



AUTUMN NEWSLETTER 2018

Hello Everyone,

I hope you all enjoyed the beautiful summer we had this year!

This year is in a much stronger financial position than before with our CEO Sorcha gaining Big Lottery Funding, other grants and donations to strengthen our position as a working charity. We hopefully can now expand our resources and the work we do to help HD families in the province with our Support Workers, Angie and Zelie.

The Summer Camp this year was at the Share Centre, Lisnaskea and all the children and young adults really enjoyed the fun and facilities. This year our own Youth Counsellor Michelle was there to talk and listen to those taking part. The Youth programme is something we will continue to grow and develop over the coming year as this is of real benefit for young people growing up in a HD family. There will be a full report on the summer camp at this year's conference.

HDANI conference this year will be for the first time be a joint all-Island venture with the HD Association of Ireland joining us and providing a great opportunity to share knowledge and especially in view of the Enrol HD centre in Dublin. As we all know through media there are amazing breakthroughs in the research and possible treatment for HD sufferers and continuing work being done on this.

I would like us all to remember our members and families who have lost loved ones this year and let them know our thoughts are with them.

Finally I would like to offer our congratulations to our CEO Sorcha on her recent marriage and look forward to seeing you all at Conference.

Jennifer Warnock
Chair, HDANI



Support Groups

Our Support Groups meet monthly as a space for peer and professional support for patients, carers, family members or friends impacted by Huntington's disease. Share experiences, learn about the disease, ask questions and meet new people. It is a welcoming group and a safe space to learn and share. We invite relevant guest speakers and help link into one to one counselling support for anyone that wants it.

Groups are free to attend and you can contact our support worker in advance on;

Belfast & Limavady zelie@hdani.org.uk
Armagh & Omagh angie@hdani.org.uk

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HDANI Christmas Lunch

HDANI members and guests are welcome to join us for a chance to meet old and new friends over Christmas lunch at the private dining room in the Glenavon Hotel Cookstown.

Arrive at 12.45pm and lunch will be served at 1.15pm

There is no charge for HDANI family members but please be aware the charity lose money if people do not show up. Guests are welcome and can pay £15 on the day.

For those wishing to travel by public transport;

From Belfast there is a bus leaving Europa Bus Centre at 11.20am arriving in Cookstown at 12.55pm and we can arrange taxis from the bus station. The bus back to Belfast leaves at 4.30pm arriving back at 5.55pm.

You can check other bus times at Translink 028 90 66 66 30



Report from the CEO

Dear members and friends,

It has been almost four years since I joined HDANI and the time has truly flown by. It has been a tremendous honour and privilege to work with, and on behalf of, the HD community in Northern Ireland.

In just a few short years the Association has grown beyond belief to a point where we now work with over 150 families across the province providing support, information and advice to carers, patients and family members. In times of crisis, our support staff have proven invaluable in advocating for those who are unable, sometimes literally, to speak for themselves. They have often been the only source of comfort and support to patients and their families as they try to navigate life with HD.

We have been dogged in our determination to strengthen our links with politicians, policy makers and health and social care professionals to ensure increased awareness, knowledge and understanding of the disease as well as continuous improvements in the accessibility and quality of service provision.

Like many charities we have found ourselves facing financial hardship and continuously work to ensure that our unique and critical services are sustained. We are eternally grateful to those sponsors, grantees and donors who have made our work possible including The Big Lottery Fund, Garfield Weston, Ulster Garden Villages, Enkalon, Halifax, The Co-Op, TBF Thompson, PHA, Mr J. Donnelly and BP McKeefry.

Above all we are indebted to the hard work, energy, and dedication of our volunteers and fundraisers without which we simply could not exist. Special mention must go to the extended family and community in Armagh who worked for a year to raise over £40,000 which will be used to fund a three-year youth project providing age-appropriate support,

information, counselling and opportunities to connect and have fun for children from 5 to young adults. This is a completely unique service in Northern Ireland and one which was sorely needed to help young people deal with the changes they see in close family members, understand the genetic implications of the disease and help them consider issues such as testing caring roles, drug trials, disease inheritance, relationships and family planning.

The road ahead over the next three years will no doubt be filled with challenges but also opportunities as we move ever closer towards effective treatments for HD. We will continue to keep 'families at the heart of all that we do' and strive to prove that we are strongest together.

