Gateway

News from Huntington's NSW & ACT

Volume 21 No 1 **Autumn 2018**

Huntington's disease receives $1.9million research grant from the Australian Government

On 24th January 2018, Greg Hunt, the Federal Minister for Health, announced the nineteen successful applications to receive funding from the landmark Medical Research Future Fund's *Rare Cancers, Rare Diseases and Unmet Needs Clinical Trials Program*.

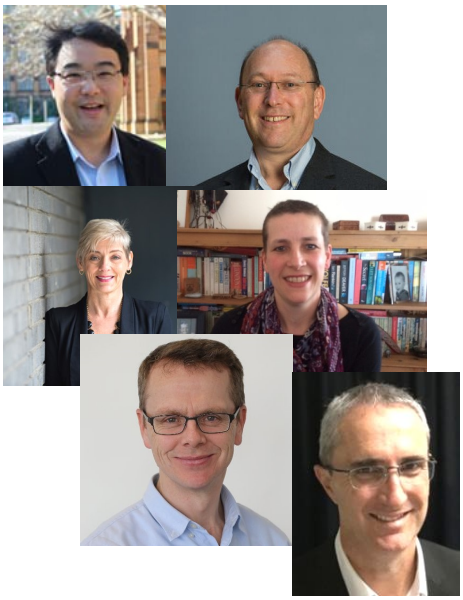
The projects will undertake clinical trials for conditions such as acute lymphoblastic leukaemia in infants, aplastic anaemia, multiple sclerosis and **Huntington's disease**. The total funding for these projects is more than $26 million.

The successful project for Huntington's disease is a randomised controlled trial of N-Acetyl Cysteine, for those who are not yet symptomatic but are gene positive for Huntington's (NAC-preHD).

The chief investigator is Associate Professor Clement Loy from the University of Sydney and the amount received for the project is $1,905,227.

Members of the research team are:

Associate Professor Clement Loy, University of Sydney
Professor Michael Berk, Deakin University
Professor Julie Stout, Monash University
Doctor Rachael Scahill, University College London (UCL)
Professor Anthony Hannan, Florey Institute of Neuroscience and Mental Health
Professor Peter Panegyres, University of Western Australia
Associate Professor Armando Teixeira-Pinto, University of Sydney
Associate Professor John O'Sullivan, UQ Centre for Clinical Research
Doctor Yifat Glikmann-Johnston, Monash University
Ms Robyn Kapp, Westmead Hospital



Members of the research team include (from top left) Clement Loy, Michael Berk, Julie Stout, Rachael Scahill, Anthony Hannon & John O'Sullivan

This is very exciting news and congratulations are extended to Dr Loy and all members of the research team.

More information will be made available, once we receive further details about the project.

Become a Brain Champion

The Australian Brain Alliance aims to establish an Australian Brain Initiative that will create advanced industries in neurotechnology, develop treatments for debilitating brain disorders, and produce high-impact transdisciplinary collaborations that will increase our understanding of the brain.

Help Crack the Brain's Code

The human brain is staggeringly complex, and Australian neuroscientists and psychologists have a long and distinguished record of achievement in unravelling its mysteries and creating new applications and technologies.

Australia - we can Crack the Brain's Code and revolutionise our healthcare and education system, and create advanced the brain.

We have the right people to crack the brain's code, but we need your support by becoming a Brain Champion.

When you sign up as a brain champion, the ABA will use your postcode to send an email on your behalf, to your local federal MP and all of the elected Senators for your state. This will help us send a clear message to Parliamentarians that constituents in their electorate want to see Australia invest in a brain initiative. If we have enough people in an electorate (and indeed, across Australia) who have stated their support for an ABI, then it will put the Brain Initiative on the policy priority list.

This exercise of signing up brain champions is a demonstration of the grassroots and community/ public support for an Australian Brain Initiative.

The aim is to sign up 10,000 Brain Champions across Australia. Please help us to achieve this goal.

