HUNTINGTON'S
DISEASE ASSOCIATION
NORTHERN IRELAND

Families at the heart of all that we do

WINTER NEWSLETTER 2019

Chair Report

Dear members,

Around 30 years ago a small group of family members, with relatives living with Huntington's Disease, came together in Belfast to offer peer support and share whatever information they could at a time when there were no services. We owe these founding members a great debt of gratitude. Over time we have grown to our current structure which includes a CEO, two support staff, an event and fundraising officer, four support groups, a youth group as well as developing information resources, providing advocacy, lobbying for improved statutory support, training health professionals and providing opportunities for families to connect. Like our family conference held in Sept this year marking HDANI 30th Birthday!

I would like to take this opportunity to pay a sincere tribute to our staff, Sorcha, Angie, Ashley and Zélie, congratulations to Sorcha on the birth of her baby, Sáerla this year. I thank them for their hard work, dedication, empathy and caring, they quietly do amazing things every day and the charity is very fortunate to have such a talented team.

The rules of Board membership changed last year meaning that, each year, a third of the Board must retire. So this year we bid farewell to Paula McElhinney and Brendan Major. Martina Stephens also tendered her resignation during the year. On your behalf, I would like to thank them for their many years of dedication and service to HDANI. Remaining with me on the Board are Raymond Crilly; Managing Director of TBF Thompson Group, Lauren Byrne; a Researcher with the Huntington's Disease Research Group based at the University College London and Dr Seamus Kearney; a Consultant Neurologist based in Belfast.

We now have vacancies on the Board and I would particularly welcome family members and users of our services to consider joining. I believe that it is important that we have a balance between the professionals with their particular areas of expertise and other stakeholders and users of our services. Everyone has an invaluable contribution to make. So, if you think that you can make a difference and help take the charity forward, please contact me, Sorcha or any board member to express an interest.

Best regards

Gerry McDermott
Chair, HDANI

Contact Us:

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Angie Smyth/Support Worker	079 2151 3561	angie@hdani.org.uk
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Report from the CEO

Sorcha McPhillips
Chief Executive

Hi all,

It has been an exciting year for me with the birth of our first child and all the changes that come with getting to know each other. It's been lovely to be able to enjoy the time with our wee girl knowing that everything was in great hands at HDANI with Angie, Zélie, Ashley and the board. We've had lots of swimming, baby yoga, music festivals, hiking adventures and we even managed a sun holiday.

During my maternity leave I also worked on planning our annual conference and it was lovely to have Sáerla along to meet you all. The training day for professionals and our annual conference were a fantastic success and the feedback has been wonderful. Thanks to all of you who came along. I'm back to work now part time until the new year. I'll be catching up on administrative work and accounts for a while as well as finding out how all of our service users are doing. In the New Year I intend on working with our board and staff team in planning our future work so it will be great to hear your feedback on our services and what else you would like to see us do. It's not possible to please everyone but we will certainly do our best to make sure that we are doing the very best we can for our HD families. I'll also be back to lobbying for improved medical services and trying to get our services users involved in HD research. As always funding is something we need to keep an eye on so I'll be looking toward to future grant and sponsorship opportunities for HDANI too. Lots of work to be getting on with and I'm looking forward to getting stuck back into it.

I hope to see some of you before Christmas but if not I wish you a happy holiday and a peaceful new year.

Sorcha

2020 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. Groups are free to attend and you can contact our support worker in advance.

zelie@hdani.org.uk for Belfast and Maghera (previously Limavady)
angie@hdani.org.uk for Newry and Omagh

Belfast Support Group meet on the first Wed of the month in the Grosvenor Community Centre, 162 Grosvenor Rd, Belfast BT12 5AT Belfast from 11- 1pm.

- 5th Feb, 4th March, 1st April, 6th May, 3rd June, 7th Oct, 4th Nov

No meeting in July, Thurs 20th Aug social lunch with all support groups in Cookstown, Sat 26th Sept HDANI annual family conference, 3rd Dec Christmas lunch, Belfast.

Maghera Support Group – The Lurach Centre, 15 Church Street, Maghera, BT46 5EA meet on the second Wed of the month from 7 - 9 pm.