Sorcha



Sorcha McPhillips
Chief Executive

TBF THOMPSON HOST HDANI AT BALMORAL SHOW

Staff and volunteers took to the Eikon Centre to join our charity partners TBF Thompson for three days at the Balmoral Show. We raised over £200 and had a great time raising much needed awareness of HD to the thousands of attendees! Thanks to all at TBF for their continued support and to everyone who help out or stopped by including professional champion boxer Carl Frampton (pictured below with volunteer and TBF employee Glen Spence). Keep on truckin!



Reece Moore manning the stand



Glen got chatting to Carl Frampton



Volunteers Glen and Ashley

Judy's Trek for HD

Judy Boucher from Limavady recently completed a sponsored walk of Irelands Way a 900km trek which raised over £1600 for HDANI. Thank you to everyone who helped and supported her efforts.



Community go the extra mile for HDANI

Dungannon Clarkes Gaelic Athletic Club held a 5km run/walk raising over £5,000 for HDANI. It's the local club of HD Nurse Specialist Majella McConville and the community really rallied round to raise much needed support and awareness. Thanks to everyone who volunteered, sponsored the event and took part!



HDANI Summer Social

Service users and our support staff enjoyed a lovely summer lunch recently at the Greenvale Hotel Cookstown. This was a great opportunity for members of our various support groups to get together and meet up in advance of conference in September. Everyone really enjoyed the food and craic!





Errol's Retirement

If you live in Northern Ireland and have been impacted or work with those impacted by HD then it's very unlikely that you haven't met or had some contact with Errol since he began working for HDANI in 2008. Errol and his wife Susan know from personal experience the devastating impact of HD and have dedicated themselves to helping other families. In his time as a Membership Development Officer and Support Worker, Errol has been on hand to provide advice, information and much needed support to anyone who needed it. He was been an invaluable asset to anyone impacted by HD and certainly to myself (Sorcha), Dolores and Angie as we joined the team sharing his wealth of experience. He is very camera shy so I've dug out some photos and asked him to share his own words. I trust you will all join me in thanking and wishing Errol well in his retirement and send our love and best wishes to himself, Susan and their family.



Dear all,

I have now retired as an HDANI staff member on December 4th 2017 but I will always remain a family member and a lifelong friend to the truly amazing people in this Association. It has been an indescribably enormous privilege to be a part of this wonderful family for nigh on 15 years and to have served on the HDANI staff in one capacity or another since 2008. It has been a life changing experience for me, one that I treasure and one that I feel has made me a better person and a more empathetic and understanding human being. You have taught me and given me so many things that have enriched my life beyond measure... love and respect for others, a degree of humility I hope, and a fierce and undying love and admiration for all those who live with this dreadful disease.

I want to thank you all from the bottom of my heart for all these precious gifts.

The past decade has been an incredible journey for all of us... from despair and hopelessness to hope beyond our wildest dreams thanks to the incredible work and passion of the dedicated scientists and researchers who make it all possible.

May your futures be blessed with love and hope and above all, in the near future, a cure for HD.

Errol xxx



In Memory of Andy

Thanks so much to the family of the late Andy Campbell who raised £2581 plus an additional £385. Huge thanks to Andy's brother Malcolm and his wife Olive pictured with Zelig. #HDHeroes



Remembering Rosaleen

HDANI Support worker Zelig pictured with friends and family members of the late Rosaleen Smyth at their recent cheque presentation of £8413.76 in Ballykinlar. Rosaleen was an active HDANI member and sadly lost her battle on 26th January 2018.

The immediate family raised £6100 through donations in lieu of flowers as well as a race night and raffle when a planned 70th birthday celebration in March turned into a memorial to celebrate Rosaleen's life.

Rosaleen's nephew Sean Roberts raised £1381.76 by undertaking a couch to 5km daily run in February. A table quiz in April in The Ballymartin Inn run by Kieran Cunningham raised a further £600 while £332 was gathered by the Ballykinlar Cross Community Group.

We at HDANI are indebted to the entire Smyth family, their friends and community for choosing to honour Rosaleen's memory in a way that will ensure that we can continue to support other families living with HD.

