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HUNTINGTON'S NEWSLETTER

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DETAILS EMERGE OF FIRST HUNTINGTON'S DISEASE GENE THERAPY CLINICAL TRIAL

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FUTURE NEWSLETTERS

To continue to receive future issues of this newsletter, we require you to contact us by:

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Know someone else who would like to receive future issues?
We invite them to also contact us!

The next issue will be out mid February 2020. In the meantime we encourage feedback from readers on what you would like to see in the newsletter as well as your submissions for consideration by the editors to be included in future issues. Feel free to include photos. Please have these in by 18th December, 2018 to *admin@hdauckland.com*

Hagley Park, Christchurch

Research Article

DETAILS EMERGE OF FIRST HUNTINGTON'S DISEASE GENE THERAPY CLINICAL TRIAL

UNIQURE ANNOUNCES KEY DETAILS OF ITS PLANNED TRIAL TO ASSESS THE SAFETY AND ABILITY OF AMT-130 GENE THERAPY TO LOWER THE PROBLEMATIC HUNTINGTIN PROTEIN USING A 'SINGLE-SHOT' VIRUS DELIVERY SYSTEM

BY DR ANNA PFALZER JULY 17, 2019 EDITED BY DR ED WILD

At the recent Huntington's Disease Society of America annual convention in Boston, UniQure announced crucial details of its planned clinical trial for its experimental therapy, AMT-130. We previously wrote about AMT-130 here, so this article covers the basics and what's just been announced.

HUNTINGTIN-LOWERING GENE THERAPY IN AN NUTSHELL

AMT-130 is a huntingtin-lowering treatment, because it seeks to reduce production of the harmful mutant huntingtin protein, which is harmful to neurons and is the cause of Huntington's disease. A virus is used to deliver AMT-130 to the brain. Once there, the virus programs neurons with new instructions to make a huntingtin-lowering molecule. However, AMT-130 differs in several important ways from the anti-sense oligonucleotide (ASO) trials that are currently underway, run by Roche and Wave Life Sciences.

A virus is used to deliver AMT-130 to the brain. Once there, the virus programs neurons with new instructions to make a huntingtin-lowering molecule.

AMT-130 is a gene therapy, which means that it seeks to permanently change the genetic makeup of the treated patient. AMT130 doesn't try to delete the HD mutation – that is much harder to achieve than you might think. Instead, AMT130 utilizes a harmless virus known as an adeno-associated virus (AAV) to add a small extra piece of genetic code to neurons. That code is a set of instructions for making a huntingtin-lowering drug.

Once a neuron is treated with AMT-130, it will continuously manufacture additional copies of the new Huntingtin-lowering molecule. So while the neuron still contains the harmful HD gene, and still sends messages to make the mutant huntingtin protein, at the same time it will be producing a new set instructions to delete the huntingtin message. The result should be reduced production of the harmful protein, with a very long duration of effect – possibly lifelong.

WHAT ABOUT THE TRIAL?

UniQure announced some preliminary but important details about its planned trial in a statement to the HD community. Here's what we know so far. The focus of the first trial will be safety and tolerability – finding out whether there any harmful or unpleasant effects of receiving AMT-130 treatment.

UniQure also includes efficacy in the stated aims of the study: that means getting an idea of whether the treatment is doing what it's supposed to do. In the broader sense, that means slowing the progression of Huntington's disease. It's theoretically possible, but very unlikely, that this small first trial will show

evidence of slowed progression. A more achievable aim is to test whether treatment reduces huntingtin production, which we can now measure using techniques we've described on HDBuzz here.

The AMT-130 trial will be based at HD clinical sites in the Unites States. We don't know what sites or how many, yet. These will be publicly announced when they come online. UniQure hopes to begin enrolling patients before the end of 2019.

The trial will enrol just 26 patients with early symptoms of Huntington's disease. That means people with abnormal movements, within the first few years after diagnosis was 'officially' confirmed by a neurologist. The age range is 25 to 65 years of age.

