HUNTINGTON'S
DISEASE ASSOCIATION
NORTHERN IRELAND

Families at the heart of all we do

OCTOBER 2025

HDANI CONNECT

2025 EDITION

Celebrating our achievements to date
& a look at what's to come
for the HD community in Northern Ireland

A Message of Hope from Bucharest:

Why HD Families in Northern Ireland are World-Class

By Sorcha McPhillips,
CEO, HDANI

Hello everyone,

I've just returned from a fantastic and incredibly important trip to Bucharest, Romania, where I attended the European Huntington's Disease Association (EHA) conference in September 2025. It was truly an honour, and I wanted to share my reflections with our amazing HDANI family.

An Uplifting Global Community

The atmosphere at the conference was overwhelmingly inspiring, uplifting, and hopeful. Imagine bringing together leading clinicians, scientists, researchers, and dedicated patient advocacy groups from 32 different countries—all focused on one goal: improving the lives of those affected by HD.

It was a brilliant opportunity to build new connections and reinforce existing friendships with the experts developing new treatments, from pharmaceutical companies to academic research centres. We heard heartbreaking and resilient life experiences shared by family members, discussed the latest research developments, and shared best practice recommendations on how to care for families better.

It was reassuring to know that the challenges we face in Northern Ireland are shared globally, but most importantly, it showed us how strong and determined the global HD community is.

Confirmation: Focusing on the Whole Family

For me, one of the most reassuring takeaways was the strong message coming from the latest research. It confirmed what we at HDANI have always believed and advocated for: the need to support the whole family, not just the person diagnosed with HD.

The research is very clear that the issues affecting families the most are often related to mental health, emotional wellbeing, and financial security. This means our focus here in NI—on helping families cope with the worry and the practical day-to-day challenges—is exactly where we need to be. It was lovely to realise that the level of service HDANI provides is truly gold-standard and is fully supported by the very latest scientific thinking and community surveys.

Why HDANI Support is World-Class

I learnt that, in many other European countries, families have to fight for access to the most basic information and services. That's a story which will be familiar to many of you. Over the past 11 years with the charity, I have been frustrated and angry on your behalf, but we turned that into determination and action. Thanks to the years of lobbying and hard work by our community, you and your family here in Northern Ireland are very fortunate. You have access to a support system that is truly exemplary:

1. The HD Nurse Specialist

Through our advocacy work, you can access one of two dedicated HD Nurse Specialist regardless of where you live in Northern Ireland. They are experts in the medical side of HD and focus on the complex physical and medical needs of the person with the disease. They work closely with neurology, genetics and all the various allied health and social care staff, helping HD patients in hospitals, care homes and in the community.

2. Experienced Neurologists

It is no secret that neurology services in Northern Ireland are at a crisis point with the average waiting time for a first appointment as long as eight years in some areas. However, through the nurse-led HD service, people with HD are able to get fast access to a neurologist with expert knowledge of HD.

3. The HD Family Support Worker

Crucially, you also have access to a dedicated HDANI Family Support Worker. They are there to help the whole family navigate the complex world of:

- Social Care
- Financial and Benefit support
- Emotional challenges and counselling
- Connecting you with other HD families for vital peer support

This approach to HD care and support ensures that every aspect of your family's life—medical, social, emotional, and financial—is supported by an expert who understands HD.

Returning from Bucharest, I feel energised and more committed than ever. It's not all rainbows and unicorns though! This work is only possible through the dedication, commitment, knowledge and goodwill of a small number of individuals without whom it would simply fall apart. The services of HDANI is dependent on charitable donations and grants with no guaranteed funds and no commitment from our government to ensure our vital services can be sustained and grow with the needs of the population. While many countries lacked the most basic services, our partners in Norway, and the Netherlands shared experiences of strategic care frameworks, clear pathways of care, dedicated HD care homes, day centres, palliative care and respite services. Colleagues from Spain spoke to the recognition and promotion of emotional and social supports within their health system rather than a focus on reactive responses, allowing people to live with a good quality of life for longer. Our work here is far from done but we are part of a wonderful community, both here in Northern Ireland and across the world. The future is hopeful, and with your help, we will continue to ensure that HD families in NI receive the very best care and support available anywhere.

Thank you for being part of our fight.

Sorcha McPhillips,

Chief Executive

Fundraising Challenge - with our trustee Janice McCartney

What inspired you to take on the challenge of walking 100 miles in February for Huntington's Disease Northern Ireland?

The charity has helped me a lot this past year, so I wanted to do something to give back to them and show my appreciation. I also wanted to get back into fitness so it really gave me a reason to get up and out of the house.

Raising nearly £4,000 is an incredible achievement! How did you manage to reach such an impressive total?

The total amount is nearly at £6000 now which I can't believe. The support started with my family and friends all of which shared the fundraising page and then the momentum kept on building. Armagh I also approached me and asked if I would share my story with them. This article then brought about a lot of donations. I even had people who I didn't even know coming into my workplace just to make a donation. I have been blown away with the support from everyone - all the shares & donations is what got me to this amazing total.

Did you face any personal challenges during the 100-mile walk, and how did you stay motivated to keep going?

It was only when I was getting close to reaching the 100 miles that I then took sick and was unable to get out walking. I appreciated that I needed time to rest and recover so I gave myself time to do so and then I got straight back to it. Thankfully I was slightly ahead in my miles so it didn't set me back too much.

Was there a particularly memorable moment or experience during the challenge that stood out to you?

Rory Best who is a retired Ireland rugby player came into my work one day and I jumped at the opportunity to get a photo with him to raise awareness. I was so thankful that he also offered to share my challenge on his social media platforms.

How did your friends, family, and community support you throughout the challenge?

My family, friends & the local community were so good to me during the challenge. The support varied from people offering to walk with me, people sharing my fundraising link and people making a donation.

I was so overwhelmed at the amount of people that wanted to contribute - it really shows how good the community spirit is.

For those who may not know much about Huntington's disease, why is supporting this cause so important to you?

My dad was diagnosed with HD and then passed away a few years later. To each child born to a parent with HD, there is a 50/50 chance that they will also inherit the disease. Last year I tested positive, so the charity has been so supportive and helpful when I needed them most.

What advice would you give to others who might be considering taking on a fundraising challenge for HDANI?

Just go for it - you have nothing to lose!! The charity is solely to help families affected by HD so I know my family is so grateful for all the fundraising that people do for HD.

I remember sitting at the kitchen table with my family and I wasn't sure whether or not to do it, but now looking back I don't know why I ever doubted myself.

What did you learn from this experience, and do you think it has changed you in any way?

I have learnt about the power of the community and how people can come together to help support each other. It has also been a great lesson in setting goals and working hard to achieve them. This challenge has also made me realise that once you believe in yourself you can do anything you put your mind to.

Do you have any plans to take on another fundraising challenge in the future? If so, what might it be?

This is my 4th fundraiser for HD so maybe in a year or two I will organise something else.

Finally, is there anything you'd like to say to the people who donated and supported your journey?

From the bottom of my heart, I would like to express my thanks to each and every single person who supported me on the journey. My family & I will be forever grateful for all the kindness that the community has shown - yous have no idea how much it means to us.

Meet our Family Support Workers

We recently said goodbye to Henna and welcomed Clara Spence, who will be covering the Northern Trust area, and Lynn Patterson, who will be working in the North West. This brings our family support team to five at the minute: Rita, Mairead, Katie, Clara, and Lynn.

Meet Clara

Hi everyone!

I have recently joined the team at HDANI and I'm really excited to get stuck in and meet more of the amazing people connected to the charity.

I have six years' experience working as a Mental Health Project Worker, as well as a Team Leader supporting people with learning disabilities and complex needs. I still spend my weekends working in both mental health and learning disability services, as I love being a familiar face in people's lives and supporting them through different stages of their journey.

I've completed my Level 5 Diploma in Leadership for Health and Social Care, and have also volunteered as a Youth Worker and as a Tutor for young people at the Belfast Hospital School.

I'm really passionate about helping others—whether that's through offering practical support, providing information, or just being someone to chat to. I feel very lucky to be part of HDANI and to be working alongside such a dedicated team and community.

When I'm not working, you'll usually find me at a Pilates class, out on a walk, reading, or getting stuck into a new DIY project. I'm looking forward to getting to know everyone better and expanding my knowledge of Huntington's Disease!

Clara

Meet Lynn

Hi all, I feel very privileged to have joined the team at HDANI on the 11th August `25 So, I'm the "new kid on the block!" I'm looking forward to meeting families affected by HD and I'm busy learning about the disease to enable me to carry out my job effectively. With more than 30 years of experience supporting families I bring deep compassion, understanding, and dedication to the HDANI team. Throughout my career, I have worked alongside families facing a wide range of challenges, helping them navigate governmental systems, strengthen relationships, and create safe, nurturing environments. I am known for my warm, compassionate and non-judgemental approach. I specialize in building trust and rapport, connecting families to essential resources, and providing guidance that respects each family's unique strengths and circumstances. In my spare time I love spending time with my family and friends and, of course, my dog, Amber. I took up kayaking last year and love it and I'm an avid shopaholic!! I have always loved this quote:

"Family is not just an important thing – it's everything!".