Personal Independence Payment (PIP)

Personal Independence Payment (PIP) is a new benefit replacing Disability Living Allowance (DLA) for people aged between 16 to 64 years. PIP and DLA cannot be claimed at the same time.

About PIP

PIP helps towards some of the extra costs arising from having a long-term health condition or disability that is expected to last for 12 months or longer. Entitlement to PIP is based on the effect a long term health condition has on your daily life, not the condition itself. DLA will stay for children up to the age of 16 years, both for existing or new claimants.

Existing claimants who were aged 65 years or over on 20 June 2016 will continue to receive DLA provided they continue to meet the eligibility criteria.

If you are aged 16 to 64 you can no longer make a claim to DLA. Instead, you should make a claim for PIP.

If you are an existing DLA claimant aged 16 to 64 years and your benefit is due to come to an end or if you report a change in your care or mobility needs, you will be invited to claim PIP. If you are aged between 16 to 64 years and have an indefinite or lifetime award for DLA, you will be randomly selected for assessment and invited to claim PIP.

How much is PIP worth?

There are two components of PIP:

- > a daily living component
- > a mobility component

Each component can be paid at either:

- > **standard rate** – where your ability to carry out daily living/mobility activities is limited by your physical or mental condition
- > **enhanced rate** – where your ability to carry out daily living/mobility activities is severely limited by your physical or mental condition

	Standard	Enhanced
Daily living component	£57.30	£85.60
Mobility component	£22.65	£59.95

How PIP is assessed

In order to qualify for PIP you will have to score a certain number of points in relation to 12 activities. Ten of these activities assess daily living and two of these activities assess mobility.

Within each activity there are a set of ‘descriptors’ or tests. There are a range of points that can be scored based on whether you fit a descriptor within these activities. You can score points for more than one activity but if more than one descriptor applies in any one activity you will be awarded whichever descriptor gives you the most points.

You will be awarded points if the descriptor applies to you all of the time, or if you can show that a descriptor applies to you for more than half of the days within a 12 month period.

In order for a descriptor to apply to you, you must be able to carry out the activity it describes “reliably”, which means:

For enquiries about Personal Independence Payment contact:

Department for Social Development (NI): 0800 587 0932 or contact HDANI on info@hdani.org.uk where one of our support workers can help you with the process of applying or appealing decisions.

Lease a car with your Personal Independence Payment (PIP)

The Motability Scheme enables disabled people to get mobile by exchanging their mobility allowance to lease a new car, scooter or powered wheelchair.

If you are awarded the Enhanced Rate of the Mobility Component of PIP (ERMC PIP) and have 12 months or more remaining on your current allowance, you may be eligible to join the Motability Scheme.

It’s simple and affordable – you’ll have over 2,000 cars, scooters and electric wheelchairs to choose from and insurance, tax and servicing is all included.

For more info call 0300 456 4566

Opening times

8am-7pm Monday to Friday

9am-1pm Saturday

Monday 9am-11am is our busiest period.

You may find it easier to call outside these times.



Our children and young adults have had a busy spring and summer with the launch of our new HDANI Youth Service in May at We Are Vertigo. This was followed by another day of jumping and climbing in June before our three camp in Lisnaskea at the Share Discovery Village in August. A huge range of water and dry activities included kayaking, raft building, inflatable water course, t-shirt designing, games and obstacle course. Our counsellor Michelle McGrath has been on hand to provide one to one and group therapeutic support and age appropriate information to children and young adults from 5yrs to 30yrs. Thanks to all our volunteers especially Ashley from the youth committee and our peer youth mentors. Our next event will be around Halloween. For more information email youth@hdani.org.uk.







How close are we to a cure for Huntington's?

Until now, there has been no effective treatment for Huntington's – an incurable brain disorder that can lead to problems with movement and thinking. Can computer games designed to improve brain function offer hope?

In the search for new treatments, science often focuses on medication first. But drugs aren't the only way to fight illness, particularly when looking at brain diseases. My research looks into how playing specially designed **computer games** might help people who are living with Huntington's disease.

Huntington's is a brain disorder that gets progressively worse over time, leading to problems with movement and thinking. We know that the disease is caused by a single faulty gene, which in itself is very unique. Often if you have particular genes, your risk of developing certain diseases might increase or decrease, but it is very rare for a disease to be caused completely by a single gene. Although research is currently ongoing, unfortunately at present there are no treatments for the underlying cause of Huntington's, or to prevent the disease getting worse.

