations throughout the world.

It is also a sign of hope – a sign that the work and achievements of the past decades are continuing."

I believe and have every hope that Huntington's NSW ACT will continue to be like that flower – to grow and bloom for the benefit of all our families impacted by HD.

In closing I wish to thank our staff – Amanda, Amy, Pauline and Stewart for their professionalism and dedication to our organisation. They have all performed above and beyond what is expected of them. My thanks also to the Board and in particular our Chairman, Brian Rumbold, for their ongoing commitment and encouragement.

"It is better to light a candle than to curse the darkness"



Robyn Kapp OAM
Executive Officer

Social and Support Programs

Social club

Our Social club welcomed two new members. We continued to enjoy a friendly meal, card and board games, trivia, footy tipping, indoor games like: bowls, quoits, darts, bowling; and creative arts.

This year we visited the Art Gallery of NSW to participate in their 'Art & Dementia' program. While some of the meaning behind contemporary art had us all scratching our heads, we had a great time and the staff were wonderful.



Also, an enthusiastic Music Therapy student has brought pleasant sounds into the cottage for the last three months. Club members are bursting with pride as they re-ignite their musical talents.

Investigations to re-establish an exercise program tailored to our community will continue.

Holiday camp – Zoo, Light house & Commonwealth Games



Camp was a place for the gents to catch-up this year. Two new members took us for a test drive and our local connection returned making for another great week.

As usual our time table was jam packed!

Lake-side walks as a starter, followed by art therapy, coaster craft, loads of games and laughter. Camp Breakaway even revamped their putt-putt course for us; where ball fudging became a trend. To keep us sustained yummy home-styled cooking was served for each meal and then quickly demolished.

A few outings had us exploring within the local area. An absolute treasure was found in the Hunter Valley Zoo. The staff were extremely friendly, exhibits were up close and personal and the grounds pristine! Our highlights were petting a koala, observing the lions, feeding the goats and lamas, and fascinated by those insane mire cats 😊 We also spent a morning walking the historical grounds of the Norah Head lighthouse and down to the rock pools.

A Commonwealth Games themed dinner and trivia night completed the festivities.

A special thanks to Karen & Mark Bevan for volunteering to assist with kitchen activities, social outings and camper support, throughout the week. Campers always enjoy your company and are appreciative of the kindness and fun you bring to each day.

'MyVoice' art club



Members have their own unique experiences within the Art club. Our new member was introduced to their inter-artist and poet while other members immersed themselves in their canvasses, still life drawing, and storytelling.

Thanks to Stephen Dernocoure, our art facilitator, for making another enjoyable year.

Education seminars

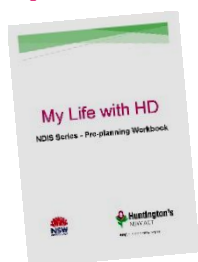
Two 'Living Well with HD' information sessions for people and families of those who were newly diagnosed were facilitated by the HD Outreach Service staff, both hosted at Elsie Court Cottage. Topics of discussion included: research happenings; tips to help manage symptoms, forming good habits; ideas to help plan; exercise; diet; and NDIS updates. Attendees were grateful to have access to this early learning and HD specialists. Sessions continue next year.

Huntington's Disease seminar (for professionals) was facilitated by the HD Outreach Service staff in Westmead. The seminar delivered on its objective to give NDIS practitioners and service providers an insight into the complexities of HD and provided them with strategies for working with HD families within the NDIS. The seminar was attended by 100+ professionals from all regions of NSW. Congratulations to the staff at the HD Outreach Service for hosting such an informative seminar, and for drawing so many practitioners together! I'd also like to commend them on how well they presented 'very specialised information' simply to a very broad audience.

NDIS

This year, many hours have been spent in understanding how we can best serve our HD community within the NDIS landscape. In collaboration with the HD Outreach Service, John Hunter Hospital, NSW Department of Family and Community Services, Multiple Sclerosis (MS) Ltd, MND NSW, Dementia Australia, Cerebral Palsy Alliance (CPA), National Disability Service and National Disability Agency we have been able to achieve the following;

My Life with HD - NDIS Series - Pre-planning Workbook



Produced a workbook specifically for people with HD, who are eligible to be an NDIS participant, designed for recording an individual's information about their own circumstances. Its purpose is to help people to prepare for their NDIS planning meetings. This workbook will continually improve as easier pathways become apparent.

