



Gateway

News from Huntington's New South Wales

Volume 20 No 1

Autumn 2017

HUNTINGTON'S NSW YOUTH CONNECTION PROGRAM

Are you aged between 7-25?
Does your mum, dad, brother, sister, yourself or
someone you know have Huntington's?

OR

Are you a parent, carer, family member or friend of a young person impacted by Huntington's?

If so, Huntington's Youth Connection can help. We offer:

Information/Advice/Support to children and young people

We offer one to one support and counselling to help you manage living in a family with HD/being at risk of carrying the gene.

This support can be offered by face-to-face home or school visits, phone calls, via email and on Facebook.

We can help you access reliable age appropriate information and answer any questions, worries or concerns you have about HD or about life in general.

We will also be running youth groups and fun holiday activities for children and young people in NSW impacted by Huntington's Disease. If you would like to be included on a mailing list for info on these groups and holiday activities email us at amy@huntingtonsnsw.org.au

Information/Advice/Support to parents

We can support you in telling your child about HD.

We can provide accurate, age appropriate information for you to share with your child/young person.

We can support you as a parent as HD progresses.

We help encourage open, accurate and honest communication in families.

If you would like to get involved or know more about our new youth program, contact our youth liaison worker, Amy Hale:

Mobile 0499031231
Office +61 2 9874 9777
Email amy@huntingtonsnsw.org.au
Facebook www.facebook.com/amyhdyouthconnection

Meet Amy on page 7



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Southern Sydney & Illawarra Outreach Club

You and your family are invited to attend the next Outreach Club run by the team at the Huntington Outreach Club, Westmead Hospital to be held on

Wednesday 26th April 2017 at
Club on East, 7 East Parade, Sutherland
11am to 2pm

A range of meals will be available from \$10.
We look forward to seeing you there!

The team at the Huntington Outreach Service

*Please **RSVP** to Terry on (02) 9845 9953.



Central Coast Support Group

This very energetic and enthusiastic group meets quarterly at Niagara Park Stadium, Washington Ave Niagara Park on

Wednesday evenings at 7.30pm.

Dates for the rest of 2017 are

17th May
16th August
15th November

They also enjoy social functions and organise fundraising events

For further information contact
Dianne Faulkner at

huntingtons.centralcoastnsw@gmail.com

West Ryde Carers' Support Group

You're invited 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.

Meetings are held on **Wednesdays at 10.30am** at the Huntington's NSW office,
21 Chatham Rd West Ryde

26 April
7th June
5th July
16th August
13th September
11th October

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

To RSVP and for further information, please contact
Huntington's NSW - 98749777 or
Jet Aserios or Cecelia Lincoln, Westmead Hospital –
98456699



MID COAST
COMMUNITIES
Where everyone belongs!

Port Macquarie Support Group

Ability Links and Huntington's NSW are working together to establish an on-going support group in the Port Macquarie region.

We held the first meeting in March and there was an overwhelming response to have an on-going support group. We are therefore holding another one to talk about making this happen.

Anyone connected with Huntington's is welcome – people with Huntington's, gene positive, gene negative, health professionals, carers, family and friends.....**anyone!**

When: Thursday 11th May 2017 - 11.00am

Where: Rydges Hotel, Hay St, Port Macquarie

For more information contact: Ross Henderson, Ability Links Phone: 6516 1920
Email: rosshenderson@midcc.org.au

Bob Montgomery's 3rd epic ride, raising funds for



Bob Montgomery began his cycling career at the age of 15 years when he used to cycle to work in Rosebery from his home in Bexley, a distance of approximately 20kms. He continued with his cycling by joining Enfield-Burwood Cycling Club and going on to win a State Premiership (Junior Division) and eventually becoming a senior A grade cyclist. He has been bike riding ever since, competing in a couple of Goulburn to Sydney races, Grafton to Inverell (one of the toughest rides in Australia) and a few 'Sydney to the Gong' for Multiple Sclerosis.

In December 2013 he embarked on a solo charity bike ride from the Three Sisters in Katoomba to Port Douglas in Far North Queensland, a distance of 3,168kms, arriving in Port Douglas in time to celebrate his 70th birthday on 5 January 2014. Bob took 26 days to complete this ride and raised \$30,000 for Motor Neurone Disease.



