



Annual Report

2018 – 2019

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Huntington's NSW & ACT Inc.

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Auditor	Thomas GLC Chartered Accountants PO Box 1563 Hornsby NSW 1635
Australian Business Number	54 571 730 306
Incorporated in NSW, 1993	Registration No. Y16575-09
Endorsed as a deductible gift recipient and income tax exempt charitable entity	
Registered for GST	
Authority to Fundraise in NSW	Number CFN13153
Licence for Conducting Charitable Collections in the ACT	Number 19000322
Public Officer	Lewis Kaplan

Board

The board members of the Association who held a position during the financial year 2018/2019 were:

President	Brian Rumbold	(re-elected 18 November 2018)
Secretary	Dr. Therese Alting	(re-elected 18 November 2018)
Treasurer	Stephen Guthrie	(re-elected 18 November 2018)
Board members	Katy Clymo	(re-elected 18 November 2018)
	Alison Hill	(re-elected 18 November 2018)
	Craig Dalli	(appointed 17 June 2019)
	Stephen Garrard	(appointed 17 June 2019)

Staff

The members of staff employed by the Association during the 2018/2019 financial year were:

Executive Officer	Robyn Kapp OAM	<i>(retired 8 February 2019)</i>
Executive Officer	Lewis Kaplan	<i>(appointed 1 February 2019)</i>
Administration Officer	Stewart Swales	
Community Programs Officer	Amanda Dickey	
Youth Liaison Worker	Amy Hale	
Marketing & Fundraising Consultant	Pauline Keyvar	

All staff are part-time, mostly 0.6 full-time equivalent.

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 New CEO

As we signalled at last year's AGM, this has been the year of transition with our CEO. I want to welcome Lewis Kaplan as he moves in to replace Robyn Kapp. Lewis comes to us with extensive experience leading major charities in NSW, particularly through periods of transition. We look forward to the contribution he will make to ensure the Association continues to serve the HD community in these times of change.

The fact is, we as an Association face major change. To tackle the big issues around getting better in-home support and better residential care for the HD community, we need to engage more fully with the NDIS. And the NDIS demands of us better national coordination. Lewis's wide experience is coming into play as we face up to these changes, deepen our relationships with the other HD Associations around the country, and develop our NDIS-funded services.

During the year we had a number of opportunities to say "thank you" to Robyn for her years of service to the Association. It has been great to see her ongoing involvement and support of the Association since her retirement—a commitment that is truly appreciated by the HD community.

Funding the Association's activities

The Board continues to look for ways to broaden our funding base, particularly since the NSW Government withdrew funding from our regional program. We are developing our NDIS engagement and seeking more corporate and trust grants, while continuing to look for opportunities of funding from the NSW and ACT governments, where they may still exist.

The financial support of the HD community through Walk 4 Hope and other fundraisers has been vital. It has made the difference in being able to maintain and develop the support group network, the youth program and our responses to individual community members needing information and help. We recognise that this financial support often comes with considerable personal sacrifice, and we again thank all of you for the support.

The Association and the HD community

Thank you both to the Board and the Staff for another year of committed service to the Association. We have welcomed two new Board members in June: Craig Dalli and Stephen Garrard. By chance, both work in local government and will bring this valuable experience plus prior knowledge of HD to the Board. We also welcomed Katy Clymo's new baby in March.

Ultimately, of course, our end purpose is the support of, and advocacy for, the HD community in NSW and ACT. We always want and welcome feedback from our Members so that we can understand your needs better and work in the best ways possible for the benefit of the HD community.



Brian Rumbold
Chairman

Executive Officer's Report

It is an honour to be drafting my first report to Members, having been in the role from 1st February 2019. In fact, Robyn Kapp led the Association for more of this year we are reporting on than I did. But as she has now retired, she has graciously encouraged me to write this piece.

My first point is to acknowledge Robyn's leadership of the Association for so many years. A hard act to follow! She has kindly provided me advice on various occasions, but only when asked.

The Association is at a turning point, not just because of Robyn's retirement, but also as we seek new ways to support our community (e.g. NDIS Support Coordination which formally started a day after the reporting period) and new ways for the community to support us. Our recent efforts have been strongly focused on increasing our government funding, partly because it's the right thing for governments to fund services such as ours, partly to reduce the pressure on our community fundraising, which relies so heavily on our members and their families when we know they are often doing it tough.

Having lost government funding last year for our regional support worker, we have re-thought our community programs, with a focus from Amanda Dickey on strengthening regional support groups.

Our youth connection program goes from strength to strength, and our youth worker, Amy Hale is very well regarded by all who meet and work with her.

We undertook a community survey for the first time in a few years, which helped inform us about your needs and expectations of your Association. Thanks to all those who took the time to respond.

There are some things we can only do if we do them collectively, such as federal / national grant applications. National meetings of the state Associations have been re-started with the CEOs of most Associations getting together in May, following a hiatus since early 2017. The Association chairs will meet in July to discuss many things including how to select a representative for the Board of the International Huntington's Association.

I thank the Board Directors for their commitment and support, and especially our Chair, Brian Rumbold for his unfailing good humour and unerring judgement. I'd like to thank the staff for accepting my somewhat eccentric ways. It can be hard to adjust to a new boss, particularly as my management style and Robyn's are a bit different. As all the staff are part-time in a world where organisations operate full-time, the challenge is to keep a very tight discipline on what we do, ensuring we do it as well as possible. As most people in the non-government world will tell you, saying "no" challenges the very values and philosophies we work to.

