

HUNTINGTON'S DISEASE ASSOCIATION NORTHERN IRELAND



Families at the heart of all that we do

AUTUMN NEWSLETTER 2017

Dear members and friends,

This has been a tough year to say the least. It's almost a year since our last newsletter because we simply didn't have the money to spend designing, printing and posting it. We had to cut back on our services and use every penny we had to keep our staff available to provide much needed support. Frankly we were worried that we would have to close our doors.

We as a community have also suffered great loss this year as have my family and I, with loss of my husband, Pip, to HD. However in times of great sadness we have found strength in our community through our HD family and friends. We have shared our stories and helped each other through the dark days. I am grateful to Errol and Angie for being there at the end of the phone and in bringing us together through the support groups which I know have been a true lifeline.

While Angie and Errol have focused on members, Sorcha and your trustees have been working tirelessly not only to save HDANI in the midst of funding cuts, the dissolution of the Assembly and the impact of Brexit, but to strengthen it.

I am happy to report that we have succeeded with enough funding secured to ensure and expand our services for the next three years. So thank you to our staff, volunteers and to you, our members, who have helped make HDANI stronger than ever.

See you soon, Jennifer



Jennifer met Deirdre Simpson at our recent Awareness Event with charity partner the Co-op Antrim Road

SUPPORT GROUPS

Errol and Angie, our support workers, facilitate monthly support groups which are open to anyone affected by HD - patients, carers, those at risk of inheritance and those bereaved. The groups are very friendly, informal and led by the needs of the members with guests often attending to provide specific information or support.

Belfast Support Group 2-4pm, 1st Floor, Ulster Bank, Donegal Square
Ulster Bank are donating use of their space for our support group but for security reasons will require all attendees names 24 hrs in advance so please let Errol know if you intend on coming. Sept 7th, Nov 2nd, Dec 7th

Omagh Support Group 8-10pm, Wave Trauma Centre, 18 Holmview Avenue, Omagh. Mon 11th Sept, Mon 13th Nov

Armagh Support Group 6-8pm, Ard Mhacha Care Home, Desert Ln, Armagh BT61 8AR
Thur 21st Sept, Thur 19th Oct, Thur 16th Nov

Limavady Support Group 8-10pm - Private dining Room, The Classic, Main St, Limavady
Sept 14th, Oct 12th, Nov 9th, Dec 14th

Contact Us:

Sorcha Mc Guinness / Chief Executive
Errol Walsh / PT Support Worker
Angie Smyth / PT Support Worker

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HDANI ANNUAL CONFERENCE:

Sharing, Learning & Connecting

REGISTER NOW

Duncairn Arts Centre, 174 Antrim Road, Belfast

Friday 6th October

Registration and refreshments from 10.15am - starts at 11am

Keynote speaker on the latest research developments, exhibitors, workshops for professionals, patients and family members, a focus on PGD (family planning), and an opportunity to connect with other HD family members.

£5pp for HDANI members (limited overnight accommodation available for an extra £30pp)

£25pp for health and social care professionals

Payment can be made in advance or on the day and includes refreshments, lunch and CPD certificate for professionals.

Bookings can be made via support groups or contact us on info@hdani.org.uk



REPORT FROM THE CEO

Dear members and friends,

I will echo Jennifer's words - it's been a very tough year. I have been busy filling out application after application for funding and banging on the doors of politicians and policy makers in an effort to save HDANI all the while facing redundancy. But we have prevailed. After nine months of living very lean and preparing for the worst we have triumphed and raised enough funds to keep HDANI going for the next three years. Funding from The Big Lottery, Ulster Garden Village, Garfield Weston, The Hospital Saturday Fund and Cash for Kids combined with the support of companies like the Co-Op and TBF Thompson and individual donors like John Donnelly (pictured below) have not only allowed us to keep the doors open and secure our staff posts but actually expand our services. This is an incredible change of fortunes and one which is greatly deserved thanks to your hard work and support – every penny raised by our families has helped us keep going long enough to turn this corner. Well done to you all.

Although we struggled financially we also managed to achieve massive amounts of awareness over the past year through your various events, our corporate partnerships with TBF Thompson which included a stall at the Balmoral Show, in store awareness events with the Co-Op and the LightItUp4HD campaign. Our Facebook and twitter has been going from strength to strength and every month new family members and professionals reach out to us for advice and support. We have developed a new professional training seminar and over one hundred health and social care professionals have received awareness and training about HD in the past six months alone. It works especially well when a carer, patient or family member can take part in training so please get in touch if you would be willing to share your HD story. Sorcha will also be going around the support groups interviewing family members as part of our awareness and education work.