- 12th Feb, 11th March, 8th April, 13th May, 10th June, 14th Oct, 11th Nov

No meeting in July, Thurs 20th Aug social lunch with all support groups in Cookstown, Sat 26th Sept HDANI annual family conference, Thurs 10th Dec Christmas lunch, Cookstown

Newry Support Group meet monthly at Rathfriland Community Centre, 21 John Street, Newry, BT34 5QH from 2-4pm

- 20th Feb, 19th March, 16th April, 21st May, 18th June, 15th Oct, 19th Nov

No meeting in July, Thurs 20th August social lunch with all support groups in Cookstown Sat 26th Sept HDANI annual family conference, Thurs 10th Dec Christmas lunch with all support groups in Cookstown.

Omagh Support Group meet monthly in the Wave Trauma Centre, Omagh from 8-10pm.

- 10th Feb, 9th March, 13th April, 11th May, 8th June, 12th Oct, 9th Nov

No meeting in July, Thurs 20th August social lunch with all support groups in Cookstown, Sat 26th Sept HDANI annual family conference, 10th Dec Christmas lunch with all support groups in Cookstown

Social Lunch Cookstown

Photographed HD service users from support groups across NI with their family and friends enjoying their annual social summer lunch in August 2019 held in Cookstown.

Also in attendance, staff members, Sorcha McPhillips (CEO), Baby Sáerla, Angie Smyth (Support Worker), Zélie Leech (Support Worker) and Ashley Clarke (Events and Fundraising Officer).

Conference 2019

This year's HDANI Conference weekend was held in Armagh City Hotel, celebrating 30 years of HDANI.

On Friday 27th September we held a learning event for health professionals which included presentations from Prof Hugh Rickards, Dr Emma Yhnell, and Prof Monica Busse , Mary Johnston participated in the afternoon workshop giving input from a carers perspective. We were delighted to have representation from across all five trusts learning about HD.

On Saturday 28th we held our family conference, thank you to all exhibitions, David from AbilityNet, Stephen McCleary from Mens' Sheds, Bernadette Donnelly from Loughshore Care Partnership, Ann and Katrina for providing therapies, Soft Waves and Master A Piece for providing workshops. We had presentations delivered from Prof Hugh Rickards, Dr Emma Ynell, Prof Monica Busse and Dr Ed Wild which provided us with very informative information as well as the latest updates on HD Research. Presentations are available if anyone would like to watch or hear again, please get in touch with us, info@hdani.org.uk. On Saturday night we had our special 30th Anniversary dinner followed by our Ritchie Remo Fundraiser.










HDANI stories and memories over the last 30 years

Rita Nelson first became involved with HDANI when her late husband was diagnosed in the 70's. Wendy Johnston introduced Rita to the support group which was held in Belfast City Hospital at this time. Rita travelled to Belfast to attend meetings once she had a car to make the journey from her home town of Armagh.

Rita made friends with Sylvia Mallon (also a HD carer), they travelled together monthly to the Belfast support group. In 2000 Rita expressed her concerns to Errol Walsh (Support Worker HDANI) as the drive was long and especially in the bad weather.

The Armagh support group was then set up by Errol and held in Dunlarg Nursing home, the group met in Dunlarg for several months. The first meeting brought in around 23 people, sadly over time less and less people attended. The support groups gave Rita a sense of relief, she felt she could ask questions, learn tips and wasn't alone caring for her late husband. Rita loved the meetings, never wanting to miss one, it gave her a lift, in Rita words, "A wee family, all in the same situation".

After the passing of Rita's son in 2015, Rita decided to stop attending the support group as she was no longer a carer.

Rita still lives in hope that one day a cure will be found, and looks forward to reading the HDANI newsletter to keep up to date with the latest news and research.

Pictured are Megan Donnelly and Mum Rosetta who have been involved with HDANI for a number of years. Megan and Rosetta were instrumental in starting a support group in the Omagh area. They started having meetings in Sally's bar in the town before moving to a room in the Wave Trauma Centre where the group have been meeting monthly for the past 10 years or so.

Memories from 2005

Cheque presentation for £6,500, raised locally, are the sons of Noreen McCann, who died from HD.