To be a Brain Champion visit https://www.brainalliance.org.au/join-us/ and don't forget to share with family and friends on Facebook and Twitter

#LightItUp4HD

May is International Huntington's Awareness Month

For many years, HD Associations in the northern hemisphere have dedicated May as Awareness Month for Huntington's disease.

In May 2015, Jamie – a volunteer from the Huntington Society of Canada – was instrumental in lighting up the CN Tower in Toronto to raise the visibility of HD. Since then more and more HD Associations around the world have organised for buildings, monuments and statues to be lit during the month of May.

This year we, at HNSW&ACT, are coming on board and joining this fantastic campaign. It is not so easy in Sydney as Vivid starts on 25th May and many of our buildings will be unavailable in the lead up to this event.

However, we can make a start by lighting up our homes in pink and green during May and sharing our photos on Facebook.

If you live outside the metropolitan area you may like to contact your local council to see if they would be willing to light up a local building.

We will let you know more about how to join in via email, our Facebook page and website. In the meantime here are some examples from homes in England last year.

By lighting up you will be helping us spread the word about HD.

Save the Dates!!

WALK4 HOPE

2018

ORANGE SUNDAY 2ND SEPTEMBER

PARRAMATTA SUNDAY 9TH SEPTEMBER

SPEERS POINT SATURDAY 15TH SEPTEMBER

CANBERRA SUNDAY 23RD SEPTEMBER

BE SEEN WEAR PINK & GREEN

PUT THE DATE IN YOUR DIARY AND WATCH OUT ON FACEBOOK AND OUR WEBSITE TO REGISTER

WE PROMISE TO HAVE A FEW SURPRISES IN STORE FOR YOU THIS YEAR

Remote Assessment of Lifestyle and Cognition in Huntington's Disease

Why is lifestyle and cognition important in Huntington's disease?

Poor sleep and little exercise can reduce thinking skills in most people.

People with Huntington's disease often have poor sleep quality and may exercise less often than others.

This means people with Huntington's disease may be able to improve their thinking skills by managing their sleep and exercise levels.

How am I investigating lifestyle and cognition?

I am looking at how the thinking skills of people with Huntington's Disease are affected by how much exercise they do and how well they sleep.

What will we learn from this research?

Understanding how sleep and physical exercise impact thinking in people with Huntington's Disease will help us learn how lifestyle (e.g. sleep and exercise) can be managed to boost thinking performance.

Who is eligible?

- Men and women, 18 - 65 years old.
- People with, and without, a diagnosis of Huntington's disease.
- No history of neurological injury (e.g. traumatic brain injury, stroke).

What will you need to do?

- Fill in a short online questionnaire to make sure you are eligible to take part in the study.
- Complete short tasks and questionnaires on a smartphone app over eight days.
- Wear a Fitbit sleep and activity monitor for eight days.

Where will you need to go?

Nowhere! The entire study can be completed in the comfort of your home! We will provide you with $40 for you time.

Ethics Approval:

Monash University Research Ethics Committee (MUHREC) CF16/280-2016000126.

Brendan McLaren
Doctor of Psychology in Clinical Neuropsychology Candidate,
Monash University

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About Brendan:

I am a registered provisional psychologist and a fourth-year Doctor of Neuropsychology candidate at Monash University.

I am interested in understanding how lifestyle factors, such as sleep and physical activity, can be managed to help boost thinking skills in people with Huntington's disease.

Organisation:

I work within the Monash Institute of Cognitive & Clinical Neuroscience.

Within this institute, I am a part of the Stout lab, headed by Professor Julie Stout.

Our lab specialises in measuring cognitive processes (e.g., thinking, memory, learning) in Huntington's disease.