HDANI Support Groups

HDANI now hosts five monthly support groups for service users. These are based in Belfast, Newry, Maghera, Omagh and this spring a new group was created in the Derry area known as the Foyle Support Group.

These are run by the Family Support Worker in the area and are open to all adults who are affected by HD.

Support groups keep everyone up to date with our work, events services and also acts as a point of information, practical and emotional support. The groups are a chance to meet and learn from other people affected by Huntington's Disease and benefit from professional support all in an informal, non-judgemental space over a cuppa.

We also invite guest speakers to these to give further information and support to our HD community - please see below some information on what has been happening at our different groups.

Belfast Support Group

Venue: Belfast Grosvenor Community Centre
Time: 11.30am-1pm
last Thurs of the month
Dates for 2025:
Thursday Jan 30th
Thursday Feb 27th
Thursday March 27th
Thursday April 24th
Thursday May 29th
Thursday June 26th
Thursday Sept 25th
Thursday Nov 27th

Newry Support Group

Venue: Newry Rathfriland Community Centre
Time: 2-4pm
3rd Thurs of the month
Dates for 2025:
Thursday Jan 16th
Thursday Feb 20th
Thursday March 20th
Thursday April 17th
Thursday May 15th
Thursday Jun 19th
Thursday 18 Sept
Thursday 20th Nov

Maghera Support Group

Venue: The Lurach Centre
Time: 18:30 -20:00
Dates for 2025:
Tuesday 14th January 2025
Tuesday 11th February 2025
Tuesday 11th March 2025
Tuesday 8th April 2025
Tuesday 13th May 2025
Tuesday 10th June 2025
Tuesday 8th July 2025
Tuesday 12th August
Tuesday 9th September
Tuesday 11th November

HDANI monthly regional support groups in Maghera for those affected by HD, their carers and families. This is an opportunity for individuals to collectively come together to share their experiences of having HD, caring for someone with HD and a safe space for them to disclose information. We regularly have speakers in from other organisations including; Make The Call, Inspire wellbeing services to name a few, and host workshops on research updates, benefit entitlement advice and much more! The group is well attended each month with a variety of the participants being regular attendees each month. We provide updates on upcoming events including our summer social events, youth events and youth camp in August 2025, our annual HDANI Conference in October and Christmas lunches hosted in Belfast and Cookstown. If you would like more information please do not hesitate to contact Henna on henna@hdani.org.uk or alternatively on 07921 513561.

Omagh Support Group

Venue: St. Patrick's Hall, Dromore, Co Tyrone (BT78 3AH).
Time: 6:00-7:30 pm
Every second Monday per month
Dates for 2025:
Monday 13th Jan 2025
Monday 10th Feb 2025
Monday 10th March 2025
Monday 14th April 2025
Monday 12th May 2025
Monday 9th June 2025
Monday 8th Sept 2025
Monday 10th November 2025

The Omagh Support Group provides crucial emotional support to those affected by Huntington's Disease (HD). We also offer advice on accessing community-based resources and share practical guidance on managing the challenges associated with HD. Attendees benefit from the insights of guest speakers, including representatives from the PSNI, the Health Improvement Officer, and Molly, who has presented on HD research. Staff from the Make The Call service have also shared valuable information. Looking ahead, we plan to invite additional organisations and guest speakers to provide comprehensive information on available resources. Our goal is to ensure that those attending continue to receive the most up-to-date guidance and support for managing HD.

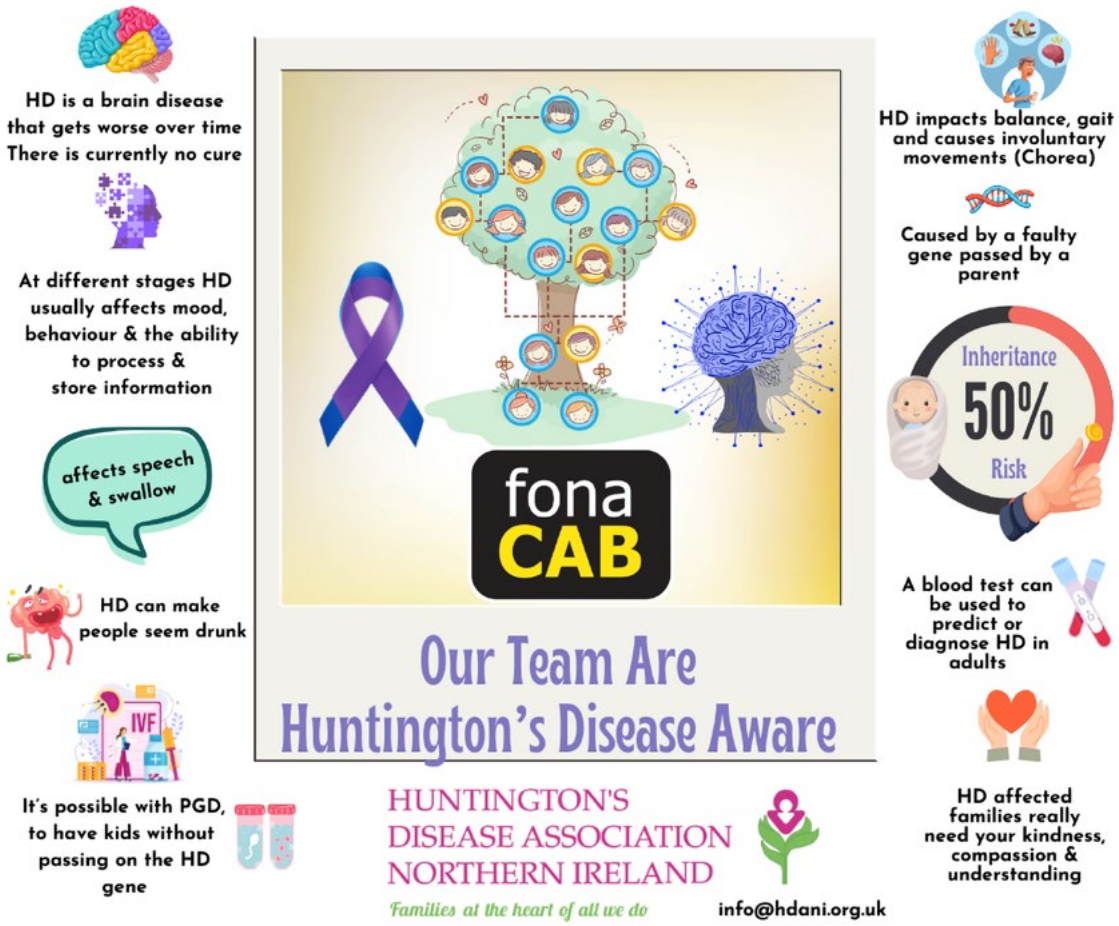
Foyle Support Group

Venue: GlenOaks Centre, Glen Road, Derry BT48 0BX
Time: 2-3pm
Dates for 2025:
Friday 10th January
Friday 11th February
Friday 14th March
Friday 11th April
Friday 9th May
Friday 13th June
Friday 12th September
Friday 14th November

Health & Wellbeing day

Our Family Support Workers, Rita & Lynn, attended the Health & Wellbeing Day in Desertmartin on September 4th, where they raised awareness about HD, and connected with the public and other service providers.

Awareness Training



Taxi Awareness

HDANI are proud to partner with Fonacab, the largest taxi company on the island of Ireland to ensure that all of their drivers and call centre staff have information about Huntington's disease.

Fonacab have over a thousand drivers operating around Belfast city and surrounding areas and around 80 call staff although this increases to up to around 100 at peak season. They are among the top ten largest taxi company in the UK and are the current (and three-time winner of) Taxi Company of the Year, NI and Ireland.

According to Sorcha McPhillips, Chief Executive of HDANI, "People with HD often struggle with transport needs and rely heavily on public transport and taxi's to allow them to engage with their communities and maintain active. By providing taxi drivers with information and tips on how to support customers with HD, we are ensuring our family members receive a better service and reducing the threat of social isolation."

HDANI have been working with Stephen Anton, Communication Manager with Fonacab, to deliver tailored and effective messaging to all Fonacab staff and drivers which will build customer confidence in using their fleet and help challenge some of the stigma faced by people with HD. This work comes in response to an issue raised by a service user who experienced difficulty accessing public transport at times because their symptom presentation of unsteady gait and slurred speech led people to believe that they were drunk. HDANI continue to build on our awareness work and invite any business or service provider to reach out for free information, training and support for their teams. For more information about HD visit **www.hdani.org.uk** or email **info@hdani.org.uk** .

Partnering with the PSNI

Over the past 12 months we have been working closely with the PSNI providing information about HD to all front line officers across Northern Ireland. This information not only explained what HD was but gave tips for officers encountering a person with HD drawing attention to the need for allowing personal space, clear communication and a non-judgmental approach. We explained how movement and behavioural symptoms can cause people to be mistaken as drunk or aggressive. The PSNI undertook both public awareness through their social media channels which reaches hundreds of thousands of people and awareness across their staff team. They also HD resources including a HDANI recorded training session available to staff.

