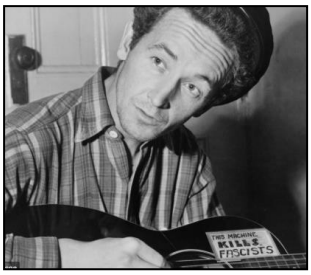
HUNTINGTON'S DISEASE TASMANIA

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

Inside this Issue:



FOR MORE INFORMATION:

03 6431 3403

hdtas.org.au

HDTasmania

From the President's Desk

Welcome to the Spring Newsletter for 2019.

It is a wonderful time of the year, time to come out of hibernation and enjoy the warmer weather.

It has been a busy few months in the office with lots of exciting events coming up.

Thank you to those who attended our AGM, which was held in September. A special thank you to Dixie Emmerton and to Hon Sue Hickey MP (pictured right) for her address. We also thank Hon Sue Hickey for presenting us with a $1000 cheque from the Government to continue our work.

It is with pleasure that I introduce our executive team for 2019-20 as elected at the AGM.

Chair of the Board -	Pam Cummings
Vice Chair-	Leanne House
Secretary-	Wendy Weeks
Treasurer-	Bek McLean
Board Members-	Paige Dale
Committee member-	Aleks Long

This is a strong committed team and we are excited to work for all who are impacted with Huntington's in Tasmania. It is wonderful to have young members joining our team; they are the future of our organisation.

Progress is continuing by our Solicitor and Website designer to complete our new Constitution and Website, hopefully we will be able to bring it to you in the very near future.

We have some exciting events happening and dates for you keep free.
We are excited that Professor Julie Stout has accepted an invitation to come and talk to us about the very latest HD Research happening both in Australia and overseas. Julie will be in Launceston November 22nd and Hobart 23rd.Please keep the date free and join us. Further information is available on page 10.

Warmest regards

Pam Cummings

Thank you

For many years, HD Tasmania has been fortunate to call this wonderful woman, Dixie Emmerton (pictured right), its Patron.

Dixie has enjoyed a successful career filled with several significant accomplishments, leading to her winning the Telstra Tasmania Business Owner in 2014. Throughout her professional career, Dixie's passion for business continues to drive her as a leader in Organisational Structures, Human Resources, Work Health Safety and Industrial Relations, as she works across 31 business sectors throughout Tasmania and the mainland.

Having attended a dinner, which talked about Huntington's Tasmania, Dixie and her husband Clive (pictured below right) started discussing ways that they could assist. What started with a sponsorship became a request to be the Patron for Huntington's Tasmania, which Dixie gladly accepted. Dixie states that her business mission is to provide excellent personalised service therefore this aligns with Huntington's Tasmania, which excels in both compassion and outstanding service delivery.

Clive Emmerton has also been a very supportive HD Board Director and Treasurer for the past three years. Together Dixie and Clive's contribution to Huntington's Tasmania has been invaluable and the strength, advice and mentoring given to this organisation cannot be easily measured.

It is with a heavy heart that we must bid farewell to this incredible couple. Clive and Dixie are relocating their Head Office to Queensland to be nearer to family. On behalf of everyone in the Tasmanian HD family, I want to thank them for their enormous contribution to our organisation, their support and their unshakable belief that together we can and will find a cure for HD.

The HD Spotlight

Noel O'Connor is currently relieving for Subha, as case manager for Huntington's disease NW.

Noel has lived and worked in Tasmania for the last 22 years, both in the West Coast and the North West Coast. He has worked as a RN in Aged Care, Psychiatric both inpatients and community and has recently worked as a case manager in Mental Health. Noel's main aim and goal whilst relieving Subha is to be a support with Huntington's Disease clients and their families. Noel has commented that it has been very good to meet with everybody over the 2 months and he looks forward to working with everyone who is involved with the care of our clients.

Insurance Breakthrough?