Photographed from left Rose Dargan (Palliative Care and Social Care Project Manager), Garvan McCann, Shane McCann, Tiernan McCann, Ronan McCann, Caolan McCann, Pat McKay (Chairperson of HDANI at the time), Patrick Morrison (Professor in Human Genetic at the Belfast City Hospital)

£3000 raised after Garvan's mother passed away in lieu of flowers, Garvans Uncle and Auntie Dessie and Gretta Farry raised £3500 through a night out in Coa

Ivinestown runner Dermot McCann, ran the Belfast Marathon raising £1,352, Dessie Farry receiving cheque on behalf of HDANI.

Memories from 2006

Another fundraiser night by Gretta and Dessie Farry in Irvinestown raising £1170.

"I have been involved with HDANI for around 10 years when my father Dessie Clarke was diagnosed. Errol was my first point of contact, as the support worker at the time he helped us through many difficult times, I was so grateful. Errol was available any time if I needed help or advice, or just needed to let some steam off!! Errol encouraged me to attend my first conference at 17 in the La Mon Country House Hotel, which was an incredible and an over whelming experience, although I attended alone I felt so welcome.

Errol has now retired, but I still continue to receive support from HDANI. Angie Smyth is now my support worker, I am grateful, questions are answered, advice is given and when needed a shoulder to cry on is provided.

Growing up in a HD family has been difficult, I was always aware my granny died of a disease but I wasn't fully aware of the details. When daddy was diagnosed it was a shock to us all, even though he was already symptomatic. I have gained knowledge about the disease and enjoyed speaking about it. I have been encouraged and supported over the years and have HDANI to thank for this.

I can remember organising my first fundraiser at 15 which was a disco night shortly after daddy was diagnosed, we had great support from family and friends in the Armagh area, raising an amazing £1500 pounds!!

Over the past ten years I have been a service user, volunteer, board member, active in the youth programme and I am now honoured to be a staff member.

HDANI have supported me through some of the most difficult times, and continue to do so. To see the organisation, grow bigger and bigger supporting more families affected by Huntington's disease is amazing, and to be a part of that is even better.

I have so many friends affected by Huntington's disease and have grown personally over the years thanks to these friends. When daddy was first diagnosed I felt so alone, and now I have friends who I call my HD family from all across Northern Ireland. It has given me the strength to continue in the fight for HD and speak out about this disease."

Jennifer Warnock joined HDANI in 2005 following her husband, Pip's positive HD diagnosis. Majella McConville (HD nurse) referred Jennifer to the Belfast support group which was held in Belfast City Hospital at this time.

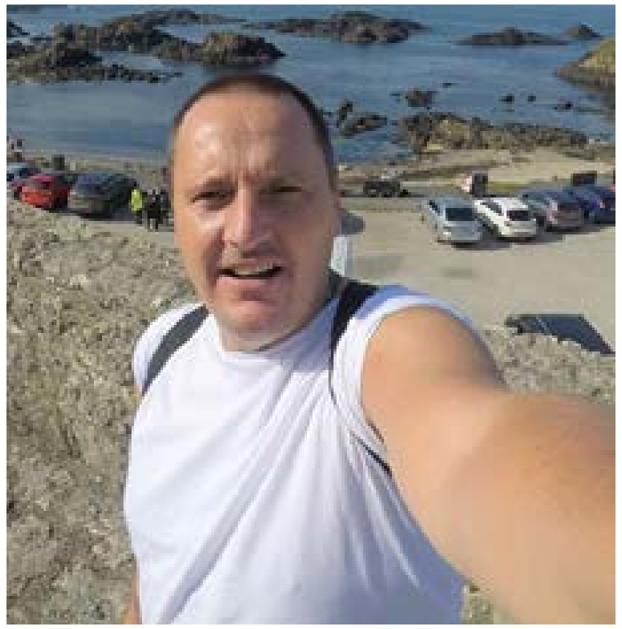
Jennifer was welcomed by two other members of HDANI when attending her first meeting. The group was made up of carers at this time, it was a chance to meet once a month, to share stories, experiences, get much needed advice, they even had a laugh or two! Jennifer got great comfort from the group knowing other people were going through similar situations. Jennifer remembers ''at my first support group I cried, because I realised, I was not alone''.