I'd also like to thank our volunteers, too many to name all, particularly those who lead support groups, help coordinate Walks For Hope and those who have lent a hand to some of the tedious but necessary back office tasks like cleaning up our database.

Looking to the future

- We have finally started Huntington's specific NDIS Support Coordination. This service will be offered by your Association from 1 July 2019.
- The Board and staff are to meet in August to draft a new strategic plan. This should be published before the end of 2019.
- The Board has approved us to run the next national Huntington's conference in late 2020. Watch this space.

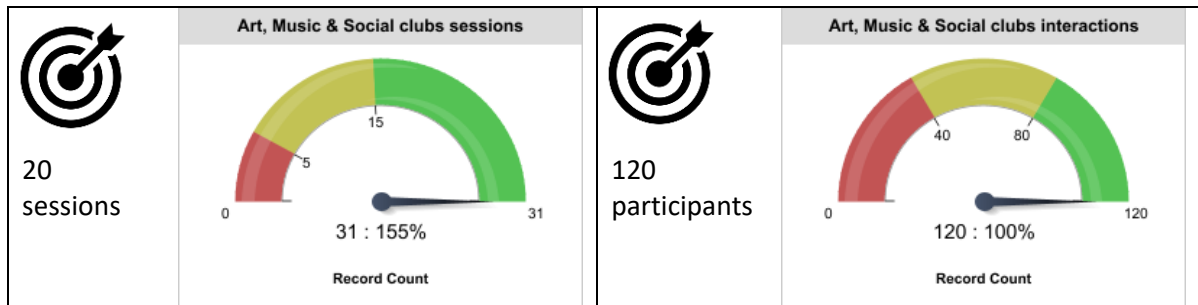


Lewis Kaplan, Executive Officer

SERVICES

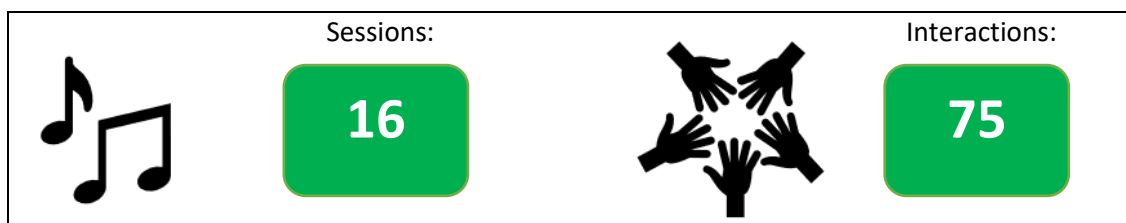
Social activities for people with HD in early to mid stages

NSW Health KPIs and what we achieved



Music & Social club

Music therapy is an evidence-based, non-pharmacological intervention for people with HD (pwHD): Research shows that pwHD are responsive to music stimulation; have a high demand for emotional expression and maintenance of a social relationship; and that music therapy interventions improved the quality of life for pwHD, in the dimensions of physical, mental, emotional and social functioning.



Music therapy ran for the last 6 months of 2018's Social club, facilitated by a music therapy student from Western Sydney University, Xiaoyan Lu. The structured activity was interactive, inclusive and educational, and was aimed at improving a person's quality of life (QoL). Within this active music therapy program an evaluation tool measuring people's motivation, enjoyment, emotions and communication was compiled that could assist with further research into gauging gains in health and QoL benefits.

The club members accepted Xiaoyan's challenge to learn Christmas songs as a group and a few chose to play guitar and ukulele solos. Everyone's hard work was on display at the Christmas concert, and a sense of pride was evident in the smiles that followed roaring applause.



The Social club then changed format in 2019 as our organisation adjusted to a loss in overall program funding, retiring staff and veteran volunteers. The therapy-based model used for the Art club was adopted; session time was reduced, lunch was replaced with a snack, and Music therapy became a permanent activity alongside a few hardcore games of UNO.

A partnership was formed with Harmony Direct Music Therapy and Education (Xiaoyon Lu) to run this new look Music and Social club. The music therapy approach chosen is resources orientated focusing on a person's strengths. Our members work towards therapeutic goals, such as responding verbally in short phrases, improving fine motor gross skills, managing difficult feelings and vocal improvisation.

Members express how much they have enjoyed the inclusion of music into the social club but hope to see lunch and longer sessions reintroduced when funding and staff resourcing allow.

'MyVoice' art club

The philosophy of this art program is phenomenological in nature; promoting the development of self-awareness. The art experience allows a creative response which is unique to the person participating.

Art provides a forum for memory and an opportunity to exercise the hands. Members enjoy the calmness of creativity, as the hand liaises for the brain, finding context in memory and offering periods of self-control. In addition, members enjoy the pleasure of friendship and a renewed sense of well-being.

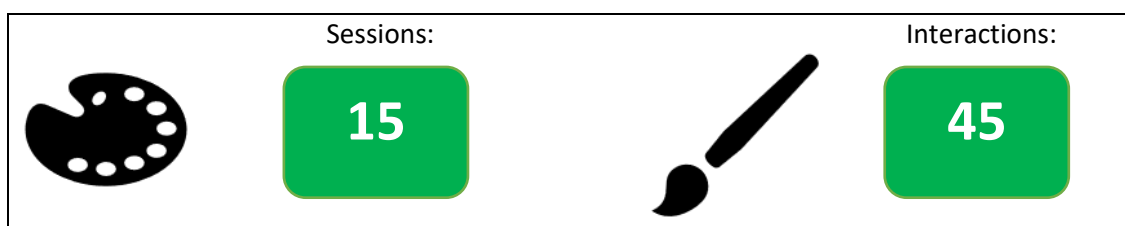
Thanks again to our brilliant art facilitator, Stephen Dernocoure. He encourages members to freely define their own creative communication through the use of visual and poetic art forms, as can be seen here ▶

*Cool grey
Chrome shift
Black & chrome across the desert
May the Freight fly.*

*Peacock Blue
bouncing off sunset wheels
Pink in the sky
Tune stretched
out & along the edges
of the Art space group.*

Mark S (Nov 2018)

Through art people with HD can be given a new voice.