On the campaign front we have been making some headway with the HSC but it is incredibly slow and we really need your continued support. You really should be angry that people in the Belfast area get a HD nursing service that others across Northern Ireland don't. Voice your anger- write letters, make videos, share your stories in the media- be heard!! I continue to work with the HD clinic and nurse to advocate for improved services and have regular meetings with the HSC to discuss ways forward. I have also built up support with MLAs at Stormont but unfortunately can't do much on that front until they get up and running again. I won't give up though!!

I hope to see many of you at conference on the 6th of October which will be a stripped down affair from our usual surrounding of LaMon but no less important in terms of information, education and a chance to connect with other family members and professionals so please make a point of attending. For only £5 what have you got to lose? As many people will be travelling from afar we have secured some accommodation in a hotel nearby at a cost of £30pp and there will be an evening meal and some entertainment provided but it's on a first come first served basis so just let us know if you are interested. We also know that there are various barriers to attending conference so if there's anything we might be able to help with do not be afraid to ask.

Hope to see you soon,

Sorcha



John Donnelly former owner of SDC Trailers has pledged £20,000 per year for the next three years

BALMORAL SHOW



Michelle O'Neill at Balmoral Show

FOCUS ON FAMILIES

The extended Heatrick family are no strangers to fundraising for HDANI having raised £10,000 last year through their marathon efforts. Their hard work and dedication to helping other HD families has continued this year to tremendous effect. The family held a coffee and craft morning which raised over £7,000 and also took part as a relay team in the Belfast City Marathon. They have spent the summer planning a barn dance with Ritchie Remo which is taking place on the 9th of September in Armagh. The whole extended family have really come together and shown that when faced with adversity there is a really opportunity to unite and build something positive.

Chloe Hawthorne has been particularly inspiring in her commitment and enthusiasm despite studying for her A-Levels, helping out at home, working two jobs and her various extra-curricular activities including being a member of our youth committee. For this reason she was nominated by HDANI to the Institute of Fundraising Awards where she was awarded Northern Ireland's Young Fundraiser of the Year at a lovely lunchtime ceremony in Riddel Hall in Belfast in July. Chloe also convinced her local Young Farmers Club in Collone to designate HDANI as their chosen charity for their annual tractor run. Check out some photos of the families activities.



A very busy and enjoyable coffee morning



Belfast Marathon relay team



Coffee morning



Claire McCollum presented Chloe with her Awards in front of a very proud mum Helen



Chloe with Mum Helen and Sorcha at the IoF Awards



Getting ready to kick off the Collone Young Farmer Tractor Run while promoting the barn dance



The family at the Belfast Marathon



Prepping for the coffee morning

Welcome to the Kelly Family...

Welcome to the Kelly Family Stephen Kelly, who lives in Benburb, got in touch to say he was interested in fundraising for HDANI. It's always great to hear from potential fundraisers but even more so to encounter new families that we can support, inform and connect. Stephens fundraiser really was a family affair with a team of volunteers collecting in Armagh and giving out leaflets and stickers to raise awareness of HD. He even got his band the St Jarlath's Pipe Band involved in what was surely the first HDANI flashmob! Thanks to everyone who took part, volunteered their time and donated money. Over £1046 was raised!!!! Check out the pics below and the video of the bands flashmob on our Facebook page.



EVENTS FOR HDANI

Our members have been busier than ever raising awareness of HD and much needed funds for HDANI. We've had Emma-Louise Millers pamper evening in Killylea and John, the chef the Dunmurry Golf Club BBQ-ing on the 10th Hole at Captains Day. Ashley and her crew held a boat rally in Belturbet. We've had the Hawthorne & Heatricks family running in the marathon, hosting a coffee morning, helping organise a tractor run and plan a mighty barn dance coming soon to Armagh. Davy and Cathal have been prepping for a Blues night in Limavady after the excitement of BBC Street Auction in Alexandra Park in July. HDANI contacted the BBC to nominate one of our family members, volunteers and trustees Paula McElhinney to be rewarded for her hard work and dedication to HDANI. After weeks of planning and gathering items Alexandra Park was transformed into a market square with stalls selling everything from pot plants to jumpers, lamps to ladles with plenty of tasty treats to keep everyone filled up. We were also treated to fantastic music and dancing so even the rain couldn't dampen our spirits! All items were donated from local people or businesses and were either sold on stall or auctioned off on the day raising over £1,000. There was a big reveal at the end when presenters Paul and Izzy announced where the money was going- a much deserved family holiday for Paula and the McElhinneys. To say Paula was surprised would be a huge understatement – it was a fantastic surprise for a fantastic family so thanks to everyone who donated, bought or supported the event. We will keep you posted on when we can watch it all on BBC1 this Autumn.