This project was funded through the NSW Department of Family and Community Services.

National Disability Service 'NDIS Essential Briefings'

Staff attended two seminars this year. These forums provide our organisation with industry specific information that then inform our decision making, as well as vital networking opportunities. NDS is also an advocacy arm that is available to us within the NDIS.

New Partnerships

Through the Huntington's Disease seminar (for professionals) we have formed partnerships that have provided further education opportunities to new practitioners. These partnerships, and others we have attained ourselves, will continue to assist our organisation in highlighting the impacts that obstacles have on people with HD and their support networks.

NSW Agency for Clinical Innovation (ACI) - Telehealth

We have been working closely with ACI, the HD Outreach Service and John Hunter Hospital regarding how we can all utilise technologies like Telehealth more effectively when supporting people with HD and their families, especially within rural and remote regions. Findings of these investigations will immerge within the next year.

Volunteers

There are so many people we need to thank this year for putting their hand up to help us out. We cannot do what we do without you by our side.

Regular assistance

Stewart has been a crucial member of our Social club for five years. His friendly nature and wit adds to the backyard BBQ atmosphere we have attempted to deliver for those attending. Stewart will not be joining us next year and we thank him making Social club a place for friends containing loads of fun and banter.

Robyn has been known as our resident cook for social club and camp for a number of years. Her home-styled cooking is the envy of us all and the care that she places into every meal is incredible. She, too, will not be joining us next year. *'Two thumbs up'* from everyone and thank you for your tireless efforts in the kitchen.

Student placement program

Unfortunately, the Sydney Medical School's Master of Genetic Counselling program, at the University of Sydney was rested for 2018. This partnership has been valuable in providing Post Graduate students an opportunity to engage with those with HD.

We would like to thank the University's coordinators for their efforts over the years and for introducing our organisation to some incredible people.

A new partnership with Western Sydney University (WSU), has seen a student of Master of Creative Music Therapy pilot a music therapy program within our Social Club over the last three months. We are now investigating how to include music therapy into our social programming. We will also explore more opportunities with WSU within other school faculties.

ACT Support (*self-managed*)

This group continues to meet bi-monthly, usually for Saturday lunch, and is attended by families from Canberra and surrounding areas. We are most grateful to Karen Van Dooren who has taken on the responsibility of organising the lunches.

Central Coast Support (*self-managed*)

This group has been running since 2010. They are a great support and social network that meet up in different forms. Outside of meetings they continue passing on valuable information and updates via Facebook, email and phone. They are also regular faces at their local Walk 4 Hope.

Coffee chats (Visiting program)

Members have been assisting, others who are more vulnerable within the group, with navigating the NDIS, planners and connecting them to local services and supports.

Carer's Support Group

This group met quarterly to share their 'lived' experience in order to support a new family and those who are now struggling. Coffee and cake were also devoured.

Family Support Group

The group met quarterly and welcomed a new family.

Fundraising and awareness ramped up this year. Their social connections ran a radio promotion for the local Walk 4 Hope; and assisted with editing the Walk 4 Hope promotional video. Their

affiliated social golf club turned on the fun at their fourth Huntington's day. While the family support group held a memorable Wine tour and Shopping tour.

Some members also took the time to join us for trivia at our Holiday Camp and help at the Parramatta Walk 4 Hope.

Thank you for another year of vital support and for proudly waving the flag for Huntington's NSW & ACT.

Central West Support (*self-managed*)

This group is in its infancy. However, with Rachael Brooking at the helm it's likely to go ahead in leaps and bounds over the next twelve months.

Mid North Coast Support

Originally managed by Ability Links, this group is now under the auspices of the Association. We are most fortunate to have Kim Frumar, a retired genetic counsellor, who has a great deal of knowledge regarding HD facilitating the group.

Wollongong Support

Until recently, this group was also managed by Ability Links. However, we are delighted to announce that Kath Walsh, a very experienced group counsellor, has agreed to take on the facilitation of this group.