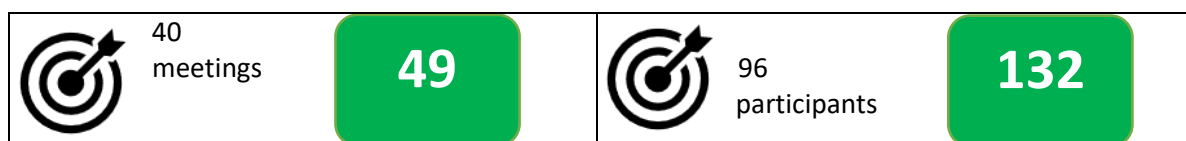


Holiday camp

We didn't offer a camp this year due to funding constraints.

Community Support Group program

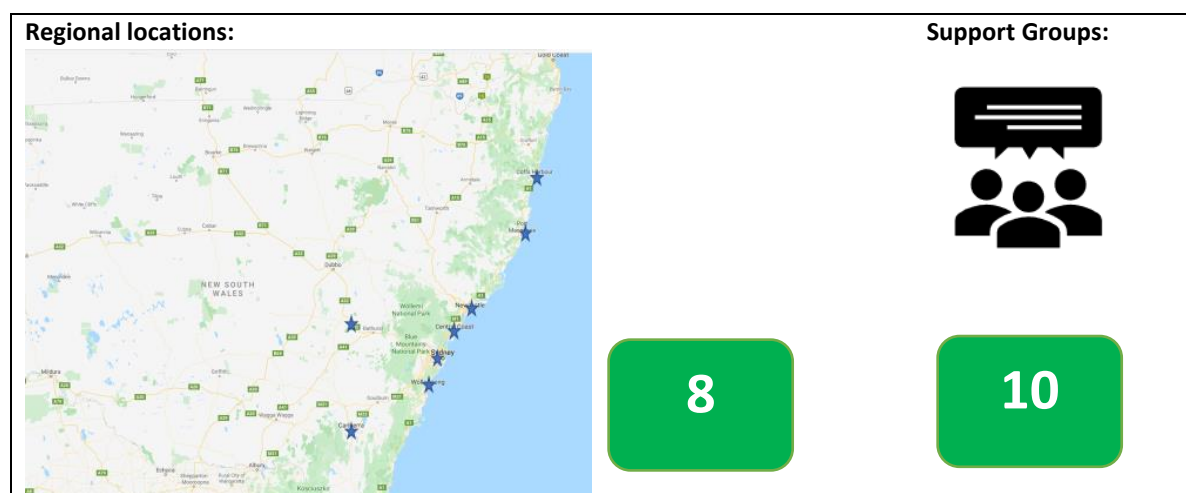
NSW Health KPIs and what we achieved



At the end of 2018 the following changed:

- Port Macquarie said goodbye and thank you to Kim Frumar for her many years of service to their community. Mark Bevan, our retired Regional Family Support worker, kindly taking the reins.
- Wollongong said goodbye to Kath Walsh and wished her well in her new job opportunities.
- Coffs Harbour was handed over to the Association to manage by Ability Links.
- Orange community requested our support to setup a regular support group.

A review was then conducted in January 2019 across the 10 current support groups operating in eight locations: ACT, Central Coast, Coffs Harbour, Newcastle, Orange, Port Macquarie, West Ryde and Wollongong.



It was found that the groups are on a broad spectrum of maturity, purpose and audience. The groups also varied in how they were facilitated, financially supported and measured by this Association.

Location	Established by	Cohort	Frequency	Facilitator	Measure
ACT	Community	Mixed	Bi-monthly	Community leader	N
Central Coast	Community	Mixed	Bi-monthly	Community leader	Y
Central Coast	Community	Carers	Monthly	Community leader	Y
Coffs Harbour	Ability Links	Mixed	Monthly	Professional	N
Newcastle	Hunter Genetics	Carers	Monthly	NSW Health	N
Newcastle	Hunter Genetics	pwHD	Bi-monthly	NSW Health	N
Orange	Community	Mixed	Monthly	Community leader/ Professional	Y
Port Macquarie	Ability Links	Mixed	Monthly	Community leader	N
West Ryde	HD Service	Carers	Monthly	NSW Health	Y
Wollongong	Ability Links	Mixed	Monthly	Professional	Y

Our new strategy looks at how to sustain this program by balancing structure with the unique requirements of each region. Our CEO plans to visit each location to say hello and to listen to the family

stories from HD carers and families, so he can better understand what the HD community need from Huntington's NSW ACT.

So far:

- Meeting venues have been reviewed for suitability and contracted (including insurance) for the year.
- Wollongong and Coffs Harbour are pilot sites for the employment of a professional facilitator through the Association. Sub-contracts have been drawn up. A HD resource library was assembled and mailed to the facilitators. Support group reporting and facilitation debriefs are conducted monthly using technologies such as OneDrive and video conferencing.
- Expressions of interest were sought for support groups wanting professional facilitation.
- Attendance measures recorded in our enterprise database, Salesforce.
- Community concerns and aspirations are recorded.
- Investigations were undertaken with Carers NSW and Dementia Australia to understand best practices in support group programming.
- Investigations are underway with universities to perform annual program evaluations.

