



## Chair Report

### *Dear members,*

I welcome this opportunity to introduce myself as the new Chairman of the Board of Trustees, as well as welcome onto the HDANI board Dr Seamus Kearney, Raymond Crilly and Lauren Byrne.

My name is Gerry McDermott and I live just outside Dromore in Co Tyrone. I am married to Marie Therese, who is a Sister in the Day Procedure Unit of the South West Acute Hospital in Enniskillen. I have three children ranging from 13 to 20 years old. Apart from providing an on-call and comprehensive taxi service for my kids, my main hobbies are running and amateur dramatics! I am a member of the Run for Enda Running Club based in Omagh and also a member of the St Dymphna's Amateur Dramatic Society in Dromore.

Believe it or not, it was running that got me involved with HDANI! I discovered that a member of my running group, Garvan McCann, was living with Huntington's Disease. I had signed up to do the Great North Run in Newcastle last September and I decided to use the run to raise some money HDANI. After the race, I emailed Sorcha and let her know how much money I had raised. I then made the mistake of ending my email by saying "please do not hesitate to contact me if I can be of further help..." I was thinking bag packing at the local ASDA, but Sorcha wrote back asking me to consider joining the Board!! I never saw it coming!

For my day job, I have been working in Human Resources for 39 years (I started working when I was 6!), initially with the Health Service in Belfast for 14 years and then in the private sector. I am currently the Divisional HR Director with Kingspan Water and Energy, based in Portadown. The role involves quite a bit of travel to other sites within the Division. I also live in Dromore, Co Tyrone so it is over an hours commute for me to the office.

I have been involved in voluntary work for many years – St Vincent de Paul, Samaritans and the Share Centre in Lisnaskea where I chaired the Board of Directors. I was also a member of the Board of Governors of South West College of Further and Higher Education – I chaired their Staffing Committee for several years.

I am acutely aware that I am on a steep learning curve in regard to Huntington's Disease and its effects on those living with the condition and on their families and friends too. However, I assure you that the Board Members and myself will channel all our energies into helping the charity achieve its mission and meet its objectives.

Finally, I would like to take this opportunity to wish our Relay Team for the Belfast Marathon every success and hope that they raise a lot of money for this great charity!

Best regards

*Gerry McDermott*  
Chair, HDANI



### Contact Us:

Sorcha McPhillips/Chief Executive  
Zelie Leech/Support Worker  
Angie Smyth  
Youth Support

On Leave Jan-Sept  
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@HDANorthernIreland



@HDAAssocNI

# 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 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 workers in advance:

[zelie@hdani.org.uk](mailto:zelie@hdani.org.uk) for Belfast and Limavady and [angie@hdani.org.uk](mailto:angie@hdani.org.uk) for Newry and Omagh.

## Belfast

Governor Community Centre, Belfast from 11-1pm.

April	May	June	July	August	Sept	Oct	Nov	Dec
3rd	1st	5th	No meeting	No meeting Social Lunch on 22nd in Cookstown with all support groups	No meeting as Annual Conference held	2nd	6th	No meeting Christmas Lunch held in Belfast

## Limavady

The Classic Bar, 48 Main Street, Limavady from 7-9pm.

April	May	June	July	August	Sept	Oct	Nov	Dec
10th	8th	12th	No meeting	No meeting Social Lunch on 22nd in Cookstown with all support groups	No meeting as Annual Conference held	9th	13th	No meeting Christmas Lunch held in Cookstown

## Newry

2-4pm. Contact [angie@hdani.org.uk](mailto:angie@hdani.org.uk) for venue details.

April	May	June	July	August	Sept	Oct	Nov	Dec
11th	16th	20th	No meeting	No meeting Social Lunch on 22nd in Cookstown with all support groups	No meeting as Annual Conference held	17th	21st	No meeting Christmas Lunch held in Cookstown

## Omagh

Wave Trauma Centre, Omagh from 8-10pm.

April	May	June	July	August	Sept	Oct	Nov	Dec
8th	13th	10th	No meeting	No meeting Social Lunch on 22nd in Cookstown with all support groups	No meeting as Annual Conference held	14th	11st	No meeting Christmas Lunch held in Cookstown

# 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. At conference last year the Association agreed to a new constitution to meet the requirements of the NI Charities Commission and we elected some new Board members.