Words Lewis Kaplan. Republished with permission from HDNSW

Following work done by genetic consumer organisations in the UK, the Moratorium on Genetic Tests in Life Insurance came into effect in Australia from 1July 2019 and will end on 30 June 2024. This means that from 1 July 2019, there will be a temporary suspension on the use of genetic test results as part of an insurance application up to the value of $500,000 (for death and total permanent disability), $200,000 for trauma and $4,000 a month for income protection.

While this is nowhere near as generous as in the UK, it's a breakthrough of sorts. More details can be found at https://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-20-life-insurance-products-and-genetic-testing-in-australia.

If you don't have access to the Internet, here's the summary.
Private health insurance is not based on a risk assessment of your health. You will not be asked about genetic test results or your family history of health conditions.
Life insurance products such as cover for death, disability, trauma and income protection are based on a risk assessment (underwritten contracts). This may impact on the cost or terms of the policy.

You are not required to have a genetic test as part of the risk assessment when applying for life insurance. If you do have a genetic test, your life insurance company must not use your genetic test results (up to the financial limits set above) unless you choose to declare them.

You may be asked

- Your age, gender, current health and medical history, including any signs, symptoms and any diagnosed conditions you have had or continue to have, even if diagnosed through a genetic test.
- The results of medical test you may have had
- Any health conditions that have been diagnosed in your first-degree relatives (parents, children, brothers, sisters) only and the age they were diagnosed.

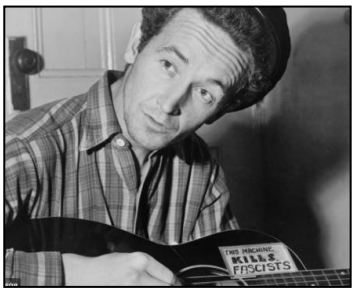
You are not required to provide any information about your first-degree relatives including their genetic test results if known to you, their name or date of birth.

The life insurance products are guaranteed renewable

- As long as premiums are paid, you do not have to notify the insurer of any change in your health or of the results of any medical or genetic test taken after your policy has started.

A genetic test undertaken after a policy has been secured that shows you have not inherited the faulty gene in the family, and you choose to declare the results, means that the impact of a family history my be removed from your risk assessment that informed the cost and terms of the contract. Contact your insurer to discuss this.
The moratorium does not apply to existing life insurance policies.
Involve your family doctor, medical or genetics specialist if necessary, in negotiations with the insurance company.

Woody and Marjorie Guthrie



Last month my husband and I attended a tribute to Woody Guthrie with his "Songs of Freedom" concert at the Theatre Royal in Hobart. It was an amazing afternoon of entertainment presented by Bruce Hearn and his band the Machinists. It was a celebration of Woody's life following his death 50 years ago from Huntington's Disease. He was one of the greatest folk singers of all time and wrote over 2,000 songs dedicated to social injustice, racism, bigotry and humanity. Among his most famous songs is "This Land Is Your Land."

It was following his death that his wife Marjorie started the first Committee to control Huntington's Disease in America. The following is a tribute to Marjorie Guthrie presented by her grand-daughter at the HDSA'S 33rd Annual Convention. It is a really lovely recount of how one person, driven by love and the quest for answers, started a global community. A full transcript is available at marjorieguthrie.com.

When my grandfather, Woody Guthrie, first became symptomatic with Huntington's, my grandmother had to invent caregiving. There were no resources for anyone with this rare disease. To be honest, the doctor's just didn't know enough about Huntington's to be helpful to families. And this is when my grandmother first became active.

Marjorie spoke to Dr. Whittier at Creedmore State Hospital in Queens, NY, where Woody spent the last year of his life. Dr. Whittier said if they just knew more families with HD, they could really make a difference. Most people were either misdiagnosed or they didn't know they were sick with Huntington's.

As Marjorie put it, "When Woody became ill I was told that the case was hopeless and helpless. Assuming that was so, I just said, well, I've got to live with hopeless and helpless. And if my children have the disease, I'm going to have to live with that too.