Training around the streets of Wentworth Falls

In September 2016 Bob undertook another long distance bike ride for MND from Perth to Sydney, a distance of over 4,000kms. This ride took him across the Nullabor Plains, up through Broken Hill and home to Leura in the Blue Mountains – it took 4 weeks and 4 days and he raised about \$46,000.



Planning meeting at MND Gladesville left-right: Pauline Keyvar (HNSW), Graham Opie (MNDNSW), Robyn Kapp (HNSW), Michael Small (Rotary), Jenny and Bob Montgomery. Bill Pixton is taking the photo.

Commencing on 14th May 2017, Bob, at the age of 72, is undertaking his third solo charity bike ride, from Darwin to Perth. This time he is raising funds for both Huntington's NSW and MND NSW. All proceeds raised will be distributed equally between the two organisations.

We are so grateful to Bob, his wife, Jenny, and the entire support team for taking on this mammoth task to raise much needed funds for HNSW and MND NSW.

To find out more about Bob and his ride from Darwin to Perth, visit his website www.bobmontgomery.com.au or to make a donation <https://darwin2perth.everydayhero.com.au/darwin2perth>



Australia and New Zealand Youth Camp January 2017



Summary of Project:

HDYO has facilitated both European-wide and North American camps as well as supporting country specific camps since its launch in 2012. HDYO knows the deep impact that a few days of education, support, connections and hope can provide to young people from HD families who are often so isolated.

At the beginning of 2016 we discussed as a team the idea of bringing camp to Australia and New Zealand as we felt there was a need and demand. Our main hurdle, aside from funding, was capacity. With two staff HDYO was already at full capacity. In March of 2016 HDYO approached Huntington's WA with the idea of asking their HD Youth Worker, Monica, if she could organize the camp on our behalf, with the support of HDYO. Once this was agreed we were able to secure funding from Teva and later the Griffin Foundation to fund the project, as well as speak with all HDAs in Aus and NZ to gather support for the event.

The purpose of camp was to provide attendees with a break from home life and its stressors, an opportunity to learn more about HD, make connections with professionals and peers, and have some fun. The camp was planned by the HDYO team and assisted by a team of professional staff and youth volunteers. The Huntington's Western Australian Youth worker (Monica Cazzolli), founder and project coordinator (Matt Ellison) and North American

Youth worker (Chandler Swope) spearheaded the planning of the location, documents and curriculum. Volunteers and staff members from various HD associations nationally and internationally made up the strong team that supported young people through the activities and sessions.

Application Process:

An application was created on Google Forms so it was easily accessible by all working on the project. If families had any concerns about sharing their data in such a format or experienced any technological issues, a paper copy would be made available. The application gathered basic demographic information, a overview of the family situation, what the camper/family hoped to gain from attending and topics they were interested in learning more about particularly. Using social media and enlisting the help of HD associations and organizations, emails were sent to professionals, families and individuals. It was posted in HD support groups and pages online to maximize its reach. Initially, funding for camp was for 25 participants, but the overwhelming response indicated that there was a greater need and wants for youth services, and efforts were made to secure more funding in order to increase the camp's size and accept as many campers as we could. In total 51 young people applied for camp by the end of the application deadline, and all participants who fitted the criteria were invited to

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attend, many of whom didn't have any support or connections in the HD community prior to camp.

As the application deadline approached, the youth worker reached out to all applicants to ensure they were still interested and able to attend. Through this process and young people realizing other conflicts and some last minute illnesses, a total of 42 campers and a group of 55 including volunteers and staff attended the four-day event.

Summary of Camp:

Day one began with campers and volunteers arriving at the Brisbane Airport throughout the morning and early afternoon of the 13th January. Campers were met at gates by camp staff. The complete group arrived by early afternoon and was situated at our designated meeting space getting to know each other before our coach arrived at 1pm to take the group on a 45min drive to Currumbundi. The first day consisted of getting settled in the camp, playing some get to know you games and ice breakers and catching up on much needed rest after travelling, some hearty meals, and the young people being assigned their groups for the duration of camp as well as their cabin groups and safety procedures. The first evening set the tone for the rest of camp, with young people pulling their tables together and the groups sitting outside quietly talking or playing cards before bed.