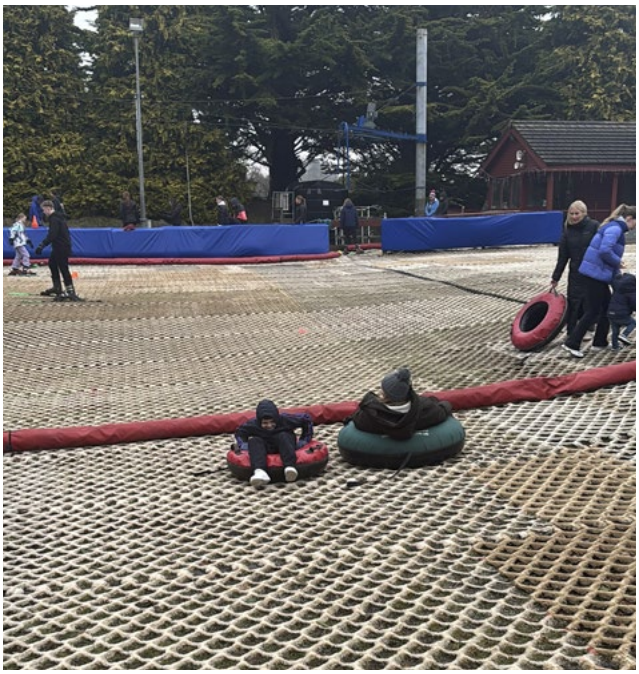
Sorcha McPhillips, HDANI Chief Executive said *"We are delighted once again to partner with the PSNI in raising awareness about Huntington's disease this May. Police Officers across the service partook in HDANI training sessions and many now have access to a HDANI recorded training session providing an overview of the causes and symptoms of HD and explaining the impact on the individual and whole family. The PSNI will continue to work with HDANI to increase awareness of HD. This partnership also increases the confidence of the HD community in their police service, knowing that they are committed to understanding, protecting and supporting them."*

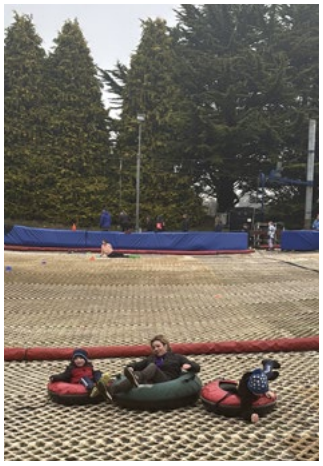
Youth events

Snow Tubing

A group of families braved the January cold and joined us for an energetic day in Craigavon

See below some pictures of the day……





Jungle NI

Some photos of our Easter youth day at the Jungle NI where our youth group enjoyed fun in and out of the water!

Summer Fun at our Family Socials

In a change from our usual summer lunches we opted for a few family days out this year where service users of all ages from across Northern Ireland had a chance to meet up.








HUNTINGTON'S DISEASE ASSOCIATION NORTHERN IRELAND

Families at the heart of all we do

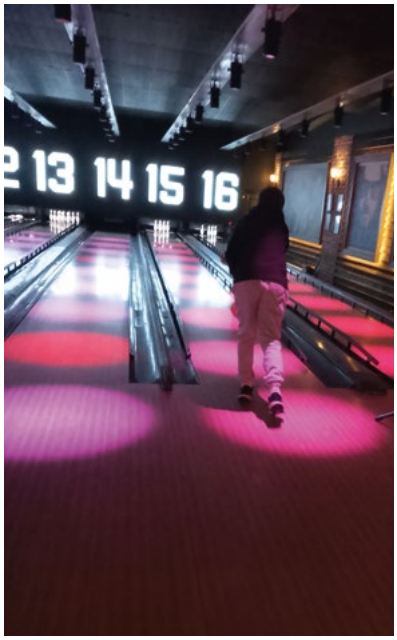
HD FAMILY SOCIAL

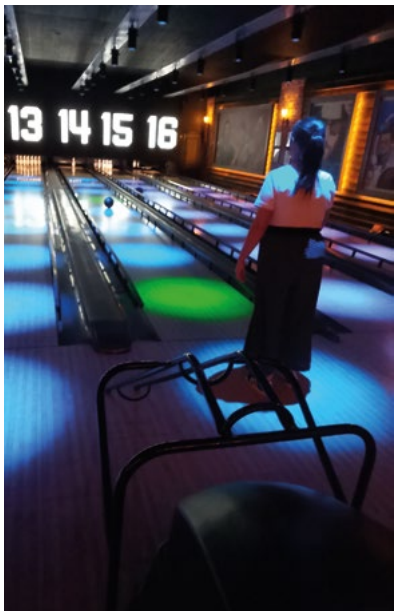
BOWLING & LUNCH

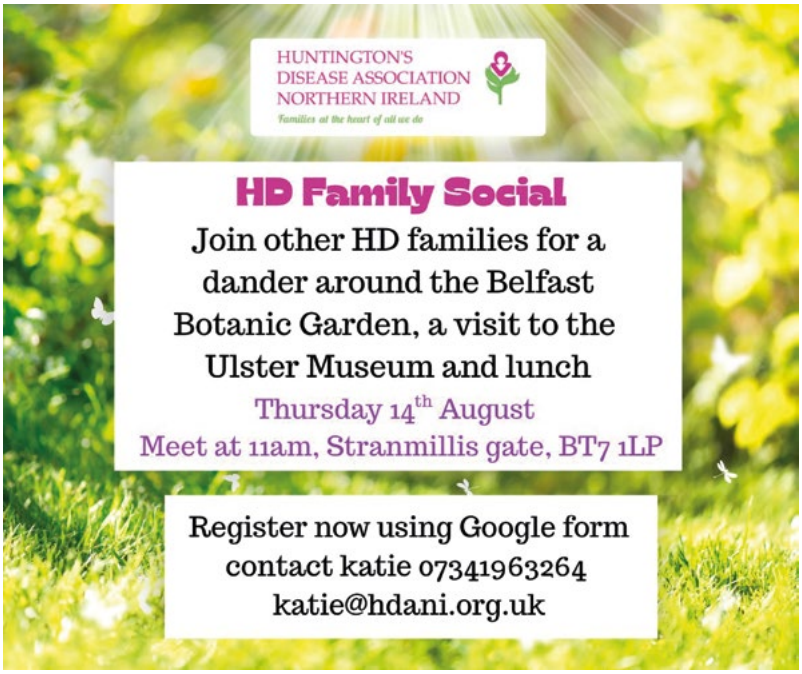
FRIDAY 4TH JULY AT 11.30AM

BRUNSWICK CINEBOWL BT48 0LU

FREE TO HDANI FAMILIES BUT YOU MUST REGISTER






HUNTINGTON'S
DISEASE ASSOCIATION
NORTHERN IRELAND
Families at the heart of all we do
HD Family Social
Join other HD families for a dander around the Belfast Botanic Garden, a visit to the Ulster Museum and lunch
Thursday 14th August
Meet at 11am, Stranmillis gate, BT7 1LP
Register now using Google form
contact katie 07341963264
katie@hdani.org.uk


ULSTER MUSEUM
TROPICAL RAVINE
ROSE GARDENS
BOWLING GREEN
PALM HOUSE

HDYO Report

Prague: Where Young People Found Their Tribe

By Katie McClean, Family Support Worker, HDANI, March 2025

I've just returned from the **Huntington's Disease Youth Organisation (HDYO) International Young Adult Congress** in Prague, and honestly, I'm still buzzing. For three days, from the 14th to the 16th of March 2025, the stunning city of Prague became the heart of the global HD youth community. Seeing the young people from every corner of the world, including Northern Ireland, connect with others facing similar challenges was truly a powerful experience.

As a Family Support Worker for HDANI, my job is often about providing one-to-one emotional support and practical guidance. But the HDYO Congress is something entirely different. It's an immersion in a community built purely on understanding, education, and empowerment. It's where the isolation that many young people feel back home simply vanishes.

Day 1: Finding Our Feet and Our Voice

The first day was all about **mental health and community building.** This is always such a vital starting point. You could see the initial nervousness melt away as the attendees realised they were in a safe space, surrounded by hundreds of others who just *get it.*

We had brilliant, open discussions around **grief, loss, and self-care**—topics that are often difficult to address in a casual setting. These workshops weren't just clinical; they were interactive sessions that helped the young adults develop practical coping strategies. Crucially, Day 1 established that fundamental sense of belonging. The evening social session was filled with laughter and networking, proving that even when dealing with something as heavy as HD, there's always room for **joy and connection.**

Day 2: The Science of Hope and Personal Truths

Day 2 was a fantastic mix of the **scientific and the personal.**

We had leading researchers and medical professionals sharing updates on the latest HD research and clinical trials. For our young people, hearing about groundbreaking work—like the progress on **HTT-lowering therapies**—directly from the scientists themselves provides tangible hope. The presentations were designed to be accessible, breaking down complex terminology (like 'CAG repeats' and 'biomarkers') so everyone could leave feeling truly informed.

But the most moving part, for me, was the focus on personal stories. Community members bravely shared their own experiences, particularly on navigating **relationship dynamics, communication challenges, and cultural stigmas** associated with HD. Hearing Khadija Chaudary from the Huntington's Disease Society of Pakistan, for instance, speak

on the "Stigmas of HD" panel was incredibly impactful, highlighting how different cultures cope—or struggle—with the generational silence and shame surrounding the disease. This kind of cross-cultural honesty is what makes the Congress so unique and so vital for fostering global advocacy.