You might be wondering how **brain training** games can possibly help those with Huntington's disease if there aren't yet any effective treatments for the disease. But, as my mum always used to say to me, "practice makes perfect" – if you practice something repeatedly you will generally get better at it.



This principle applies to brain training, too. If you practice tasks or games that are designed to help with thinking, you will probably get better at thinking. This is sometimes referred to as the "use it or lose it" approach. If you use your thinking skills and keep them active, you will probably be able to maintain them. But if you don't practice something regularly you may forget it and not be as good at it as you once were. This is particularly relevant if you know that your thinking ability is going to get worse.

Using computer games to train the brain has been studied in the healthy ageing population, and also with other diseases which affect the brain such as Alzheimer's and Parkinson's. These studies have generally found that brain training is beneficial for improving thinking – although there is much debate about whether brain training could improve movement problems or improve quality of life for people living with these brain diseases.

At present, there is very little evidence about computer game training and how it might impact people with Huntington's disease. But we are now conducting a feasibility study to work out whether the research can actually be done before progressing to a bigger study. Full scale studies require lots of participants and funding, so it is important to demonstrate

that the research can actually work with a small number of people first.

Using this initial study, we want to demonstrate that computer game brain training is acceptable for people who are impacted by Huntington's disease. We know that lack of motivation and apathy can be characteristic symptoms of Huntington's disease. So we are asking people who have the disease to play brain training computer games to see how they get on.

Half of the participants will be asked to play the brain training computer games and half will continue as **control** and pleasure. So we have carefully chosen the games our participants will play to make sure that the games specifically train thinking skills. The brain training games that we are using are focused on training thinking skills of executive function – the higher thinking skills of the brain. These include number puzzles, word games and tasks that measure attention.

Although our study is focused on Huntington's disease, it will help us learn about brain training more generally, too. We already know that the more often you play a game, the better you get at it. If you play the card game Snap!, for example, you might get much quicker at pairing the cards and beating your opponent, but how does this translate to the rest of your life?

Brain training will not be able to change the faulty gene that causes Huntington's, but it might just help improve day to day life for people who are impacted by the disease.

Emma Yhnell is a Health and Care Research Wales fellow at Cardiff University. This article first appeared on The Conversation (theconversation.com)

Roche announces details of its 'pivotal' huntingtin-lowering study

September 17, 2018

It's a time of huge developments in the field of huntingtin-lowering drugs, which aim to reduce production of the huntingtin protein that causes Huntington's disease. At the European Huntington's Disease Network (EHDN) meeting this past week, Roche announced firm details of the first ever pivotal study of a huntingtin lowering drug – RG6042, which you might know better as Ionis-HTTRx. So what do we know about the trial?

What is huntingtin lowering?

First, a brief recap about huntingtin lowering as a treatment for Huntington's disease. Remember, the damage to brains in HD is caused by a harmful protein, called mutant huntingtin. The HD gene - sometimes called the huntingtin gene - is a recipe for making the huntingtin protein.

When a cell needs more of a specific protein, say the huntingtin protein, it makes a sort of scratch copy of the gene – a messenger molecule that's written using a slightly different chemical, called RNA. Because this RNA is carrying a message, scientists call it messenger RNA or mRNA. Any break in this chain, from gene to messenger to protein, and the cell wouldn't make any of that specific protein.

This is how huntingtin lowering approaches to treating HD work – by targeting the huntingtin messenger RNA and telling cells to ignore or delete it. Less message, less protein. Most HD researchers find this approach very exciting, because common sense and a ton of animal

research suggests that if you reduce or eliminate the mutant huntingtin protein, you lessen the severity of HD symptoms.

ASOs in Huntington's disease

An early leader in the field of huntingtin lowering is a biotech company called Ionis Pharmaceuticals, of Carlsbad California. Over decades, they've developed an approach called antisense oligonucleotides which are heavily modified DNA-like molecules that are programmed to recognize only one specific messenger RNA floating around inside of a cell. When these ASOs stick to their programmed target, cells destroy it, dramatically reducing levels of one specific messenger RNA. Less messenger means less protein, even though the genetic code for the Huntingtin gene is still there in the DNA.