HDANI was originally made up of a small committee of people, who were passionate about those affected by Huntington's disease. Jennifer explained ''If no one stepped up It would go under'' so Jennifer took on the challenge, taking over from Pat McKay as chair of HDANI. Jennifer was one of the younger members, at the time Marilyn Kerr wanted to retire, so with the help of Pat McKay and Errol Walsh, Jennifer was willing to take on the challenge and at the AGM and conference in the La Mon hotel Jennifer was voted in as chair in 2014. Jennifer was Chair for four years, stepping down in 2018 when Gerry Mc Dermott was voted in.

Jennifer has been involved with HDANI for around 15 years and continues to show her support, she has been involved in many fundraising events over the years working alongside Christine Collins who was a great friend to her. After the passing of her husband Pip in 2017 her three children received negative diagnosis. Jennifer will always be part of the HDANI family.

Simon Clark has Huntington's Disease and has been involved with HDANI for around 10 years, Simon shares with us some photos of his family and his memories as well as his fantastic art work.

"My earliest memories are attending the meetings in a small pub just outside Limavady when I drove, unfortunately I don't drive anymore due to my illness, but over the years I have met some amazing people, who have helped me more times than I can count. I've also seen family grow up, we are just one big family. I attend Melrose Day Centre in Derry twice a week and love doing my art plus again, I've met some amazing people."
– Simon Clark



Mark Clark has Huntington's Disease and originally from London made the decision move to Northern Ireland around 5 years ago. Mark's brother Simon Clark and father Michael Clark were living here at the time, Mark found the Northern Ireland care system to be of a much higher standard for HD patients than London.

Mark remembers meeting Errol Walsh, who introduced him to other members of HDANI, they enjoyed lots of days out together. Mark felt reassured to know he was not alone with this condition, and felt normal amongst the HDANI family. Mark attends the HDANI Limavady support group every month, which is really important to him. Mark explained that it allows him to connect with his HD family and catch up with all the great friends he has made over the years in a comfortable environment. Mark enjoys all events run by HDANI, including the support groups, the annual family conference, the social support group lunch, days out, as well as the one to one support he receives, allowing him to manage everyday life living with HD.

Mark moved into Seabank Residential Home in Portrush in March, Marks explained, "I now have quality time for myself and the energy to go out and enjoy life. I did not have this luxury before when managing life on my own in my flat, which would not have been possible without HDANI and my support worker Zélie."

Mark enjoys getting out and about, and is passionate about the environment. Check out his You Tube Page "Mark Clark Portrush".

Ritchie Remo Fundraiser

This year HDANI organised a Ritchie Remo Fundraiser at Armagh City Hotel on Saturday 28th September after our family conference to celebrate 30 years of HDANI. We are delighted to announce that we have raised £4,720 which is phenomenal.

Ritchie Remo entertained the crowds while they put on their dancing shoes; it was wonderful to see friends, family and members of HDANI on the dance floor enjoying themselves.

HDANI would like the thank all the generous businesses who donated to the raffle both at Ritchie Remo and the conference dinner.

Mairead Brady and Thomas Wedlock won the jiving competition which was judged by Ritchie Remo himself! Mairead and Thomas very kindly donated the £100 cash prize back to HDANI, thank you to you both.

Light it up for HD - May 2019

HDANI were overwhelmed by the support of local businesses and councils during our light it up campaign on the Tuesday 7th May 2019.

As darkness set across Northern Ireland on Tuesday 7th May, we saw the country light up blue and purple for Huntington's Disease Awareness.

HDANI would like to thank all the volunteers for visiting and taking a photo of each site/monument. You will find the photos taken on our Facebook page in the "HDANI Light it up for HD 2019" album.

Huntington's Disease is a rare disease, but on the evening of Tuesday 7th May light was shone on HD!

HDANI Youth Events Update

Our Youth enjoyed three fun filled days at Lisnaskea Share Centre during HDANI's Annual Summer Camp from the 5th-7th August. Cat Martin from HDYO attended this year delivering three age appropriate information workshops. During workshops, our youth were able to engage openly with Cat in a safe environment to talk and learn about Huntington's Disease. Cat stayed for the duration of camp and was available for one to ones across the three days.

We enjoyed lots fun activities at the Share Centre including canoeing, banana boating, archery, wall climbing and laser tag.

HDANI would like to thank all our youth for attending and the volunteers who supported Ashley during camp.

HDANI youth had their Halloween event in Carrowmena Activity Centre this year. It was a great day exploring the high ropes, catching up with each other, facing fears as some took the leap of faith, which took lots of courage. The day ended with a special Halloween goodie bag for the trip home!