Research Update

Dear members of the Huntington's community,

On March 1, 2018, Ionis Pharmaceuticals, Inc. and Roche presented initial results from the completed Phase 1/2a study of IONIS-HTTRx (now known as "RG6042") in people with Huntington's disease (HD) at the 13th Annual CHDI HD Therapeutics conference. The study was a 13-week, randomized, placebo-controlled, dose escalation study in 46 participants with early stage HD. The study evaluated IONIS-HTTRx (RG6042) at five different doses, given monthly, for a total of four doses. We are excited to provide you with a summary of information from the completed study.

- In the Phase 1/2a study, the mutant huntingtin protein (mHTT), which causes HD, was substantially reduced in a dose-dependent manner in participants treated with IONIS-HTTRx (RG6042).
- Participants who received either of the two highest doses of IONIS-HTTRx (RG6042) (90 mg or 120 mg) experienced a reduction of mHTT levels in their cerebral spinal fluid (CSF) that were, on average, approximately 40% lower than at the start of the study, with some individuals experiencing a lowering as high as 60%. At the last measurement, the levels of mHTT were continuing to decline in most IONIS-HTTRx (RG6042)-treated participants, suggesting that larger reductions may be possible with continued dosing.
- This magnitude of reduction of mHTT in CSF is within the range predicted to provide clinical benefit, based on available evidence of what was needed for improvement in animal models of HD.

The purpose of the Phase 1/2a study was to determine safety and tolerability of IONIS-HTTRx (RG6042). This study was not designed to detect an effect on clinical symptoms. We are pleased that the study showed IONIS-HTTRx (RG6042) was safe and well-tolerated at all doses and lowered CSF mHTT levels in a dose-dependent manner, and therefore supports continued development. Since mid-December 2017, Roche is leading the future studies and development of this investigational medicine, which was renamed RG6042.

Recent progress:

- An open-label extension study of IONIS-HTTRx (RG6042) has started for those who participated in the recently completed Ph1/2a study. This study looks at the safety and tolerability of longer-term dosing of IONIS-HTTRx (RG6042).
- The next step is to conduct a larger study designed to detect clinical benefit and evaluate longer-term safety. In this study it will determine whether the lowering of mHTT, observed in the first study of IONIS-HTTRx (RG6042), translates into meaningful benefit for people living with HD.
- Roche is collaborating with the HD community and engaging global health authorities on the design of this larger study. Roche will share details about this planned study, including eligibility criteria, planned start date, and study sites around the world, as soon as these aspects are finalized.

This study will answer critical questions for regulatory approval and broad access. At this time, because the benefits and risks of IONIS-HTTRx (RG6042) are not fully understood, we are not able to grant pre-approval or compassionate access.

In summary, we are very encouraged by the promise of IONIS-HTTRx (RG6042) and look forward to continuing to partner with the HD community. We recognize the urgent need to bring effective therapies to individuals affected by HD, and our teams are working to advance IONIS-HTTRx (RG6042) into the next clinical study as quickly as possible.

Sincerely,
Your Roche & Ionis Team

HUNTINGTON'S DISEASE YOUTH ORGANIZATION

Australia & New Zealand Youth Camp January 2018

In January this year I attended my first HDYO Australia and New Zealand Youth Camp in Queensland. The camp was an opportunity for young people impacted by HD to get away, find new friendships, support each other through shared experience, hear about the latest HD science and developments and participate in some great activities including caving, tie-dye, games and rock climbing.

The whole crowd! Campers, volunteers and staff

It was truly inspirational to be able to spend time with so many amazing young people from our HD community. The ages ranged from 13 – 26. What really struck me was how incredibly brave all of these young people were in sharing their own life stories and in turn, how open, mature and wholehearted they were in hearing the stories of others, holding space for those stories and supporting each other with hugs, kindness, practical advice and hope. It was also great to experience was how brilliantly the HDYO staff are in the way they organise, facilitate and participate in these camps. I have no doubt that every camper walked away feeling more heard, more supported and more knowledgeable as they continue on their HD journey.

Campers – and me – on the rock wall – a great way to relieve some tension and also a great bonding experience for all.