Day 3: Planning for the Future

The final day turned our focus outward, offering **practical guidance and future planning.** The sessions covered critical life stages:

- **Genetic Testing Decisions:** Helping young adults navigate the complex emotions and practicalities surrounding the choice to be tested or remain at risk.
- **Family Planning:** Discussing options like PGD (preimplantation genetic diagnosis) for those hoping to have children without passing on the gene.
- **Navigating Life at Risk:** Strategies for maintaining a healthy lifestyle and managing the emotional challenge of 'survivor's guilt' that many experience.

These sessions gave our young people the tools and knowledge to make informed decisions about their futures, empowering them with agency rather than letting the disease dictate their path.

An Essential Investment

I am incredibly proud of every representative who attended. They came away not only with a greater understanding of the science and the latest trials but, most importantly, with an expanded **support network.** The Congress is more than just an event; it's a profound reminder that none of our young people are fighting this battle alone.

It truly reinforced HDYO's mission: to support, educate, and empower. We must ensure these opportunities continue, allowing the next generation of HD families to find resilience and strength together.

If you are a young person affected by HD in Northern Ireland and missed out this time, or if you simply need someone to talk to, please know that we at HDANI are here for you. We look forward to bringing the inspiration and learning from Prague back into our local families!

HDYO
HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

Research

What Causes Huntington's Disease (HD)? A Simple Guide for Families

1. The Basics: Hereditary and Neurodegenerative

Huntington's Disease is a progressive condition that affects the brain. To understand what causes it, we use two main terms:

- **Hereditary:** This means the disease is passed down in a family through our genes (the instruction manual inside our cells).
- **Neurodegenerative:** This means the disease causes brain cells to gradually waste away or stop working properly over time.

2. The Body's Instruction Manual (DNA and Genes)

Inside almost every cell of your body is your DNA—your unique set of instructions for building and running you.

- This DNA is neatly packaged into 23 pairs of structures called chromosomes.
- Along the chromosomes are thousands of small sections called genes. Each gene holds the specific instructions to make a certain protein, which performs a job in the body.

3. The Fault on Chromosome 4

The cause of HD is a small, specific fault in one gene, located on chromosome 4. This particular gene is called the Huntingtin gene (HTT).

The fault in the HTT gene causes it to create a version of the Huntingtin protein that is too long and sticky. This abnormal protein becomes toxic (poisonous) and gradually damages the brain's nerve cells, especially in areas that control movement, thinking, and behaviour.

4. The CAG Repeats: What the Numbers Mean

The fault in the HD gene is an expanded section of DNA known by the letters CAG. Everyone has a CAG section in this gene, but the difference between a healthy person and someone who develops HD is the number of times that CAG code is repeated.

CAG Repeats	Genetic Status	Likelihood of Developing HD	Key Information
10 – 26	**Normal** 🟢	You **will not** develop Huntington's Disease.	This is the typical, healthy range.
27 – 35	**Intermediate** 🟡	You **will not** develop symptoms in your lifetime.	The gene is slightly unstable. There is a small risk of expansion for your children.
36 – 39	**Reduced Penetrance** 🟠	You **may or may not** develop HD, usually much later in life (70+).	The **50/50 risk** of passing it on to children begins in this range.
40 or More	**Full Penetrance** 🔴	You **will** develop HD symptoms at some point in your life.	The most common age for symptom onset is usually between **35 and 50**.

2024 HDBuzz Prize:

Social Skills - The Hidden Gemin Improving Quality of Life for People with Huntington's disease?

By Maille (Molly) Gracey,
November 4, 2024,
Edited by Dr Sarah Hernandez

People with Huntington's disease (HD) may develop a number of symptoms which can be identified by other people. These symptoms include uncontrollable muscle movements, difficulty with swallowing, and struggling to move around. These symptoms are often the focus for many research projects because they are easier to recognise for other people, as problems that people with HD can face. However, what about social struggles people with HD may have, which are not as obvious to other people? Scientists are now beginning to investigate these less obvious effects of HD because there is an increasing awareness of how much these can impact an individual and their quality of life.

Dr Maille Gracey, PhD, HDANI Family Member and 2024 HDBuzz Prize winner

The missing link – a connection between quality of life and social skills?

Quality of life simply means how satisfied a person is with their life, overall. Quality of life may be considered from multiple approaches. Some of these approaches include, **physical** well-being (how healthy someone feels), **emotional** well-being (mood and mental health), and **social** well-being (strength of relationships and how supported they feel). Physical, emotional, and social well-being are believed to be the three building blocks to determine a person's quality of life.

A reduced quality of life in people with Huntington's disease, may be linked to having trouble expressing their usual feelings – like if your choc-o-holic friend doesn't crack a smile over a free chocolate bar.

People with HD may struggle with social skills, causing greater difficulty with social situations. For example, **understanding** and **explaining** how other people might feel in particular social situations. In addition, people with HD may experience an increased difficulty in understanding emotions from **facial expressions** and **body language** in other people.

Previous scientific research has uncovered two interesting findings about people with HD. Firstly, they have shown that quality of life is reduced in people with HD (particularly at later stages of the condition), compared to the general population. Secondly, some people with HD have greater difficulty with social situations. However, scientists had not yet researched if there was a **link** between these two ideas until recently, in work led by Professor Hugh Rickards from the University of Birmingham in the United Kingdom.

So, how do we tap into our life satisfaction radar?

Hugh and his team are studying what could link these two ideas, on quality of life and difficulties with social situations in people with HD. To

understand quality of life, a **questionnaire** was given to people with HD that measures physical, emotional, and social well-being. Scientists also asked people with HD questions about feelings they were experiencing. Some questions explored how frustrated people with HD could become, or how overwhelmed they felt. These questions helped scientists to understand the many different emotions people with HD can experience.

Scientists were particularly interested if people with HD were having trouble **expressing** their **usual** feelings. For example, your friend has a real sweet-tooth and presenting them with their favourite bar of chocolate usually makes them feel very happy. However, one day you give your friend their favourite chocolate bar and strangely, they do not seem to express any feelings of happiness. This represents a situation where a person may not be expressing their usual feelings.

"The key message from these findings is that when people with HD struggle to understand social situations, it can really affect their quality of life."

What's your social IQ?: measuring interpersonal skills in people with HD

To understand difficulties with social situations, people with HD were invited to complete different tasks. One example is the 'Animations Task'. In the **Animations Task**, people with HD watched cartoons of two triangles. These triangles moved in ways that looked like real-life social situations. For example, two triangles dancing together, or one triangle trying to '**persuade**' the other triangle to come out of the box. After watching the cartoon, people with HD had to **explain** what they thought the triangles were doing.

How well people can think and plan activities may also affect how they respond to social situations. Imagine a chef preparing a complicated meal. The chef would have to **plan** what ingredients they need to gather, **organise** the pots and pans needed, and **control their impulses** to eat the entire lasagne in one go! This is the perfect example of the many important skills required when thinking and planning activities.

One question you might be wondering is, how were these thinking and planning skills measured in people with HD? These skills were measured using a '**Trail Making Test**'. In part one of this test, people with HD had to draw lines between circles which each contained a number in the centre (from numbers 1-25). These lines had to connect the circles from the lowest number to the highest number.

Part two of this test was more complicated. This time, there were circles containing letters (A-L) and circles containing numbers (1-12). People with HD had to **switch** between drawing lines from circles with numbers, to circles with letters. They joined the circles up from the lowest number to the highest number and in alphabetical order. For example, a line would be drawn from circle 1 to circle A and then from circle A to circle 2, and so on. This task helped to give the scientists a **measure** of how well people with HD can **think and plan**.

Does being the Sherlock Holmes of social skills mean a happier life?

Like Sherlock Holmes, being able to simply observe and deduce crucial information from other people to understand their inner thoughts and feelings is critical to 'master' some key social skills. This could improve quality of life for people with Huntington's disease.

This study found that a reduced quality of life (specifically, a decrease in social and emotional well-being) in people with HD could be predicted by several social skills and behaviours. One social skill that predicted a reduced quality of life in people with HD is the ability '**to put yourself in someone else's shoes**' to figure out their thoughts and feelings.

This was shown in the study when people with HD, who had a poorer overall social well-being, were less likely to be able to explain what the cartoon triangles looked like they were doing (in the Animations Task). For example, one triangle appears to be trying to **persuade** or **encourage** the other triangle to come out of a box. When people with HD (who had a lower social and emotional well-being) were asked to **explain** what the triangles were doing in this video, they simply described that the triangles appear to be 'moving' around each other.
Additionally, the results concluded that a reduced quality of life in people with HD could also be linked to having trouble **expressing** their usual feelings (think back to the chocolate bar example).

Take a deep breath and make a plan

Another interesting finding from this study suggested that a reduced quality of life (in terms of a person's ability to carry out daily tasks at work and/or home), in people with HD, can be linked to how **overwhelmed** or **frustrated** they feel. This decreased ability to carry out daily activities could also be due to having trouble when trying to **plan** activities (remember all those important **planning** and **organisational** skills a chef needs to make the perfect lasagne!).