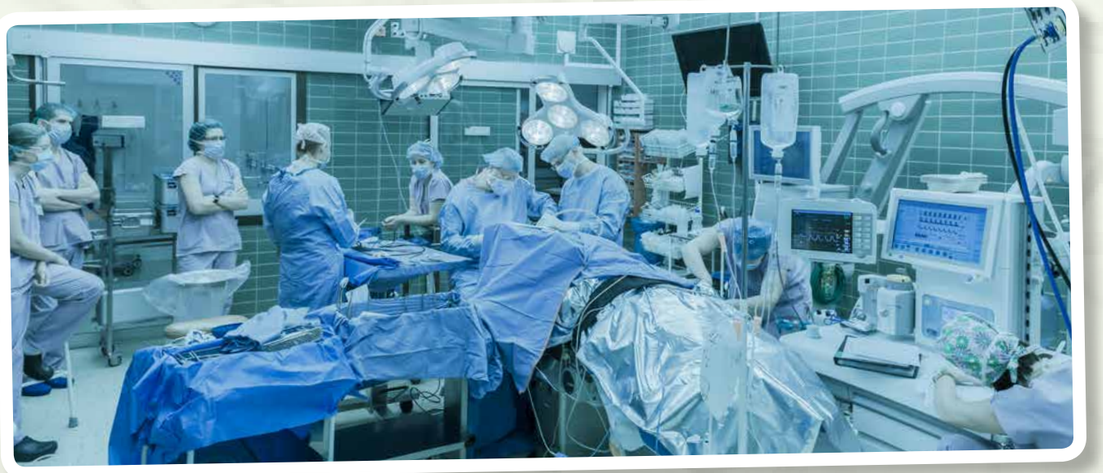
Unusually, uniQure has set a cutoff of 44 CAG repeats or more in the HD gene. About 50% of people with a positive genetic test for HD have between 40 and 45 repeats, so this cutoff may well exclude quite a few people. It's likely that uniQure set this cutoff to skew the trial towards people likely to progress more quickly, so that they can get a better chance of showing that AMT-130 slows progression.

Treatment with AMT-130 requires major brain surgery, which comes with risks of its own. This is true of all currently planned 'gene therapy' treatments.

The 26 patients will be split at random into two groups. 16 patients will receive active treatment with AMT-130, at either a low dose or a high dose. 10 patients will undergo "imitation" treatment, which could also be referred to as "placebo" or "sham" treatment.

The potentially big benefit of treatment with AMT-130 is that it's only performed once per participant, but it's a big deal. It involves brain surgery, carried out under general anaesthesia. Between two and six small holes will be drilled in the skull, and thin tubes called catheters inserted into the brain. The AMT-130 cocktail is then injected down the tubes into the brain.
Patients assigned to the imitation treatment will undergo general anaesthesia, and shallow holes will be drilled into the outer layer of the skull but won't pass right through it. No tubes or injections are involved.

The purpose of the imitation group is to help figure out whether any effects seen in the trial – be they helpful or harmful – are caused by the AMT-130 therapy itself, the placebo effect (the psychological boost that comes from being in a clinical trial), or the effects of undergoing anaesthesia and surgery.
Patients will be followed up intensively for 18 months, with investigations including MRI scans and lumbar punctures (spinal taps). Patients in the active group will then be asked to return for annual visits for 5 years.



Treatment with AMT-130 requires major brain surgery, which comes with risks of its own. This is true of all currently planned 'gene therapy' treatments.

AMT-130 will be injected into a deep part of the brain called the striatum, shown here in orange. The striatum is affected early in HD, but will the virus spread the huntingtin-lowering treatment far enough to produce benefits for patients?

The neurosurgical team will know which patients are in which group, but the patient and the HD trial team will not know. This means the study is double-blinded and helps minimize the placebo effect, enabling the trial to deliver on its scientific aim of figuring out whether the drug is safe and whether it works.

The upside for patients assigned to the imitation group is that 18 months after their mini-operation, if an independent review of the trial data is satisfactory, they will be invited to undergo full treatment with AMT-130 in a second, bigger operation.

RISK AND REWARD

The main potential advantage of AMT-130 is also its biggest potential drawback. It's a gene therapy, so a single treatment is expected to be permanent.

If everything works out as planned, it will be a treatment that could be given early after a positive genetic test result, that will have long-lasting, possibly lifelong benefits. It could slow progression or even delay the onset of HD without requiring repeated dosing.

AMT-130 will be injected into a deep part of the brain called the striatum, shown here in orange. The striatum is affected early in HD, but will the virus spread the huntingtin-lowering treatment far enough to produce benefits for patients?

However, if the treatment turns out to have harmful side-effects, these could be long-lasting too – and there is no way to switch off the treatment once it's been given. As a purely fictional example, what if the treatment for some reason causes a worsening of movement control, an acceleration of the person's Huntington's disease, or a permanent feeling of nausea? Patients might be left with major symptoms or even disabilities. The medical team would do everything they could to improve things, but removing the treatment or switching it off won't be an option.