I was originally to attend as a volunteer with minimal duties — more of an observational role —however as one of the youth workers was sick and not able to attend, I was asked by the HDYO staff to be a group leader and facilitator. This was a fortuitous learning opportunity for me as I had previously not conducted any HD groups with young people. We covered topics such as diagnosis, grief and death, testing, how to tell others about HD status, supporting others with HD, self-care and life planning. I had a group of seven older young people – with ages ranging from about 20-24. It was a very rich emotional experience for all and it was a great honour to facilitate this group. They were mature, thoughtful, vulnerable and so open and willing to share their stories and learning with each other.

Ready to hit the caves! This was taken just before we all entered 100 meters of man-made cave tubes! Tricky, exhausting and hilarious at times.

Beautiful lantern tribute. Each camper created a lantern and lit it in memory of someone in their life impacted by HD.

All in all it was a very challenging but very rewarding experience. I look forward to building on the therapeutic relationships I have made with the young people I met from NSW and am very keen to attend the camp next year as a group facilitator.

Amy Hale,
Youth Liaison Worker
HNSW & ACT

The Huntington Study Group (HSG), which was formed in 1993, is the world's first HD cooperative therapeutic research organization. Today, HSG is a world leader in facilitating high quality clinical research trials and studies that bring us closer to finding more effective treatments for HD and reducing the burden of HD for families affected by the disease.

HSG is an organization of compassionate professionals dedicated to finding treatments that make a difference, providing rigorous care initiatives, and improving the quality of life and outcomes for HD families. How? By bringing together families, medical professionals, clinical researchers, HD advocacy groups, and sponsors to raise awareness of HD, share knowledge and best practices, and develop innovative treatments.

The vision of the HSG is to be an invaluable research partner to Families, HSG Members, Sponsors, and Partners. Their mission is to seek treatments that make a difference and their network is made up of Families, HSG Members, Sponsors, and Partners.

Families: Individuals affected by HD and their families and caregivers, HD organizations and volunteers around the world participating in the development of innovative HD treatments through participation in clinical trials, education, advocacy, awareness, and care.

HSG Members: An interdisciplinary network of healthcare providers including HSG Credentialed Research Site investigators and coordinators, nursing and medical staff, and researchers and clinicians from a wide range of disciplines. They are members of academic institutions that contribute to the advancement of HD research and/or care and are committed to seeking HD treatments that make a difference. The HD research team at Westmead Hospital are members of the Huntington Study Group.

Sponsors & Partners: Partnering organizations including pharmaceutical companies, CROs, foundations, and government agencies committed to advancing therapies for HD.

HD Education

Individuals with HD and their family members need the expertise of clinicians specializing in neurology, movement disorders, psychiatry, mental health, genetics, and palliative care, as well as ancillary and primary care providers at some point during the complex and progressive course of the disease. Because the disease is so rare, little dedicated attention is given to HD disease in standard medical education programs, and knowledgeable providers can be difficult for families to access. HSG and its members aim to provide educational opportunities to providers so they can offer higher quality care to their patients and families impacted by HD.

HSG members are world experts in caring for individuals and families impacted by Huntington disease. HSG wants to share their knowledge with as many health care professionals as possible so families can more easily find care in their own communities. The popular CME4HD program provided at HSG's annual event is now available online, anytime, anywhere – for FREE.

HSG's CME4HD is an in-person continuing medical education program designed to teach healthcare providers how to care for and manage individuals with HD, hosted by the HSG. Attendees will gain the knowledge, tools, and resources they need to provide excellent care to families impacted by HD, and they learn from world experts in HD care.

This program was planned and implemented by the North American Center for Continuing Education, LLC (NACCME) and the Huntington Study Group. This program was made possible, in part, by an independent educational grant from TEVA Pharmaceuticals.