What's next:

- Source grant funding to structure and support this program.
- Compile HD-specific Support Group guidelines, training opportunities and client satisfaction measurements.
- Investigate the viability of employing professional facilitators and
- Promote the program.

Education seminars

A 'Living Well with HD' information session for people and families facilitated by the Westmead HD Service was gratefully received by 20 new people. Feedback on the sessions was collated and will be used to plan the topics for the next information session.

A Huntington's Disease seminar (for professionals) was facilitated in August by the HD 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

The business planning and recruitment process for our new Senior NDIS Support Coordinator is complete. Thanks to a grant from the Stronger Communities Program via our local federal Member of Parliament we have been able to purchase an NDIS client and case management system that integrates with our existing database.

Student placement program

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 a three-month period. From this we include music therapy into our social programming. We will continue to explore opportunities with WSU.

Amanda Dickey
Community Programs Officer

Youth Connection Program



What did we set out to do?

The overarching goal for Huntington's NSW ACT Youth Connection Program is to build resilience in and empower children and families in our Huntington's community. This will enhance their psychological and emotional wellbeing and improve their quality of life in their difficult and unique circumstances.

What have we done so far and how have we achieved this?

This year, we have:

- conducted 68 individual child/young person counselling sessions
- had 145 opportunities to educate families, kids and professionals in our community about Huntington's disease
- carried out 62 counselling sessions with parents; educating and enabling them to best understand Huntington's disease and support their children
- conducted 2 group activities for kids affected by Huntington's, and
- facilitated 13 school staff information sessions.

For the 2018/2019 period, Huntington's NSW ACT's Youth Connection Program has met all project goals. In January this year we received a \$50,000 St George Foundation Community Grant, which has assisted us greatly over the last six months. We are working to foster an on-going relationship with St George and have updated them at regular intervals on the program's achievements.

Our youth social worker has been out in the community conducting face-to-face engagements with young people and their families, with visits to homes, schools and in the community. Our collaboration with schools has continued to play an essential part in the success of this project as it allows us to connect with kids and young people in a safe, structured environment away from their homes.

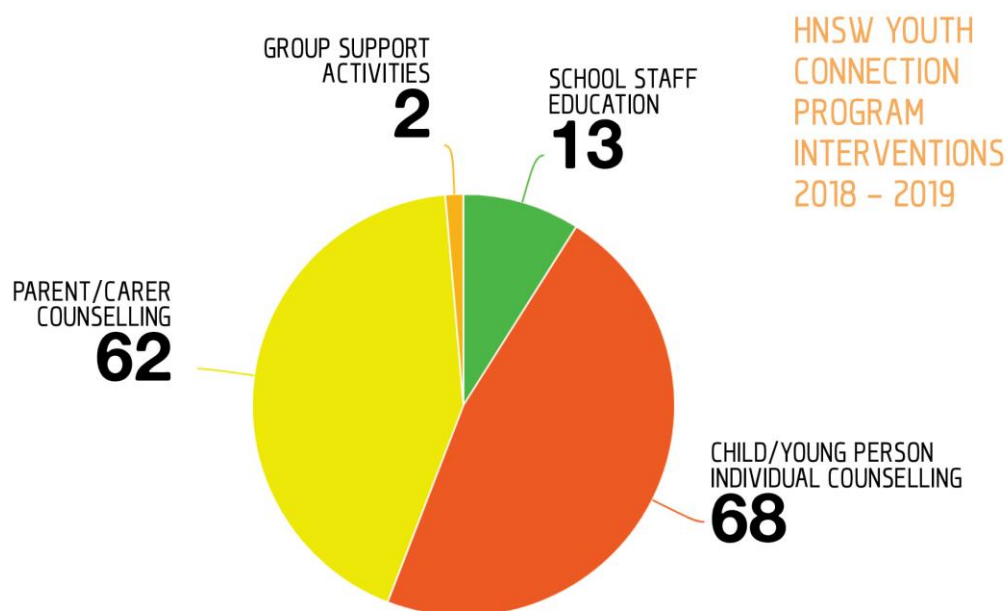
The Program has afforded the space to talk about, draw and express the experiences and challenges of living in a family affected by Huntington's.

Over the course of the year, our youth social worker has been able to build therapeutic relationships with these kids and provide them with some basic psychology and language to increase their understanding of what they are experiencing emotionally. We provide them with a range of up-to-date psychological strategies to help them cope with their difficult situations. [Please see case study on page 16 for a more in-depth look at this type of intervention.]

In addition, they are helped to create emotional and practical 'safety plans' to follow when things escalate at home. We have sent educational material to our rural clients and followed up with phone discussions with parents, counsellors and school staff.

Collaboration with Huntington's Queensland has also provided some great opportunities. Our youth social worker was asked to facilitate a session on speaking to children about HD at the Queensland Huntington's Forum in May. The forum provided a great opportunity to broaden our experience and speak with other youth workers including Cat Martin from HDYO (Huntington's Disease Youth Organisation) about their youth work practice.

We were also asked to assist Huntington's Queensland to run their inaugural 3-day HD youth camp. Our youth social worker facilitated many sessions with young people from all over Australia. Two young people from NSW attended this camp. One opted to fund their own way there, and one was funded by Huntington's NSW ACT. This was a great experience for these young people, for us and for all others involved.