Another important detail is that AMT-130 is designed to reduce production of both forms of the huntingtin protein – not just the harmful mutant form, but its innocent 'normal' sibling, which scientists call 'wild-type'. One concern is that reducing wild-type huntingtin in the brain of adults with HD might come with risks of its own,

which could eclipse any benefits from lowering the mutant protein. These concerns come largely from experiments carried out in mice, which all have major differences from human patients, and at the moment the actual effects of lowering wild-type huntingtin in patients are unknown. Important insights on this will hopefully come from the two ongoing huntingtin-lowering programs involving drug injections into the spine: Roche's RG6042, which lowers both forms of the protein, and Wave's Precision-HD program, which is attempting to lower the mutant form selectively.

AMT-130 has been tested in animals, and would not have been permitted to proceed to a human trial if unacceptable risks had been discovered. But only humans can tell us what benefits and harms might be seen. On top of the risks of surgery, patients considering volunteering in this trial can expect to be thoroughly counselled about the possible risks, without any firm expectation that they will benefit personally from taking part. Such volunteers will be asked to undertake significant sacrifice on behalf of others - those that volunteer for first-in-human trials are among the HD community's greatest individual heroes.

AN IMPORTANT ADVANCE

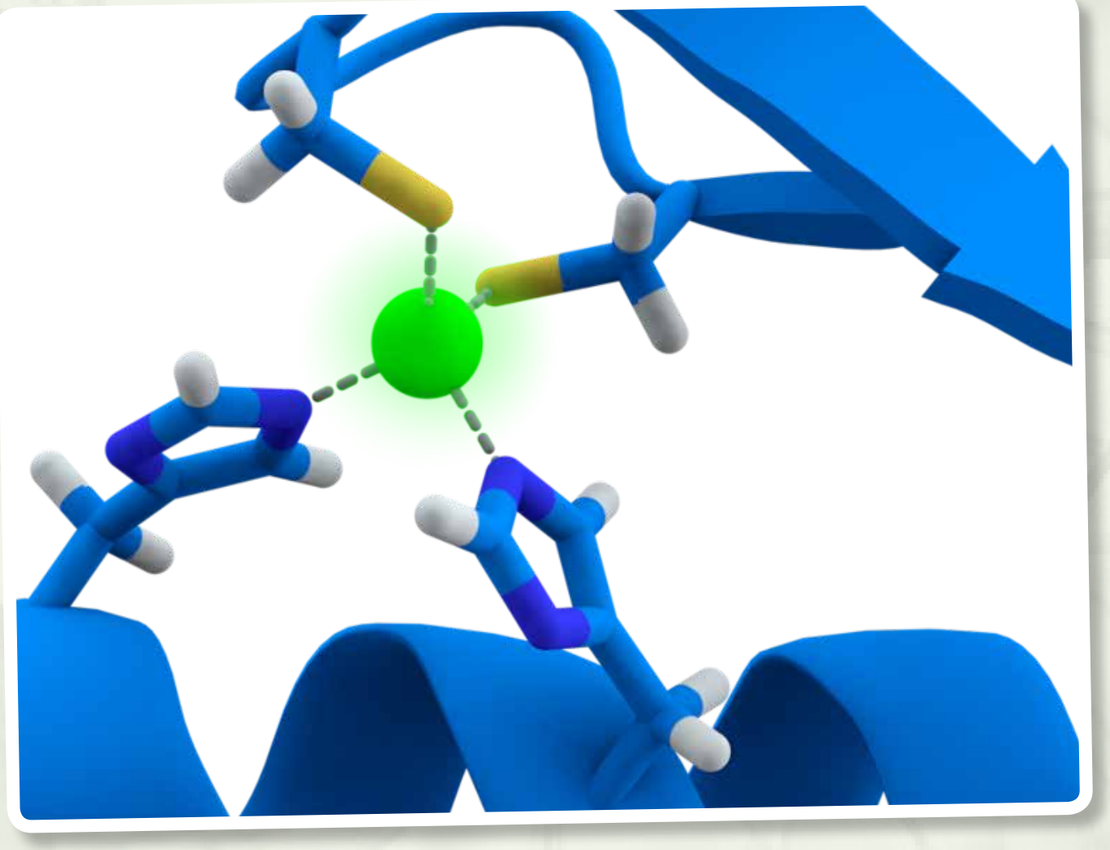
Here at HDBuzz, our favourite cocktail is called Substantive Hope. It's equal parts optimism and realism. After our previous reporting on huntingtin-lowering therapies, we've received some feedback that we're being too positive, and some that we're being too negative (the word "HDBuzzKill" has even been bandied about, and we're OK with that). Perhaps this means we're getting it about right – but it's up to you to decide.