Together, these results may hint that by improving these particular social skills in people with HD, it could improve their quality of life.

"Some specific social skills to address include, improving people's ability to express their feelings, addressing their difficulties with planning and organisation, or tackling their feelings of frustration."

In a nutshell: key insights and the road ahead

The key message from these findings is that when people with HD struggle to **understand** social situations, it can really affect their **quality of life**. In the future, scientists should consider exploring **solutions** to help people with HD improve their social skills.

Some specific social skills to address include, improving people's ability to express their feelings, addressing their difficulties with planning and organisation, or tackling their feelings of frustration. This is because these are the social skills that have been highlighted as important in determining quality of life, in people with HD.

So no need to break out your cherrywood pipe or wool plaid hat to search for hidden jewels – working on these social skills could be the gem itself in improving quality of life and increased feelings of happiness for people with HD.

https://en.hdbuzz.net/387

Huntington's disease successfully treated for first time

Professors Ed Wild and Sarah Tabrizi led the UK part of the trial
IMAGE SOURCE,BBC/FERGUS WALSH

By James Gallagher

Health and science correspondent

Published 24 September 2025

One of the cruellest and most devastating diseases – Huntington's – has been successfully treated for the first time, say doctors.The disease runs through families, relentlessly kills brain cells and resembles a combination of dementia, Parkinson's and motor neurone disease.

An emotional research team became tearful as they described how data shows the disease was slowed by 75% in patients.

It means the decline you would normally expect in one year would take four years after treatment, giving patients decades of "good quality life", Prof Sarah Tabrizi told BBC News.

The new treatment is a type of gene therapy given during 12 to 18 hours of delicate brain surgery.The first symptoms of Huntington's disease tend to appear in your 30s or 40s and is normally fatal within two decades – opening the possibility that earlier treatment could prevent symptoms from ever emerging.

Prof Tabrizi, director of the University College London Huntington's Disease Centre, described the results as "spectacular".

"We never in our wildest dreams would have expected a 75% slowing of clinical progression," she said.

None of the patients who have been treated are being identified, but one was medically retired and has returned to work. Others in the trial are still walking despite being expected to need a wheelchair.

Treatment is likely to be very expensive. However, this is a moment of real hope in a disease that hits people in their prime and devastates families.

https://www.bbc.co.uk/news/articles/cevz13xkxpro

BBC

Huntington's breakthrough 'amazing' but with 'caveats'

BBC

By Niall Glynn
Role, BBC News NI
25 September 2025

Dr Lauren Byrne

A woman whose father died from Huntington's disease has said news that it has been successfully treated for the first time is "an amazing step", but cautioned there were "caveats" to the breakthrough.

Dr Lauren Byrne said her dad, who died earlier this year, was one of eight siblings "and so far five of them have it and there's now around 40 people at risk at my last count".

The disease runs through families, relentlessly kills brain cells and resembles a combination of dementia, Parkinson's and motor neurone disease.

She said: "You have to watch your loved one get sick for decades and look and see your own future if you are at risk."

Dr Byrne, who is originally from Newcastle in County Down, is a principal research fellow at University College London (UCL) Huntington's Disease Centre and a trustee on the Huntington's Disease Association Northern Ireland.

She was not directly involved in the trial, but has worked closely with the UCL team who made the breakthrough.

The UCL research team told the BBC the data shows the disease was slowed by 75% in patients.

Dr Byrne told the Good Morning Ulster programme, Huntington's was "such a debilitating disease that has such a wide impact for the whole family.

"I'm gene-negative, but the majority of my family are still at risk, including my siblings."

Lauren's dad Peter died earlier this year with Huntington's

Dr Byrne said "it was a crazy day in the office yesterday" as she watched the news about the successful trial come out with some of her colleagues.

"It's definitely a momentous result for the community," she said.

"As a scientist it's amazing, this is proof of concept that lowering Huntington's in the brain of Huntington's patients can slow disease symptoms and we can't take away from that.

"There's also caveats - it's a very small trial, around 30 participants," she explained.
"Its gene therapy administered through brain surgery, so there's high risks involved."

Dr Byrne is a principal research fellow at University College London (UCL) Huntington's Disease Centre

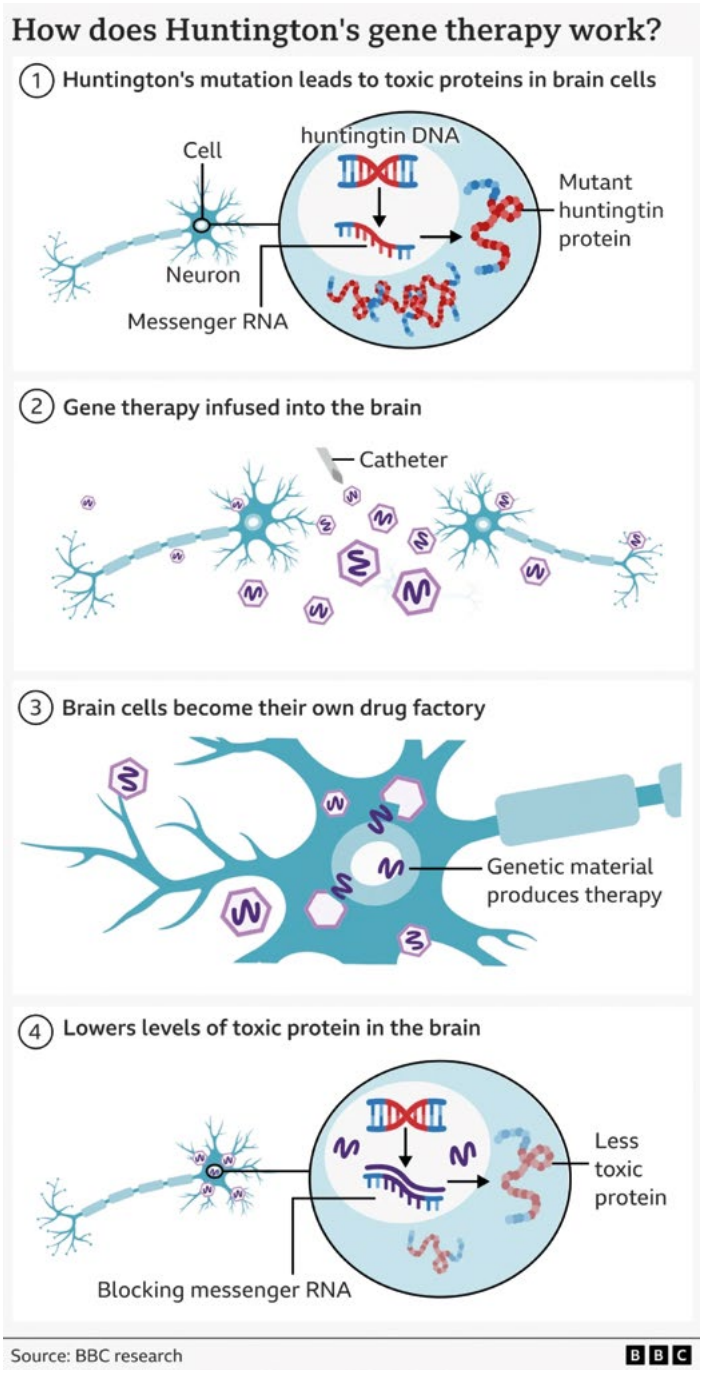
Dr Byrne said work will now be undertaken to get the new treatment approved in the US next year, but it will then take time to make it available in the UK and Europe.
As a result, she said she found herself "trying to balance the optimism".

However, she said the successful trial "has a further impact beyond this therapy itself".
"There's multiple different drugs that are in different stages of development that are also Huntington lowering – maybe a pill or an injection into the spine, so lots of different ways," she said.

"The fact that this works is going to have a real positive benefit for all of these programmes.

"So there's a lot of hope for the community at the minute. even if someone can't get this, there are other things coming that will be easier to get access to."

Peter Byrne was one of eight children, five of whom went on to have Huntington's disease



A Monumental Step Forward:
The AMT-130 Trial Results

We know that news about research can sometimes feel confusing or overwhelming, but we wanted to share this truly brilliant news from the uniQure clinical trial of a drug called AMT-130 in an accessible way.

This information comes from a recent update following a Phase I/II clinical trial (the early stages of testing) for Huntington's Disease. It's a significant moment of hope for our entire community.

The Big News: Slowing Down HD Progression

The most important finding is that for the first time ever, a drug has shown the potential to slow down the progression of Huntington's Disease in people.

The trial was testing AMT-130, which is a pioneering gene therapy. In essence, it's designed to be a one-time treatment that works to reduce the amount of the harmful huntingtin protein being made in the brain—the protein that causes the damage in HD.

How the Treatment Works

Instead of being a pill or repeated injection, AMT-130 is delivered directly into specific areas of the brain via a single surgical procedure. Scientists use a harmless, specially designed virus (like a "Trojan Horse") to carry the instructions into the cells, telling them to reduce the production of the huntingtin protein. The hope is that by lowering this protein, the disease's effects are reduced over time.

What is AMT-130?