Based on success in animal tests, Ionis led an initial study in 46 brave volunteer HD patients that started in 2015. This small study was designed only to see whether its huntingtin-lowering drug, called HTTRx, was safe, and whether the treatment with HTTRx reduced production of the huntingtin protein in the nervous system. We can't take a brain tissue sample, but we can measure levels of the mutant huntingtin protein in the spinal fluid that bathes the brain.

As discussed on HDBuzz, in December 2017, Ionis and their partner Roche announced that the trial had been a success. Remarkably, none of the 46 patients had dropped out of the study, despite the monthly spinal fluid injections required. And even more remarkably, treatment with HTTRx led to a striking reduction in the levels of the Huntingtin protein in the spinal fluid.

Roche is a huge drug company based in Switzerland and its US arm is called Genentech. Alongside the good news from the first trial, Roche confirmed that it would be planning

and leading the next trial of HTTRx, which it renamed RG6042 as part of the handover. Get used to stories about RG6042 – but remember it's the same HTTRx drug we've been rooting for all along.

A trial to test efficacy

Of course, both researchers and the Huntington's disease community are interested in slowing the progression of HD, not changing the levels of some measurement in the spinal fluid. But Ionis's successful safety study had just three months of dosing in 46 patients – that's too short and too small to tell whether treatment had any effect on HD symptoms.

"GENERATION-HD1 will launch at the end of 2018, with the first patients enrolled in the beginning of 2019. It will take place at around 80-90 sites in about 15 countries."

Now that we know Ionis/Roche's drug lowers the protein, and appears to be safe, what we need now is a large study in a much bigger group of people – called a phase 3 trial – to determine whether RG6042 slows the progression of Huntington's disease.

Since December, we've been eagerly awaiting an announcement about this larger trial. And on 16th September, we got it!

GENERATION-HD1

At the 2018 European Huntington's Disease Network (EHDN) meeting, Scott Schobel from Roche gave the first official overview of the upcoming study. The trial will be known as GENERATION-HD1.

(The name GENERATION-HD1 comes from Global Evaluation of Efficacy and safety of Roche/genentech AnTIsense OligoNucleotide for Huntington's Disease. Probably best just to remember the acronym...)

Size is important

GENERATION-HD1 will launch at the end of 2018, with the first patients enrolled in the beginning of 2019. It will take place at around 80-90 sites in around 15 countries.

No specific site announcements have been made, meaning there's no public information yet on whether any given clinic or even country will host the study. We expect that information

to come soon. It will be a very large study – enrolling 660 patients with manifest HD. 'Manifest HD' simply means that they will be enrolling people formally diagnosed with clinical signs and symptoms of HD, not people with the mutation but without definite symptoms (premanifest or prodromal HD).

Eligibility

There are two main clinical deciders, or inclusion criteria. First, patients need to be "ambulatory" and "verbal" – that is, able to walk and talk. Second, they need to score 70% or more on an independent test called the Functional Assessment. That means a level of daily functioning where they can wash themselves, and perform "limited" household duties like cooking and using a knife.

Those are much broader clinical inclusion criteria than the previous trial, which was very strictly limited to very early HD with near-normal daily functioning.

There's also a specific requirement that something called a CAP score has to be above a certain value.

The CAP score is a simple mathematical way to combine someone's age and their CAG repeat count – the length of the abnormal bit of DNA that causes Huntington's disease. This score is used because people with more severe HD mutations (longer CAG repeats) tend to have HD symptoms at a younger age. So if we want to track the progression of HD symptoms over time in a person, we have to take into account both their age and their CAG size. Setting a minimum CAP score requirement means the trial can be focused on people most likely to show benefit from the drug, which makes it as small and as fast as possible.

Lots of lumbar punctures

The trial will include a placebo or dummy treatment group, of approximately one third of the trial participants. This group is absolutely necessary to cope with the placebo effect – the fact that participating in a trial like makes people feel better, and even function better, even if the drug doesn't work.

The other two thirds of the participants will be split into two groups, both receiving the active drug. Half of the treated group will receive the drug every month, and the other half every other month. This is exciting, because it could let us treat less frequently, if that proves equally effective to monthly dosing.