We encourage all readers to get their information from multiple sources. Our 'Ten Golden Rules' article, published in 2011, might help you cultivate a mind that's open to cool new ideas but healthily skeptical towards hype. We are unashamedly in favour of HD family members volunteering for research projects including clinical trials: this is the only way we will ever make real progress in the fight against Huntington's disease. We encourage anyone thinking of volunteering to weigh the risks and benefits and seek advice from smart people you trust, before signing up.

Our take on AMT-130: the first huntingtin-lowering gene therapy trial has the potential to pave the way for a new generation of truly revolutionary drugs. Those taking part are no less brave than the astronauts who stepped onto the surface of the moon almost exactly fifty years ago. At significant personal risk, they will volunteer to take a not-so-small step into the unknown, in the hope of producing a giant leap for HD families.

We'll publish further updates about this and other huntingtin-lowering programs as they develop.

Anna Pfalzer declares no conflict of interest. Ed Wild is employed by University College London and works with multiple commercial companies to help them develop HD treatments: he has undertaken consultancy work and/or his team has received research funding from Roche, Ionis, Wave Life Sciences, UniQure, Mitoconix, Triplet and Loqus23. He team has undertaken an unpaid research collaboration with uniQure, the subject of this article. He has no financial interest in the outcome of this therapeutic program.



Glossary

huntingtin protein The protein produced by the HD gene.
clinical trial Very carefully planned experiments designed to answer specific questions about how a drug affects human beings
anti-sense The half of the DNA double-helix that is mostly used as a backup, but sometimes produces message molecules
wild-type The opposite of 'mutant'. Wild-type huntingtin, for example, is the 'normal', 'healthy' protein.
efficacy A measure of whether a treatment works or not
neuron Brain cells that store and transmit information
placebo A placebo is a dummy medicine containing no active ingredients. The placebo effect is a psychological effect that causes people to feel better even if they're taking a pill that doesn't work.
magnetic resonance A technique using powerful magnetic fields to produce detailed images of the brain in living humans and animals
ASOs A type of gene silencing treatment in which specially designed DNA molecules are used to switch off a gene
AAV A virus that can be used to deliver gene therapy drugs to cells. AAV stands for adeno-associated virus.

AUCKLAND & NORTHLAND

Kia ora everyone!

On behalf of the HD Association, I am pleased to report that this first half of the year has been an incredibly productive one within the community. I had the privilege of attending and holding a booth at the annual Brain Day event - which was held at the University of Auckland. Our very own patron, Sir Richard Faull was there to present about "The Magic and Excitement of the Human Brain". It was great to see some familiar faces from the HD community attending and participating in these educational events.

We also attended the ATSNZ Expo to find out about any new assistive technology that would benefit our HD people.

In addition to this, I have had the privilege of taking some of our community members to special shows including the live musical production of Aladdin. The tickets were generously donated to us and our two lovely ladies thoroughly enjoyed their time.

Thanks to the Southern Stars Charitable Trust, I also had the opportunity to take a group of youth to a production of Robin Hood. Another great show for which the kids loved.

It is coming up to being a year since joining HDA. I continue to make my regular community visits and am slowly getting to know more of you all. I look forward to what the rest of the year has to hold.

– Cheenee

A huge thank you to the Mt Wellington foundation whose donation made it possible for us to hold the HD Big Day out at Auckland Zoo again this was a great success we were able to offer 300 free tickets for families/Whanau to a have a great day out together. Sir Richard Faull and his family/whanau also join us for the fun day and gave everybody an update on the lasted research. We also had our international HDYO Executive Director Cat Martin Join us and tell us about the first HD congress for young adults (please see back page for more details).

We continue to visit families/whenua in their own homes, support our residential providers with teaching session and offering direct contact with the Regional Huntington's Service we attended clinic in the four DHBs Waitemata, Auckland Counties Manukau and Northland to support this Regional service.