AMT-130 is designed to deliver a new "instruction" to brain cells. In HD, there's a faulty instruction that causes a harmful protein to build up. AMT-130 aims to help cells produce less of this harmful protein.

Why go into the brain directly?

Most medicines can't easily get from your bloodstream into your brain. The brain has a very good protective barrier. For AMT-130 to work effectively where it's needed most, it has to be delivered directly into the brain.

The Procedure: A Single Operation

Patients in the UniQure trial received AMT-130 during a single surgical operation. This means it was a one-off procedure, not something they needed to have done repeatedly.

- Small Holes in the Skull: Surgeons carefully made very small holes in the patient's skull.
- Specialised Needles: Through these holes, tiny, specially designed needles were guided by imaging (like an MRI scan) to specific areas deep within the brain. These areas are called the striatum and the thalamus, which are particularly affected by HD.
- Slow Infusion: The AMT-130 was then slowly and carefully "infused" or dripped into these brain regions. This is a very precise process to make sure the treatment reaches the right cells.

Who Performed the Surgery?

The surgery was performed by neurosurgical teams at specialised centres. Key clinical and scientific leaders involved in the trial include:

- Professor Ed Wild (Principal Investigator for the UK trial site at UCL Huntington's Disease Centre) and Professor Sarah Tabrizi (Lead Scientific Advisor on the trial, Director of the UCL HD Centre).
- For the UK arm specifically, the neurosurgeries were conducted in Cardiff by a team led by Professor Liam Gray at the Advanced NeuroTherapies Centre with Cardiff University.
- Dr. Victor Sung (Movement Disorders Neurologist at the University of Alabama at Birmingham) was a Principal Investigator for the US arm.

How Long Did It Take?

The procedure was a single, long operation due to the precision required for the gene therapy infusion.

- The total neurosurgical procedure, which involves placing a thin tube (micro-catheter) into the deep parts of the brain using MRI-guidance and then slowly infusing the drug, was reported to take approximately 12 to 18 hours (or up to 20 hours in some reports).
- The drug (AMT-130) itself was slowly infused over 12 to 18 hours into the target areas.

What happens after?

After the infusion, the needles were removed, and the small holes in the skull were closed. Patients would then recover from the surgery. The idea is that once the new genetic instructions are delivered to the brain cells, they start working to reduce the harmful protein, hopefully slowing down the disease.

What the Results Showed

The participants who received the higher dose of the drug showed very encouraging results, especially when compared to how the disease usually progresses:

- Slowing Decline: On the main clinical measure used to track HD symptoms (called cUHDRS), the high-dose group showed a remarkable 75% slowing of disease progression. This suggests that the decline you might expect in one year could potentially take four years after treatment.
- Daily Function: Crucially, the drug also appeared to slow the decline in Total Functional Capacity (TFC), which measures a person's ability to handle everyday activities like work, finances, and living independently.

- Biomarkers: They also saw positive changes in a protein called NfL (Neurofilament light), which is often a sign of brain cell stress. The drop in NfL levels suggests less ongoing damage in the brains of the treated participants.

Hope Must Be Balanced with Caution

This news offers genuine hope, and it confirms that reducing the huntingtin protein is a promising way to treat HD. However, as we look ahead, a wee bit of caution is needed to manage expectations:

1. **Small Trial Size:** The results come from a very small number of participants (fewer than 30 overall). While the results are promising, larger, more traditional studies are needed to confirm the long-term safety and effectiveness for everyone.

2. **Complex Delivery:** This is a one-off treatment, but it requires brain surgery. Rolling out such a treatment worldwide will be a major logistical challenge, requiring specialist neurosurgical teams.

3. **The Road to Northern Ireland:** The company is based in the US and is currently aiming for potential approval there first. They have confirmed they are keen to engage with European regulators (the EMA), who oversee drug approvals for the UK. Even with a positive result, the journey from US approval to becoming available through the NHS in Northern Ireland is a long and complex one involving many stages of review and planning.

4. **Cost:** Like other gene therapies, this treatment is expected to be extremely costly, which will be a key discussion point for health systems globally.

Looking Ahead

These findings are a huge "domino effect" moment for HD research, strengthening the case for all other drugs trying to lower huntingtin protein levels.

The incredible bravery of the trial participants and the commitment of the entire HD community—especially those who have contributed to global research like Enroll-HD—is what made this progress possible.
While we await more data, this news gives us something truly exciting to look forward to. We are now in a future where treating and modifying the course of Huntington's is a real, tangible possibility. We must continue to support research and advocate for the fastest possible route to making these advancements available to everyone who needs them, including in Northern Ireland.

For more information on HD research visit:

https://enroll-hd.org/

We hope to establish the first-ever Northern Ireland Enroll HD site in the next year

SKY-0515 Lowers Huntingtin In People With Huntington's Disease In Trial Update

SKY-0515, an oral drug, safely lowers huntingtin in people with HD and may also reduce PMS1. This could offer a possible two-pronged approach to treat HD. SKY-0515 is now being tested in a larger Phase 2/3 trial.

By Dr Rachel Harding
September 18, 2025
Edited by Dr Sarah Hernandez

On September 17, 2025, we received an encouraging update from Skyhawk Therapeutics' Phase 1 study, taking place in Australia. The recent update suggests that SKY-0515 can lower the huntingtin protein as well as PMS1, another protein which is thought might also drive Huntington's disease (HD). Importantly, the drug also appears to be safe and well tolerated. A larger Phase 2/3 trial called FALCON-HD is already underway. Let's get into what we learned from this latest update.

What is SKY-0515 and how does it work?

SKY-0515 is a pill, taken by mouth, designed to change which proteins are made in the body. The drug works by targeting message molecules, or RNA, which are copied from the DNA code and have the instructions to make different types of proteins. SKY-0515 changes how cells process RNA messages.

SKY-0515, like PTC Therapeutics' votoplam, isn't specific for huntingtin. The pill targets many different messages throughout the body, but huntingtin happens to be one that it targets quite strongly. Because it's not specific, it also influences the levels of other proteins in the body. Two of the proteins whose levels are changed by the SKY-0515 drug are huntingtin and, perhaps serendipitously, PMS1.

Lowering huntingtin levels is one of the main approaches companies are testing in the clinic to try and treat HD. The idea is that by reducing the levels of the toxic, expanded form of the protein made in people who have the gene for HD, we can target the root cause of the disease. SKY-0515 is actually a "total" huntingtin lowering drug, meaning it lowers both the expanded and regular forms of the huntingtin protein.

With multiple huntingtin-lowering approaches now in clinical trials, the HD community is closer than ever to finding therapies that go beyond symptom management.

PMS1 also seems to be targeted by this drug. PMS1 is a DNA repair protein that, when reduced, is thought to slow the "somatic expansion" of CAG repeats. This is the molecular process that makes CAG repeats longer in some cells in the body over time. By reducing the toxic huntingtin protein and also potentially slowing down another one of the disease drivers, the scientists at Skyhawk think they might get a 2 for 1 effect with this drug.

Testing the waters with SKY-0515

This Phase 1 trial is actually divided into three parts (A, B, and C) and the results we are learning about yesterday come from part C of the trial, which is testing the drug in people with HD. Parts A and B looked at the drug in healthy people without the gene for HD and we already learned about how the drug was

working in a previous update from Skyhawk. That update showed the drug appeared safe and working as expected to lower huntingtin in the people in which it was tested.
Part C of this trial tested 2 different doses of the drug, a low (3 mg) and high (9 mg) dose, and also included people who received a placebo sugar pill. Folks in the trial are then monitored and all sorts of measurements are made from samples, like blood, to see how well the drug might be working. Safety is the top priority in Phase 1 trials, but other data is collected too to give insights into designing the next round of trials and see if the drug appears to work as expected.

As with all Phase 1 trials, the primary goal of this trial is safety of SKY-0515. However, at the same time, they're collecting data from blood samples to measure huntingtin and PMS1 to get an indication if the drug is doing what it's intended to do.

So what's new?

In this latest update, we got some interim data about Part C of the trial – where they test this drug in people with HD. Skyhawk reported that the drug appears to be generally safe at the doses tested – great news! SKY-0515 was also reported in this update to get into the brain very effectively, a critical challenge for HD therapies.

We also learned that the drug seems to do a good job of lowering the levels of the huntingtin protein, with data shared up to day 84 (12 weeks) into the study. In fact, the more drug participants got, the more lowering Skyhawk could measure in the blood. This "dose-dependent" lowering is a favourable hallmark researchers look out for when testing a new drug and fine-tuning what dose might work best.

Why is this important?

The results so far suggest that SKY-0515 can lower huntingtin protein in people with HD to a greater extent than has been reported before with a pill. That's exciting, because until now most huntingtin-lowering approaches have required injections or infusions into the spinal fluid, which are far less convenient and come with additional safety challenges. Having an oral drug that can reach the brain effectively and reduce huntingtin to this degree is a very encouraging step forward.

Another promising feature of SKY-0515 is that it does more than just lower huntingtin. It may also reduce levels of PMS1, a protein involved in the process that makes CAG repeats longer in some cells over time. By targeting both huntingtin and PMS1 at once, SKY-0515 could potentially tackle HD through two different disease mechanisms.

