



Gateway

News from Huntington's New South Wales

Volume 18 No 3

Spring 2015

A Drug to treat Huntington's is closer than ever – but those who need it remain cautious

It has worked on mice and monkeys. And starting next month in Vancouver, scientists will begin a long-awaited trial to see if a new drug might also slow the progression of Huntington's disease in humans.

The Centre for Huntington Disease at the University of British Columbia, led by neurologist Dr Blair Leavitt, is already in the process of identifying six patient candidates who in August will participate in a trial for a drug known as ASO-HTT, the first drug to target the cause of HD: a mutant gene that produces a toxic protein.

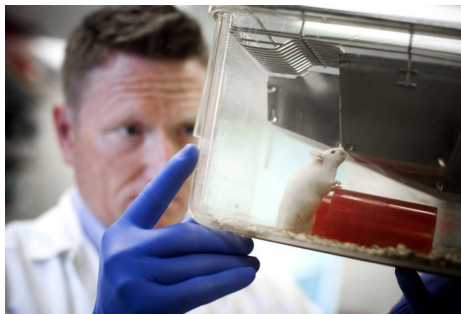
The Vancouver trial group will be followed by other groups in Britain and Germany, bringing the total number of patients receiving ASO-HTT to 36. As well, there are a half-dozen other potential HD treatments in various stages of testing around the world, fuelled by a recent influx of millions of research dollars from a private charitable foundation.

No one is claiming ASO-HTT or the other proposed therapies are outright cures, but researchers are excited about the potential to reduce the debilitating impact of the disease. "I believe that we are going to find effective treatments, not just in my lifetime, but soon," Leavitt says.

If ASO-HTT effectively slows the progression of HD, it might also be used to develop treatments

for other neurological diseases such as Alzheimer's, Parkinson's and ALS.

But among those who have the most at stake, the news of a potential breakthrough treatment has been greeted with caution, even ambivalence.



Dr Blair Leavitt

"I don't like to get hyped over things any more," says Michelle, a 26-year-old in Ontario who tested positive for the gene four years ago. Michelle, who asked that her full name not be used, had watched the disease slowly kill her grandmother, and now her

58-year-old father struggles with it. "I also don't like to put all my energy into that," she says. "I don't know what to think, to be honest."

Not everybody at risk wants to be tested for the gene. It's typical for families to deny the existence of HD and for those who are diagnosed to keep it a secret. And sometimes the disease simply goes unrecognized. If a family member shows symptoms when elderly, their tremors, lack of balance and confusion are usually attributed to old age.

HD has touched my own life. My former partner has the disease. His father was the first to be diagnosed in his family. My ex's brother also tested positive. They have a sister who does not want to be tested.

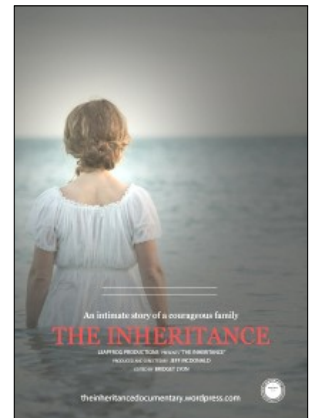
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"The Inheritance"

The Inheritance is now available to buy on DVD or Rent or Buy on Demand at <http://theinheritancedocumentary.com>

Bridget Lyon and her partner, Jeff McDonald, have made a documentary to honour Bridget's mother, Judy's efforts to strengthen public awareness of Huntington's disease. Judy wanted people to know what it was and how it affected entire families, generation after generation.

Bridget is a documentary editor and Jeff is a documentary producer/director. They want to share their story to help alleviate stigma and invigorate funding for family support and research into treatments.



They believe that, as Charles Sabine says: *"Communication leads to understanding and understanding dilutes fear and if we can lessen fear, hope can take its place."*

"Truly one of the most moving and inspirational stories I have ever witnessed on the big screen." - The Dominion Post

"Absolutely an incredible documentary - the type of which, once you see it, you never forget it." - ABC Radio

"Twitch"

Genetic Testing for Huntington's Disease: a personal experience

Twitch follows 18-year-old Kristen Powers as she undergoes genetic testing for Huntington's disease, the illness that took the life of her mother.