What difference did we make? How do we know this?

We see the difference our project makes every day. We see the improved psychological wellbeing that our interventions provide in these individuals. Kids tell us they have been able to lessen their anxiety around what is happening for them by practicing and using the psychological tools and techniques they have learned in their counselling sessions. We see the huge emotional weight slowly begin to dissipate for parents over the course of our sessions as they begin to work out, with our support, how to discuss Huntington's as a family. We see the 'ah-ha' moments in school staff when they reach new levels of understanding around what is being faced by their students living in a family affected by Huntington's disease; we see school staff start to think about how to make changes in how they work with these kids, bringing new levels of empathy and understanding to their interactions.

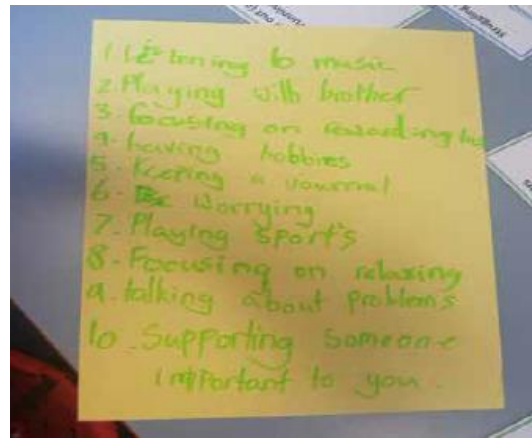
We understand however that the changes that are obvious to us are incredibly difficult to quantify.

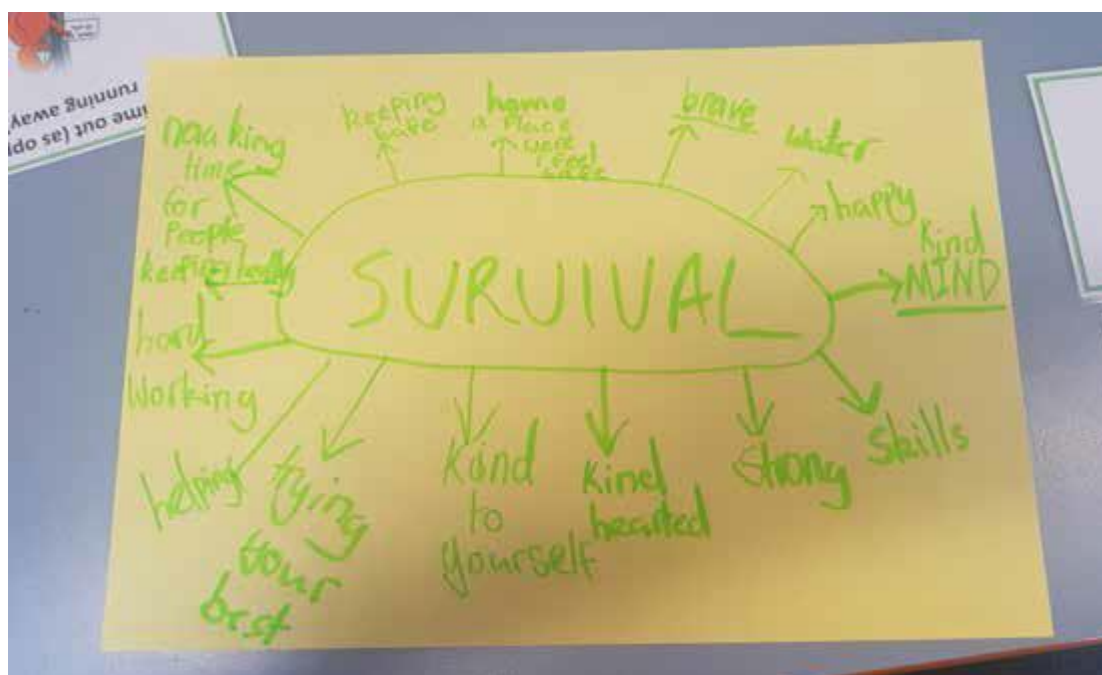
Next year we aim to conduct some research of our own in order to dive further into understanding the nuances of change within our unique community.

What else is next?