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 whom 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

## Our New Events and Fundraising Officer

HDANI were successful in securing an internship through the Rank Foundation, Ashley has been appointed as our new Events and Fundraising Officer for one year. Ashley will be available to help with any fundraising enquires and will also be responsible for organising the youth events throughout the year. We have several fundraising and awareness campaigns currently in progress, including three relay teams for the Belfast Marathon, Light it up for HD campaign and the Balmoral Show. Ashley will also be running youth events throughout the year. Please contact Ashley for further details [ashley@hdani.org.uk](mailto:ashley@hdani.org.uk).

### About Ashley

"I have been a volunteer with HDANI from the age of 16 and enjoy being involved with HDANI, my hobbies include writing my blog #Imnotdrunk, spending time on Lough Erne wakeboarding and travelling. My dad has HD and I understand not only on a personal level but also on a professional level how important HD support is to families. I am extremely excited to work for HDANI this year, it is a dream come true, I hope I will make everyone proud. I graduated Ulster University with Bsc Hons in Leisure and Events Management."



### Baby News

We are delighted to announce that our Chief Executive Sorcha McPhillips and her husband welcomed a beautiful baby girl into their family.

"Sáerla was born on Wednesday 6th Feb 2019 at 9.38am weighing 8lb 10 and measuring over 54cm long so she will be very tall like her Mammy.

Sáerla (Sear-ylah) is an old Gaelic name meaning freeborn woman/Noble princess and Medb (May-ve) was an ancient Irish warrior queen. She is a very chilled baby but no doubt will be a force to be reckoned with and she looks forward to meeting you all at the conference in September :) – From Sorcha."



# HDANI Christmas Lunch



Photographed our members across NI with family and friends enjoying their annual Christmas lunch held in Cookstown and Belfast in December, also in attendance, Ashley Clarke (Events and Fundraising Officer), Zelig Leech and Angie Smyth (Support Workers).



# Conference 2018

For the first time HDANI held a joint inaugural conference in the Canal Court Hotel Newry. The conference began on Friday 28th September launching HDANI new E Learning Resource to HSC professionals.

Saturday included HDANI's annual AGM followed by guest speakers including Professor Asa Petersen (Lund University - HD Centre), Lauren Byrne (HD Department Dublin), Aofie Gallaher (Bloomfield Hospital Dublin), Dr David Craufurd (University of Manchester Genomic Medicine), Dr Niall Pender (Principle Neuropsychologist Beaumont Hospital Dublin), finishing off with evening entertainment.



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***INVITE YOU TO THEIR ANNUAL CONFERENCE  
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**FRIDAY 27TH & SATURDAY 28TH SEPTEMBER 2019  
ARMAGH CITY HOTEL**

**Full programme of speakers, workshops & social activities to follow**

**For information**  
**sorcha@hdani.org.uk**

# Youth News

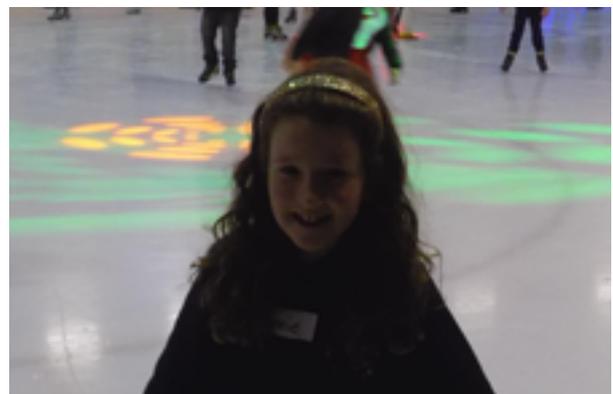


Our children and young adults are looking forward to a busy spring and summer this year having already enjoyed a fun filled day at Dundonald Ice Bowl in February.

The youth group will be attending Gortin Outdoor Activity Centre, Omagh on Friday 19th April, which will include lots of outdoor activities and a workshop.

Summer camp will be held at Lisnaskea Share Centre from the 5th -7th August, and will be full of fun activities such as banana boating, wall climbing, aqua park and canoeing. A member of HDYO will be providing workshops. An excellent opportunity to make new friends and learn new skills.