Twitch chronicles Kristen's emotional, social and medical journey through testing, as well as the impact it has on her future. *Twitch* also explores the science of HD with experts and activists. Watch as Kristen explains the rationale behind her decision to be tested. Would you want to know?



Join us for a screening of this documentary film, followed by a Q&A with Kristen Powers and Associate Professor Kris Barlow-Stewart, Director of the Sydney Master of Genetic Counselling program, and Dr Ainsley Newson, Director of the Sydney Master of Bioethics program.

Thursday 10th September, 2015 at 6-8pm

Lecture Theatre 4002 (Messel), Sydney Nanoscience Hub (Enter via Physics Rd)
(take path between Physics Building and Edward Ford)

The University of Sydney

This is a free event with **online registration requested** at <http://whatson.sydney.edu.au/events/published/sydney-ideas-twitch-film-screening-and-expert-q-and-a>



**Join us to celebrate our 40th Anniversary
Take the Walk 4 Hope challenge and be involved**

3 Dates

3 Venues

Triple the Fun

**Speers Point
Sat 19th Sept
10am**

**Lake Burley Griffin
Sat 26th Sept
10am**

**Parramatta Park
Sun 27th Sept
10am**

To make **Walk 4 Hope** a success you can:

- Join one of our **Walks 4 Hope** by visiting our website and registering at <http://www.huntingtonsnsw.org.au/walk4hope>
- Start your **Fundraising** <https://give.everydayhero.com/au/team-walk-4-hope-2015>
- If you prefer please complete the enclosed registration form and send it back in the reply paid envelope or email it to info@huntingtonsnsw.org.au
- Make a donation via our website www.huntingtonsnsw.org.au
- Make a donation by using the reply paid envelope enclosed
- Invite your family and friends to join you
- Encourage your workmates, friends and family to sponsor you

And don't forget – **Be Seen, Wear Pink and Green**

September is Huntington's Awareness Month

Walk 4 Hope Raffle

Of course it would be a Huntington's event without a raffle!!

If you would like to purchase tickets, please complete the enclosed form and send it with your payment in the reply paid envelope.

There are lots of fabulous prizes and it will be drawn on Sunday 27th September at 1pm at Parramatta Park.

Home Enteral Nutrition Services in NSW

What is Home Enteral Nutrition (HEN)?

Home enteral nutrition (HEN) is a way of providing nutrition when children and adults living at home cannot eat and drink normally or get enough food or drink to keep them well and healthy. For people with HD, HEN can provide nutritional supplements (eg Sustagen) or thickened fluids at a reduced price.

Who may need HEN?

People may need HEN for many different reasons. For example a person may:

- Not be able to eat or drink enough to meet their nutritional needs through their diet alone.
- Have swallowing problems after a stroke or as a result of treatment for head and neck cancer
- Have a physical or intellectual disability and have difficulty eating or drinking.
- Not be able to absorb enough nutrition from their food and drinks due to bowel disease or surgery.

What help is available?

There is help available to:

- Have the HEN products (nutritional drinks, formulas and thickened fluids) you need delivered to your home
- Find the right health professional
- Provide the information you need.

Who can help?

Your doctor will be able to tell you if you need HEN. Other health professionals who can help are:

- **The dietitian** – this person can help you work out what food, drink or nutrition formula you need to stay healthy and can register you with the HEN program so that you can order nutritional drinks and formula.
- **The speech pathologist** – this person will assess the safety of your swallowing for food and drinks. They can order thickened fluids or thickening powder if you need them.

Where can I get HEN products?

Some nutrition supplements and thickened fluids can be purchased at a chemist. People who need these products may be able to obtain them from the HEN program at lower prices, delivered to their home. To be eligible, you must:

- Need HEN for more than one month
- See a dietitian or speech pathologist who works for a NSW Health facility at least every 12 months. This



means they work in a hospital, a community health centre, or as part of a service provided by Ageing, Disability and Home Care (ADHC).

To access HEN services, does it matter where I live?

You can get HEN services if you live anywhere in NSW. People live in many different types of homes such as:

- A private home
- Supported accommodation service eg group home
- Alternative family placement.