the market yard

VILLIERS AND THE VILLAINS

SATURDAY 2ND SEPTEMBER FROM 10PM

All proceeds in aid of:
HUNTINGTON'S DISEASE ASSOCIATION NORTHERN IRELAND
 Families at the heart of all that we do

Sponsored by:
R. HOGG & Sons, Ltd.
Civil Engineering Contractors & Quarry Owners
LA Paints Interiors
THE EDGE WATERSPORTS
AT THE CRANNAGH ACTIVITY CENTRE

TICKET NO: 001

Huntingtons Disease Charity Barn Dance
 with
Ritchie Remo
 and his Big Band
 on Saturday 9th September, 2017
 at Speers Silo, Keady, Armagh Road

Doors open at 8.30pm Tickets £15.00 strictly over 18's

For Tickets contact Alan 07768273022 or Colin 07738818810

Refreshments Available

Pamper Evening

Friday 26th May 2017
 7pm-10pm
Venue:
 Killylea Primary School

Come along to our pamper evening with friends & family
 Have that essential bit
Of 'Me Time'

Tickets £5
 (Includes glass bubbles or juice, some nibbles and a goodie bag)



Paula with BBC Street Auction presenters Paul and Izzy



Mickey Mc Nulty with Simon Clark



A packed Alexandra Park in Limavady



Landmark venues across NI join global campaign to *#LightItUp4HD*

On Monday May 15th Northern Ireland took part for the first time in a global effort to shine a light on HD which affects hundreds of families across the province. Over a dozen buildings throughout the province took part by lighting up in Blue or Purple.

Ashley Clarke, 24, from Armagh helped organise the event as part of her university placement with HDANI. She has helped care for her Dad Des since he was diagnosed ten years ago and knows first-hand how the lack of understanding and judgment that can cause sufferers and their families to hide the disease or become socially isolated.

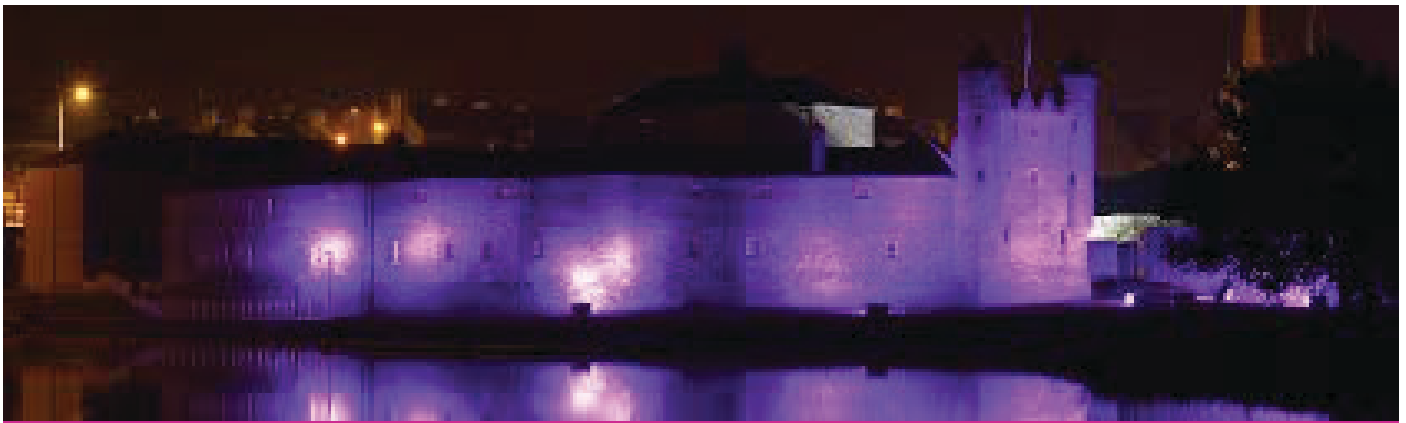
“My brother and I had my Dad at an event one day during the summer in his wheelchair and this woman came over and said it was a disgrace that he was drunk at noon. I was so angry and upset. I don’t want to stop Dad going out but it can be really difficult and I can understand why some people are too embarrassed or worried about people looking at them”.



