HUNTINGTON'S DISEASE TASMANIA

Providing a voice for people with Huntington's Disease and their families

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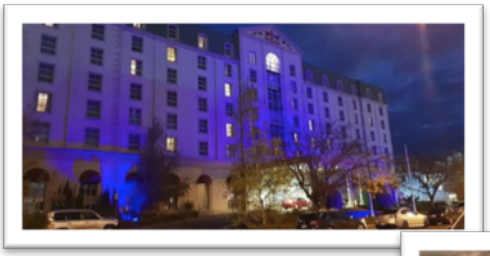

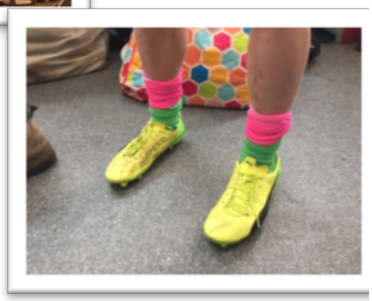

FOR MORE INFORMATION:

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hdtas.org.au

HDTasmania

From the President's Desk

Welcome to the Winter edition of our Newsletter.

It is a busy but exciting time to be part of Huntington's Tasmania as we embark on a new vision and branding to support our cause supporting all affected by HD in Tasmania. Our Huntington's Tas team are very excited to introduce you to our new logo designed by our talented young committee member Rebekkah McLean. The new colours and logo symbols were designed to represent every member of our HD family. Purple represents those who have Juvenile HD, blue represents adults affected by HD and green represents families and carers affected by HD. We believe it provides a fresh new look to support the rebranding of our organisation.

HUNTINGTON'S DISEASE TASMANIA

Huntington Tasmania participated for the first time this year in "Light it Up 4 HD. This annual event is a global initiative led by Huntington's Society of Canada to show support and bring awareness for HD. We are proud of our success with many iconic buildings and business lighting up across the state including those pictured right. We are already planning to increase our sites next year.

In May I attend the National CEO meeting hosted by Huntington's Queensland in Brisbane. It was a great opportunity to build relationships across all states and Territories, reinforcing the need to work together nationally, sharing information, resources and advocacy. The following day I was fortunate to attend the Planning for the Future 2019 Forum entitled "Looking to the future for people impacted by Huntington's Disease" hosted by Jan Samuels and her Queensland HD team.
Speakers included:
Catherine Martin-Executive Director, HDYO
Professor Julie Stout-Monash University
Dr. Robert Adams – Neurologist RBWH. Dr Michael Gattas, Clinical Geneticist-Queensland Health
Family members and Allied Health staff.

Recently we were able to finance two of our young family members to attend a camp on the Sunshine Coast organised by Huntington Queensland. The purpose of the camp is to provide an opportunity to learn about HD, form connections, share their stories and most importantly, to have fun. We were thrilled with the feedback from the particpants:
'I enjoyed meeting people for the first time who were effected by HD and not in my family. I wish I had known and had the opportunity to attend something similar earlier.'

'I feel like listening to other people's stories and sharing my own made it easier for me to talk about HD compared to when I first got here.'

'Testing – listening to everyone's stories was really helpful"

'I think it was a great opportunity to meet others going through similar issues to me. I just wish discussing HD was easier and that it was better known.'

By working as a community, helping each other, seeking support and advice and raising awareness, the wishes of our young HD participants can be granted. Together we can do it!

Warmest regards

Pam Cummings

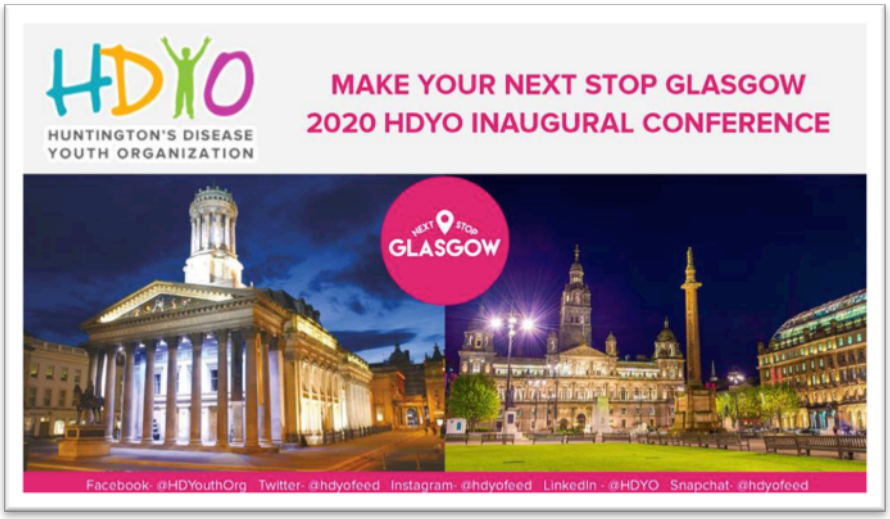
Our Condolences

We send our sincere sympathy to the family of Bronwyn Moran who passed away recently. Bronwyn was in the care of the staff at Emmerton Park Nursing Care Centre and we thank them for the loving care they gave to her, and to her family who will miss her so much.