If you move to another state or territory in Australia, you may need to find out about the local HEN services as they may be different. Your doctor or health professional can help with this. Some residents in nursing homes may not be eligible and are funded by the federal government.

Where can I get more information or support?

- Your doctor
- Your health professional
- Karen Keast, Dietitian, HD Outreach Service, Westmead Hospital. Tel: 9845 9956

Acknowledgement: Adapted from the information sheet developed by the ACI HEN Network; EnableNSW and Ageing, Disability & Home Care.

SBS Foundation Partners with Huntington's NSW

We are delighted to announce that Huntington's NSW has been selected as an SBS Foundation Partner for 2015 to 2016 along with ten other charities and community organisations.



This means that we will be given television airtime to increase awareness of our activities and work within the community. The air time gives us a unique opportunity to raise awareness of our cause with the diverse audiences of SBS. Each year SBS supports charities and organisations with both a national campaign focus as well as charities from regional areas of Australia.



According to the SBS website, "This year's selected partners each demonstrated a strong alignment with the SBS Charter, which informs our purpose to explore, appreciate and celebrate our diverse world, and in doing so contribute to a cohesive society. SBS is proud to assist in promoting their cause."



SBS works together with the SBS Foundation partners to maximise the value of their allotted airtime and assist them to achieve the results they want from their on-air campaigns.



The SBS Foundation was launched in 2009 and has since partnered with over 100 charities and non-profit organisations, spanning the arts, health, sport, environment, multicultural and regional sectors.

We have been very fortunate to obtain the services of a very talented group of people who have generously given their time to make two community service announcements—one for W4H and a more general one to shown throughout the year. So switch to SBS and keep an eye out for our ads.

An exciting day of filming at the Entertainment Quarter, Moore Park

Annual General Meeting

The AGM will be held on Saturday 14th November 2015 at 21 Chatham Rd, West Ryde at 12 noon.

The formal part of the meeting will be followed by a delicious BBQ lunch. We'll take a trip down memory lane to celebrate our 40th anniversary and we'll look forward to our plans for the future.

We'll also acknowledge the wonderful work of some people who have been committed to the Huntington's cause over many years.

It's also a great opportunity to take a look at our recently refurbished offices.

We do hope you can make it—put the date in your diary now.

More information will be available on our website in the near future, www.huntingtonsnsw.org.au

Save the Date

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Like most people, I didn't know anything about HD before meeting my ex. When his personality changed and he became apathetic, clumsy and prone to angry outbursts, I didn't understand that the disease was the cause. He later told me that he worried each time he couldn't remember something, or when he broke a glass. In his early 40s, when symptoms started interfering with his work, he finally got tested.

An HD diagnosis isn't like a cancer diagnosis, where family and friends rally around. People don't understand the personality changes that go along with HD, which can have profound effects on relationships. My experience as his advocate gave me some insight into the isolating aspects of the disease and how it can tear families apart. It's a cruel genetic lottery – siblings who don't test positive can suffer from guilt. The ones who do test positive need to find a way to live their lives without dwelling on what lies ahead.

Talk of testing the ASO-HTT drug on humans first emerged at the World Congress on Huntington's Disease in Melbourne, Australia, in 2011, and has since generated a lot of excitement. "This could change everything for people living with this disease," Bev Heim-Myers, chief executive officer of the Huntington Society of Canada, says.

And yet, those closest to the disease – people who have it built into their DNA – are more cautious. They have a lot more at stake if they get their hopes up. They feel safer living in the present with what they know.

Manny Abecia, 36, didn't know HD was in his family until his mother was diagnosed in 2010. He remembers watching a TV show about the disease and realizing that his mother had the same symptoms. For his own testing, Abecia brought along his three best female friends for support. When the doctor told him he'd tested positive, they all cried. But he says it was also a huge relief: "It was like a ton of bricks off my shoulders, because I finally had clarity."



Manny Abecia

Abecia would like to get married and have children, so he could easily be buoyed by the potential of a new wonder drug. But his reaction is more complicated, because clinging to hope can be exhausting.