Elaine and Trevor at Lagan Valley



Glen with a local councillor at Carrickfergus

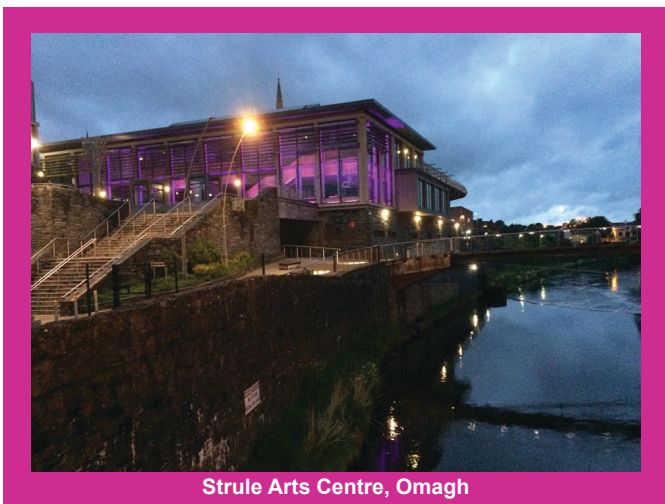


Enniskillen Castle

#LightItUp4HD is a global campaign which aims to raise awareness and increase understanding of Huntingtons Disease and the effort to find a cure. Belfast Castle, Armagh Gaol, Antrim Civic Centre, and Newry Town Hall are among a dozen buildings across Northern Ireland that joined global landmarks like Niagara Falls and Barcelona's Grand Plaza, to illuminate in the international HD colours of purple and blue to show support for families affected by the condition.



Omagh



Strule Arts Centre, Omagh



Student's Union, Queen's University Belfast

In addition to the buildings taking part there was also a worldwide campaign on social media using the **#LightItUp4HD** to help raise awareness.

IN LOVING MEMORY...

Ken Spence

In loving memory of one family's very own HD hero
Kenneth Spence. 05/09/1949 - 17/06/2017

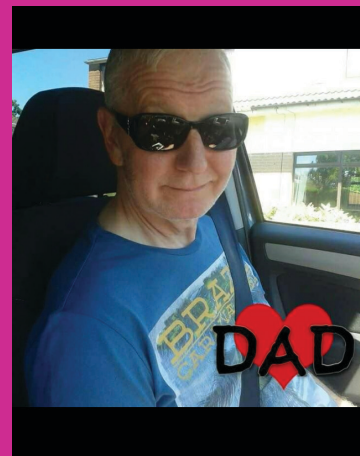
A quiet man who suffered like a gentleman for more than 20 years. He was funny, caring and kind and was loved as a husband, father and grandfather. He died peacefully in the Macmillan Unit of Antrim Area. His family hope that he now rests in peace.