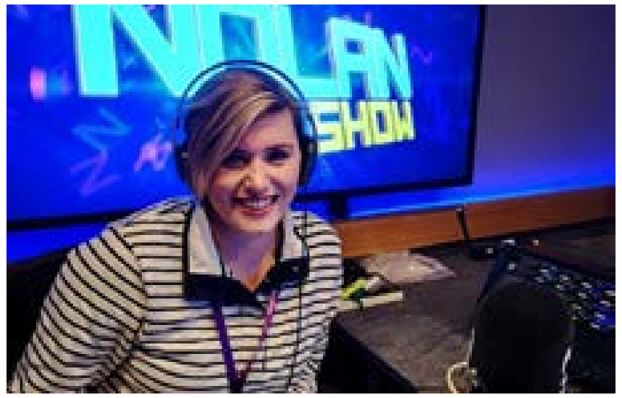
If you would like your child/children to be involved with our youth events, please contact Ashley for more details. The youth events are held around mid-term, Easter, Summer and Halloween.

Ashley - 07810330949 - ashley@hdani.org.uk

HDANI Appeal on BBC Radio Ulster

HDANI are extremely grateful and proud of Heather Hooisma and Edel Quinn for speaking out about their own HD Story and experience of Huntington's Disease.

HDANI was featured on BBC Radio Ulster on 29th and 30th September, along with this radio recording we also have two awareness raising video's sharing the story of Heather and Edel.



HD Heroes Winter 2019 Newsletter

As we reflect back over 2019, we are overwhelmed by the continued support, our donations come in many forms including, collection boxes, coffee mornings, fundraising nights/events, wedding favours, online donations, as well as one off donations.

So many of you have been busy raising awareness of Huntington's Disease, events do not happen without your time, effort, dedication and hard work. We are very grateful to each and every one of you.
All funds raised allow us to continue to provide services throughout Northern Ireland to patients, friends and family of those living with, at risk or affected by HD.

If you would like to plan an event or fundraise/ raise awareness of Huntington's Disease, please get in touch with us info@hdani.org.uk.

Thank you Leah Carson for raising a total of £1775.71, by hosting a fundraising night as well as selling raffle tickets in memory of her Granddad who sadly passed away in August 2018 after many years of suffering from Huntington's Disease. Thank you for your amazing work Leah and all involved with the night, a fantastic effort, well done.

HDANI would like to thank the following HD Heroes photographed below, presenting cheques to Ashley Clarke (Events and Fundraising Officer).

The Square bistro, Lisburn for hosting a fabulous fundraising dinner raising £2,120, the staff of Danske Bank, Lisburn for donating £200 and CASC for donating £500. All money raised have been made in lieu of retirement gifts to Trevor Lamont, who is an active member of HDANI. We hope you enjoy retirement Trevor, spending time with your wife and playing the odd game of golf!

A huge thank you to all involved, a special thanks to Trevor Lamont and the Square Bistro who went over and beyond to support us. Thank you!

Thank to Nazareth House Primary School who organised a Green Day – St Patricks Day raising a total of £653.13. On behalf of HDANI, Laura Clark received a cheque from Mr Moran the Principal of Nazareth House Primary School and Nursery Unit. Thank you to you all those involved.

Harper Ireland raised an amazing £1800 during their annual Harper Ireland dinner and Paddy's Ball. Students from Harper Ireland presented Ashley Clarke (Event's and Fundraising Officer) with a cheque during Balmoral Show, thank you to all involved and Harper Ireland for choosing HDANI.

Zélie Leech (Support Worker) receiving cheque from Marie E Curragh who held a public coffee morning on Saturday 25th May to raise funds for HDANI and has raised a huge £802.75. What a fantastic effort well done Marie and to all those involved in the day, thank you.

Marie has been affected by HD when her husband was diagnosed in Feb 2017, all funds raised will help HDANI continue to provide local support to people living with, affected by and at risk of Huntington's Disease.

Thank you to Mr and Mrs Leeman for choosing to make a donation to HDANI in lieu of wedding favours.

HDANI are very close to their hearts and we are delighted they thought of us. Congratulations Mr and Mrs Leeman, what a beautful photo.