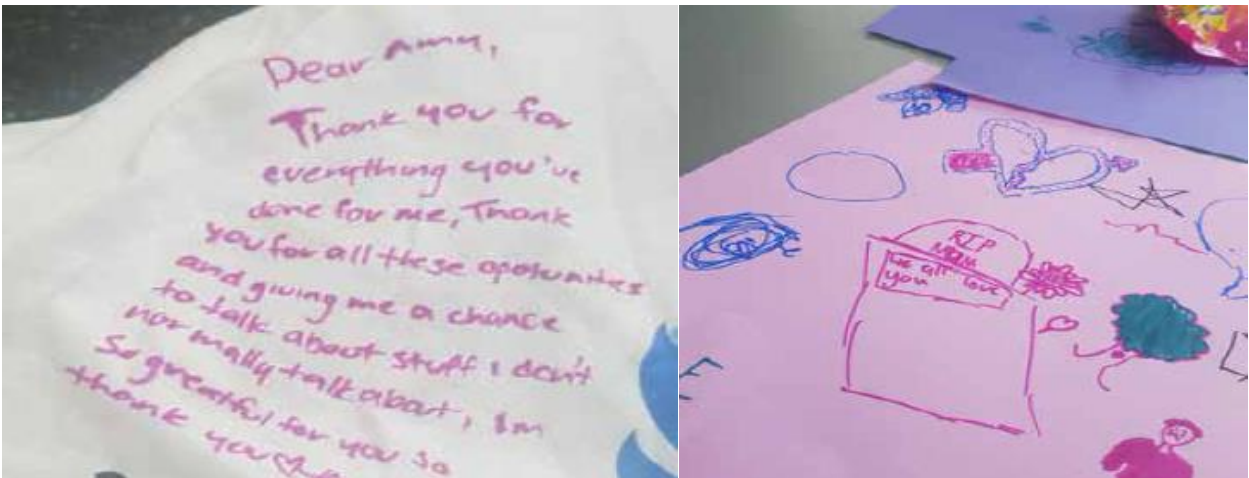
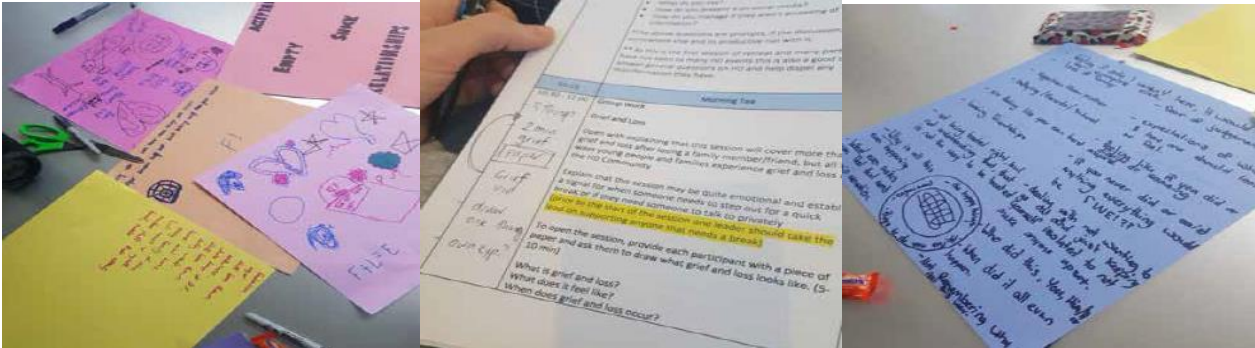
Next year we will:

- continue to provide a professional, high standard of support, counselling and education to Huntington's kids, young people, families and educators;
- continue to learn more about the specific needs of our community through our relationships with Huntington's disease researchers and professionals;
- build the evidence base for our work in order to seek government funding to keep meeting the needs of our community and continue building relationships with our clients into the future.





Gold Coast Kids HD camp
with Huntington's Queensland



Case Study – Daniel, 14yo

Huntington's Youth Connection Program received a referral from the Huntington's care team at Westmead Hospital for Daniel, a 14-year-old boy in a crisis situation.

The referral came about after the social workers at Westmead learned that their client, Daniel's mother, was no longer able to provide care for him and her other two young children due to the progression of her Huntington's disease. This resulted in Daniel and his siblings being predominantly in the care of their father, who was absent from the home for long periods due to work commitments. This often left only Daniel to provide care for the family.

When our youth social worker first met Daniel, he appeared shy, reserved, anxious and not keen to engage. He had been referred to other mental health services but had thus far refused to be involved. During the initial visits it became clear that Daniel was suffering from anxiety, depression and was at high risk of leaving school. He was struggling under the burden of maintaining his school attendance whilst caring for himself, his 2-year-old brother and his 9-year-old sister who lives with a severe disability.

As it became clear that the Huntington's NSW ACT Youth Connection Program was the only service Daniel was actively engaging with, our youth social worker undertook to visit Daniel on a regular basis. During this time a therapeutic relationship was gradually established, consisting of Huntington's specific counselling, support and education.

Each visit lasted longer than the last as Daniel opened up more about his home life, sadness, fear around Huntington's disease, his ambitions and what he felt was holding him back for reaching his potential. It became clear that he was overwhelmed with responsibility for his siblings, had a lot of unexpressed grief around his mother's disease and feared he would not be able to continue his education due to his commitments to his family. He expressed a belief that they deserved a higher level of care than his father was providing, and he felt that, whilst only 14, it was his job to give them that level of care. Daniel was not only anxious and depressed but also engaging regularly in self-harm at the end of each evening as a method to cope with this stress and anxiety.

Over many visits, the relationship between Daniel and our youth social worker grew to a point where Daniel was able to articulate his emotions, both helpful and unhelpful, and create a safety plan around his self-harm which, over the course of a few months, led to him ceasing this behaviour altogether. The youth social worker introduced to Daniel some sustainable self-care methods as alternatives in dealing with stress and a conversation was started between Daniel and his father around his self-harm, adding a protective factor to this behaviour.

It was revealed that Daniel was missing a lot of school activities as his family did not have the money to pay for any of these. He felt left out as he was not able to attend camps and excursions and did not have the correct school uniform. This problem was addressed with the assistance of our youth social worker. He was encouraged and helped to apply for the 2019 Young Carers Bursary Program. The successful application resulted in him being awarded \$3,000 over the course of this year to assist him with his education. This has been a great help for him already as it is allowing him to fully participate in his education. He also plans to purchase a laptop so he can do his homework whilst providing care in the afternoons for his younger siblings.