But after a long period, in and out of that hospital, I said to myself, "Why is it hopeless and helpless?" And with my kids now being old enough to be able to take care of themselves, I went to Dr. Whittier, who was in charge of Creedmoor Institute, where Woody was at that time, and said, "I want to help". And he introduced me to some other scientists and they said, "You might be able to help if you could just find families. We believe that this disorder is all over the world, it is hidden, families don't even know they have it, and those that do are so ashamed they won't tell anybody because there's a stigma attached." With that kind of help, I began to look for families with this disease and then founded the Committee to Combat Huntington's Disease. We found the disorder was much more prevalent than anybody believed possible."

In 1966, she put an ad in a NY paper asking for anyone who knew anything about Huntington's to please call her. One man called, his wife had it. They got together and talked about their experiences. Like how she sewed elastic into Woody's pants to accommodate his decreasing waist or how she put him in work boots so he could just slip his feet into them and not struggle with laces. The next week, she put another ad in and 2 more people called. They came to her apartment on West 72nd Street, NYC and this was the beginning of CCHD (the Committee to Combat Huntington's Disease).

Then she travelled around the country and eventually around the world, attending neurological conferences. She would set up a table with information on Huntington's and she stopped any doctor that walked by. She invited them to her booth and persuaded them to redirect their focus to Huntington's. She helped create local chapters around the US for families to have access to resources for patient care, education, and be help caregivers so that they could find support in a community of people who were living with this illness.

In 1977, she worked with President Jimmy Carter to create the Presidential Commission for Mental Health and neurological diseases. She believed that the government should help fund research and help Americans suffering from this disease. Basically, my grandmother brought Huntington's out of the darkness and into the light.

Okay, so, back to the present and HDSA's 33rd Annual Convention…
I was amazed to see the progress in all areas that my grandmother had to "figure out". There were tables lining the convention hall focused on every aspect of HD. There were tables that had special chairs and beds for patients who are living at home. There were information tables for patient advocacy, support groups for patients, caregivers, and those at risk, HD Trialfinder, Enroll HD, tables for different Centres of Excellence, and so much more. Through my work with Woody Guthrie Publications, I shared an exhibit called "The Note of Hope" with some of Woody's lyrics and photos.

The weekend was full of and educational presentations during the day and fun, bonding events in the evenings. Some of the symposiums & presentations were on topics like; living with HD, new research and trials for HD therapies, how to manage anxiety, family planning, and what are first symptoms. In the evenings, everyone bonded over the fun events HDSA planned. On the first night, there was an indoor carnival. The second evening had an incredible talent show with performances by the HD Youth Alliance, and the final night was the big gala with an awards program and a very moving candle lighting ceremony.
Marjorie organized people to come together and work on so many different aspect of Huntington's and here they were, each arm of the illness being focused on in its own spotlight. What began as a small grassroots movement was now a huge organization of people, all working together in different ways towards a cure and hope for the future.

A full transcript is available at marjorieguthrie.com.

Research News:

What Would Dr. Huntington Think Today?

HUNTINGTON'S DISEASE NEWS

Written by Steven Beatty APRIL 25, 2019

It's time for us to enter our Huntington's disease (HD) time machine and travel back to the year 1872. It is here that we find Dr. George Huntington sitting in his clinic's office handling a package. He runs his thumbs along the seam to ensure its closure, turns it over in his hands, and reviews the destination: The Medical and Surgical Reporter.

"Looks good," he says as he hands the package to the postman. "Please, have this to the outgoing mail."

"Yes, Dr. Huntington, sir," the postman replies with a smile. "Consider it done, sir."

The doctor sits back in his chair, looks up at a framed picture of his grandfather hanging on the wall, and smiles.

***

It's hard to imagine that the doctor who would have Huntington's disease named after him was only 22 years old when he published his famous treatise called "On Chorea " in 1872. At the time, the condition he documented wasn't known as "Huntington's disease." In his description, he referred to it as "hereditary chorea."

The young George Huntington was not alone in describing Huntington's disease. Both his father and grandfather before him were physicians and worked in the same community that contained a population of people suffering from what would come to be known as Huntington's disease. Most of the data collection and analysis that led to the paper being published in The Medical and Surgical Reporter so many years ago was completed well before the youngest Dr. Huntington was into his own practice.