Pictured are Dessie Farry and his wife Gretta. Dessie's family are affected by HD and has been fundraising for HDANI for over 12 years now, not only does he manage 8 collection boxes in shops across his local community in Fintona, Irvinestown, Trillick, Kesh and Dromore but they raise an impressive £100 each month which is a fantastic effort well done. We are extremely grateful to Dessie and Gretta for their tireless work and ongoing support which allows us to continue raising awareness and providing vital support to people living with Huntington's Disease across NI.

Thank you to all staff at Musgrave Park Hospital and especially to Heather Hooisma who made it possible by organising a fantastic coffee morning last Thursday 19th September raising a total of £114 for HDANI.

Belfast Marathon 2019

On Sunday 5th May HDANI had 15 HD Hero's running the Belfast Marathon relay race as well as Tim Clark who ran the full marathon!! HDANI would like to thank each runner for representing HDANI during the race, TBF Thompson for sponsoring the event and everyone who donated, and came along for moral support. It may have been a chilly Sunday but the atmosphere was amazing! We are overwhelmed by the overall total being £5,126.16!!

Made up of £3556.16 from the 15 runners who ran the HDANI Relay and Tim Clark who ran the full marathon and raising £1,570.00 well done to you all.

A HUGE Thank you to everyone involved.

We are so proud of Kirsty Mc Murray who completed the London Marathon on Sunday 28th April raising a total of £1,378.00. Kirsty ran in honour of her brother Eddie who had HD, well done from us all!

Sharon Sowney receiving £185 on behalf of HDANI from Joanna Neeson who hosted a Norwex eco-friendly household, beauty and personal care product night at Lissan G.A.C clubhouse last month. Thank you Joanna for being a HD Hero!

Glen Spence receiving a cheque of £100 on behalf of HDANI, thank you to all the donors from Al-sanity Circuits. A HUGE thank you to Glen Spence for organising and your on-going support to HDANI, we could not do it without you!

Thank you to Lisa Cooper, who completed her 5K run raising £193.

Well done Lisa what get achievement all in aid of HDANI!

Thank you to #Imnotdrunk's Highest Peak Challenge, Chloe and Ashley are hiking to the highest peak of each county on the Island of Ireland, there are 32 counties in total on the Island of Ireland, 26 of which are in the Republic of Ireland and 6 in Northern Ireland to raise funds for HDANI. So far they have raised £40, please continue to support this challenge by visiting Local Giving page https://localgiving.org/fundraising/Highest-Peak-Challenge-4HD/ to donate. Good luck to you both, from HDANI.

Thank you to Fintona Pearses GAA / Conor Kelly who raised a fantastic total of £600 for HDANI, well done to all the runners and to all that donated. Photographed above Ashley Clarke receiving cheque on behalf of HDANI.

The Northern Ireland Supporters' Club (London NISC) is proud to bring together members from all backgrounds right across Northern Ireland who now live in London and SE England. Every year they try to help good causes 'back home'.

HDANI was nominated by a member and has received a donation of £500 through the sale of mini Lego-style figures of Northern Ireland manager Michael O'Neill.

HDANI would like to thank The London Northern Ireland Supporters Club, their members and everyone who purchased a Michael O'Neill Lego figure.

We would like to thank Naomi Orr Dance who raised £160.15, this would not have been possible without Irene and Lynn Haywood, so a big thank you to you both for your fantastic efforts well done.

Thank you to Tiarnan O'Callaghan who raised a phenomenal £4240 for HDANI in April by walking on the Camino de Santiago, following the Portuguese costal route from Porto to Santiago de Compostela.

Over the course of 14 days he walked at least 300kms all in aid of HDANI.

We cannot thank you enough and to all those that made donations.

Thank you to Leeanne McClean who very kindly donated commission made for each bar of Luna and shimmer she sold in the month of September to HDANI, raising £30, thank you.

S.D Kells invited HDANI to attend their Official Opening of the refurbished Enniskillen store in May, our Events and Fundraising Officer Ashley attended to raise awareness of HD.

£72.06 was donated on the night, thank you to S.D Kells for supporting HDANI.

The Balmoral Show 2019

Photographed HDANI attending this year's Balmoral Show in May, spreading awareness about Huntington's Disease as well as raising £179 over the three days.