This free on-line program is available to health professionals throughout the world and can be found at http://huntingtonstudygroup.org/cme4hd/

Acknowledgement:
http://huntingtonstudygroup.org/

The structure of the protein that causes Huntington's disease, revealed

Huntingtin protein's structure is now clear thanks to cryo-electron microscopy. This is kind of a big deal.

By Caroline Casey, Edited by Dr Ed Wild

The cause of Huntington's disease has been known since 1993, but the physical structure of the healthy huntingtin protein proved difficult to discover until now. German scientists have now revealed the shape of the huntingtin protein for the first time. Although the structure of the mutant form of the protein was not investigated, this study provides an excellent platform to build upon and will boost drug development efforts.

Know your enemy

One of the biggest issues in HD research to date is that although we know what causes the disease - a harmful protein called mutant huntingtin. We even know some ways in which the mutant protein wreaks havoc within the human brain. But until now we've had no idea what the protein actually looks like. That makes trying to prevent it causing damage very difficult! Imagine you're a farmer whose crops are being damaged by an animal every night. If you had a photo of the animal that was causing the damage, it would be easier to figure out how to prevent it. A drunk elephant would require a different strategy from a swarm of locusts. It's the same when we're fighting brain diseases: knowing what a protein looks like is a huge help when it comes to understanding how it operates and how to make drugs to change its behaviour.

Cool science – literally

The technique used in this particular study is the crème de la crème of microscopy, so much so that it was awarded the Nobel Prize for Chemistry last year. It's called cryo-electron microscopy, otherwise known as cryo-EM. It involves shooting a beam of electrons at a sample that's been frozen using a super-cold liquid. When we say cool we don't mean like a beer or a smoothie – this technique involves cooling proteins to several hundred degrees below freezing.

Things tend to slow down when it gets cold. Cryo-electron microscopy uses low temperatures to hold protein molecules still, then an electron beam captures hundreds of 'photographs'.

When the electrons hit the sample, it causes them to scatter slightly before striking an electron detector, which builds up an image like the light detector in a digital camera. But one image isn't enough - hundreds of 'photos' have to be taken from different angles, then combined by computer to reveal the 3D shape of the protein.

The images generated by cryo-EM are so precise that the authors of this study – a team led by Stefan Kochanek at the University of Ulm – were able to document the structure of huntingtin down to a billionth of a centimetre! The study found that the protein was essentially composed of two parts, connected by a bridge region. This is a very important finding as it suggests that the function of huntingtin could be to act as a kind of protein hub. In other words, it's a mothership that lots of different protein spaceships dock into.

What's the big deal?

You might be thinking to yourself, why has it taken such a long time to figure this out? Basically, it's due to how complicated and bendy the huntingtin protein is. In order to build up a 3D image of the protein, it has to be photographed from multiple different angles, but for the pieces of the puzzle to slot together perfectly, the protein has to remain in the same position for this entire process. Unfortunately for us, this doesn't happen with the huntingtin protein alone. To get around this, the researchers of this study used another protein called 'huntingtin-associated protein 40' or HAP40, which was able to bind to both segments of HTT as well as the bridge region and essentially fix it in

(Continued from page 8)
one position, to stop it moving around. This stabilised the protein for long enough that the 'photoshoot' could take place.

What about the mutant protein?

The structure that was just announced was of the normal, healthy huntingtin protein that scientists call 'wild-type'. But what about the structure of mutant huntingtin? Surely we need to know the what that protein looks like, to actually help in HD?

Dr Kochanek unveiled the structure of huntingtin (the squiggly ribbons) in February at the therapeutics conference, as a birthday present to the HD community celebrating 25 years since the discovery of the gene.

On the one hand yes, there is still an urgent need to identify the structure of the harmful version of huntingtin, and that would be super-helpful for designing therapies to combat the mutant protein's harmful effects. However, that poses a whole host of other potential challenges to researchers.