"People have been hoping, for like, 20 years," he says. "But it's definitely grounds to be excited – especially because we're seeing the top doctors in the world getting really excited. That's something totally new."

The gene that causes HD was identified in 1993, and in the past 10 years scientists have studied gene-silencing drugs from every angle, except the one that matters the most: how the drug interacts with the human brain. With this human trial launching in Vancouver, researchers get their chance.

The selected participants, who must all be showing early signs of HD, will receive ASO-HTT by intrathecal injection – a reverse spinal tap – to ensure it reaches the brain.

Leavitt's team will watch the participants over the next six months. This first phase tests for safety and serious side effects. Second and third phases move into efficacy testing. A greater number of patients would be invited to participate as the trial goes along.

We all have two copies of the huntingtin gene, one each inherited from our mother and father, which play a crucial role in our brain development. When a gene carries the HD mutation, however, there's a certain segment of DNA that goes wrong, repeating over and over, until it forms a dangerously long repeated sequence. If that CAG (cytosine, adenine and guanine) segment is repeated more than 40 times, the person will get Huntington's disease.

The problem is not only the mutant gene, but also the huntingtin protein created. The mutant DNA passes along instructions to a messenger, called ribonucleic acid (RNA). That RNA copy then produces a harmful protein that wreaks havoc in brain cells.

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The ASO-HTT drug takes a “shoot the messenger” approach, entering cells and destroying the RNA so that the toxic huntingtin protein is not produced. Lab mice injected with the drug showed dramatic improvement in their HD symptoms. In humans, it’s estimated the drug will take about four to six weeks to take effect.

Because scientists know exactly what causes HD and who’s going to get it, researchers say it has an advantage over other neurological diseases in terms of finding a treatment or cure.

“It’s pretty simplistic compared to Alzheimer’s and Parkinson’s and ALS and other neurodegenerative diseases,” says Lisa Genova, the neuroscientist turned author, who recently released her new bestselling novel *Inside the O’Briens*, about a man who discovers he has HD and grapples with finding out if his four children have it, too. Genova previously wrote *Still Alice*, the bestseller about a woman with early onset Alzheimer’s, which was made into a movie. “So if we can figure out how to solve Huntington’s,” she adds, “what we learn may apply to the other diseases as well.”

There is another advantage that HD has over other diseases: the ultra-discreet billionaire Andrew Shechtel. (An investigative story by Bloomberg Press outed his astoundingly generous philanthropy last year, reportedly to his chagrin.) But the researchers all know him. Shechtel and his partners formed a non-profit research foundation called CHDI and have been funnelling more than \$100-million a year into HD research.

Scientists in the field give CHDI a hefty share of the credit for the current flurry of research in HD. There are a total of five trials of varying drug therapies on humans under way this year, including the ASO-HTT trials in Vancouver and Europe (it is supported by CHDI, and is also a partnership between Isis Pharmaceuticals in California and the Swiss pharma giant Roche). In Israel, Dr Michael Hayden, founder of UBC’s Centre for Huntington’s Disease, now heads up research at global pharmaceutical giant Teva, which is involved in two of the trials.

Dr Jeff Carroll is famous in the HD community because he is not only a researcher looking for a cure, but he is also gene-positive. Among six siblings, he’s one of four who have the gene, but no one is showing symptoms. Carroll is 37 and married with two children who do not have the gene, thanks to genetic screening and in-vitro fertilization.

On a tour of the Huntington’s research lab at Vancouver-based Centre for Molecular Medicine and Therapeutics, I was shown a pair of mice – a healthy, plump, muscular one and her slow-moving sister, an emaciated HD mouse with grey fur. The subject of spinal taps came up, which is how doctors can check for a build-up of mutant huntingtin gene in the nervous system. “Won’t that hurt?” I asked. “Oh, we’ve tapped Jeff,” a clinic staffer said, chuckling.

It’s true, he confirmed. He donated his cerebral spinal fluid for the cause.

“The only way to be part of it is to get behind the bus and push,” says Carroll, who worked at the UBC lab before joining Western Washington University in Bellingham, Wash.

Carroll, who has also received CHDI funding, doesn’t expect an overnight cure. He sees therapies unfolding incrementally, much the way HIV treatment has evolved so that few patients in Canada develop full-blown AIDS any more.