Spaces are limited at our youth events, so if you are interested in any of the upcoming events please contact Ashley via email on [ashley@hdani.org.uk](mailto:ashley@hdani.org.uk).





# Research



## **GENERATION HD1: Spain and UK sites announced today! What's new?**

Published by Maiken Arnesen on 27th February 2019

Today, Roche announced their enrollment of European participants from Spain and UK in GENERATION HD1. Over the next two years, safety and efficacy of the drug RG6042 will be studied.

You can find the Spain and United Kingdom sites below.

One month ago, Roche announced that the first patient entered the GENERATION HD1 study. The trial will investigate the efficacy and safety of the huntingtin lowering drug RG6042, formerly known as IONIS-HTRx.

Today it was announced that sites in Europe will start to enroll participants in the nearest future.

At the moment, this applies to clinics in Spain and the UK. Other European countries will follow soon. You can stay informed by visiting [ClinicalTrials.gov](https://ClinicalTrials.gov).

Over the last couple of years, the safety and short-term effects of RG6042 have been studied in 46 participants. Now longer-term safety and efficacy will be studied in more than 600 participants.

One month ago, participants started enrolling in USA and Canada. Now European participants will enter the trial.

### **What's GENERATION HD1?**

GENERATION HD1 is a Phase III study, meaning that it is designed to determine whether RG6042 is safe and effective. Hopefully, the drug will "slow down" the progression of the disease and have a positive effect on symptoms.

Over a period of 25 months, some of the participants will receive RG6042 while others will receive a placebo drug. This is done in order to determine how RG6042 works.

### **What's RG6042?**

RG6042 was the first drug to lower the expression of Huntingtin protein in humans. Why is this important?

'Sick' or mutant Huntingtin protein is not fully understood, but it is toxic to certain cell types – especially in the brain.

Reducing the amount of the 'sick' Huntingtin protein is therefore hypothesized as an important aspect in slowing down Huntington's disease.

In previous trials, RG6042 is found to reduce the amount of 'sick' Huntingtin protein and this is further found to somewhat improve symptoms of Huntington's disease.

However, the long-term effect and safety of this Huntingtin lowering is not yet known. In addition, the drug is only tested in a small group of people – which makes it difficult to say anything about the efficacy in general.

More participants is needed, as well as measurements over a longer period of time. And that is why GENERATION HD1 started one month ago.

### **Spain: expected sites for GENERATION HD1 study**

Badajoz, Badajoz – Hospital Infanta Cristina  
Barakaldo, Vizcaya – Hospital Universitario De Cruces  
Barcelona, Barcelona – Hospital Clínic De Barcelona  
Barcelona, Barcelona – Hospital De La Santa Creu I Sant Pau  
Burgos, Burgos – Hospital Universitario De Burgos  
Madrid, Madrid – Hospital Ramón Y Cajal  
Madrid, Madrid – Hospital Universitario Fundación Jiménez Díaz  
Sevilla, Sevilla – Hospital Virgen Macarena  
Valencia, Valencia – Hospital Universitari I Politècnic La Fe

The Roche Spain Medical Information team can be contacted for more information about these sites/the study: [spain.medinfo@roche.com](mailto:spain.medinfo@roche.com)

### **United Kingdom: expected sites for GENERATION HD1 study**

Aberdeen – Aberdeen Royal Infirmary  
Birmingham – Birmingham and Solihull Mental Health Foundation Trust  
Cambridge – Cambridge Centre for Brain Repair  
Cardiff – University Hospital of Wales  
Glasgow – Queen Elizabeth University Hospital Glasgow  
Leeds – Leeds General Infirmary  
London – National Hospital for Neurology and Neurosurgery  
Manchester – Central Manchester University Hospitals NHS Foundation Trust  
Oxford – John Radcliffe Hospital  
Sheffield – Sheffield Children's NHS Trust  
Southampton – University Hospital Southampton NHS Foundation Trust

The Roche UK Medical Information team can be contacted for more information about these sites/the study: (+44) 0800 3281629 or [medinfo.uk@roche.com](mailto:medinfo.uk@roche.com)

Another trial, HD Natural History study, have also started recruiting participants. Sites in Canada, USA, Germany and UK were announced in November 2018. Information about the study, including individual site status, is posted on [ClinicalTrials.gov](https://clinicaltrials.gov) (ID: NCT03664804)

The decision to join a clinical trial is personal and involves many factors. People interested in participating in any clinical research should discuss with their HD specialist about what may be best for their situation.