Unfortunately, the presence of the mutation changes the the way the protein interacts with other proteins. That's probably one of the things that makes it harmful. Remember that the success of the photoshoot depended on huntingtin sticking to another protein, HAP40. But the presence of the mutation may mean that huntingtin and HAP40 no longer stick together so well, meaning the cryo-EM photoshoot doesn't work so well. The authors hinted at this problem in their article.

How can this help?

The structure of the mutant protein will hopefully come in time, now that the healthy one has shown its face. But just knowing the structure of the healthy huntingtin protein is already a big deal. Despite decades of research, we still don't understand all the jobs huntingtin carries out in our cells, not just in the brain but the whole body. But since the structure of a protein basically dictates how it interacts with other molecules, we can now use these results to work out what different functions huntingtin might have, and how it achieves them. Essentially, this finding is a lightbulb that means we're no longer shooting in the dark to understand and reveal huntingtin function.

Finally, this finding will be a big boost for efforts to invent new drugs to fight Huntington's disease, especially if it does lead to uncovering what the mutant protein looks like. It could enable the design of targeted drugs that make the huntingtin protein less toxic whilst protecting the helpful functions of the healthy protein. Hopefully, this discovery will kickstart a new era for targeted drug development in Huntington's disease, focused on the known structure of the huntingtin protein.

Acknowledgement: https://en.hdbuzz.net/256

Caroline Casey—Caroline is a PhD student at University College London Institute of Neurology. Caroline works with Sarah Tabrizi to turn stem cells into neurons to study Huntington's disease The aim of the project is to gain a better understanding of brain changes in HD; Caroline hopes her findings will contribute towards developing novel therapies for the disease.

Dr Ed Wild—Ed Wild is a Principal Investigator at UCL Institute of Neurology and a Consultant Neurologist at the National Hospital for Neurology and Neurosurgery, Queen Square, London. Ed studied medicine at Cambridge University and has worked in neuroscience since 2005. His PhD research was on biomarkers for Huntington's disease. Ed's research team studies cerebrospinal fluid in Huntington's disease and he is the global Chief Investigator of the HDClarity study. He also runs clinical trials of new treatments in HD including 'gene silencing' drugs. Since 2009 he has been collaborating with Dr Jeff Carroll to make HD research news accessible to the global HD community.

Travelling with Huntington's Disease

A Fact Sheet reproduced and modified with the consent of the Huntington Society of Canada and reprinted from Contact West, the newsletter of Huntington's WA, Autumn 2018.

Everyone enjoys the opportunity to take a break from their normal routines and travel. With any illness including HD, it can be more challenging to travel – especially as the disease progresses. Careful planning can help manage new surroundings and make travel easier. This fact sheet provides some tips and strategies for making travel more enjoyable .

Have A Plan

- If travelling is new for your family, starting out with a shorter trip may be a good idea to get accustomed to travel before going on a long journey.
- Because people with HD often have difficulty regulating their body temperature, it is important to consider the weather for the time of the year that you plan to travel. It is also advisable to not travel in high tourist season so as not to overwhelm the person with HD.
- If possible, request quiet and safe spaces for the person with HD to relax and re-group.
- Caregivers should also remember to take time out for themselves to rejuvenate.
- Before the trip, include everyone in the planning of where you will go and what you will see and do. Once the trip is planned, make an itinerary available so the trip details can be reviewed whenever necessary.
- Learn as much as you can about the place you are visiting, so you can anticipate what you will need for the trip.
- Consult with your health care team before your trip about your travel plans and ask about contingency plans and strategies that could be helpful in an emergency situation.
- Establish and practise relaxation techniques to help with stress and anxiety related to flying if that is an issue for anyone in your travel group; over the counter medications and/or prescriptions may also be available to help with anxiety associated with travel.
- Ask your doctor or pharmacist about safe anti-nausea and other medications to help with controlling nausea and other travel-related illness.
- Carry 4-5 days of medications in your carry-on baggage just in case your luggage is lost.
- Ask your pharmacist for a list of all medications with the generic names of the drugs and proper dosages in case your luggage is lost or there is an emergency; locate a local pharmacy at your destination ahead of time, so you have a plan to replace any lost medications needed. In some countries, this may require a visit to a local clinic to get a new prescription.
- Consider taking extra medication with you that may be difficult to get in the country – especially if travelling overseas.
- Educate people travelling in the group about the symptoms, changes in behaviour and potential severity of symptoms. Understanding Behaviour in Huntington Disease: A Guide for Professionals is a good resource to learn more.