Thank you to TBF Thompson for continuing to support HDANI at the annual Balmoral Show.

Seeing a collection box in a local shop is a great way to raise awareness HD. We are grateful to all of you who take the time to drop off, collect and lodge funds for HDANI.

We would like to thank the following donations

- Dympa Farry Enniskillen £59.91
- Gavin The Mill Dromore- £27.79
- £159.90 - from collection boxes made up of £14.81 from NISA in Gorton (Moira McNulty) £25.11 and Valerie Crompton
- Total of £120.22 from Jeff at Orangefield shop in Armagh
- £41.30 from shop in Ballenaleck through Dympna Farry
- Killylea Shop (Kyra Brothwell) - £57.07
- £25.96 Gortin Chippy (Moria McNulty)

Thank you so much to Carmel Knipe who has raised £1,135 by going sober for October to raise funds for HDANI.

Carmel's explains "My Mum was in her early forties when she was diagnosed with Huntington's Disease, she passed away at just 54 years old. Over the years we have received support from HDANI and wanted to give a little back to help them continue their great work."

Well done and thank you all those that donated through sponsorship forms and through the Local Giving Page, we could not do it without you.

Thank you to the Redrock Tuesday Club who have raised £1,000 for HDANI through various raffles throughout the year. Photographed above, Mervyn Dougan B.E.M and and Helen Hawthorne presenting cheque to our Events and Fundraising Officer Ashley. Well done to you all.

Well done to Rachelle Glass who raised £1,303 for HDANI on Sat 21st September. We are very grateful to Rachelle, she is one of HDANI's regular fundraisers and to all those who purchased tickets, brought raffles and supported the Blues night, it looks like it was great night!

HDANI would like say a special thank you to the Director of TBF Thompson, Raymond Crilly who continues to support HDANI. TBF Thompson have provided vital funds in the past, and this year provided sponsorship for the three relay teams to run the Belfast Marathon as well as our Ritchie Remo Fundraiser. Raymond is on the HDANI Board and provides ongoing day to day support to us all, so a huge thank you.

Thank you for recent cheque donations from

- Richard Hamilton £70
- Hayden W Blair £234.12

Donation in Memory of Loved Ones

In Loving Memory

When a loved one passes we are honoured that family think of requesting donations to HDANI.

Amy photographed with her Granny.

- We are honoured to receive a total of £2,525 in lieu of flowers for the late Mr George McCallion. Our thoughts are with his daughter Frances and the wider family as they remember George dearly. Thank you to each and every one that donated and especially to the McCallion family.
- £400 donated in lieu of flowers from Eileen Pickering who sadly passed away on the 29th Jan 2019, she will be dearly missed by her sons Dougie and William Pickering, daughter in law Lorraine and grandchildren.
- £25 for donations received in memory of the late George Ward.
- £90 received in lieu of flowers in memory of the late Eileen Agnes Spence who died on the 18th June 2019. Eileen will be missed dearly by her children Glen and Julieann Spence, daughter in law Alison and grandchildren.

Research

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.

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.

For more information visit HD Buzz
https://en.hdbuzz.net/

HD and Medication

Deciding on medications for someone affected by Huntington's disease can be very difficult due to the fact that you don't directly treat the disease, you treat its symptoms. This can mean that a huge array of medications are available for the person affected, therefore fathoming their symptoms and the right medication to suit them can be confusing. In this article, Professor Hugh Rickards at the University of Birmingham discusses medications for a range of Huntington's disease symptoms.

What kind of symptoms can be treated?

The sorts of problems that can be helped with medications are as follows; Low mood (depression), anxiety, irritability (short temper) and jerky movements. Most of those problems will have other treatments too that should be considered alongside, or instead of, the medications. This might include changes in the environment and in the way other people interact with the person who has Huntington's disease, physical exercise and adaptations.

Some Huntington's disease-related problems can't usually be treated with medication. These include apathy, memory difficulties, planning problems, problems with social understanding and balance. In these situations, there are often non-medication treatments and strategies that can be used.

What types of medication are out there?

There are a number of medications out there that can help to manage the problems that Huntington's disease causes for people and their families. At the moment, there are no medications in existence that can stop or reverse the underlying problem. Those sorts of treatments are being researched currently but they can't be routinely given in the clinic.