West Ryde Carers Group

This group has been facilitated by Cecelia Lincoln, Social Worker at the HD Service, Westmead Hospital with some input from our Executive Officer and other staff members of the Association, over the past twelve months. The meetings are hosted by the Association at its premises in West Ryde. The group continues to attract about twelve participants each month and their regular attendance indicates that they are finding the group helpful and supportive.

Newcastle Carers Group

This group, facilitated by John Conaghan, Social Worker, John Hunter Hospital, continues to meet monthly with a steady attendance of between 6 and 9.

Amanda Dickey
Programs Officer

Rural and Regional Support Program

Regional Trips

During the past year three regional trips were undertaken. There were also a number of one-day visits to Wollongong, Port Macquarie and Coffs Harbour to attend the support group meetings held in those areas.

Partnerships

The partnership with Carers NSW continued with one Talk-Link programme conducted. Those who participated found it a very worthwhile experience. The Ability Links partnership to launch support groups in regional areas also continued. Once the support group is well established, Ability Links pulls back. We are pleased that we have been able to continue the two groups in Port Macquarie and Wollongong with the assistance of two well-qualified facilitators.

Funding

The loss of government funding for the Rural and Regional Support Program has had a massive negative impact on the program. However, the Board and Staff of the Association are committed to supporting those families in rural and regional NSW within the constraints of our limited resources.

Robyn Kapp

Representation and Relationships

Our Executive Officer, Robyn Kapp, represents Huntington's NSW & ACT on the Neurodegenerative and Neuromuscular Working Party of the NSW 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. Robyn is also the Support Group Representative on the NSW Brain Banks Donor Committee.

The NSW Agency for Clinical Innovation invited us to be part of a Non-Government Organisation workshop to consult on, and provide input to, two projects: the development of a Consumer Enablement Framework and the NSW Telehealth Framework and Implementation Strategy work plan. We are represented at this roundtable by Amanda Dickey.

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; 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.

Youth Liaison Program

Over the last twelve months, the Huntington's NSW Youth Connection Program has undergone a real shift from research and program design into more active client engagement.



Last year the focus was on learning about the needs of this community in order to design and implement a program that could best meet these needs. This year, the time spent researching and learning has started to pay off as we have been able to put into action all that was learned (and continues to be learned). This is enabling us to start really getting to know some of the kids and young people (YP) in our community and begin work to address their sometimes complex and diverse needs.

This shift from research and planning to implementation has seen the program grow in numbers. We are now actively and consistently engaged with 25 kids/YP ranging in ages from 6-33, all from families where a parent has Huntington's disease (HD).

Of these 25 actively engaged kids/ YP, we also work and liaise with approximately 20 of their parents, carers and/or grandparents. In addition to this there are a further 12 kids/YP that we have met with but are not currently actively involved with due to them being too young or having decided that they are coping well at this time and may or may not re-engage with the program at some stage.

The flexibility of this service delivery model in engaging and building relationships with these young clients and their families has been a really important factor in actually getting out to see these kids/YP and providing the most effective engagements. It was learned quite early on that these families are stretched sometimes to capacity and often engagement with the HD youth worker is all of the support they have space for. This has necessitated a range of support and services needing to be provided by our program. This support has included: Genetic testing support, grief/loss/death counselling, individual counselling, family counselling, grant applications for kids/YP, parent and teaching staff education around HD, referral support to allied health, referral support for medical appointments, reports and written support to schools, government agencies and universities, flight and transport solutions for rural kids/YP and more.

Strengthening of relationships with other organisations.

This year has seen a growth and strengthening of interagency relationships between HDYC and other organisations. As more of these agencies have become aware that our organisation has expanded to provide this service to kids/YP and their families, we have received an increasing number of referrals. The bulk of these interagency referrals have come from the social workers, genetic counsellors and neurologists at Westmead Hospital. We are working more closely together all the time, often sharing clients and structuring support between ourselves in order to meet the family's needs together. It is hoped and expected that these relationships will continue to grow between our agencies and that these good relationships lead to more comprehensive care for those in our HD community.

Another thing that evolved this year is the increase in seeing kids/YP at school and working more closely with these schools in order to provide service delivery there. This has been beneficial for a number of reasons. The most important being that the child/YP gets to access our service without the parent or carer having to add another task to their always busy workload in working and/or caring for their HD affected relative. Another huge benefit that has been experienced through this approach is the building of relationships between our HDYC youth worker and the staff at the child's school.