Amy Spence with her granddad Ken

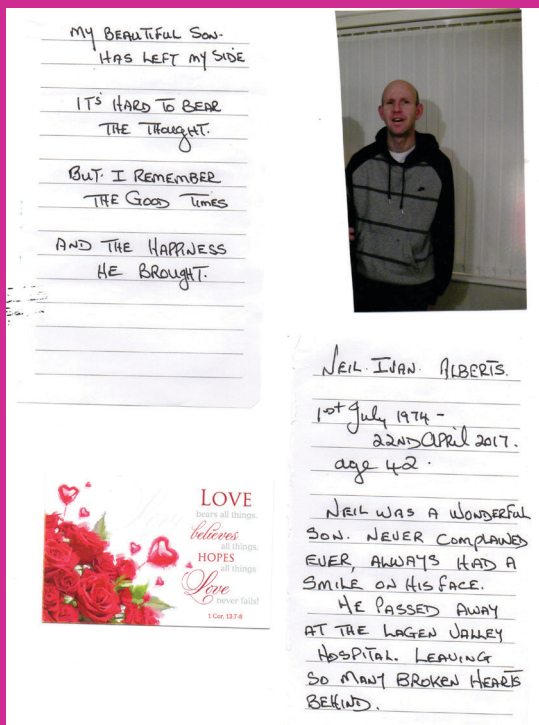


Ken with his loving wife Eileen



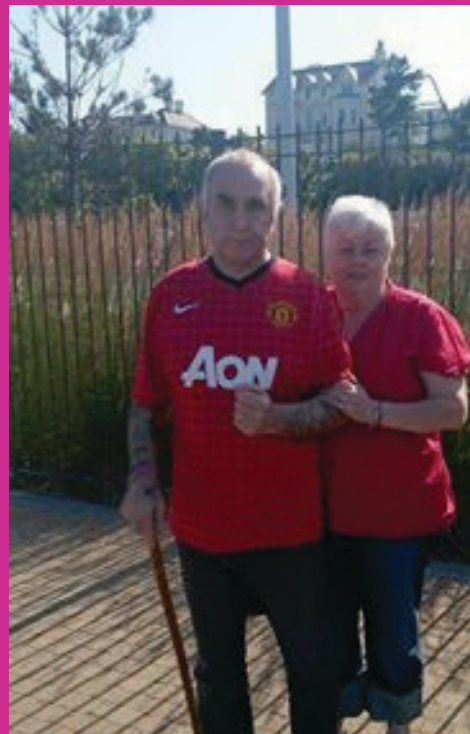
Ken Spence, a much loved dad

Neil Alberts



A tribute from his devoted mum Linda

Pip Warnock



Pip with his beloved wife Jennifer

DONATIONS IN LIEU...



Black family donation £360 in lieu of flowers in memory of Richard Black

We are especially grateful to the families who think of HDANI when their loved one passes away and leave a legacy which helps us to support other families like them.

Most recently we received the following donations in lieu of flowers:

£133 In memory of the late Michael George Leeman, Dundonald

£150 In memory of the late Charlie O'Hara Greysteel, Co. Derry

£160 In memory of the late Ken Spence, Newtownabbey

NUTRITION

The HD Kitchen

Having the right equipment can make preparing and serving meals for the person with HD much easier. Of course, what becomes “essential” is a matter of individual needs and preferences, as well as budget.

- A blender and/or food processor can be very helpful in preparing shakes, soups and sauces, as well as pureeing favorite foods when a very soft consistency is needed. If possible, get one that has more than one container, to allow for preparation of multiple foods quickly.
- A juicer can be useful for a person with dental problems, who cannot chew fruits and vegetables well, If swallowing is a problem, try adding thickening powder, or mix the juice into a thick shake for soup for some needed calories.
- A cappuccino maker may seem like a luxury, but switching from regular coffee to cappuccino made with whole milk and added cream (or vanilla ice cream!) can add some needed calories.
- A pastry cutter or potato masher can serve many purposes in mixing and mashing foods. These are also useful for adding “extras” like butter or sour cream into a dish.
- Dishes with sides, also called “soup plates” or “pasta dishes” can make picking up food much easier and less messy. They are readily available in most department, house ware or medical supply stores.
- “Sports” cups with a cover and straw attached can be helpful in preventing spills.
- Spoons or forks with larger handles can make picking up food easier. Rubber sleeves for utensils can be bought at a medical supply store.
- A heated “baby dish” for a warming tray can keep food warm throughout a meal for a slow eater

Baked Chicken Salad (High Calorie recipe from Anna Gaba, MS, RD, EdM)

- 4 cups diced cooked chicken
- 1 1/2 cups cooked rice
- 1 can cream of chicken or cream of mushroom soup
- 1 cup mayonnaise
- Salt and pepper to taste
- 1 cup shredded cheese

Mix chicken, rice soup, mayonnaise, salt and pepper together and place in a shallow baking pan. Top with shredded cheese.

Bake at 350 degrees for about 30 minutes.

Makes four servings.



FAMOUS FACES SUPPORT HDNAI



Peter Canavan with Sorcha and Adrian Logan



Susan Cooke with former President Mary McAleese and Errol



Tommy Bowe with Sorcha



Huntington's disease research news. In plain language. Written by scientists. For the global HD community.

Precision huntingtin-lowering drug trials target the mutant protein

WAVE Life Sciences launches PRECISION clinical trial to suppress the mutant Huntington's disease protein
By Dr Michael Flower on August 25, 2017
Edited by Dr Tamara Maiuri

A new exciting chapter in Huntington's disease (HD) treatment is just beginning – WAVE Life Sciences have announced PRECISION-HD1 and 2, clinical trials of two new drugs that lower the mutant Huntington's disease protein. We're excited about this novel approach to huntingtin lowering therapies, but these are early days and we've got a long way to go to show they're safe and effective in people.