If we were able to put George the third into our Huntington's disease time machine and bring him to today, I wonder what he would think about the disease and community that bears his name? I suspect it would be something like this:

He would be proud.
I have no doubt that Dr. Huntington would feel very proud of what his father, his grandfather, and he had achieved. When you think about the state of medical knowledge and understanding back in 1872, it's astonishing that he was able to so accurately describe HD, including the complicated genetics and hereditary nature of the condition. He was also clear in his understanding of the cognitive and mental health decline associated with Huntington's disease as well as the tendency for the condition to make its appearance in adulthood.

I'm sure the fine doctor would be impressed with the fact that, so many decades later, his description of HD has remained consistent and mostly accurate with what we know of the disease today.

He would admire the community.
I have no doubt that Dr. Huntington would look at the HD community and admire it greatly. He would see the associations that have formed around the world and be impressed at the level of support that we provide to each other and our families.

We could show George all the fundraising and awareness activities that are taking place every month of every year by members of this Huntington's disease community. I know I'm blown away by it, as I'm sure he would be, too.

He would be excited about the science.
Dr. Huntington would be excited about how close science is to an effective treatment for the root cause of HD. Given his history of learning about genetics from his father and grandfather, George would understand that we know so much about HD today and it will not be long before we beat Huntington's disease.

He would be looking forward to being retired to the history books.
Finally, I believe that Dr. Huntington would be looking forward to the day when we can all happily forget his name and retire it to the history books. He would be happy to see all the HD associations that host his surname close their doors because there is no longer a need for them.

That will be the day we cure this disease. You. Me. Us.

Our Condolences

We send our thoughts and love to the families of Judy Wickham, Mandy Deverell and Matt Barnes who sadly passed away recently.

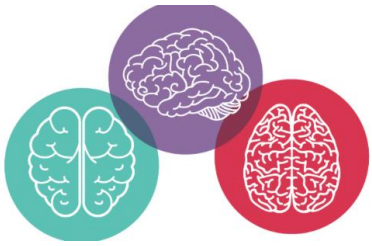
Understanding HD

Each newsletter, we aim to provide some answers to questions our HD Tas members have asked, as well as to offer some practical advice. Please let us know any questions you would like addressing in future newsletters.

What is Chorea?

Chorea is a movement disorder that causes involuntary, unpredictable body movements. Chorea symptoms can range from minor movements, such as fidgeting, to severe uncontrolled arm and leg movements. It can also interfere with:

- speech
- swallowing
- posture
- gait



What are the signs of chorea?

Chorea symptoms usually depend upon the condition causing it. A common symptom is "milkmaid's grip." People with this condition don't have coordinated hand muscles and will squeeze and release their hand, as if milking. Another symptom is involuntarily sticking out the tongue.

Chorea movements can be fast or slow. A person may appear to be writhing in pain and have no bodily control. These movements have also been called dance-like or similar to piano playing.

People with Huntington's disease can experience chorea symptoms such as involuntary jerking or writhing. Milkmaid's grip is also a common symptom.
Chorea is more common in people with adult-onset Huntington's disease. Over time, symptoms may get worse and movements may affect the legs and arms.

Home care

Chorea increases a person's likelihood for falls. Home care measures include installing nonslip surfaces on stairs and in bathrooms to prevent injury. Talk to your doctor about other ways to modify your home for safety.