However, all participants in every group will have to have monthly injections into the spinal fluid, every month, for two years. The placebo group will get a placebo injection every month. The monthly drug group will get the drug every month. And the two-monthly group will alternate between drug and placebo injections. That means nobody will know what group they have been assigned to. Bottom line: everyone in the trial will need to be OK with getting a lot of spinal taps and spinal injections - as many as twenty-five over two years.

Outcome measures

Success or failure in the trial will be determined in the USA by something called the total functional capacity scale, or TFC for short. This is a very simple rating scale based on a person's ability to conduct basic duties around the house, work and take care of themselves.

In Europe, the trial will be using a slightly more sophisticated measure, called the composite Unified Huntington's Disease Rating Scale or cUHDRS. This score takes into account a broader range of HD symptoms, combining the TFC, a movement score and some thinking tests.

"It will be a very large study – enrolling 660 patients with manifest HD. "

It's slightly unusual, but not unheard of, to have a trial with different endpoints in different countries. But these scores are all measuring the same underlying process, which is HD getting worse over time, and the different regulatory agencies appear to have different opinions about how best to measure that. In the end, we would expect both scores to move in the same direction if the drug works. Not every patient enrolls on the first day of the trial, so a trial in which each participant is involved for 25 months will take around twice that long to run, and possibly longer.

But wait, there's more

Roche also announced another study - called the Natural History Study, aimed at providing crucial information about HD progression. Up to 100 patients will be enrolled, matched to participants in the already-running Open-Label Extension study of RG6042. Those open-label participants are the people from the first clinical trial, who are now all getting the drug regularly, so the natural history study will help understand emerging data from the open-label study. If all goes to plan, participants in the Natural History study will be offered open-label treatment too, after 15 months of participation including regular lumbar punctures.

The EHDN meeting included updates on other exciting huntingtin-lowering programs, including Wave Life Sciences, PTC Therapeutics and Unique. We'll be providing updates about those and other tidbits from EHDN 2018 shortly.

Now what?

Following on from the first study that demonstrated short-term safety, and successful huntingtin-lowering, we now have solid details about a 'pivotal' study to prove whether RG6042 works or not, and a very clear timeline on which that will happen.

It's important to bear in mind that people who take part in GENERATION-HD1 will have a long and challenging road ahead in front of them, and taking part will be hard work, physically and mentally.

Inevitably, there will also be many people who are unable to take part for any one of a number of reasons. While that may be hugely disappointing for those people, the drug will get tested by volunteers across the world, and it's important to try to remember that the purpose of the trial is to test the drug for everyone and for future generations – not to give the drug to any individual person. That said, this is huge news. After many years of work by hundreds of people, we finally have a schedule to understand whether treatment with this huntingtin lowering drug, RG6042, could benefit HD symptoms.

We're really excited about this announcement, and the state of the huntingtin-lowering field more generally. We think it's fair for HD community members to feel the same way. Stay tuned to HDBuzz, for updates on this and other trial developments.

OUR HD FUNDRAISING HEROES



Over the past year so many of you have been busy raising awareness of Huntington's Disease and collecting vital funds for HDANI. We are so grateful or all of your support!



Workplace Heroes

Holding events in your workplace is a great way to raise awareness of HD and help increase understanding about the condition among colleagues. We can supply you with volunteer t-shirts, posters, sponsorship forms, information leaflets as well as keyring, badges and wristbands to sell.

Laura Kane and staff at the Utility Regulator held a bacon butty morning raising £357.83



Donations in Memory of Loved Ones

When a loved one passes we are honoured that family think of requesting donations to HDANI in lieu of flowers. Today we received £140 from a funeral director donated in lieu of flowers in memory of Joe Haywood, Lisburn, who passed away in May. We are grateful to his wife Irene and their family for thinking of us at such a difficult time. May he rest in peace.

We also received donations in lieu of flowers totalling £160 in memory of Ken Spence who passed away in June 17 from Mr & Mrs Short, Omagh, The Clarke Family, Omagh, Lilian King, Newtownabbey, Marie Parker, Cheshire and Martin Strange Carrickfergus.

Donations of £150 were received from Harold, the husband of the late Agnes Iris Davidson, Lisburn who died on the 29th July 2017.



This photo is from the Co-Op local Causes celebration day where HDANI received £2601 from funds generated through local customers.