Why are we trying to lower the amount of huntingtin protein?

If genes are the instruction manual that our cells use to make our body, then DNA is the language that the manual is written in. Each chapter makes a different protein, and it's these thousands of different proteins that make up all the cells of our body. Officially, the HD gene is called HTT and the protein whose instructions it contains is called huntingtin.

Humans have two copies of the HTT gene, HD happens when a mutation makes one copy too big. The expanded protein made from this mutant copy of the gene is toxic to our cells, particularly those in the brain. We know that lowering the level of mutant huntingtin protein in HD mouse models significantly improves symptoms reminiscent of HD, providing hope that similar treatments in people may be effective.



The WAVE ASO acts like a drone that wants to shoot down the bad HD gene, or kite, but can't tell the difference between the good and bad kites. However, it can recognise the different coloured ribbons in the tail. Shooting at the ribbon instead of the kite is good enough to take down the whole thing.

Image credit: Mike Flower

What is huntingtin lowering?

In the same way we've done with many antibiotics and cancer drugs, we can take advantage of one of nature's natural processes in order to suppress the huntingtin protein. In this case it's a means by which cells maintain and copy their own DNA.

The DNA found inside of our cells is usually made of two intertwined strands of DNA, curled around each other in the well-known double helix form.

These paired strands allow the cell to replicate or copy their DNA by pulling apart each strand and using it as a template for a new copy. At various points in this process, cells use RNA as a sort of scaffold to help replicate DNA. When the copying is done these scaffolds need to be removed, so cells have gotten really efficient at degrading bits of RNA and DNA bound together.

Cells use RNA for another purpose, which is carrying genetic messages throughout cells. When a cell needs a specific protein – say, the Huntingtin protein – to carry out their function, a request is sent to cells DNA managers. DNA is precious – if we screw up our DNA we end up with cancer, or dead – so the cellular managers of the DNA make a copy of the requested gene. The copy is made not in DNA, but in the language of RNA. This RNA message – called mRNA – is used by the cells manufacturing plants to create more huntingtin protein.

This intermediate mRNA shuttling information between DNA and protein-making machinery is the target of huntingtin lowering drugs. The goal of these drugs is to, in various ways, destroy this message, denying the protein making machinery of the cell the instructions for making a specific protein.

What does this have to do with HD? Enter antisense oligonucleotides, or 'ASOs'. ASOs don't occur naturally, but are made by scientists to trick the cell into destroying a specific messenger RNA molecule. Essentially, ASOs resemble short stretches of DNA that have been modified to be able to enter cells. Once in, the ASO sticks to one specific sequence, found only in the messenger RNA of the HD gene.

Remember the scaffolds for copying DNA and how they're cleaned up? When cells see a stretch of DNA (the ASO, in this case) stuck to a piece of RNA (the HD message), they think it's a bit of scaffolding left over and destroy it. Voila, we've tricked a cell into destroying just one of the many tens of thousands of RNA molecules found inside that cell.

A major challenge is getting these manufactured ASOs into the brain because they can't get across the walls of the blood vessels in our brains. We've been able to get around this by injecting them directly into the cerebrospinal fluid (CSF), the fluid surrounding and cushioning the brain and spinal cord. From there, the ASOs get taken up into brain cells where they continue to suppress their target protein for a month or so, after which time more needs to be injected.

How is this different than the ongoing ASO trial?

Ionis pharmaceuticals are currently nearing the end of an exciting clinical trial using an ASO that targets the huntingtin RNA. The Ionis ASO doesn't distinguish between RNA coming from the normal and mutant copy of the gene, so it lowers the amount of both the normal and mutant protein. This is one of the reasons we're moving forward so carefully with this treatment – lowering the amount of normal protein may well be safe, but could also potentially be harmful in the long term. We know having the normal protein is really important for a baby's development. However, studies in several animals have shown that partially suppressing both normal and mutant versions by about 50% in adults is safe and improves symptoms.

What WAVE has done might get around these issues because their two drugs specifically target the mutant gene, leaving the normal copy alone. They do this by aiming for little genetic differences in DNA called single nucleotide polymorphisms, or 'SNPs' (pronounced 'snips'). Think of these SNPs as different coloured ribbons hanging from a kite. Everyone with HD is flying two kites – a 'good' one and a 'bad' one. Imagine the ASO as a drone that wants to shoot down the bad kite. Unfortunately, the drone can't tell the difference between the kites themselves. However, it can recognize the different coloured ribbons in the tail and shooting at the ribbon instead of the kite is just as good in terms of taking down the whole thing.