“I would love a magic bullet, but I don’t expect it,” he says. “It will be five years [of longer life] here, five more years there – and next thing you know, nobody dies any more, unless they don’t take their pills. You might be twitchy or loopy when you are 60 or 70 or something. There will be a push-back on the age of onset, but it won’t be obvious that it’s happening.”

Back in Vancouver, Leavitt – who’s been working on HD for 16 years – tells me the disease is often referred to as rare, but he thinks it’s far more common than it’s believed to be. About 14 people per 100,000 in Canada are affected, but for every person with the disease, it affects another five people. And there are still those who don’t know that it’s lurking in their families.

“If we can find a treatment that slows it down even by 50 per cent, that now pushes the age of

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Meet the People Behind HDYO

HDYO (Huntington's Disease Youth Organisation) has an amazing website that truly is for young people by young people and Huntington's NSW is proud to be a financial supporter of HDYO.

Let's meet some of the young people behind this awesome organization and find out why they became involved.

BJ Viau **Chair of Board**

I am involved with HDYO because my family who is affected by Huntington's disease taught me from day one to fight back by getting involved in HD events and activities. My Mother Debbie who passed away in March 2011 from Huntington's disease is my motivation, inspiration and hero which keeps me going every day to try to give back to others. I first started getting involved by holding 'Hoopathons' at a local level to raise money and awareness for HD. I attended the Huntington's Disease World Congress in Vancouver in 2009, where I met Matt, Brynne and many other young people doing great things in their local communities. After continuously talking to Matt I realized that the missing piece within the Huntington's disease community was the support for young people. Since then I have tried to make the best effort as possible to get young people the sufficient support, education and motivation to also fight back against Huntington's disease. We can all make a difference so please join HDYO in the continued, but hopefully not long fight against Huntington's Disease!



Catherine Martin **Vice-Chair**



Like the other board members, Huntington's disease has had a massive impact on my life but mostly positive!!!! I grew up with my Gran and other members of

my family being affected by Huntington's disease but they taught me that if we talked and worked together we could overcome anything. Huntington's disease was never something we

hid and we have always been involved in fundraising, awareness raising and sharing our experiences. My family were involved in establishing the Scottish Huntington's Association (SHA) and creating the first family support group so that they could find out more information and meet other families living the Huntington's disease.

As for me I am now caring for my Mum who has been symptomatic with Huntington's disease for 18 years and is the most frustrating, amazing, inspiring and loving person I know, and a true hero. I previously worked as the Specialist Advisor for Parents and Young People with SHA and I am now an elected Board Member of the Association.

My professional background is in youth work and social & community regeneration and it is with these skills and my personal experiences that I am grateful to Matt, BJ and Brynne for allowing me to be part of HDYO and helping them raise the bar for young people across the world living with Huntington's disease.

Kristen Powers **Secretary**



My mum passed away from complications due to HD in 2011. My two younger brothers are also at-risk for the disease. I want to make this the last generation to understand what it means to live with HD. As a teen growing up in an HD family, there were very few resources available to me. Now HDYO is here. It's going to have an amazing impact on affected teens and young people everywhere.

What is your recommendation for others that are looking to make a difference in the fight against HD?

Participate in clinical trials. You do not have to know your gene status for many trials. Anyone can do it; we can't find the cure without more participation in research.

Matt Ellison (founder) **Project Coordinator**

I come from a family that is affected by Huntington's disease. My father was diagnosed with the disease when I was 7 years old and I grew up witnessing him progress with the condition. This had a big impact on my childhood, especially my teenage years - which were very difficult for me.



When I turned 18 I began getting more involved with Huntington's disease and started facing the issue in my life - I wanted to know what I could do to help. As time went on I got more interested in the youth side of things and felt this was the area I could make an impact in. I started studying for a degree in childhood and youth studies and spent a year going to youth events for Huntington's disease in various places around the world, to see what youth support was like on a worldwide scale. I found that support was poor in many places and there was a huge lack of information available for young people. Put simply there was a gap in support for young people affected by Huntington's disease and something needed to be done to try and fill that gap. This is where the idea of HDYO emerged, a place for all young people to access support and educational information. No matter what the support is like for each young person in their area, HDYO is here to provide support and understanding.