Professor Ed Wild, HDBuzz Editor Emeritus, who is involved in the study, summed it up by saying:

"This is what success looks like at the 3-month timepoint, setting the stage for meaningful impact for people living with HD across the world – for whom an orally administered huntingtin-lowering treatment such as SKY-0515 would be truly transformative."

What we still don't know

It's worth pointing out that this update from Skyhawk is still quite limited in details. While the company shared a graph showing reductions in huntingtin protein levels by dose, they didn't provide all the details behind some of the claims.

The most recent press release suggests that SKY-0515 lowers PMS1, but we've not yet seen this data. This would be fantastic if it lowered PMS1 to a meaningful level! But without the data, we don't know if the levels to which PMS1 are lowered would be considered significant. So the questions remain: How much is PMS1 being lowered by SKY-0515? Is PMS1 being lowered to a level that would be meaningful? Is the lowering of PMS1 significant enough to influence somatic expansion of the CAG repeat within the huntingtin gene?

This kind of early communication is sometimes called "science by press release." The full picture, including the more complete

results from this trial, won't be available until mid-2026. So, while these first signs are encouraging, it's important to keep expectations realistic and remember that there's still a lot we don't yet know.

So what happens next?

After the first 3 months, people in the study will keep taking SKY-0515 in a longer follow-up, where everyone stays on treatment at a low or a high dose for up to a year. We should hear the main results from this part of the trial in mid-2026.

At the same time, a bigger Phase 2/3 study called FALCON-HD is already underway across 10 sites in Australia and New Zealand. This trial will involve about 120 people with stage 2 or early stage 3 HD, as per the HD Integrated Staging System or HD-ISS, and will test different doses of SKY-0515 to be compared with placebo. Importantly, this study will not just look at effects beyond safety and levels of huntingtin and PMS1. It will also see if the drug can help with symptoms like movement, thinking, and daily life, and whether it influences how the brain structure changes with HD.

Full results from the ongoing Phase 1 trial are expected by mid-2026. At the same time, a larger Phase 2/3 study called FALCON-HD is underway, testing the ability of SKY-0515 to target both huntingtin and PMS1 while measuring signs and symptoms of Huntington's disease.

What does this mean for the HD community?

For people affected by HD, these results are both hopeful and cautious news. On the hopeful side, SKY-0515 is the first oral therapy to achieve such strong huntingtin lowering in people with HD that can be fine-tuned by changing the dose of the drug. SKY-0515 also seems to target PMS1, potentially tackling an additional potential driver of HD. Most importantly, the drug appears to be generally safe.

By reducing the toxic huntingtin protein and also potentially slowing down another one of the disease drivers, the scientists at Skyhawk think they might get a 2 for 1 effect with this drug.

That said this is very early data in a small group of people with HD. The trial is also focused on safety and whether the drug is working as expected, but not whether it can slow, halt, or reverse symptoms of HD. It will take larger, longer trials to know if SKY-0515 actually slows or improves the course of HD.

Still, this is a big step forward for the field. With multiple huntingtin-lowering approaches now in clinical trials, the HD community is closer than ever to finding therapies that go beyond symptom management.

Summary

- SKY-0515 is an oral drug that alters RNA processing, lowering levels of huntingtin and potentially PMS1, a DNA repair protein linked to CAG repeat expansion in Huntington's disease (HD).
- Phase 1 results show safety and brain penetration, with dose-dependent reductions in huntingtin protein—greater than previously achieved with an oral therapy.
- Dual targeting of huntingtin and PMS1 could provide a "two-for-one" therapeutic effect, addressing both toxic protein buildup and CAG repeat expansion, though PMS1 data remain limited.
- Next steps: Full Phase 1 results are expected in mid-2026, while the larger Phase 2/3 FALCON-HD trial is already underway to test effects on symptoms, brain changes, and overall disease progression.

https://en.hdbuzz.net/sky-0515-lowers-huntingtin-in-people-with-huntingtons-disease-in-trial-update/

Charity Partnership

The Grand Orange Lodge of Ireland is delighted to announce that this year's Grand Master's nominated local charity is Huntington's Disease Association Northern Ireland.

The Grand Master, Most Wor. Bro. Edward Stevenson said, *"Huntington's Disease affects an estimated 285 people in Northern Ireland, and a further 1,035 are said to be at risk of inheriting the Disease".*

He continued, *"Raising awareness of Huntington's Disease and highlighting the help that is currently available for those affected is an important way of encouraging people to find out more and contribute to future research initiatives."*

"Throughout the year, the Grand Orange Lodge of Ireland will encourage those attending some of our high-profile events to support the work of HDANI. These include our annual Gala Dinner in October and our Joyful Noise praise event in November. Last year, we were proud to raise funds for Northern Ireland Pancreatic Cancer (NIPANC), and we look forward to working with HDANI in the months ahead."

Sorcha McPhillips, Chief Executive of HDANI added, *"We are delighted and deeply appreciative to have been selected as the chosen charity. The Grand Orange Lodge of Ireland oversees over 1,000 lodges on the island of Ireland, which represents a tremendous opportunity not only to raise vital funds but to educate people about HD and reach families who may not be aware of our services".*

GOLI raised awareness of HD and the work of the Huntington's Disease Association NI at this year's Balmoral Show where they sold their popular orange hats in return for a donation.

Join Our Board

Hello friends, supporters, and HDANI family,
I'm Gerry McDermott, Chair of the Board here at HDANI, and I'm absolutely delighted to deliver some exciting news—and a heartfelt invitation!

First off: wow, what a year it's been. Each day, I see the incredible impact our initiatives make for people with HD and their loved ones across Northern Ireland. But here's the thing—I know we can do even more, and ***that's where you come in!***

Are you someone with....

- a knack for **human resources** or **volunteer management**– maybe you're great at mentoring, recruitment, or team-building?
- expertise in **clinical delivery** or **scientific research?**
- a **head for accountancy** – love spreadsheets, budgets, or financial planning?
- a passion for shaping **policy** – you've got insights into legislation, advocacy, or organisational development?
- personal experience of **Huntington's disease**?
- experience in **management or leadership** – skilled at overseeing projects, building partnerships, or steering strategy?
- a love of PR, **Social media** and awareness raising?

If any of that feels like you, I want to personally invite you to explore joining our volunteer board.

What's in it for you?

- **Real reward, real impact** – You won't just attend meetings—you'll help shape policies, launch initiatives, and directly enhance the lives of service users across NI.
- **Grow your network and your skillset** – Board-level engagement offers fantastic professional development, plus the chance to work alongside other inspiring leaders.
- **Flexible involvement, friendly atmosphere** – We value what you bring, whether you can commit full days or just a few hours each month. Plus, we love a good laugh along the way!
- **Bring your passions to life** – Whether you're keen on strategy, finance, HR, or policy, there's a spot where your talents can shine.

Why join the HDANI Board?

- Well, let me tell you—it's not just a seat at the table. It's a chance to shape the future of an organisation making a real difference to people across Northern Ireland impacted by Huntington's disease.

The commitment? It's very manageable:

Quarterly meetings x4 per year (online or in person) – 90 minutes long

Reading board papers beforehand – so you know what's what

Optional extra involvement – if you fancy rolling up your sleeves for fundraising, events, or special projects, we'd LOVE that. But no pressure.

Interested? Here's what to do next:

1. Drop a quick expression of interest—just email **sorcha@hdani.org.uk** Let us know a bit about you—your background, what excites you about the board, and how much time you'd like to give.

2. We'll invite you to a friendly chat (and yes, tea and biscuits are on us!)—just to share more about the role and get to know each other.

No pressure—just a friendly conversation about your ideas, passions, and hopes. And if now isn't the right time, no worries! But if you've been looking for a fun, meaningful way to give back—and grow—this could be it.

Whether you've got decades of experience or you're keen to grow your leadership skills, HDANI is a place where you can make a difference—and have fun doing it.
So, what do you say? Ready to help steer our ship? We'd love to hear from you.
With appreciation and excitement,

Gerry McDermott

Chair of the Board, HDANI

Easyfundraising

Unlock free donations for Huntingtons Disease Association Northern Ireland when you shop online! Over 8000 retailers you know and love will donate to us when you shop with them. Sainsbury's, Argos, eBay and thousands more are signed up to help. No cost to you. A huge difference to us.

visit
https://www.easyfundraising.org.uk

click
Find a Cause on the top menu

Type
Huntingtons Disease Association Northern Ireland

Training & Educating Health and Social Care Staff

So far this year

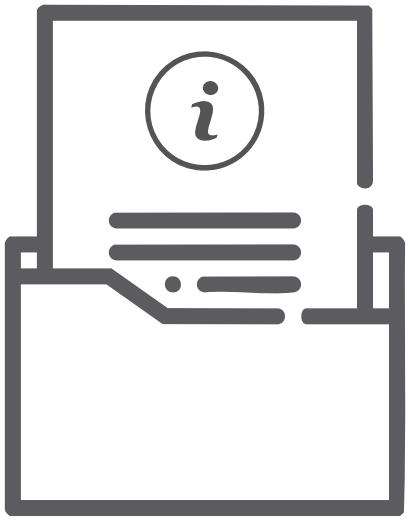
235

health and social care professionals have joined our online training sessions

and our network of

4,500

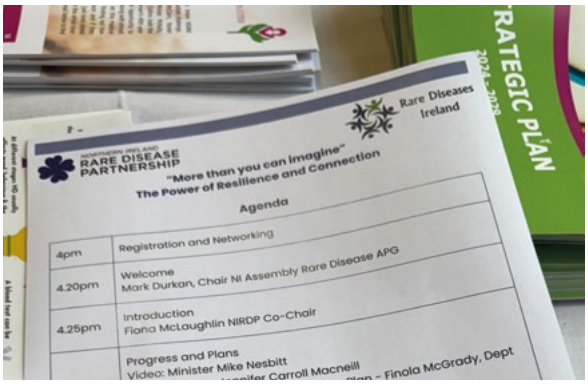
have received HD information and resources



Northern Ireland Rare Disease Partnership

We were delighted to join the Rare Disease Partnership Day at Stormont recently with Northern Ireland Rare Disease Partnership and join their campaign to connect, share our stories, and work towards a better future together and highlight Huntington's Disease along with others. Pictured is our Family Support Worker Katie along with our stand!