The school staff have, thus far, been so keen to engage and learn as much as they can about Huntington's in order to best support their students in a holistic way. This has, on occasion,

extended to them offering their support and help to the student's family by way of counselling and referral, whereas prior to our engagement, they did not know what the family was going through.

Another way this has directly benefited the children/YP involved has been through these teachers being newly aware of HD and requesting the Board of Studies give leniency to these kids/YP during exam times. We have liaised with school teachers and the BOC a few times this year to provide written support for this leniency to occur.

Youth support activities

This year a couple of youth support activities for our younger clients were set to go ahead but unfortunately did not eventuate due to the families involved not having the resources to provide transport for their kids to and from these events. When first approached about the possibilities of meeting up with other kids and families affected by HD, all parents were keen for their children to be involved, however, on each of these occasions, most parents were unable to commit.

This is something that will require revisiting perhaps with a little more creativity next year in order for these meetings to occur. I have no doubt that the kids involved would benefit greatly from meeting other kids in similar circumstances.

We have had a lot more success engaging the older clients in such activities. Earlier this year we facilitated a group dinner for 18-25year olds. This went really well. They met, shared time and food and had a chat and a laugh about all of the stresses having a parent with HD can bring. All of those involved expressed later how much they had benefited from experiencing others in a similar situation.

After this meet up, a Facebook group was created to keep them connected to each other. In this group they regularly post questions to each other about HD and on this forum we were able to create our next event. They were asked what they wanted to do and voted to participate in a paintball day. This took place last Saturday. It was a great day. All involved were exhausted by the end and all reported that they had a great time. They spoke of planning another activity and are all keen to stay in touch and be involved.

HDYO 2018 Summer Camp

At the beginning of this year, HDYC was invited to attend the HDYO 2018 Summer Camp. Our youth worker was unexpectedly asked to facilitate and lead a group of campers through the daily discussions and activities. Being part of such a well-run, inspiring event provided an amazing learning opportunity. The topics covered in individual groups included, diagnosis, grief and death, testing, how to tell others about HD status, supporting others with HD, self-care and life planning.

It was a very rich emotional experience being surrounded by these mature, thoughtful, vulnerable young people so willing to tell their stories and learn from each other and such a great learning experience to be around the staff from HDYO with their vast HD experience in teaching and supporting young people from HD affected families. We hope to be as involved again next year.

*Amy Hale
Youth Liaison Worker*

Fundraising Highlights

Darwin to Port Douglas

This year Bob Montgomery cycled from Darwin to Port Douglas in October, nominating funds to be directed to Huntington's NSW ACT and an MND organisation called Iggy Get Out. Bob once again kicked off the bike ride with a golf day in April at Blackheath Golf Club in the Blue Mountains.

Bob recently whispered to me that he is planning a Cycle ride over the mountains in Italy next year, is there no stopping him!!

Hunter Bikers Motor Bike Raffle

Unbelievably the Hunter Bikers continued to sell raffle tickets until May when the Bike Raffle was won by Chris Stacey from Sydney.

We are so very grateful to all the people and businesses involved with the success of the Hunter Bikers Motor Bike Raffle, particularly Michael Curtis, Stephen Meek, Aunty Mal, Kelly Faulkner, Brittani and Matt Taplin who gave up so many weekends selling tickets.

Orange Happenings



Rachael Brooking as always is committed to get the community involved in the HD events, she has organised over the past few years. She has a great deal of success in ensuring the local media are involved with the Walk 4 Hope and RedHead Hunt 4HD as well as the Ladies Golf Day and High Tea at Dundry League Golf Club on Mother's Day. Rachael has also made contact with local politicians to keep them up to date with the situation in relation to rural funding for Huntington's families.

Kirrawee Kangaroos Games Night

Warren and Nicole Lombo did an amazing job of putting together a games night by gathering family and friends at the Kirrawee Kangaroos Club. They gave instructions to their family to each bring 10 friends and they did! There was prizes galore and everything was \$2 to enter, with the support of the Kirrawee Kangaroos Club they raised over \$6300.