Day two started with breaking into their small groups, the young people competed in some teambuilding activities before going into the more emotional content of the day's sessions, covering grief and loss, care giving and testing. The day's sessions had both professional and peer perspectives and in small groups the staff and volunteers checked in as to how everyone was travelling. These sessions were broken up by activities and free time to give space for campers to relax away from the content and to process their emotions. The entire group split into two, with one half testing their courage on the giant swing and the other working as a team rock-climbing to negotiate the course. The other group would have a turn on the alternate activity the following day. After dinner a tie dying activity as a whole group provided some light hearted fun and bonding, and left campers with a souvenir of their time at camp.

Day three sessions consisted of coping, families and partners. The day was a little less emotional than the previous day and campers were really beginning to be comfortable with each other after



the prior day's sharing. An HD advocate and Olympian, Sarah, joined small groups and shared her story in a setting that allowed for open interaction and candid questions. Simon Turnbull shared his inspirational experiences with training, running and trekking through incredible terrain to the entire group. The group again split in two and the groups had a turn at the alternate activity. The other activity of the day was a group relax and swim in the pool, with optional pool games. Due to the very hot temperatures and extremely high humidity this was a much needed chance for everyone to cool down and unwind! Filming took place over this day for the HDYO camp video. After dinner everyone gathered in their HDYO shirts on the oval to take a group picture with a drone brought by our filmographer. After this was the awards ceremony and party, with a chance to thank all campers and volunteers for their bravery and openness in taking a chance on camp and the unknown. Awards were presented based on personality and strengths demonstrated at camp. The night wound up with lots of dancing and sing alongs until bedtime. A final debrief for volunteers and staff took place that evening with everyone sharing feedback and any potential follow up with young people.

On the morning of our fourth and final day emotions were high as no one was quite ready for camp to be over. Everyone was packed and cabins cleaned by 8am before heading to breakfast and our small group meetings. The morning was dedicated to Science and Research, with a talk by Professor Julie Stout that was met enthusiastically by young people, followed by a question and answer. After that a jelly brain activity allowed everyone to channel a little of their inner scientist in a fun and final activity demonstrating the idea of gene silencing and reinforcing the science learnt in their small groups. A packed lunch was taken on the bus and goodbyes were shared as young people, staff

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and volunteers were dropped at the domestic and international airports!

Statistical feedback:

- 65% of campers thought camp was 'excellent', the highest score; the other 35% thought it was 'good' the second highest option; nobody scored less than good.
- 45% of all our educational and support sessions were rated excellent, 38% were rated good, only 2% were rated poor or very poor.
- 60% said they felt better able to cope after camp, with only 5% saying they didn't feel better able to cope (the rest were unsure).
- Only 4% said they didn't feel they had more support than before camp.
- And finally, only 1 camper from 42 said they would not attend again, although they did say they would fully recommend camp for any other young people.

Feedback from Campers on Camp:

"I loved the experience! Being able to connect with peers so deeply on things I have never felt understood about was such a surreal experience. I felt like I have made some friendships that will continue to grow deeper provide future support for me and from me. Thank you for being so willing to talk and provide information and a listening ear. It was been encouraging and hope building, and I feel like maybe all is not lost and something good might happen in research. I have never felt so understood in all my complexities in my entire life! Thank you from the bottom of my heart, it really makes me feel less isolated. The way you have cared for us all has been incredible."

"the camp for me was fantastic. The staff and volunteers were amazing and the small group sessions were awesome!"

"Highlights in no particular order

The caving, food, beach, some free time, card games, meet and greet, sharing an hearing stories, testing info talk, Simon's talk, coping techniques, rock-climbing, cricket, sleeping, etc"

"A lot of what was said I already knew so it was hard to focus doing seminars but the small group sessions really helped me to connect and develop a deeper understanding of situations Huntington's brings and it's not all negative circumstances."

"This has been the most amazing experience and I'm so glad I applied to attend. I have gained so much from this opportunity and really hope it will be run again. Thank you:)"

"It has been amazing to get to know people in the same boat as me and also at a similar age. Camp has been an amazing way to hear about people's experiences with HD and to learn more info about it"

"Considering I have never met anyone else (beside family) with HD. To know that there are people (especially youth) who are in similar situations is empowering and relieving. Oh and it's also a great respite for carers!"