Symptoms and accompanying medications

Depression and anxiety

These are common conditions in Huntington's disease patients but also in those who are caring for people with Huntington's disease. They often occur together. The main symptom of depression is an issue with enjoying everyday experiences such as drinking a good cup of tea, enjoying a programme on the TV or radio or seeing family. When this problem extends to all situations, all of the time, it's often time to think about medication.

Anxiety comprises of excessive worry and often includes physical symptoms like a feeling of a lump in the chest, fast heart beating, sweating and wanting to run away. There are many medication treatments for these conditions and they can often be effective. Mild side effects are common but often wear off over time.

The common treatments are in a group called SSRIS, which boost a chemical called serotonin in the brain. When taking these treatments, people can often feel more agitated for the first few days of taking the medication but this almost always wears off. Other common side effects are feeling a bit nauseous, changes in sleep pattern and in sexual function (often harder to reach orgasm). Most of these problems wear off with time or with a slightly lower dose, so it's important that more than one person is aware that the medication is being consumed. Of course, there are lots of other things that can be done as part of the treatment of depression and anxiety, including exercise, good diet, regular routine, meditation and being with friends. Some types of counselling can also be helpful.

Irritability

Irritability is really common in people affected by Huntington's disease. In fact, most people with Huntington's have periods of becoming short-tempered. This is usually because they find it difficult to understand some social situations or they become overloaded with things to think about. In people who have more advanced Huntington's disease, irritability may happen because of another physical problem that the person is not able to communicate such as pain, constipation or infection, so it's important to try and rule that out. Before going for the medication option, it's usually best to really look closely at the types of situations where a person with Huntington's disease might become irritable. There's usually a pattern if you look hard enough. This means that other people might be able to change their approach to prevent temper outbursts, rather than using medications.

There are very many different types of medication used for irritability. There are no high-quality studies in this area so treatments are usually based on experts talking to each other and comparing treatments. Usually, irritability is treatable with a combination of medication and changes in the environment including changing the way other people relate to the person with Huntington's disease.

Excessive movement

Huntington's disease was often thought of as solely a movement disorder. This is why it used to be called Huntington's chorea, as chorea meant 'dancing movement'. This was probably because it was the most obviously 'different' thing about a person with Huntington's disease. However, this is not a very useful way to look at it because jerky movement is not something that usually bothers people with Huntington's disease and, in most cases, it's not what stops them doing the things that they want to do. As well as this, medications for excessive movements can often make people feel low in mood and make it harder for them to think clearly.

Sometimes, medication is needed to reduce movements. The sorts of situations where this can be useful are when jerky movements are disturbing sleep, or throwing a person off balance, or leading to injury. In those situations, people use a variety of medications that block the effect of a brain chemical called dopamine. Examples of these medications include risperidone, olanzapine, tetrabenazine, sulpiride and haloperidol. These sorts of medications quite often will reduce jerkiness but can often lead to more sleepiness and stiffness. Weight gain is a common effect of these drugs (especially olanzapine) but sometimes this is a good thing for Huntington's disease as part of a strategy for keeping weight up. This group of medications can sometimes make people feel down in their spirits and they find it difficult to motivate or develop stiffness in the limbs or body.

Sometimes people with Huntington's disease or their relatives want to treat the jerky movements to prevent the relatives from feeling embarrassed or judged by other people. This is not usually a good reason to give medications which can have negative effects.

Where to find medications

Firstly you need to work out what the problem is before deciding if medication is the answer. For this, you need to see a doctor. This is usually the GP at first but then they may need to ask for help from the specialist if you have one. All of the medications above can be prescribed by a GP and collected from a pharmacy.

Some specialist treatments have to be prescribed by the specialist. Some medicines aren't available at some pharmacies, but they will always try and get hold of the medicine as long as it is available in your country.

Most symptoms should be managed with a combination of approaches with medication as one part of a bigger plan.

If you have any further questions regarding medication for Huntington's disease or you are affected by the disease and are in need of support, please contact us info@hdani.org.uk.

On the 29th October The National Lottery Community Fund celebrated their 25th Birthday.

Without your funding we would have been unable to have staff out across Northern Ireland raising awareness, running support groups, providing one to one support to families, people living with, affected by, and at risk of Huntington's Disease.

So a huge thank you to The Big Lottery