– Jo

Warm greetings everyone, nice to meet you! My name is Andrew and I have just recently embarked on my PhD journey into the Huntington's disease world. Over the last 2 decades, we've made significant progress in our understanding about Huntington's disease, we know the gene responsible, we can accurately diagnose people (many many years before the symptoms manifest) and provide meaningful and useful advice for families that present with the disorder. However, one area that has been eluding us for all these years is the exact mechanisms that give rise to the disease, what makes a non-HD individual different from an HD individual? This forms the core of my project, finding out the exact mechanisms that lead to disease onset.

Through a collaboration with Fudan University in Shanghai, China we will be employing a brand new, state of the art technology called single cell RNA-seq where we characterise all the RNA molecules (RNA is a the step down from DNA and is responsible for the expression of genes) in the human brain between a person with Huntington's disease and a person without Huntington's disease. By doing so, we can then pinpoint the differences in the genes being expressed and characterise a molecular mechanism that leads to disease onset. I'm super excited to see where this can lead to.

– Andrew

WAIKATO

Kia ora and Welcome from the Mighty Waikato!

I hope everyone is keeping warm and dry this winter. We are now midway through and I am already looking forward to summer rolling around again.

We observed HD Awareness month in May with a display in the Hamilton City Library and an information stall at Chartwell Shopping Centre. Many thanks to the volunteers who helped on the day, we greatly appreciate your support. It was disappointing that we were not able to participate in "Lightup4HD" this year due Anzac Parade Bridge being under maintenance.

Recently I was invited to dinner at The Cambridge Lions Club, where I witnessed a moving presentation by Leanne Knox, (Co-Chairperson of HDYONZ), who spoke about her family's experience with HD. I also had the opportunity to speak about how MS Waikato supports our HD community and express my gratitude, on behalf of MS Waikato and our families, for their kind donation that funded our HD Family Day Out in April. It was an honour to share what the donation meant for our families – to have family fun together, participating in sports and activities in a safe and encouraging environment and having the opportunity to connect with others who are navigating the challenges and complexities of Huntington's disease. It was such a wonderful success and we are excited to announce that our HD Family Day Out for 2020 has been booked. **Keep Saturday 22nd February 2020 free!** Due to holding it slightly earlier in the year we are able to have a greater choice of activities, it should be warm enough for us to try some water based activities.

Our next HD Education Evening is now in the planning and is scheduled for **Wednesday 4th December 2019,** so circle the calendar. This year we have Mr Matt Phillips, Neurologist, Waikato Hospital presenting. Mr Phillips has been instrumental in establishing the HD Clinic at Waikato Hospital, we are very excited about this new initiative as we believe it will be very helpful for our clients and families and further enhance the relationship between community support and medical care. If any Waikato-based patients haven't been seen at the HD clinic and would like to, please ring me on 07 8344745.

Please also contact me on 07 8344745 to register for the HD Education Evening and 2020 HD Family Day Out.

– Tracey

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HAWKES BAY

What's been happening....

Hello from Hawkes Bay and Tairawhiti!

We launched in to 2019 with a very well attended BBQ lunch on January 12th, once again generously hosted by Selena and Johnny in their lovely garden. John and his son had kindly set up a big marque as Hawkes Bay temperatures had been nudging 31C in the preceding days, however Saturday arrived with a pleasant breeze and 23C so we had a great time together with everyone bringing along something to share.

Hawkes Bay produce in summer is unbelievably good so impressive salads arrived plus bowls of fresh raspberries, strawberries, trifle and other delectables. Thanks to everyone for making it such a memorable day and especially to Johnny and Selena for all the behind the scenes work you do to make the BBQ such a success.

For our next social occasion, in April we enjoyed a Devonshire tea (and coffee) at the Old Customhouse Building sited in the old maritime precinct of Ahuriri, Napier. This was an excellent venue as we had the place to ourselves and parking is at the door. The sun was shining and the gourmet sandwiches and scones were well received, not to mention the petit fours….

So you may be thinking that all we do is socialise and eat in Hawkes Bay. Well, here are some words of wisdom from peace activist and author Benedictine Nun Joan Chittister, who in May this year was interviewed by Oprah Winfrey.

'Hospitality means we take people into the space that is our lives and our minds and our hearts and our work and our efforts. Hospitality is the way we come out of ourselves. It is the first step towards dismantling the barriers of the world. Hospitality is the way we turn a prejudiced world around, one heart at a time. And in the Hawkes Bay, we like doing that."

Of course, not everyone can make it to our social gatherings so keeping in touch with those that are working, unable to travel or live rurally continues to be an important link.