"I felt like I am normal, which I missed out on as a kid. So it was great to feel like we all connected."

"I found camp a great experience as I got to chat to those in a similar situation and found I was stronger than I gave myself credit for."

"Considering it was the first camp run in Australia it was excelling! Not only did it bring me together with other people from the Huntington's community but I was introduced to so much new information and local organizations. As well as being able to discuss issues involved with HD was such a release and comforting experience. The camp was so much more than I ever imagined! Thank you."

You can view the camp highlights video: https://www.youtube.com/watch?v=w7R_s83DiTo

Thank you to Teva, the Griffin Foundation and all Australian and NZ HD Associations for your support with this project! We hope you can see the impact of camp on young people's lives within this report.

Meet our new Youth Worker Amy Hale

"Hi everyone! I'm so excited to be on board with Huntington's NSW as the new Youth Liaison Worker developing and facilitating the new program, HDYC (Huntington's Disease Youth Connection, NSW).

As a social worker, I am constantly inspired by working with teenagers and young people – they are full of potential, inspiration, humour, complexity, creativity and more. I can't wait to meet some of the amazing young people in our HD community and help them to become more resilient as they learn to cope with the usual stresses of life combined with the often extraordinary challenges of having a life impacted by HD.

As well as this background in social work, I have worked in the creative arts and film industries editing documentaries, mental health video campaigns and short films as well as designing newspapers and publications. I love music and art, books, sport and culture and will hopefully get the chance to combine some of these interests in this new role.

As this program is flexible and youth focussed, our main goal is to listen to, connect and support young people and their families in whatever way most benefits them, helping them find coping strategies and solutions to all HD and non-HD related issues or problems that arise in their lives. We can provide this support, counselling and advocacy through face to face home or school visits, phone calls, via email and on social media and will also be organising group events to enable young people to connect with other young people impacted by HD for support, fun and education.

If you would like to connect, offer a suggestion for the program or simply know more about what we have to offer, please contact me, I look forward to meeting you soon."

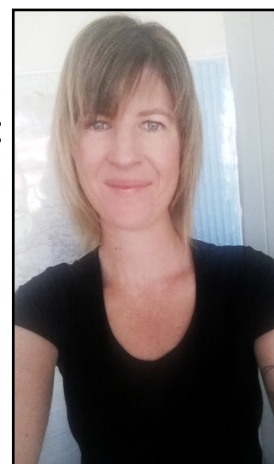
Amy is contactable via mobile, email or Facebook Messenger, or by calling the office...

Mobile 0499 031 231

Office: (02) 9874 9777

Facebook www.facebook.com/amyhdyouthconnection

Email amy@huntingtonsnsw.org.au



Rural Social Work Service

Unfortunately our Rural Social Worker, Julie Leto, suffered an injury just prior to Christmas and is unable to drive long distances. Consequently she has not been able to undertake any rural visits so far this year.

However, Julie is still contactable by phone and email so please do not hesitate to get in touch with her on 0456 013 612 or at julie@huntingtonsnsw.org.au

In the mean time Julie will also endeavour to connect with as many of our families in rural and regional NSW and the ACT as possible by phone.

We do hope it won't be too long before Julie is on the road again!

Do you have a story to share?

If you have a story that you would like to share in "Gateway" please contact Robyn at robyn.kapp@huntingtonsnsw.org.au

Having a Family, the HD Way

For people at risk of Huntington's disease, having a baby who might inherit HD can make decisions around planning a family extremely difficult. This article explains the options available, and how modern reproductive science can make a difference right now to families touched by HD.

Introduction

Many people with Huntington's disease, or at risk of it, would like to know if there are ways to have children without passing the disease on to the next generation.

The short answer is yes!

'Assisted fertility' techniques are one area where scientific progress can make a real difference right now to the future of HD families. Several choices are available to people who are either at risk of Huntington's disease, or have had a positive gene test.