WAVE designed ASOs that target two SNPs in the HTT gene, which is why they're launching two separate clinical trials. These SNPs were chosen because their sequences tend to be different in the normal and mutant HTT gene: the ribbons at that point in the good and bad kites' tails tend to be a different colour, distinguishable by the drone. At the location of the first SNP, which in scientific language is called 'rs362307', half of HD patients have different coloured ribbons in their good and bad kites. For the second SNP, 'rs362331', there are different coloured ribbons in 40% of HD patients. Overall, at least two thirds of people with HD in Europe and the US should have different ribbons that allow one of these drugs to shoot down the bad kite.

Unfortunately, that means that about one third of people have the same ribbons at these points on both the good and bad kites, so these drugs wouldn't specifically target the mutant HTT gene. However, should the drugs work in people, there would be a strong incentive to look into developing new ASOs targeting other ribbons.

What's the evidence that these drugs will work?

These trials from WAVE are slightly unique, because the company has not conducted studies in HD animal models with their specific drugs. Mice, and other animals loved by researchers, also have two copies of the HD gene. However, there's a lot more genetic variation between humans and mice than there is amongst humans. This means the SNP variations targeted by WAVE's ASOs aren't shared with mice, and so can't be tested in them.

What has WAVE done? The specific drugs designed by WAVE have been tested in cells in a petri dish, where they successfully lowered the mutant protein whilst leaving the normal version relatively untouched. Researchers at WAVE reason that – for HD – the case for lowering the HD gene is so clear that additional animal studies would be a waste of time.

This doesn't mean these trials aren't safe – before any drug is administered to people, even experimentally, it must be thoroughly tested in animals to ensure it is not toxic. WAVE haven't publicly detailed the work they've done in animals to prove these drugs are nontoxic, but rest assured that the regulatory agencies in charge of letting these trials go forward will have seen the results of such experiments.

How are the trials organized?

The WAVE trials are officially called phase 1b/2a trials. A phase 1 study is one in which the primary goal of the study is to understand whether the drug is safe in a small number of volunteers. Normally, a phase 2 study is conducted in a slightly larger number of people, with the goal of collecting a little bit of evidence that the drug may work. In this case, because everyone wants to move as quickly as possible, WAVE have structured the trial to combine aspects of a phase 1 and 2 trial. This means that they'll test to see if the drug is toxic (phase 1), but also if it has an impact on various important symptoms of HD (phase 2).

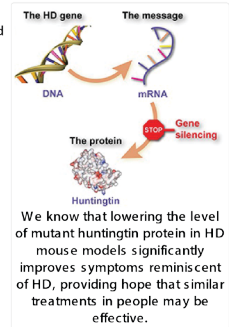
Similar to the ongoing Ionis trial, WAVE's drug will be injected into the CSF by lumbar puncture. This allows researchers to collect a little bit of the spinal fluid that surrounds the brain and spinal cord, in which we can now measure levels of the harmful huntingtin protein. We hope this will allow WAVE to actually measure what they're trying to do, which is to reduce the levels of the mutant huntingtin protein in the brain.

How can someone get into the trial?

WAVE aims to recruit 50 people with HD worldwide onto each of the two trials. That's a small number, but if the drug is safe they'll move on to bigger trials with more people to look at whether it's actually working. The current study will start in Canada, then will enrol patients in Europe and the US. To be considered, you have to be an adult over the age of 18, and must have started developing symptoms. There's no way to tell what colour the ribbons in your DNA are just by looking at you, so eligible people will have a genetic test and if they have either of the two SNPs they'll be included in the trial. The best way to get involved is to express your interest in research to your clinical team.

What does this mean for HD?

We're all hopeful that the Ionis ASO will be the first drug to slow down or stop HD. However, it's important to realise that this is the first time these drugs have been used in people. Though they made mice much better, humans are a very different species. Even if they do lower protein level in adults, they may not be effective because damage done earlier in life is irreparable. They could also have side effects in humans that didn't happen in mice. Whilst WAVE's drugs shouldn't affect the level of the normal protein, they might react with other RNAs causing their protein levels to be reduced. However, we're excited and optimistic about huntingtin lowering treatments, and WAVE's latest refinement looks like it could be an exciting advance.



We know that lowering the level of mutant huntingtin protein in HD mouse models significantly improves symptoms reminiscent of HD, providing hope that similar treatments in people may be effective.