How are the clinical study sites selected? A variety of factors influence site selection, including assessments on experience with HD studies, clinic infrastructure capacity to run the study as well as usual site activities, ability to operationalise the study as quickly and completely as possible, patient population, and geographic location.

# 8 TOP TIPS ON BEING A HUNTINGTON'S FAMILY CARER

## 1 GIVE MORE TIME FOR ANSWERS

The changes caused by Huntington's disease means we must alter the way we communicate to make it easier for the person affected. Ways that you can help include things like giving more time for answers, avoiding distractions and listening.



## 2 AVOID DISTRACTIONS

Focusing the conversation is very important when addressing someone with Huntington's. Get the person's attention and then tell them what you would like to say. Avoid talking to someone if the TV or radio is on. Where possible, keep them away from noise and hubbub when talking to them. Don't expect them to walk and talk or eat and talk at the same time.

## 3 BE AWARE OF TEMPERATURE

People with Huntington's sometimes have difficulty regulating their body temperature and this can affect their mood, motivation and overall well being. Always ask and look for signs of heat or cold. Consider clothing, room temperature, fans, blankets, etc.



## 4 DON'T BE AFRAID TO ASK FOR EMOTIONAL SUPPORT

Caring for someone with Huntington's can be incredibly difficult emotionally. What sets it apart from many other illnesses is its genetic nature; carers may have cared for others in their family with the same disease, and may even be at risk themselves. You and the person you are caring for may need a range of emotional support to keep you going.

## 5 CLUE UP ON OFFERED FINANCIAL AID

As a carer, you are likely to be affected financially by the costs of caring and the impact of being a caregiver on your ability to work. There are a number of different benefits available to carers such as Carer's Allowance, Carer Premium and Carer's Credit.



## 6 MAKE TIME FOR YOU

When caring for someone with Huntington's, you may find your energy and mood low sometimes. It can help greatly if you are able to make time for activities that help you feel better, physically and mentally, such as exercise and hobbies or even seeing friends. Depending on the stage of the illness, you can also enjoy activities with the person you are caring for.

## 7 DON'T IGNORE THE BIG DECISIONS

Although a difficult topic to approach, managing your loved one's affairs is very important. If the person you are caring for is an adult, they may at some point become unable to manage their own affairs, such as paying bills or legal matters and Lasting Power of Attorney will need to be discussed. There are two types of LPA: health/welfare and property/financial affairs, you can choose to make one type or both.



## 8 TALK TO OTHERS

It can be hard to talk to others about caring for someone with Huntington's. Many people haven't even heard of it and won't know the symptoms or understand what it means for the future. It's helpful to have people you can openly talk to. The Huntington's Disease Association's advisory service along with support groups and branches can help with this.



# Huntington's Disease and Diet



## Why do I need to eat well?

People with HD can find it difficult to maintain their body weight, or they can be underweight. People who are very underweight are prone to infection, have slower wound healing and progressive muscle wasting and lethargy. People with HD usually need a much higher calorie intake than normal.

## I am hungry but find eating difficult

You do not have to eat large meals. Small frequent snacks, high in calories (little and often) can be just as helpful. Do not drink large amounts of fluids with meals as these will make you feel full quickly but do try to drink plenty of fluids in between meals. Take your time over meals. Sit comfortably.

## Add extra calories

**MILK** is a good source of protein. Try to drink at least one pint of full cream milk a day.

**YOGHURT** or similar desserts can be used on fruit and puddings. Those with added cream or the thick 'n' creamy ones are ideal. Avoid low fat or diet yoghurts.

**CHEESE** is a good source of both protein and calories. Full fat cheeses such as cheddar and Lancashire are the best. It can be sprinkled on creamed potatoes, soft vegetables, soups, and fish in sauce, minced meats and baked beans. Add cheese to omelettes and scrambled eggs. Cheese in a sandwich, on biscuits or on toast is an excellent snack.

**MEAT AND FISH** in any form is useful. Cook well and serve with plenty of gravy or sauce. Tinned fish in oil or mayonnaise rather than brine or tomato sauce has more calories.