We also send our condolences to the family of Andrew Conlon who recently passed away. We send our thoughts and prayers to his family at this difficult time.

HDYO Glasgow 2020

Excitement is building as the first ever International Young Adults Conference to be held in Glasgow Scotland in May next year builds momentum. This will be an amazing opportunity for young adults 18-35-years old to come together to share experiences and help to shape services and support for young people impacted by HD worldwide. Organizers are hoping to host 500 young Adults over 3 days. More information is available at info@hdyo.org If you are interested and need support to attend please contact the HD Tasmania office. It would wonderful to see some representation from Tasmania.



Thank you RACT

Thank you to the RACT Community Act of Royalty Program for accepting our application and to everyone who voted for Huntington's Tasmania over the April/May/June quarter.

Huntington's Disease Association of Tasmania came in 1st place! This means that we will receive a $3,000 donation.

This money will go towards helping our families in many ways including purchasing nutritional supplements, specially made sturdy iPads for those having communication problems, smoking aprons for protection, mobility items such as walkers, wheelchairs as well as other daily living aids and resource materials and manuals for medical practitioners, health clinics, service/care providers and families of sufferers.

Thank you again to everyone who voted and all involved at RACT.

Grab – a – Sav for Huntingtons

What a treat to work with North West Coast Football League once again this year to raise both awareness of Huntington's as well as some funds. The league donated $1 from each sav sold on the day to our association. We supplied the green and pink socks for the host teams - Devonport, Latrobe, Wynyard and Penguin to wear on the day. How good they looked!

Three of the four host teams played their games at their home grounds on Saturday 22nd June with Penguin to host and play their game on the 27th July. Saturday 22nd turned out to be a beautiful sunny day and was a great day for people to be at the football. This was an emotional game for some of the players, as they know a person living with Huntington's.

We are so thankful to the NWFL teams for partnering with us. Thank you to all who helped in any way to make this event a success.

Donations received:	Wynyard	$300
	Latrobe	$200
	Devonport	$200 - 300
	Penguin	Yet to play

Maybe it is time for us to spread our wings and approach the NFL to partner with us as well.

Research News:

How the Gene-Silencing Studies Changed My Outlook on HD

Nobody is guaranteed a long life. Some people's experience on this planet is going to be shorter than others', even if they do everything they can to live a healthy lifestyle along the way. Having grown up with the dark cloud of Huntington's disease (HD) over the family, I was fully aware of that.

Prior to the positive result on my HD genetic test, I tried to avoid educating myself on the condition very much. All I really knew at the time was that it affected the brains of people who were afflicted with it at a young age. To me, Huntington's disease was a death sentence, pure and simple. Why would I want to know anything more?

My genetic test result

As I mentioned in a previous column, my genetic test results were given to me via a telephone call from the genetics counselor. There was a week in between that call and my follow-up appointment with the geneticist to discuss the plan of action moving forward. That week was the worst I've ever experienced.

I was still under the belief that Huntington's disease was an automatic ticket to an early demise. I remember having thoughts like, "I'm not going to see my kids grow up," and, "I won't be growing old with my wife." It was a horrible period of time.

When the follow-up appointment finally arrived, the doctor shared a great deal of information with me, but one topic stood out. He mentioned that there were a number of exciting advances in Huntington's disease research that were already happening or in

the pipeline. He even went so far as to suggest that there may be a treatment available for me when I need it.

Me? I'm already in my 40s. Could that really be true?

My whole outlook on Huntington's disease changed

There was no time to waste, I needed to know more. No more ignoring the Huntington's disease elephant in the room out of fear. I began to read and learn as much as I could about the disease and all the exciting science and research surrounding it. A few weeks into this period of time, I attended an education event held by the Huntington Society of Canada at which they provided updates on the latest clinical studies that were being developed.

It was at this event that I began to learn more about gene silencing – more specifically, the study involving ISIS-HTT Rx (now known as the Genentech/Roche huntingtin-lowering therapy RG6042), which was in Phase 1 clinical study at the time. This was the first study to directly focus on the underlying cause of Huntington's disease: the mutant huntingtin protein. And it was to be administered to real people. Not mice. Not monkeys. People.

The hype and excitement surrounding this study, which is now in Phase 3, was palpable, and has continued to grow to this day. I embraced the excitement, and for the first time since learning the results of my genetic test, I was feeling hopeful. I realized the geneticist was being completely genuine when he said there may be a Huntington's disease treatment available in time for me.

My outlook changed because of the existence of that gene-silencing study. I experienced a real call to action and began to get more involved in fundraising and my local Huntington's disease community. But most importantly, I no longer felt the future was already written, with nothing ahead of me but a black tunnel. Now, there was light.

Let this science change your outlook, as well

An effective treatment for delaying the onset of Huntington's disease symptoms is close. Whether it be the gene-silencing method or another technique, it will come. Soon, there will be a treatment that can be taken orally (a pill), instead of through more invasive methods, such as lumbar puncture.