Special thanks to Stephen McMahon for driving things from the Co-Op end and to our Chair Jennifer for representing HDANI!

Bombardier Aerospace Shorts Staff Charity Fund donated £500 thanks to nomination from staff member Leanne Blakeney. Why not ask if your workplace has a nominated charity.

Daryl Northrop raised £820 through a cycle challenge and secured a further match funding of £500 from his employers Lloyds banking group.

In September 2017 we received incredible support from Cathy at BP McKeefrey Trust with a cheque for £5000!

Thanks to the customers and staff of Asda Strabane for supporting HDANI through their green token scheme. We received a cheque for £200.



Charity partnership with TBF Thompson



Our continued partnership with TBF Thompson has involved HDANI joining them at Balmoral Show this year and a number of staff taking part in various challenges. In addition some of their customers have kindly sent donations like Mr Murray who dropped a £200 donation.

TBF Garvagh's Gareth Carruthers ran an event called the Diff Lock Trophy 4x4 and raised £600 for HDANI

TBF Thompson are getting fit for Huntington's Disease Association Northern Ireland by taking part in the Belfast City Half Marathon, 23rd September. Director and veteran runner, Raymond Crilly, is going to complete the 13.1mile slog along with complete beginner, Rachael McKerr.



Family Heroes



In addition to the Smyth and Campbell families featured in the newsletter we've had tremendous efforts from families right across the province. We received £100 from the Fee family in Co Fermanagh. Stephen Kingston's surprise 60th Birthday party in Dungannon raised an incredible £910 for HDANI.

Cecil & Pearl Short from Seskinore, Co Tyrone (parents of Alison Spence) recently celebrated their Golden Wedding Anniversary with family and friends and instead of gifts asked for donations to HDANI. They raised a fantastic £800!!

Running for HDANI!

Not only were the community of Dungannon running to raise funds for HDANI but lots of individuals have too! Geraldine & Garvan McCann raised almost £1,000 in sponsorship for their Omagh Half Marathon which was matched by Geraldine's employer Santander bringing the total to £2,000. Lynn Black raised £112 on her St Patricks Day 10k run.



Gerry McDermott recently undertook the Great Northern Run, a 13.1mile race in North East England. He raised over £1,000 online alone!



Kirsty McMurray, pictured above with Angie, ran the Belfast Marathon in aid of HDANI and raised £1217. Kirsty is also running London marathon in April 2019 on our behalf. Kirsty's brother Eddie Davies passed away from HD in April this year, a few weeks before Kirsty ran the marathon. Mum June Davies is a member of Armagh Support Group.

Events for HD



£1640 was raised by Digby's bar in Killylea by Jimmy Gillespie who organised the fantasy Grand Prix



The Limavady Music Night raised £1140 thanks to Davy Hank and Cathal McElhinney

Collone Young Farmers Annual Tractor Run 27th Aug raised £1315

Cullybackey Womens Institute kindly donated £240



£400 was received from Samantha Lamont on behalf of the The North Coast Riding Club



Wedding Favours

If you are getting married why not consider HDANI pins, cards, keyrings or wristbands as favours to help raise awareness of the condition.

Congratulations to Emma Watt from Ballyclare who got married recently and opted to make a donation of £100 to HDANI in lieu of wedding favours in memory of her granda Michael Doyle who last his fight with HD in April 2017.

Collection Boxes

Seeing a collection box in the local shop is a great way to raise awareness of the disease and every penny counts. We are grateful to all of you who take the time to drop off, collect and lodge funds for HDANI. A special thanks must go to Des Farry who sending in £100 every month from his local shop in Trillick.

Des Farry £600 Trillick

Moira McNulty £25.35 from Gortin

Jeff at Orangefield shop in Armagh £59.43

Heather Hoosima in Belfast £74.31

Birdies Takeaway (Strathfoyle) - £24.15

Spar (Strathfoyle) - £16.47

Jenny McGonigle- £16.66

Laura Clark (Derry) £24.85

Vivienne Gibson (Belfast) £55.95

Pat McKay (Dunmurry) £115

Grants for HDANI

We received **£7500** from Cash for Kids to help fund our youth events.

The Public Health Agency supported our 2017 conference with a grant of **£2000**.



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