Over the course of the year Daniel's confidence has grown. He has been recognised by Young Carers Australia as a young carer, which has given him a sense of being acknowledged in the care he provides for his siblings. He is at a point now where he is able to speak more freely about his Mum and her illness. He has found his voice in this and has been assisted and encouraged to speak to his friends at school about Huntington's disease. He has also been encouraged to form deeper relationships with other relatives he trusts to help him with the burdens he carries in providing care for his siblings. This has opened up opportunities for a lot of new support for him in his school and family life.

With support and funding from Huntington's NSW ACT Youth Connection Program, Daniel was able to attend a Huntington's Youth camp in Queensland where he had the opportunity to meet and speak with other kids from families affected by Huntington's disease. Although initially very nervous, he was soon able to participate in all discussions and activities; from the latest HD science, to dealing with the grief and loss Huntington's can bring. He also had the opportunity to form friendships with other young people from families affected by HD. He expressed that he was changed by the experience and felt that the increased knowledge around HD that the camp gave him has decreased his anxiety around having Huntington's in his life.

The flexibility and consistency of the Huntington's Youth Connection Program in engaging with Daniel has been so important, as this therapeutic relationship has taken time to build. This relationship will continue and aims to assist Daniel with the struggles that he will inevitably face as he continues his journey in a family affected by Huntington's disease.

Amy Hale
Social Worker

Youth Connection Program Groupwork



Fundraising Highlights

We have found that we are out of sync in our annual reporting on fundraising, which should cover July – June, so this year’s annual report will have some repetition from last year as we adjust. Apologies.

Darwin to Port Douglas

Bob Montgomery cycled from Darwin to Port Douglas in October 2018, nominating funds to be directed to Huntington’s NSW ACT and motor neuron disease organisation called *Iggy Get Out*. Bob kicked off the marathon bike ride with a golf day in April at Blackheath Golf Club in the Blue Mountains.

Bob is planning his next big bike ride with his 11 year old grandson Tom. Watch this space.

Orange Happenings

Rachael Brooking as always is committed to get the community involved in the many HD events she’s 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 the Red Head Hunt 4HD as well as the Ladies Golf Day and High Tea at the local Duntry League Golf Club on Mother’s Day.

Rachael is also in touch with local politicians to keep them up to date with the situation in relation to rural funding for Huntington’s families.



The Hunt 4 Hope Op Shop in Maroubra was launched by Matina Moutzouris in September. It’s a terrific initiative and we know her shop will be a great success with the intention to donate all the profits to Huntington’s NSW ACT. Check out the Facebook page <https://www.facebook.com/hunt4hope/> and please share with your friends.

Compared to most large charity shops which discard about 75% of the clothes donated to them, Hunt 4 Hope announced their waste percentage is down to 10%!!

Matina said “we do this by REDONATING our good clothes and linen to The Clothing Clean up, have regular \$1 sales for the more fast fashion items, REPAIRING what we can, WASHING what we can, REDESIGNING what we can and REUSING where we can.

Need a Spring Clean? Hunt 4 Hope Shop is keen to receive:

- Quality women’s, men’s or children’s clothing
- Fashion accessories like scarves, hats, jewellery, shoes and handbags
- Homewares, Manchester, kitchenware and bric-a-brac.

Year 5 for Walk 4 Hope

There was plenty going on in September:

- 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. The venue was changed in Canberra to Weston Park and Central Coast / Newcastle returned to Speers Point.

Walk 4 Hope 2018 raised over \$134,213 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! A very big thank you to:

- Walk 4 Hope Orange – Rachael Brooking and her team of volunteers
- Walk 4 Hope Speers Point – Peta Brennan, Nat Myers, Angela & Dennis 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, Parramatta Lions Club, John Geoghegan and his team from St Joseph's Hospital

Whilst fundraising is certainly a key goal of the Walk 4 Hope it is definitely not the only one. In the five years that we have run the walks it is evident that families use the opportunity to come together and want to be involved with Huntington's NSW ACT and the wider Huntington's community. We see new faces but also many of the same families and people come along to support.

Registration fees assist with the infrastructure and back office costs such as public liability insurance necessary to host the walks each year. It is understandable that for some people the fees may be prohibitive, and they feel they can't afford to join the walks. We want everyone to have the opportunity to join in the Walk 4 Hope in whatever way they can.

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.

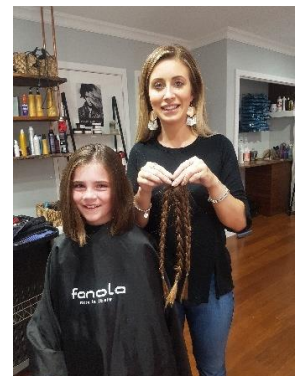
Community Fundraisers

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 Russell has HD and yes, raised **\$1,000.**

Sadly, Russell passed away this year and is greatly missed by his family.

Kirrawee Kangaroos Club. Warren and Nicole Lombo did an amazing job putting together a games night. They gathered family and friends at the Kirrawee Kangaroos Club, giving instructions to each bring 10 friends and they did! There were prizes galore and everything was \$2 to enter.

With the support of the Kirrawee Kangaroos Club they raised over **\$6,300.**



Rock the



Socks Off Huntington's

A fantastic fundraising rock and roll night was held at Forestville RSL in May, organised by Tim Clarkson and friends. It was a great fun night and reunion of their band 'The Wompers' from the 1980s. Tim's good friend Nick, now affected by HD, was a big part of the band when they were rocking along in the 1980s. There were plenty of auctions, raffles, dancing and loud music. **They raised \$16,724.**

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 & Lee Dickens, Deb Faulkner, Dianne Faulkner, Kelly Faulkner, Mark Faulkner, Julie George, Alex Gualtieri, Angela and Dennis Hiscock, 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 & Sallee 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, Tim Clarkson, EJ EH Holden Club, HD Support Group – Central Coast, HLB Mann Judd, Hunter Biker's Inc., Huskisson Hotel, Inner Wheel, Lions Clubs of Parramatta and Elmore Vale, Kirrawee Kangaroos Club, Lake Macquarie Council, Loviz Arts, Macquarie Bank Foundation, 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, Sega Down Under, Settler's Tavern Social Golf Club, Suncorp, Toyota Financial Services, 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 through 2019 - 2020.