We hope this article will bring you up to speed on these options, but it's important to bear in mind that not all techniques are available everywhere, and in some countries, they can involve major expense. So if you're thinking about any of them, we recommend you contact a specialist genetic counsellor for individual advice. The earlier you do, the more options you'll have.

The old-fashioned way

Deciding whether or not to have children who might be at risk of inheriting Huntington's disease is a dilemma that still faces prospective parents. Doing things the 'old-fashioned way' remains an option, and is of course free of charge and fun!

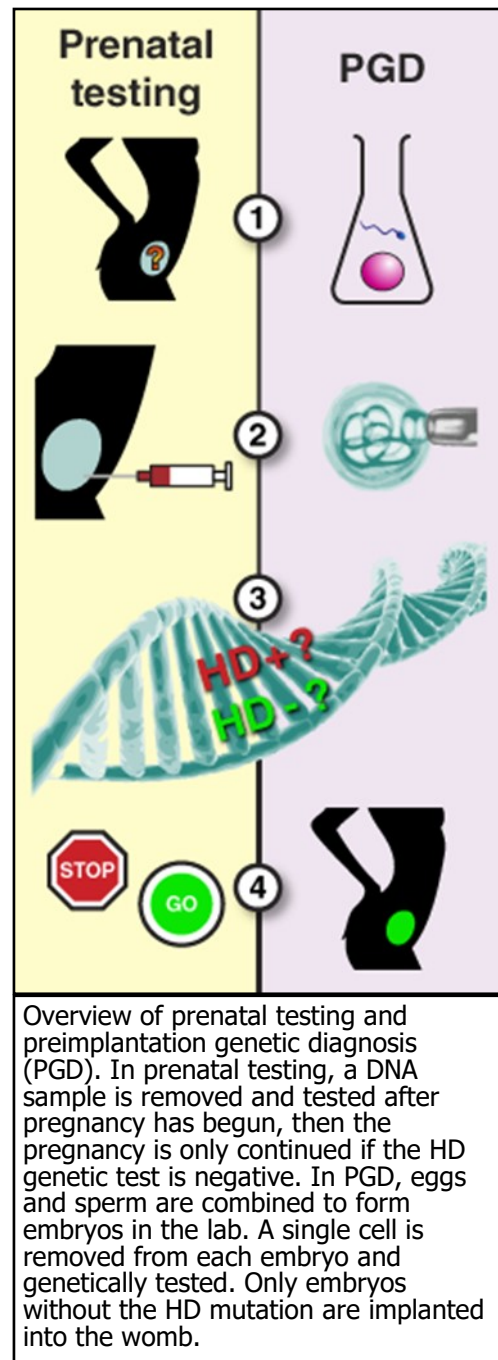
As every HDBuzz article confirms, scientists are making real progress towards finding treatments for Huntington's disease. We believe a time will come when at-risk children are born into a world where HD is a treatable condition. However, there are no guarantees, and it's impossible to predict when disease-slowing treatments may become available.

Some people feel that they don't want to take any chances and would like to avoid the risk of passing on HD at all. That's where 'assisted fertility' techniques come in.

Testing during pregnancy

It's possible to perform a genetic test during pregnancy to see whether the developing baby carries the gene that causes HD. This is called prenatal testing.

Deciding whether to test an unborn baby is a difficult decision. It is important to understand that prenatal testing in HD can only be



performed when a couple feel sure they would terminate the pregnancy if the baby were found to carry the gene. That's a huge and intensely personal choice.

Importantly, the decision has to be made beforehand. That's because testing a pregnancy, but not going ahead with a termination after a positive test result, would take away the child's

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right to choose whether to have the genetic test, later in life. After all, most people at risk of HD choose not to have the test before they develop symptoms. We know that major difficulties can occur when a child is identified, from birth, as someone who will develop HD.

So, it's important to think carefully about prenatal testing for HD, and how you feel about pregnancy termination, in advance of getting pregnant.

Once a woman is pregnant, there is very little time to absorb the information about the prenatal test and make these important decisions, as the testing has to be carried out early during a pregnancy.

In addition, most testing in pregnancy can only be done if tests have been carried out on the couple beforehand. Often, there is not enough time to do this background work when a pregnancy has already started.

How does prenatal testing work?