**LENTILS AND BEANS** are also a good protein source. They can be added to soups, casseroles, and stews, or used just as a vegetable. Baked beans on toast are a useful snack.

## Foods you may find difficult to swallow

Raw or hard cooked vegetables, salads, peas, sweetcorn, broad beans, tomato skins; hard fruits such as apples, pears, grapes, pineapples, fruit skins or fruit peel; crusty bread, pre-sliced bread, granary bread, high fibre white bread, bread crusts, toast, crackers and crisp breads; sponge cakes; crisps; hard chips; flaky and puff pastry; hard pastry crusts; nuts and food containing nuts; dried fruit and foods containing dried fruit; shredded wheat.

## Care of the mouth

To keep your mouth in a healthy condition:

- Use mouthwashes regularly. Ask your nurse or Doctor about the best one for you to use
- If your lips are dry, apply a lip salve e.g. Vaseline.
- Clean your teeth frequently. Use dental floss
- Visit your dentist for regular check-ups.
- If you wear dentures, keep them clean and make sure they fit correctly. Ask your dentist for advice. Dentures are one of the first things to become loose when people lose weight.
- Sometimes foods may not taste the same or seem to have no taste - good mouth care can minimise this.

## Keeping food down

- Sit upright to eat your meals. Try not to lie flat immediately after a meal.
- Eat your meals in a well ventilated room and wear comfortable clothing.
- Try to ensure there is a calm, relaxed environment.
- Minimise what is going on around you so you can concentrate on eating.

Discuss with your doctor, speech and language therapist or a dietician any problems regarding eating you may be having.



- Meals need to look attractive
- All utensils should be kept clean
- Meals may need warming during serving if feeding takes time.
- Remember a calm relaxed environment will help!
- Nutritional supplements which can help to add calories to your diet are available.
- A dietician can advise you on your individual needs. Referral can be arranged by your GP.
- A referral to a speech and language therapist can be helpful in resolving some of your swallowing problems.

# May is HD Awareness Month



## Belfast Marathon Sunday 5th May 2019

HDANI have entered three teams into the Belfast Marathon Relay Race, we are extremely grateful to TBF Thompson for sponsoring the teams.

Our teams will be running five legs from 3.9 to 6.9 miles. We invite friends and family to come along on the day and show your support for our amazing volunteers.

To donate, please visit <https://localgiving.org/fundraising/HDANIbelfastmarathonrelayteam>

We are very grateful to Tim Clark who will be running his 13th Marathon this year!! Tim has chosen to fundraise for HDANI, please show your support by visiting his local giving page. Good luck Tim!

<https://localgiving.org/fundraising/timclark13>



## Light it up for HD - Tuesday 7th May 2019

HDANI will be taking part in the global campaign #lightitupforHD

Join a global movement to raise awareness for Huntington's disease by lighting up in blue (HD) and/or purple (Juvenile HD) on Tuesday 7th May.

We are asking public buildings, monuments, businesses, community spaces and homes to take part in a worldwide act to support and shine a light on this deadly brain disease which affects hundreds of families in Northern Ireland.

If you know or want to bring to our attention any monuments or buildings which could change their outside lights blue or purple please contact [ashley@hdani.org.uk](mailto:ashley@hdani.org.uk).

This campaign will tie in with May being Huntington's disease awareness month



## Balmoral Show 15th – 18th May 2019

HDANI will also be working with the partner TBF Thompson at this year's Balmoral Show, spreading awareness about Huntington's disease - if you would like to volunteer please get in contact with [ashley@hdani.org.uk](mailto:ashley@hdani.org.uk)

## Our HD Fundraising Heroes

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Over the past 6 months so many have been busy raising awareness of Huntington's Disease and collecting vital funds for HDANI. We are so grateful for all your support.

*In  
Loving  
Memory*

### Donations in Memory of Loved Ones

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

We received a cheque totalling £587.50 in respect of donations received for HDANI in memory of the late Mrs Patricia Crowe, we are grateful to her family for thinking of us at such a difficult time. May she rest in peace.

Special thank you to Des Farry who raised £100 in memory of his late sister Catherine McCann, Fintona Co Tyrone.