HUNT 4 HOPE
Op Shop

The Hunt 4 Hope Op Shop in Maroubra was launched by Matina Moutzouris in September to coincide with September Awareness month. She is now up and running and proposes to donate all the profits from the Op Shop to Huntington's NSW ACT. It's a great initiative and we know her shop will be a great success. Check out her Facebook page

<https://www.facebook.com/hunt4hope/> and please share with your friends, at the moment the website is still under construction.

Year 5 for Walk 4 Hope

There was plenty going on in September for Huntington's:

- Trivia at the Huskisson Hotel
- Walk 4 Hope – Speers Point, Canberra, Parramatta and Orange
- 'Hunt for Red Head' in Orange
- St Joseph's Hospital Stall
- HD Support Group Central Coast Trip to the Hunter Valley
- Settler's Tavern Golf Day



The walks were all well attended although each one was different. We changed our venue in Canberra to Weston Park and returned to Speers Point.

This year you raised over \$124,000 across all four walks.

It was wonderful to see people teaming up with their families and friends to take up the Walk 4 Hope Challenge and asking local businesses to promote the walk, in fact 10 of the 25 teams who took part in the walks raised almost \$45,000!

- Walk 4 Hope Orange – Rachael Brooking and her team of volunteers
- Walk 4 Hope Speers Point – Peta Brennan, Nat Myers, Angela Hiscock and their team of volunteers
- Walk 4 Hope Canberra – Glen Allardyce and the volunteers from EJ EH Holden Club
- Walk 4 Hope Parramatta – Suncorp Volunteers, John Geoghegan and his team from St Joseph's Hospital

Congratulations and thank you to all our fundraisers for your support and generosity.

None of these fundraising events would have been possible without the many volunteers and participants who put their hand up to fundraise and signed up on the day.

It's the little things that become big things and mean so much, such as little Emma aged 8 who cut her hair because her Pop has HD and yes, raised \$1000.

In the Media

ABC Hunter, ABC Central West, Prime TV, Win TV, NOVA Radio network, Blue Mountains Gazette

Thank You

Special mention and thanks to the following people and organisations for rolling up their sleeves to raise funds and increase the awareness for Huntington's disease throughout the year.



Melanie Stevens, Glen Allardyce, Ingrid Boyd, Peta Brennan, Rachael Brooking, Alexandra Crichton, Michael Curtis, Kirsty Dickens, Deb Faulkner, Dianne Faulkner, Kelly Faulkner, Mark Faulkner, Julie George, Alex Gualtieri, Angela and Dennis Hiscock, Hunter Biker's Inc, Glenette Jeffrey-Konig, Jasmin Kohl, Chelsey Kosalka, Warren & Nicole Lombo, Clement Loy, Xiaoyan Lu, Stephen Meek, Bob and Jenny Montgomery, Matina Moutzouris, Nat Myers, Melissa Oake, Emma O'Donoghue, Amy Quirk, Bill Pixton, Christine & David Sharp, Debra Sharp, Jody Sowter, Brittani & Matt Taplin, Garry Wrench, Luke Zammit. If I have missed anyone Mea Culpa!

Blue Eye Dragon, Blue Illusion, Balmain, CFMEU Hunter, EJ EH Holden Club, HD Support Group – Central Coast, Huskisson Hotel, Inner Wheel, Lions Clubs of Parramatta and Elmore Vale, Kirrawee Kangaroos Club, Lake Macquarie Council, Loviz Arts, McCormack Barber, Neverfail Water, NPV Roofing, Orange Audit, Orange Family Physiotherapy, Pfizer Australia, Piggs Peake Winery, Rotary, Orange and Upper Blue Mountains Sunrise, Sally Foundation, Segal Down Under, Settler's Tavern Social Golf Club, Suncorp, Tulloch Winery, The Star.



All in all, it was a busy year and we are so looking forward to once again working with HD families and friends to support new ideas for successful fundraising and awareness throughout 2019.

Pauline Keyvar
Fundraising & Marketing Consultant

Special Acknowledgements

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

- NSW Health
- NSW Family & Community Services
- 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;
 - Cecelia Lincoln, Colleen McKinnon, Terry McGill and the staff of the NSW Huntington Disease Service;
 - Dr Elizabeth McCusker, Therese Alting and the Research Team, Westmead Hospital;
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