I have been fortunate to have had two trips overseas this year and would like to thank Jeanette Wiggins from Wellington for providing advice during my absence. Jeanette and Karen Evans in MidCentral are great work colleagues and share their knowledge most generously.

The lack of suitable residential or home support care for younger people with HD continues to be challenging both in the Hawkes Bay and Tairawhiti DHB catchments. Forging strong links with the community support team members is vital and the long term conditions outreach nurse model used by Three Rivers Medical Practice in Gisborne is to be commended.

And now to plan our next get together!
Until next time,

– Jocelyn Pack, RN

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TARANAKI, WHANGANUI & MANAWATU

Kia ora everybody,

My days are racing by and here we are into the second half of the year in the midst of winter. I hope your winter weather hasn't been too taxing so far. Driving conditions are tougher and the roads are so busy it can be a trying experience getting from A to B.

I know some of you are not as confident with driving as you once were so minimizing outings in your car, especially in bad weather is a good idea and asking someone else to pick you up for that trip to the shop or appointment. I'm happy to help in this regard where I can. Supporting your independence for as long as possible is my aim.

Social activities slow down in colder weather but I have noticed a revival in mid-winter Christmas celebrations and Martariki celebrations are also gaining ground. I'm able to have fairly regular cafe get togethers with some people for a coffee or hot chocolate for no particular reason, which is great.

I've met a number of people with newly diagnosed HD this year and thank them for their forthrightness and trust in the knowledge I can impart. When facing the future as newly diagnosed or the stress of being at risk, it's good to talk. The important recent research into more advanced treatments is keeping us quietly excited and eager to talk about it. A growing awareness of Huntington's through mentions in the media has prompted discussion with interested people in the community as well.

Amaryllis House in Lower Hutt has continued to be a welcoming place for people from my area to stay for respite. Their understanding care, in a warm welcoming environment has been very much appreciated by families.

Please feel free to contact me if you need help or information, support and a listening ear, I'm here for you and want to assist.

– Karen

E: kevans.wellingtonhda@hotmail.com P: 027 496 6500

What's been happening....

WELLINGTON

Kia ora everyone!

It has been a busy first half of the year in Wellington. There have been a number of new referrals and new residents transitioning into Amaryllis House

We had a very successful movie fundraiser in May where we saw Red Joan, and we have just held a Karma Keg event where we benefit from the sales of a keg of craft beer donated.

Both events were well attended and it is a good chance for families to meet socially and support us. The information from Disability Support Services, Ministry of Health, along with the changes in COGS funding certainly make funding challenging for all charities.

I have been to Nelson twice this year and visited some of the facilities that we have clients in to give presentations to staff. It is great to be able to meet with so many carers and residents, along with having lovely sunny days in Nelson.

I continue to work closely with care providers and other agencies to support clients in their own homes. This is often complex requiring a number of agencies to get things right on an individual basis and it is difficult to advocate for what is necessary when there are continuing pressures on finances in all areas.

The makers of The Inheritance, Bridget Lyon and her partner Jeff McDonald have received funding to make another documentary which they have just started. We are fortunate to have such skilled filmmakers in our community telling our stories.

Here's hoping the rest of winter is not too cold and we can look forward to summer and a good rest of the year. For those that haven't seen it, The Inheritance can now be seen free on You tube https://www.youtube.com/watch?v=sdvRfcWf5lw&t=14s.

– Jeanette

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CHRISTCHURCH

Greetings from Christchurch,

It has been a very emotional time for the people of Christchurch with the events that unfolded on March 15th. It did remind us all that life is important and the right to live your life no matter what is wrong with you or who you are, it is your right. No one should have the power to take that away from you.

Christchurch stood up to this with a strong message going out to everyone and I think that has made us all a little stronger, more accepting and hopefully more understanding. Kia Kaha – Stay strong.

The Christchurch HD Association held there AGM in June this year. While we only get small turnouts to these it is always good having the chance to tell those present of the good work that the association is doing out there.

We were fortunate to have Emma Burnip as our guest speaker this year.

Emma is studying towards a PhD investigating swallowing impairment and rehabilitation in Huntington's Disease. Emma is a qualified Speech and Language Therapist from the UK. Emma has been inspired by a lack of rehabilitation options for progressive neurological conditions (particularly Huntington's Disease), and her PhD aims to investigate skill-based training in this population. Emma has presented the findings of her systematic review evaluating existing research of rehabilitation in Huntington's Disease to the world dysphagia summit, (Barcelona 2017). The next part of her project will evaluate appropriate outcome measures and the feasibility of a skill-based swallowing therapy for individuals with dysphagia caused by Huntington's Disease.