Pauline Keyvar
Fundraising & Marketing Consultant

Regional Support / NSW Health / ACT Health Directorate

We have actively lobbied the NSW and ACT governments to fund for HD-specific regional social worker positions in all local health districts. We won't know the outcome of our advocacy until next year's state budget in May or June 2020.

We are keen for members and supporters to get behind our lobbying activities as MPs often respond better to us if this is complemented by local approaches, particularly if they are made by lots of people.

Representation and Relationships

Our EO, Lewis Kaplan, represents Huntington's NSW ACT and the other Huntington's state associations on the Neurological Alliance Australia. The Alliance provides an opportunity for a number of national groups working to support people with neurological diseases to find common cause and lobby together. This year a pre-election commitments paper was published and a joint submission to the Aged Care Royal Commission was being prepared (submitted in August 2019).

Lewis also represents the state associations on the Genetic Alliance Australia group which meets quarterly in Sydney. Most of its members are organisations even smaller than Huntington's! Lewis has asked the group to focus on the issue of excessive waiting times for genetic testing.

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

Following a hiatus since early 2017, a national meeting of CEOs of state Huntington's associations was held in Brisbane in May 2019 and two more meetings are planned for the second half of 2019.

The Association is currently a member of

- Carers NSW
- NSW Council of Social Service (NCOSS)
- National Disability Service (NDS)

Administration

There have been a number of changes and highlights during the year. Notably, Robyn's retirement in early 2019 saw me take on additional responsibilities with payroll and accounts management using our online Quickbooks application.

During the latter part of 2018 we applied for a grant through the local federal member, John Alexander, MP, under the Stronger Communities program. It was for small capital projects and required the organisation to fund 50% of the project. Our submission was successful, and we received a \$15,000 grant, which we had to match. The grant went toward an upgrade our IT systems in preparation for us to commence support co-ordination and case management through the NDIS.

Soon after I first commenced in the Administration Co-ordinator role back in 2014 we updated our office printers to the Ricoh brand with Camnet as our service provider. Since 2014, I have regularly been contacted by printing companies wanting our business. It only became feasible in 2018 for a competitor

to provide a deal that would be worthwhile to all parties. So, in August 2018 we successfully moved to Upstream Solutions for our printing requirements. It meant a sizeable reduction in our printing costs and new Fuji Xerox machines.

The other major administrative change came in January 2019. Our original air conditioner decided to stop in the middle of one of our Sydney heatwaves. Due diligence required a check on whether it was worth repairing. The obvious answer was that it was well past its use by date. Quotes were sought and a good local company, Delmar Air Conditioning in Gladesville was engaged to replace the ageing unit. Additional vents were installed to improve the air flow and the new machine will provide further cost savings through its more modern efficiency.

Stewart Swales
Administration Coordinator

Financial report

The financial situation for 2019 was a tough one for the Association, in comparison to both the prior financial year and against our budget for 2019.

From a revenue perspective, we suffered from both the loss of the NSW FACS grant (which we reported last year) plus the lack of an alternative fundraising source following the very successful Doctors Orchestra fundraising in 2018. As a result, our combined income fell by \$187,500 year on year.

Against a known and expected reduction in income, the Board reigned in expenditure wherever possible, reducing total expenditure for the Association by \$83,000 in comparison to the prior year.

However, this still left the Association with an overall operating deficit of \$101,555. This is not sustainable, and the Board is working closely with the CEO and fundraising team to rectify the situation, both by increasing income and managing expenditure.

Our commitment to develop an NDIS support coordination service is not expected to break even for 12-14 months, i.e. well into 2020-2021 financial year, however we see this investment as crucial in servicing our members and the wider HD community. In the 2019 year our net expenditure on NDIS support was over \$33,000 and we are pleased that since July 2019 we have started to see income flows from this service. We believe this project is well worth the investment of the Association's funds in the medium term.

Fundraising from Walk 4 Hope continues to be the most important source of income for the association, however we were successful in winning a \$50,000 grant from St George Foundation for our youth connection program and a \$15,800 grant from the Commonwealth Government's Stronger Communities Program to assist with an upgrade to our computer system.

Stephen Guthrie
Hon. Treasurer

Special acknowledgements

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

- Western Sydney Local Health District, NSW Health
- Our donors including those who give through our telemarketing program which we are gradually closing down from July 2019, hoping that telemarketing supporters will continue their generous donations.
- Organisations and health professionals who have worked alongside the Association, especially:
 - Prof Clement Loy, Director, NSW HD Service, Westmead Hospital
 - Cecelia Lincoln, Terry McGill, Felicity Stehouwer and the staff of the NSW Huntington Disease Service at Westmead Hospital
 - Dr Elizabeth McCusker, Dr Therese Alting and the Research Team at Westmead Hospital
 - John Conaghan, Social Worker, John Hunter Hospital
 - John Geoghegan and the staff of the Sister Maria Cunningham Centre at St Joseph's Hospital, Auburn.