## 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.

Thank you to Bombardier Aerospace Belfast who raised £400 at their "Christmas jumper day" held on 14th Dec 2018. Money raised in memory of the late Phil Whyte who sadly passed away in early 2018 with HD.

## Family Heroes



A huge thank you to the Keenan family in Coalisland who raised £1160 through a craft fair weekend in memory of Bridie (wife of Charlie) who sadly passed away last year following a long battle with HD.

## Running for HDANI!



Our Events and Fundraising Officer Ashley Clarke receiving cheque from TBF Thompson Director Raymond Crilly and Rachel McKerr

who completed the Belfast City Half Marathon on the 23rd Sept 2018, raising a total of £1521.25, a huge thank you to you both.

HDANI are very grateful to Tiarnan O'Callaghan who will be steppin' out in April on the Camino de Santiago, following the Portuguese coastal route from Porto to Santiago de Compostela.

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

Please follow link below to show your support for Tiaran.

<https://localgiving.org/fundraising/wee-dander-in-spain/>



Kirsty McMurray ran the Belfast Marathon last May raising over £1200 in memory of her brother Eddie Davies who sadly passed away from HD last April. We are delighted and extremely grateful that she is running the London Marathon on the 28th April, choosing to donate to us again!! A massive thanks from HDANI and good luck with your training. Please visit Kirsty's fundraising page to support and make a donation



[uk.virginmoneygiving.com/KirstyMcMurray3](http://uk.virginmoneygiving.com/KirstyMcMurray3)

## Celebrating!

### Howard Rainey turns 60

**BIG THANK YOU TO EVERYONE WHO HAS SUPPORTED ME IN THIS FUNDRAISING VENTURE!!**

60th Birthday and swim both past now, thanks to all my family and friends for their support, including anonymous donors. I've tried to make sure a message of thanks has gone to all donors, apologies if I have missed anyone. Apart from electronic donations, I also received donations directly from my golfing buddies, other friends and very kindly the Peter O'Callaghan connections - Paddy Maguinness, Emma Arthurs and Paul McKernan + Joseph Doherty of Re-Gen Waste Ltd. who not only

made a generous financial donation, but, also, as you'll see from the photo opposite provided me with a hat to keep me warm post-swim.

Your donations combined with gift-aid mean that over £1,000 is going to our local Huntington's Association to enable them to provide crucial advice and support.

*Howard xxx*

**Total raised £1810**



## Events for HD



Well done to Rachelle Glass who organised and held a fundraising night on the 14th October for HD, she raised over £1600, what a successful night! Pictured above at her hair salon in Belfast our support worker Zelig receiving cheque on behalf of HDANI



HDANI would like to thank Armagh Lions Club for choosing us as one of their charities for 2018 by running a series of local community fundraising events raising an impressive £3000. Well done to all involved, what an achievement.



Pictured above our support worker Angie Smyth receiving cheque from Conor Kelly from Seskinore, who was the Rose of Tralee escort in Co Tyrone and as part of his fundraising efforts held a BBQ which raised £3,500 for HDANI, a massive thanks.



Well done Sharon Sowney for organising and raising £500 at a local coffee morning, great work. Pictured above Zelig our support worker receiving cheque from Sharon on behalf of HDANI.

## 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 Lorna and Jason Brownlee pictured above on their beautiful wedding day which took place on the 22nd December 2018. Lorna and Jason very kindly decided to make a donation to HDANI in lieu of favours, thank you so much from HDANI we couldn't do it without #hdheros like you.

## 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.

We would like thank the following for donations

**Des Farry £100 Oct 2018 collection boxes in Trillick**

**£36.17 from Marie Curragh collected at the Bean Café**

**£100 donation from Mr McGowan Coleraine Armagh Regatta £38.50 (Kyra Bothwell)**

**Belfast Regatta £55.00 and continued support from Killylea Spar (Kyra Bothwell)**

## In lieu of Christmas Cards

Special thanks to those of you who made donations to HDANI in lieu of sending Christmas cards. We received a donation of £1500 from Skipway in lieu of cards to their customers.

### Contact Us:

Sorcha McPhillips/Chief Executive  
Zelie Leech/Support Worker  
Angie Smyth  
Youth Support

On Leave Jan-Sept  
077 3393 5863  
079 2151 3561

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