Emma has also been seconded onto our Youth Team. Welcome aboard Emma!

Our Big day out this year was a visit to the Antarctic Centre which we held at the beginning of July. This saw the families and clients enjoy an afternoon of fun and learning with lots of pats with the Husky's who loved all the attention.

The Hagglund ride was enjoyed by many including an 85year old grandad.

This was a great afternoon outing and was enjoyed by everyone who came.

Our thanks to the Christchurch Antarctic Centre who gave us a reduced price so our families could enjoy this outing.

The support that families give each other is encouraging, no one knows better than someone also walking in the same shoes how you are feeling or the weight of the worry. This support comes in many forms with a random text, email, telephone call or a visit from Maggie.

Maggie Jury is our eyes and ears in the community, she sees the need and tries to get an outcome for the family/person that will make things a little easier or improve it. We rely on her to bridge that gap between us and the HD families which she does very well, almost seamless at times and does not necessarily get the recognition for it. So on behalf of the association and families we thank you Maggie for all that you do every day without question and often without thanks.

Exerts from my Chairperson Report for the 2019 AGM

Maggie's role in our HD families life's is often critical, timely and very beneficial, Maggie's role has evolved over time but for us all her empathy, sound judgement, professionalism and "never give up attitude" is what our families have come to rely on, the family's needs are meet in a timely manner due to this.

The way she talks from her heart about the many struggles and challenges that the families face on a daily basis I hear the passion, the frustration and the triumphs and know that our families are all in very good hands.

Maggie on behalf of us all - Thank You for what you do, for not accepting No, as an answer and for always having the families best interests at heart.

Te Ruru, Strathearn, St John of God and The Village Palms

These facilities continue to provide excellent care for our loved ones, there are some wonderful staff who do an incredible job seeing to our loved ones daily needs.

To these teams who provide 24 hour care, who go home exhausted at the end of a shift, thank you all, for what you do on a daily basis.

These teams take over when it is too hard for us at home, when we can no longer look after our loved ones safely, when their needs are past our capabilities.

We all know how quick these needs can change and how HD takes many turns and provides many challenges, the daily struggles and how the ever changing progression of Huntington's makes things very hard at times.

We know how exhausting the repetitive HD behaviour is to the carer and family

So to the staff at these facilities we thank you for taking over and providing the care that we their families are no longer able to provide

Thank you for everything you do for our loved ones.

Well that's it from Christchurch, keep warm, winter is nearly over.

– Dianne

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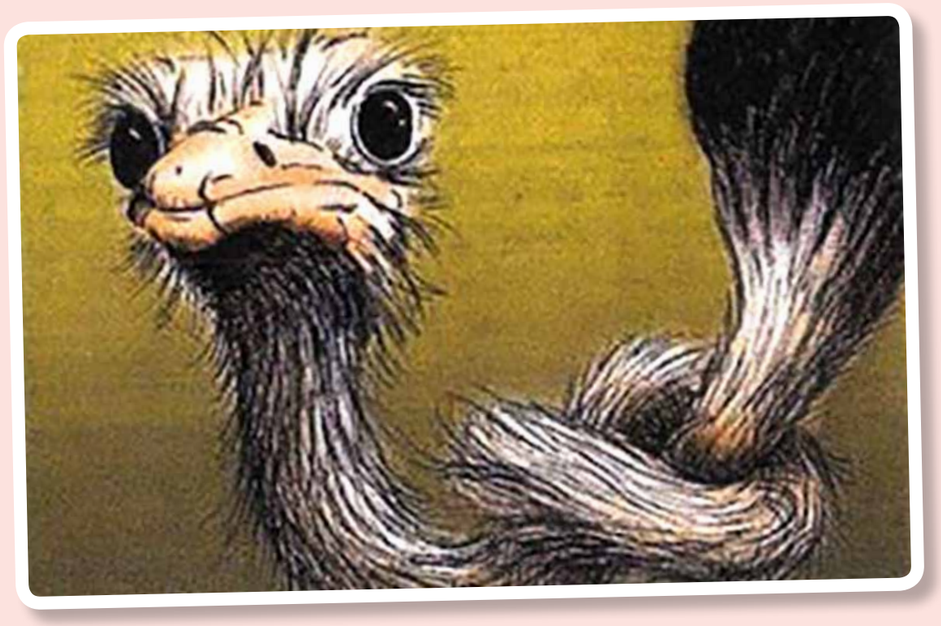
SWALLOWING TRAINING RESEARCH RECRUITING NOW

DO YOU HAVE SWALLOWING PROBLEMS?