To test the developing baby, a procedure called chorionic villus sampling (CVS) is performed during early pregnancy. CVS involves collecting a small sample of the placenta (the 'afterbirth'), which has the same genes as the fetus.

CVS is done under local anesthetic and is a quick procedure in the outpatient clinic. Depending on where the placenta is attached to the wall of the uterus, a very fine needle is passed either through the cervix or through the skin of the abdomen, using an ultrasound scanner to guide it. A small sample of cells is then collected from the placenta. These cells can be used to test for the HD genetic abnormality.

The main complication of the procedure is an increased risk of miscarriage, which happens after CVS in about 1 in 50 pregnancies.

CVS is usually carried out between 10 and 12 weeks into a pregnancy. At this stage, a pregnancy can still be kept private from family and friends. If the genetic test is positive, a termination can usually be carried out under general anesthetic until about 12-13 weeks - depending on the country's laws. Sometimes a termination can be carried out later.

"HD-free with PGD"

Pre-implantation genetic diagnosis (PGD) is another way of going about things. It is a way of having an HD-free kid without having to think about terminating a pregnancy. It's more

complicated, and more expensive than pre-natal testing and it can be a long and stressful process.

PGD involves using eggs and sperm to create embryos in a lab, then performing the HD test on the embryos, and putting only the HD-negative embryos into the woman's womb.

The PGD Process

PGD is done as part of IVF (in-vitro fertilization). IVF is a medical procedure which involves a woman taking medications to cause the body to produce more eggs than normal.

The eggs are then collected and fertilized using a sperm sample given by the man. The fertilized eggs are left for a few days to develop into embryos.

The embryo is grown in the laboratory for two to three days until the cells have divided and the embryo has about eight cells. One or two cells are removed from each embryo at this stage. Removing cells at this early stage of development doesn't affect the way that the embryo develops. The removed cells from each embryo are then tested genetically to see whether it has the HD mutation.

Finally, one or two embryos that don't have the mutation are transferred to the womb to allow them to develop.

Any healthy unaffected embryos can be frozen for later use.

About two weeks after the embryos are transferred, the woman will have a pregnancy blood test. If the transfer has been successful, pregnancy then carries on like normal.

The downside of PGD

IVF - the process of stimulating egg release, collecting eggs, fertilizing them outside the body and returning embryos to the womb - is always a time-consuming and exhausting process. It can also be dangerous, carrying risks of the woman becoming unwell. Various things can go wrong, like not enough eggs or embryos being produced.

There's also more chance of having twins with IVF, which is harder work and more risky for the mother and babies.

On top of the risks of the IVF procedure, things can go wrong with the genetic bit of PGD.

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Embryos can be damaged when cells are removed, and sometimes the HD test doesn't work because there isn't enough DNA. Bad luck can mean that all the embryos have the HD mutation. In the end, sometimes only one embryo is available for implantation - and sometimes none at all. To top it off, a pregnancy can fail after implantation.

Overall, each attempt at PGD gives a 20-30% chance of an HD-free pregnancy. Women under the age of 35 have the highest success rates - another reason to think ahead about fertility. Unfortunately, the chances of success over the age of 40 are nearly zero.

How much does PGD cost?

PGD can be expensive. However Westmead Fertility Centre offers PGD at a more affordable cost than most other private clinics. *(More information is available at the end of this article)*

Other options

One way to have HD-free kids is to use donor eggs or sperm instead of those of the at-risk person.

Deciding to have a child with the help of a donor is a difficult decision, but avoids the need to consider termination of a pregnancy. It can be done for people who've had a positive predictive test, as well as those at risk who don't want to be tested themselves.

Like all choices, there's a downside. The child won't be genetically related to the at-risk parent, and the parents will need to think about how and when to share the information with the child. There is plenty of support available to people who decide to go down this route, and this can be discussed before deciding to embark on the process.

Many couples think about adopting children. In many places, couples with one partner at risk of HD are not allowed to adopt, because of the possible effect on the adopted child of a parent developing HD. However, at-risk couples may be able to be foster-carers for children.

Summary

There are options available to people at risk of HD who wish to start a family.

The two main techniques for couples wishing to ensure HD-free kids are prenatal testing, where a pregnancy is genetically tested for HD using chorionic villus sampling, and preimplantation genetic diagnosis, where embryos created by in-

vitro fertilization are tested and only HD-negative ones returned to the womb.