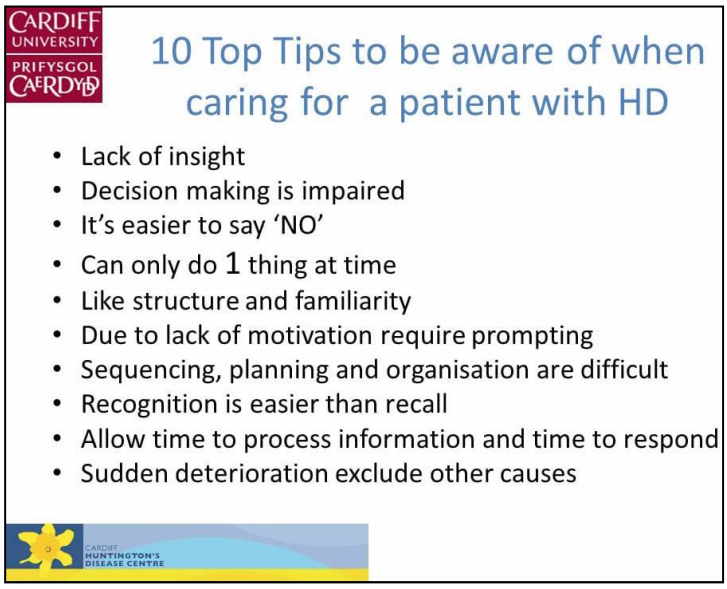
https://www.healthline.com/health/chorea

How can I support my family member with HD?

Caring for a family member or friend with HD can be challenging at times. The most important thing is to be patient and well informed.
Thanks to Cardiff HD Centre for these tips -

- Always listen when your loved one is upset and respond with care. Sometimes they just need you to be there.

- Apologize if you upset them and figure out what you can do to prevent upsetting them again.
- Remember to give them time to understand and let them respond whenever they are ready.
- Learn what helps soothe their mind like silence or what they like to focus their mind on like music, reading, walking, going out, baths, or food.
- Avoid speaking negatively around them.
- Educate yourself about HD.
- Remember that carers need a break sometimes too.



Save the Date

On November 22nd and 23rd Professor Julie Stout will be in Tassie to provide us with the very latest update on Huntington's Disease Research.

Professor Julie Stout has been Professor of the school of Psychology, Psychiatry and Psychological Medicine and Director of the Clinical and Cognitive Neuroscience Laboratory at Monash University Melbourne since 2007. Her special interest is in the research for a cure of Huntington's Disease.

2 Dates and Venues:

Launceston	Friday November 22nd 4-6pm **Wine and cheese provided**	Colonial Motor Inn 31 Elizabeth Street
Hobart	Saturday November 23rd 2-4pm **Afternoon tea provided**	Wrest Point Casino 410 Sandy Bay Road Sandy Bay Parking Available

This is a free event and a wonderful opportunity to find out more about HD. Please come along, bring relatives, friends and any other interested people. RSVP by 18th November for catering purpose to 64313403 or 0417309818.

HD Telegroup

Our monthly Telegroup continues on the 2nd Wednesday of every month from 6-7pm.

Our next guest speaker will be Jo Bourke, Genetic Councillor, Tasmanian Genetic Counselling Service

The next telegroup will be on Wednesday November 13th.

All are welcome. Contact the office 64313403 or 0417309818 for details.

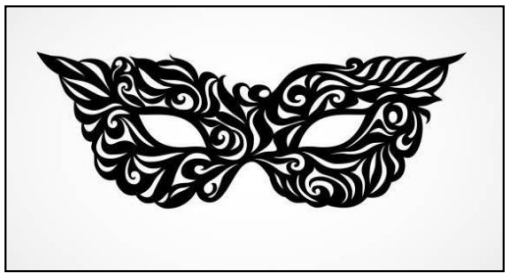
HDYO International Young Adult Congress 2020

This is the inaugural International HD Young Adult Congress.

A three-day event filled with education, support, connection, motivation and fun. Young people (18-35ish) from around the world are invited to convene in Glasgow May 9-11 2020.

For more information go to http://hdyocongress.org/ or contact the office 64313403 for more details.

Masquerade Ball 2020



We are so excited to announce our HD Gala Masquerade Ball will take place on May 16th 2020.

It will take at the Grand Chancellor in Launceston and will be a night to remember. More information will follow in 2020 newsletters.

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Australian Huntington's Disease Association (Tas) Inc.
Office 4 Brownell Place
11Wilson St.
Burnie Tasmania 7320

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