Swallowing problems such as coughing or choking during mealtimes can lead to food or drink going down the 'wrong way' which can cause pneumonia. There are currently no therapies to improve or slow the decline of swallowing problems in HD.

Our research is evaluating a new swallowing training using a computer game for 2 weeks. If you would like more information, please contact Emma Burnip (PhD researcher) on 03 369 2385 or email emma.burnip@pg.canterbury.ac.nz

We look forward to hearing from you!

Recipe

ROASTED SWEET POTATO MASH RECIPE

Ready in **60 minutes** | Makes **6 servings**

INGREDIENTS

- **125 mL** (½ cup) Vanilla Ensure® Regular
- **680 g** (1 ½ lb) sweet potatoes, peeled and cut into 1-inch pieces
- **1** large baking apple, peeled, cored, and cut into 8 pieces
- **10 mL** (2 tsp) fresh ginger, grated
- **1 mL** (¼ tsp) ground cinnamon
- **½ mL** (⅛ tsp) ground cardamom
- **2 mL** (½ tsp) salt
- **5 mL** (1 tsp) vegetable oil

DIRECTIONS

1. **Preheat oven to 200°C (400°F).**
2. **In a medium oven-safe baking dish, combine sweet potatoes, apple bits, ginger, cinnamon, cardamom, salt, and oil. Toss together.**
3. **Bake for 20 minutes, stirring occasionally. Bake an additional 15 to 20 minutes or until the potatoes are soft and slightly caramelized. (If potatoes are sticking to the pan, carefully add a few tablespoons of water.)**
4. **Transfer mixture to a mixing bowl, add Ensure® Regular and mash with potato masher. Serve hot.**

Nutrition facts

Serving size: 75 mL (⅓ cup)

Calories	190
Fat	3 g
Sodium	250 mg
Carbohydrate	25 g
Dietary fibre	3 g
Protein	3 g

Tip

Try this recipe with butternut squash or turnips.

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CLING TO JOY

A charity project with the goal to raise money and awareness for Huntington's Disease.

IN 2013, KATE FOUND OUT THAT HER MUM HAD HD. IN 2014, AT THE AGE OF 23, SHE TESTED POSITIVE FOR THE DISEASE AS WELL.

Kate is an Auckland based wife, mum and graphic designer. This year (2019) she decided to go public about her family history of Huntington's Disease. After years of keeping HD a secret, she wanted to do something to help. She wanted to use her creative skill and passion to create something that would spread the word, enlighten and inspire. And so she created **Cling to Joy.** A design that told a story and could be worn on all occasions - and not just by people affected with Huntington's Disease. Something that was more than just a product to buy for a cause. Something people would actually want to wear that represents Huntington's Disease in a hopeful and uplifting way.

Cling to Joy is about desperately holding on to every happy moment and making the most of every day. It's about how no one, even people not affected by HD, is promised tomorrow. The symbolism of the sun rise and sunset represents the hopeful start of a new day, a step closer to finding a cure.

The design, at first glance, is symmetrical but looking closer, there are irregularities. This represents the changes in the brain that happen once the symptoms of HD set in. The before and after. But it is also a reminder that people with HD are still the same person despite the changes they go through.

CLING TO JOY IS FOR EVERYONE.

This is about raising awareness. About shining a light on the symptoms of Huntington's Disease. About sharing the general mindset that families with HD have to adopt to get through life.

It's about clinging to every joyful moment.

FOR EVERY PURCHASE MADE, YOU DONATE TO SUPPORT FAMILIES WITH HUNTINGTON'S DISEASE THROUGH THE HUNTINGTON'S DISEASE ASSOCIATION (AUCKLAND) INC.

Huntington's Disease Association (Auckland) Inc. was formed in the early 80's to provide support for those living with Huntington's disease. Their services include:

+ Ensuring those who need it get the right support services and medical attention;

+ Enabling others to understand the disease; and

+ Furthering research to manage and cure Huntington's Disease.

HDAUCKLAND.COM

FOR MORE.. www.kate-key.com/thehdqueen thehdqueen@gmail.com thehdqueen