Allow yourself to follow the HD news and updates because there is a whole lot of good news out there. If you're like I was and think of Huntington's disease as an automatic death sentence, you will soon learn it is not.

Article written by Steve Beatty and published on June 6th 2019
huntingtonsdiseasenews.com

HUNTINGTON'S DISEASE NEWS

Research News:

Genetic Testing for Huntington's Declined Due to Lack of Effective Treatments, U.S. Study Shows

Most people at risk for Huntington's decide not to undergo genetic testing for the disease due to the lack of effective treatment – and because they can't unlearn the knowledge that they may have the neurodegenerative disorder, a study shows.

Researchers say choosing not to know if one is a carrier of the Huntington's gene is a decision that deserves the respect and understanding of doctors and genetic counselors, who nevertheless should offer them supportive counseling.

The study,"The choice not to undergo genetic testing for Huntington disease: Results from the PHAROS study," was published in the journal Clinical Genetics.

"Back in 1993, when the genetic mutation causing HD [Huntington's disease] was discovered, we anticipated that many people at risk would want to be tested, just to deal with the uncertainty, but that is not the case. Only about 10 to 15 percent of people who know they are at risk for HD have been tested since the test became available, and that percentage really hasn't changed much over time. This study shows there are important, relevant reasons why people don't want to be tested," Karen E. Anderson, MD, a professor at Georgetown University Medical Center and the study's lead researcher, said in a press release.

Huntington's is caused by an inherited mutation in the *huntingtin* (*HTT*) gene, due to expansions of DNA repeats (CAG) within the gene. Its inheritance is autosomal dominant, which means that only one mutated copy – inherited from one parent –

is sufficient to cause the disease. Thus, every child of a parent with Huntington's has a 50% chance of inheriting the gene.

Disease onset typically happens in a person's 30s and 40s. In more rare cases, onset occurs during childhood or adolescence, or even after the age of 80. The age at onset depends on the number of times the DNA repeat is expanded. The longer this expansion, the earlier the symptoms of the disease.

While no cure is available, there are treatments intended to alleviate symptoms.

Noting that as many as 90% of individuals who have a parent with Huntington's choose not to take a gene test, a team of researchers at Georgetown University Medical Center sought to find out why.

"Understanding the 'why' matters as new clinical trials testing therapies for people who haven't yet developed symptoms of Huntington's disease require participants to be tested for the HD gene to be included in the trials," the investigators said.

The team queried 733 potential Huntington's mutation carriers enrolling in a clinical trial about the reasons why they chose not to know their gene status. That trial, the Prospective Huntington At-Risk Observational Study (PHAROS) study, (NCT00052143), was carried out between 1999 and 2008 at several sites in the U.S.

As part of this study, participants gave consent for genetic testing with the condition they would not be told the results.

Most of them said the major reasons they chose not to undergo genetic testing were the lack of an effective cure or treatment (66%) and their inability to undo the acquired knowledge (66%).

Many were not concerned about the length of the testing process (61%) or the burden of participating in the test (59%). A majority – 56% of participants – felt optimistic that a treatment to improve symptoms would be developed within the next 10 years, while 53% believed therapies to delay disease onset would appear within that same time frame.

However, some (36%) were less sure about the prospects for a treatment that could completely prevent Huntington's disease from developing.
"This study shows us that, as new treatments develop that will require genetic testing for clinical trial participation, we should reassess attitudes about how

people at risk for disease approach this life-altering choice. It tells us that we should understand, and respect, decisions not to have that testing," Anderson said.
Understanding why people chose not to take the test also makes it easier for physicians and genetic counselors to bring up the subject with individuals at risk, especially if they are considering a clinical trial, she added.

"These data can promote understanding of how to counsel and support those who consider genetic testing for HD, by increasing knowledge about factors that go into this complex decision," the researchers said.

As many subjects worried for the lack of a cure or effective treatment, this suggests they should not undergo testing only to participate in clinical trials, which may provide no benefit in slowing disease or treating symptoms, the team said.

This is becoming increasingly important "as individuals are confronted with or reconsider the decision not to test, particularly if required to do so to participate in a promising treatment study," the researchers added.

According to the Huntington's Disease Society of America, there are about 30,000 people in the U.S. who are symptomatic and more than 200,000 who are at risk of developing the disease.

Article written by Ana Pena and published on June 13th 2019
huntingtonsdiseasenews.com

HUNTINGTON'S DISEASE NEWS

Save the Date

We welcome any member to join us for the Annual General Meeting in September.

Date:	Saturday 21st September 2019
Where:	Kingsmeadows Community Health Centre, McHugh Street, Kingsmeadows (Joan Marshall Room)
Time:	12-2pm
RSVP:	16th September to allow for catered lunch provided.

HD Telegroup

The Huntington's Tasmania carer's Telegroup continues every second Wednesday of the month from 6-7 pm.

This is a supportive group of likeminded family members who come together to share experiences, information, education and support. You can say a lot, say a little, or just listen. There is no pressure.

We welcome you to become a part of this supportive group.

To join us, ring Pam on 0417 309 818.

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NEWSLETTER

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