HDANI IN THE NEWS

As you all know awareness is key to helping people better understand Huntingtons Disease. We've been gifted with some families and individuals who are happy to share their HD stories to improve knowledge of the disease and its impact. It can be hard to get the media to pick up on stories but we've been very lucky in recent months to have coverage of HD in local and national newspapers and websites. The Patient Client Council hosted a recent blog about the inequalities in HD nursing services which is read by thousands of people across Northern Ireland. Special thanks to Janice, Chloe, Helen and Lyndsay for sharing their stories and promoting their events. All the links are on our Facebook page for you to read. It's important that the voices of those impacted by HD is heard so that we can show the need for improved services and funding to support families. If you would be willing to share your HD story get in touch with Sorcha...



FUNDRAISING

Ann McElhom and friends - backpack B&M stores Derry £286 & 21.70 Euros

CHARITABLE DONATIONS

Omagh Lions Club donated £250 towards cost of Omagh Support Group

The Honourable the Irish Society £1500 towards befriending

Hospital Saturday fund granted £2,000 to cover support workers for 1 month and a further £750 to support an individual member.

COLLECTION BOXES

Dessie Farry in Trillick has been an incredible support with the collection boxes submitting so far this year amounts of £142, £160, £100 and £100

Kyra Bothwell £20 from Killylea Shop

Moira McNulty £12.91 & £27.07

Valerie Crompton £10.23 & £17.86

THE FOLLOWING DONATIONS WERE GRATEFULLY RECEIVED FROM MEMBERS

£200 – gifted by Mark Clark, Portstewart

£120 & £50 - donations collected from Brian and Maggie Fee, Omagh Support Group

£326.94- James Farry raised at a fundraiser in Manchester

£50 - Hawthorne Family in lieu of Christmas cards

£1,000 was donated by Skipway owner Trevor Heatrick

We have an invaluable new regular donor in Simon Clark who set up a direct debit for £20 per month. His daughter Laura recently held a coffee morning at Melrose Day Centre where he attends raising over £156!



Simon attends Melrose Day Centre in Derry. Laura, Ellie and centre manager Robert Donnelly at the coffee morning which raised £156.51

£100 donated in a collection from the patrons of Keady Clachan cottage- Errols gig at Danny Boy Jazz and Blues fest Limavady. The Kilbeggan Crafts group sent in £200 via Anne Smyth.

NOTICE Reminder to members:

Richard Hamilton has kindly offered the use of his 4 bed property in the Fermanagh lakelands free of charge for any of our families who would like the opportunity to get away for a few days respite. It is booked up in July and August but if you are interested in any other dates please get in touch.

DUNMURRY GOLF CLUB

We have been honoured to receive such incredible support from the Club over the past couple of years most recently, £890 was raised by Andrew Kennedy from Dunmurry Golf Club in the Dublin city marathon.



Andrew Kennedy after the Dublin City marathon

Huge thanks to John Finlay, a chef at Dunmurry Golf Club, who donated his tips of £215 which he received while BBQing on the 10th hole at Captain Trevor Lamonts Golf Day Dunmurry Golf Club.



John Finlay, chef at Dunmurry Golf Club, donated his Captains Day BBQ tips of £215 to HDANI



Club members Des and Trevor present Sorcha with a cheque for £460

Ashley Clarke's boat rally raised an amazing £660.



Glen, Glens and more Glens

Glen Spence continues to be a true HD Hero giving his time freely to raise awareness and funds for HDANI at every opportunity and helping us connect with his employers TBF Thompson who chose us as their Charity of the Year for the new two years.

Among his recent activities Glen decided to go healthy for HDANI while managing to raise £782 and he roped a few friends in to get down and dirty by taking part in Tough Mudder - an off road obstacle race.

Those HDANI t-shirts were put through the ringer! Keep up the great work Glen!



The Glen Vintage Club have been a regular supporter to HDANI and once again donated funds from their vintage run which raised a fantastic £250 for our support services. Thanks to all involved.



Sticking with the Glens this time it was the Glen Runners who got behind HDANI by choosing us as the beneficiary of their annual club event in the Glens of Antrim. Andrea and her committee were real stars doing everything they could to ensure awareness raising for HDANI and Errol went along on the day of their big run, cycle, walk to talk about HD and the work of the charity. Some of our family members even took part! It was a tremendous effort which raised an incredible £3081. That's enough money to run two regional support groups for a whole year! Huge thanks to all who organised and took part.