Simplify

- Try to maintain the regular schedule of eating, sleeping, exercise, rest and other routines as much as possible.
- Use a medication reminder system (there are apps available for cell phones that provide an alert) to help with remembering to take medications as there will be some inevitable disruption to routine.
- Ask your pharmacist to prepare blister packs of your medication for the duration of the trip. The blister packs are sealed and identify the drug and the pharmacy who prepared it. This will aid in getting through security or customs.
- Choose the trip and style of travel that will work best for you. Some families will want to experience an all-inclusive vacation to keep meal preparation and other tasks to a minimum.

(Continued from page 10)

It will also allow for activities to be pre-planned.

- It is important to find out if the hotel/ship/resort is able to accommodate a special diet (e.g. puréed and/or soft foods).
- If flying to a destination, choose a direct flight if possible.
- If travelling by car, consider shortening each day of travel and extending the overall length of the trip to make it more enjoyable and less tiring. Taking frequent stretch breaks may be helpful.

Ask for Help

- Go with a travel buddy if possible. Choose someone who will be able to provide the level of support needed.
- If you booked your trip with a travel agent, ask him/her for advice and ideas for support and assistance.
- Inform the airline ahead of time that you are travelling with someone who has HD and ask for any accommodations needed including early boarding, a wheelchair, transportation upon arrival, help with carry-on baggage and boarding and getting off the plane.
- If flying, request extra leg room and a seat close to the washrooms.
- Ask for a contact at the hotel who can help if there are any issues or concerns throughout your stay.
- When travelling in unfamiliar places or foreign destinations with language barriers especially, carry a list of the name, address and phone number of the hotel or ask the hotel for its business card which has the address on it. If you get lost or lose your group, it will be possible to hire a cab or ask someone for directions.
- For individuals with HD, you may like to carry the Huntington's NSW & ACT business size information card so it is easy to educate people about HD
- In addition, a letter from your doctor that would describe any special characteristics of the disease would be particularly beneficial when going through security or customs.

HSC suggests that families register with a medical alert system like the "MedicAlert Safely Home" program to help provide identification for loved ones. The MedicAlert engraved identification bracelet enables police and emergency responders - internationally - to quickly identify a person who gets separated. Bracelets can include information about medical conditions to help first responders provide the best care possible.

RESOURCES

The Huntington Society of Canada wishes to thank the Alzheimer Society of Canada for sharing their tips for travelling. The information has been modified with permission from the Alzheimer Society of Canada (www.alzheimer.ca).

Understanding Behaviour in Huntington Disease: A Guide for Professionals (Third Edition) is available online.

Acknowledgements: Huntington Society of Canada
https://www.huntingtonsociety.ca

Huntington's WA
https://www.huntingtonswa.org.au

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Huntington's NSW & ACT Inc.
The Association is a not-for-profit organisation established in 1975.

Our Mission
The energies and resources of Huntington's NSW & ACT 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: Katy Clymo
Alison Hill

Association and Other Useful Contacts

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(02) 8890 6310 or
0438 604 719 (Mon & Thur)

HD Clinic Appointments

Outpatients Department
Westmead Hospital
(02) 8890 6544

Huntington's Unit St Joseph's Hospital

(02) 9749 0215

Hunter HD Service

John Conaghan
Social Worker
John Hunter Hospital
(02) 4922 3076

Predictive Testing

Find your nearest Genetics Clinic at
http://
www.genetics.edu.au/genetic-services/general-genetics-clinics