As with so many things in life, forward planning and understanding all the options is key. It is also important to think carefully about what extra support would be available to you (for example, from both families, child care) if the parent at risk becomes unwell with HD while the children are still young. In this situation it is often extremely difficult for the well parent to manage caring for the children, earning an income, and caring for the partner with HD, without some outside assistance.

Expert advice, in the form of genetic counselling, will help you understand the exact options available to you. In NSW and the ACT there are genetic counsellors based at major hospitals. You can find out your nearest counsellor at <http://www.genetics.edu.au/Genetics-Services/genetic-counselling-services>

*Acknowledgements: HDBuzz, <https://en.hdbuzz.net>
Fiona Richards, Social Worker, Children's Hospital, Westmead*

Westmead Fertility Centre



Westmead Fertility Centre (WFC) is affiliated with Westmead Hospital and the University of Sydney and is located at Westmead Hospital.

WFC offers PGD for those who would like to have an HD-free child at a more affordable cost.

The following is an **approximate** guide to the type of treatment costs, which are all inclusive, you can expect to pay.

Treatment fees

An IVF cycle costs between \$1,735–\$5,085 at WFC but after Medicare refunds, out-of-pocket expenses are usually between \$317–\$1,586 for a first cycle. Additional Health Fund Insurance is not required to have treatment at WFC.

In addition, PGD charges billed by the Genetics Laboratory range from \$2,250 – \$3,000.

For more specific information please contact Westmead Fertility Centre on 9845 7484 or visit the website <https://www.westmeadivf.com.au/>

NATIONAL DISABILITY INSURANCE SCHEME – NDIS

The National Disability Insurance Scheme (NDIS) is coming soon.
Are you ready?



What is the NDIS?

The NDIS is a new way of delivering the reasonable and necessary supports a person living with a significant disability requires in order to live a life of quality. The NDIS takes a flexible, lifetime approach to develop individualised plans that will provide these supports. The NDIS provides participants with choice and control over how, when and where their supports are provided. It also provides certainty and security for people with disability or permanent significant impairment that they will receive the support they need over their lifetime. This is truly a remarkable innovation for Australian residents that will offer great improvement for thousands of people who in many cases, have not previously had access to the quality services and supports they require.

When is the NDIS starting?

It already has! It will be operating state wide throughout NSW by July 2018, ultimately providing support to about 140,000 people.

People currently receiving supports through the NSW Government specialist disability services program will be moving to the NDIS first. Existing commonwealth and state based supports will continue until you are covered by the NDIS.

Roll out in NSW

1 July 2016 - 30 June 2017

Central Coast	Hunter New England	Nepean Blue Mountains
Northern Sydney	South Western Sydney	Southern NSW
Western Sydney		

1 July 2017 - 30 June 2018

Illawarra Shoalhaven	Mid North Coast	Murrumbidgee
Northern NSW	South Eastern Sydney	Sydney
Western NSW	Far West	

What type of services/supports will the NDIS cover for an eligible participant?

- Aids & appliances, home & vehicle modifications
- Personal care
- Transport assistance
- Supported employment services
- Specialist accommodation support
- Domestic assistance
- Therapies – physiotherapy, occupational therapy, speech therapy, counselling
- Crisis/emergency support
- Community access supports
- Respite

How do I find out more about the NDIS and whether I'm eligible for NDIS participation?

Visit the NDIS website <https://www.ndis.gov.au/>
Talk to your key worker at the HD Service at Westmead Hospital



Huntington's New South Wales

PO Box 178, West Ryde, NSW 1685
21 Chatham Road, West Ryde, NSW 2114
Telephone: (02) 9874 9777
Free Call: 1800 244 735 (Country NSW only)
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

Stewart Swales
Administration Co-ordinator

Julie Leto
Rural Social Worker
0456 013 612

Amanda Dickey
Programs Officer

Amy Hale
Youth Liaison Worker
0499031231

Pauline Keyvar
Fundraising & Marketing

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
(02) 9845 6699

Outreach Service
Colleen McKinnon
Westmead Hospital
(02) 9845 9960

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