I continue to work hard on improving support for young people in my role with HDYO, as do all those involved with the organisation. I am eternally grateful to all the great people who work on or with HDYO.



Karen Forrest Keenan **Board member**

I currently work as a Research Fellow at the University of Aberdeen, Scotland. My background is in qualitative research and face to face work with young people impacted by HD. My qualitative research has focused upon the

experiences of families impacted by genetic conditions, including HD. In 2004 I joined the Scottish HD Association as their Youth Advisor, and then Youth Service Manager. From 2004-2010 I helped to develop a National Youth Service which now provides information and support to over 150 young people impacted by HD in Scotland! In 2010 I rejoined the University of Aberdeen to work on an exciting research project funded by the Scottish Government. It is called 'Sharing information with children and young people about genetic risk.' We are focusing upon two genetic conditions, one of which is HD.

I am not a family member and I don't have any close friends who have HD, however I have a strong commitment to working in this area, mainly because I have met some remarkable people over the years.

Good information and the right support can make a difference to the lives of young people and families impacted by HD.

The creation of HDYO has made it possible to reach out to young people all over the world. I am hugely excited by the global community HDYO has created for young people and I look forward to seeing it grow – and ultimately improve youth support all over the world!

My main recommendation to young people – talk to other people in the HD community. There is a lot of knowledge and experience out there, someone will have asked the same question or fought the same battle as you.

Rhona MacLeod **Board member**

Rhona is a consultant genetic counsellor based at St Mary's hospital in Manchester. She has been involved in genetic counselling and predictive testing for HD since 1992 and is Co-facilitator of the European HD Network Working Group, 'Genetic Counselling and Testing'. Rhona is strongly supportive of adolescents and young people having the opportunity to ask any questions they wish in relation to HD and feels that HDYO will be a terrific additional resource for young people.



Acknowledgement: www.hdyo.org

People at the Centre of Clinical Research — An Approach to Finding a Treatment for HD



Lisa M Stanek, Ph.D., is a Staff Scientist in the neurobiology research group at Genzyme Corporation. Dr Stanek received her B.Sc. (1999) from Union College and Ph.D.

(2005) in Neuroscience from Emory University in Atlanta Georgia. She trained as a postdoctoral fellow at Harvard University and Massachusetts General Hospital, where she performed research on the role of MicroRNAs in synaptic plasticity and cognitive function using transgenic mouse models. She joined Genzyme as a Staff Scientist in 2008 to work on Neurodegenerative disease initiatives with a focus on Huntington's disease.

She is currently evaluating gene lowering technologies including antisense oligonucleotides and viral gene delivery vectors for the treatment of Huntington's disease. Lisa has published 16 scientific research articles, 2 book chapters, and is a co-author on 2 issued patents in the area of biotechnology. She is a member of the Sigma Xi scientific research society and the Society for Neuroscience. Presently, she is responsible for leading the Huntington's disease discovery research project at Genzyme.

Lisa recently spoke to the Huffington Post.

"Imagine you are 18 years old and you've just learned the results of a genetic test indicating you have a mutation in the gene that is associated with the development of Huntington's disease (HD). This result would impact every decision you make from this point forward. Your expectations, aspirations and goals would all be impacted by the knowledge that you will develop this progressively degenerative disorder that will lead to the breakdown of your brain's nerve cells.

This is the story I heard from a young man who spoke at the very first HD conference I attended. I am a senior researcher in neuroscience at Genzyme, and have been leading the HD research program since 2008. I will never forget this young man's story and I keep him in mind every day as I work to develop potential treatments for this devastating disease.

People with HD develop symptoms between the ages of 30 and 50 -- during the prime of their lives -- and the patients and caregivers I've met over the years fuel my passion for HD research. Knowing that the work we perform in the lab has the potential to impact the lives of these patients is what motivates our team to work diligently to research and develop new therapeutic strategies.

I believe there is an important relationship between scientists and patients. As scientists, our goals are clear: to slow or stop the progression of this devastating disease, and provide patients with hope. Hope for a healthier future and a life without the challenges of their disease. The patients in turn provide us with the motivation to face highly complex problems in the laboratory and the determination to keep pushing forward despite obstacles and scientific setbacks. Their strength in the face of this disease is inspirational and makes any research hurdle seem surmountable.

We engage with HD patients directly and have ongoing conversations with advocacy organizations to help shape our scientific approach. This type of cross-functional collaboration provides us with a unique and sometimes unexpected understanding of the disease, beyond what we learn in textbooks and the scientific literature. Direct engagement with people living with HD guides both our research and importantly, the design of clinical studies. For example, while the motor manifestations of HD tend to be the most prominent and trigger a

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clinical diagnosis, patients tell us that the cognitive aspects of their disease are the most troublesome and debilitating. Clearly this information helps shape our ideas for a successful therapeutic strategy.

Research into HD has been a long-standing interest at Genzyme. We helped map the disease gene on chromosome 4, work that provided the foundation for the development of the first diagnostic test for the disorder. Currently, we are collaborating with Voyager Therapeutics and CHDI, one of the largest private foundations for HD research, on the development of a gene therapeutic strategy for treating HD.

Our scientists are inspired by the people they are able to impact through their work and scientific discoveries. While there is much more research still to be done, we are committed to continuing to work hard every day on behalf of all of the people affected by HD.

Acknowledgment: www.huffingtonpost.com/

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onset to 75 – and that’s pretty darn good right there,” Leavitt says. “I don’t think that’s an unreasonable goal.”

As news of the UBC clinical trial has spread within the HD community, some patients have been eager to volunteer – Leavitt says he has received calls from as far away as Louisiana.

But there are strict criteria that must be met and one of them is living close to the clinic. As well, it’s a double-blind study, so a percentage of the participants will be receiving a placebo. Even Leavitt won’t know which patient is getting the actual drug.

“Clinical trials are massively expensive, and developing drugs for brain disease is really, really hard,” Leavitt says. “Less than 1 per cent of drugs developed for brain disease ever make it as an approved drug. So, the fact so many companies are interested and so many drugs are moving forward is an optimistic sign that we’re getting close to things that will work.

“My goal is to not work on HD – because it will be fixed,” he says, smiling. “And then I will go work on something else.”

Acknowledgement: Kerry Gold, The Globe & Mail, 2nd August 2015 <http://www.theglobeandmail.com/>



Membership Renewal

Thank you to everyone who has renewed their membership for this year. We are also very grateful to those who were able to make a donation—your generosity is much appreciated.

For those who haven’t yet renewed, it’s not too late. A strong membership will ensure that the Association continues to be representative of, and relevant to, people affected by HD in NSW and Australia.

A membership form can be downloaded from our website www.huntingtonsnsw.org.au

Donations are always appreciated and are also tax deductible.



Huntington's New South Wales

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

AHDA (NSW) Inc

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

Our Mission

The energies and resources of the Australian Huntington's Disease Association (NSW) Inc are directed towards satisfying the needs of people with or at risk for Huntington's Disease and their families in NSW and the ACT by providing and/or facilitating delivery of a range of quality services.

Our Philosophy

People with Huntington's Disease and their families are individuals with equal value to all other members of Australian society, with the right to treatment and care by knowledgeable professionals and care givers, the right to appropriate support services and the right to have the best quality of life possible.

Our Services

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

Our Board

President: Brian Rumbold
Vice President: Deb Cockrell
Treasurer: Richard Bobbitt
Secretary: Amanda Dickey
Member: Felicity O'Neil

Association and Other Useful Contacts

Huntington's NSW

Robyn Kapp OAM
Executive Officer

Stewart Swales
Administration Co-ordinator

Pauline Keyvar
Fundraising & Marketing

Mark Bevan
Regional Family Support
Worker

Karen Bevan
Activities Co-ordinator

Huntington Disease Service

Dr Clement Loy
Director
Westmead Hospital
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Dr Sam Kim
Neurologist
Westmead Hospital
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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

Huntington's Unit
St Joseph's Hospital
(02) 9749 0215

Predictive Testing

Fiona Richards
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