Our board member Janice McCartney who is living with HD also raised awareness of the disease by speaking at a Rare Disease event in Armagh during the Summer.



ONSIDE

Women's Drop-in Group

The ONSIDE Women's Group meets every Monday for a fun hour of crafts, chat, quizzes, discussion & trivia.

Men's Drop-in Group

The OMG (Onside Men's Group) is continuing to meet on Wednesdays for discussions, jokes & good craic.

Although ONSIDE has now concluded, you can still join one of our Drop-in Groups or use our online resources at the Community Hub and our **'How to videos'** on the ONSIDE YouTube channel.
You may also sign up to e-mailing lists with Disability Action and ILMI – Independent Living Movement Ireland to receive updates and further information.

The ONSIDE (Outreach & Navigation for Social Inclusion & Digital Engagement) programme was a cross border project led by Disability Action NI in partnership with the Northern Ireland Housing Executive, the Independent Living Movement Ireland, and Supporting Communities.

The project was supported by an award of €5.56m by the European Union's INTERREG VA Programme, a programme managed by the Special EU Programmes Body (SEUPB). Match-funding was also provided by the Departments of Health in Northern Ireland and Ireland.

Why ONSIDE?

Research showed the proportion of disabled people (13.3%) who report feeling lonely "often or always" is almost four times that of non-disabled people (3.4%), with the greatest disparity for young adults, aged 16 to 24 years old. (ONS, 2021). The ONSIDE project was a cross border project created to address the social isolation often experienced by disabled people. We wanted to enable and empower persons with disabilities to take control of their social connections.
ONSIDE sought to improve the life outcomes of people with disabilities living in Northern Ireland & the border counties in the Republic of Ireland. We offered a cross border community support service to support disabled people who were socially isolated.

What we did?

ONSIDE was available to (16+) persons with disabilities across Northern Ireland (Counties Antrim, Armagh, Derry, Down, Fermanagh & Tyrone); and the Border region of Ireland (Counties Louth, Monaghan, Cavan, Leitrim, Sligo & Donegal).

ONSIDE had a pan disability approach: working with people with physical, sensory, learning, mental health or hidden disabilities. The Project started by offering digital training including the provision of a laptop to participants.

Providing tailored 1-2-1 support and training, ONSIDE enabled participants to gain independence, choice and control over their social connections and become active in their local and online communities. The project was pan-disability and all services were **free**, **independent** and **impartial.**

We carried out Peer Research, steered and conducted by people who lived experience of disability. ONSIDE wanted to identify and address the social and physical barriers that create social isolation for disabled people. ONSIDE created a digital hub for persons with disabilities, highlighting local health and wellbeing services and community services and engagement opportunities.

ONSIDE also offered participants Peer Volunteer support made possible by past participants and disability advocates.
Our Peer Volunteers helped, trained and supported participants through their ONSIDE journey.

HUNTINGTON'S DISEASE ASSOCIATION NORTHERN IRELAND

Families at the heart of all we do

How might a HDANI Family Support Worker help me?

Our team of Family Support Workers help families all across Northern Ireland.

They;

- Provide **reliable, HD-specific information** – what causes HD, testing options, family planning, and how symptoms may progress.
- Help explain HD to **family, friends, school and employers**.
- Offer **information tailored for children and teens.**
- Work with you and your family to create a **personalised support** plan – covering medical, emotional, financial, employment, housing, transport, and practical needs.
- With your consent, **link you to other services**, attend medical appointments, and assist with forms.
- Provide access to free **counselling and well-being therapies**.
- Introduce you to **other HD families** and welcome you to HDANI events.
- Facilitate in-person and online **support groups**.
- Raise **awareness** about HD among professionals and the general public.
- Keep you updated about **research and services.**

Support can be **as little or as much as you need**, reviewed over time. If you'd like to learn more or arrange a chat with a Family Support Worker contact us on the details below from Monday to Friday 9am-5pm.

Free, confidential support for anyone in Northern Ireland affected by HD

Belfast Health and Social Care Trust

What is a HD Nurse Specialist?

A Huntington's Disease (HD) Nurse Specialist is a dedicated healthcare professional with expertise in Huntington's Disease, employed by the Belfast Trust to help families anywhere in Northern Ireland.

They provide:

- **Specialist nursing care and advice** for individuals and families.
- Guidance on **managing symptoms** such as movement, mood, behaviour, and swallowing difficulties.
- Support with **medications and treatment plans.**
- **Education and training** for families, carers, health professionals, care providers or other services.
- A key point of contact for **ongoing care and service coordination** with social work, speech and language, dietitian, physiotherapist, GP, occupational therapist and other care providers.
- Partnership working with HDANI Family Support Workers to ensure **joined-up, holistic support.**

They also:

- Run **nurse-led HD clinics** at locations across Northern Ireland where they work alongside specialist doctors.
- Offer **home visits** to people living with HD.
- Provide support in **residential and nursing homes.**
- Contribute to **research** and disease-specific data collection to help improve services.

How do I access a HD Nurse Specialist?

- You can request an appointment via your GP or any Trust medical professional via Encompass
- You can ask a HDANI Family Support Worker to make a referral for you
- You or a family member can contact the HD Service directly on **028 9504 7852**

Orba Yoga Retreat & Health Spa

Thanks so much to all at Orba Yoga Retreat & Health Spa who invited HDANI for a look around to see all they offer and also to present a cheque from their recent fundraising.

A fabulous venue with yoga, hot yoga, massage, reiki, reflexology and a facility for spa treatments with an infra red sauna as well as an outdoor hot tub where you can chill out after a walk through the woods and nature. A very very relaxing environment, even when there for a work trip to look around rather than to get involved! The facility is totally accessible including accessible shower and toilet.

You come away feeling very zen and chilled no matter what! Thanks so much to Bridin and Aoife for showing me around! Thanks also for all of the fundraising support you are offering to HDANI from the Winter Solstice event to further upcoming events.....watch this space!

Funded Counselling and Therapeutic Service

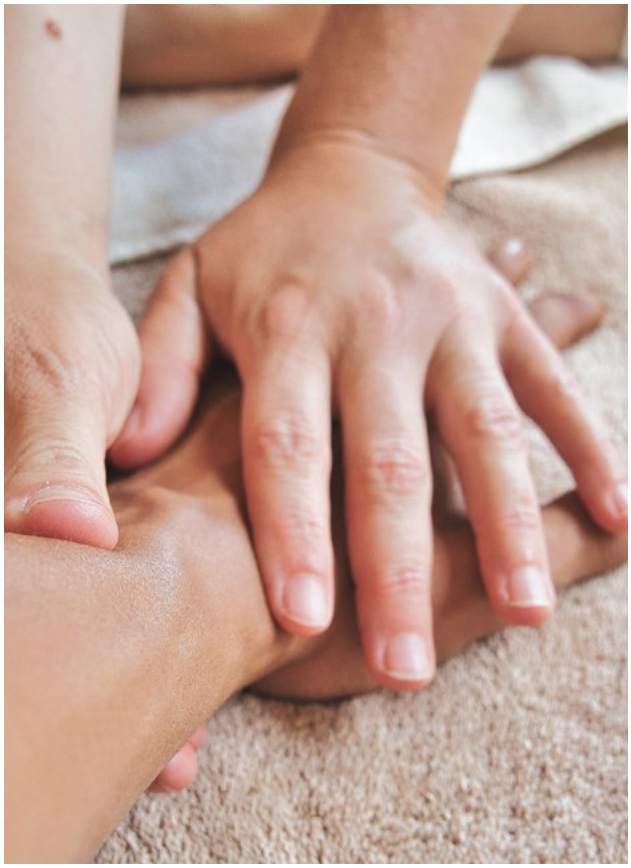
We launched our Funded Counselling and Therapeutic Service in September 2020. It was impacted by COVID in that face to face was not possible a lot of this time so since things have eased with the end of the pandemic we have helped over 40 Service Users access services to help them with a variety of needs. This programme has been made possible through funding that has been secured, for which we are very thankful.

This service offers service users the opportunity to avail of six sessions of counselling or holistic therapies which they would like. Counselling can be delivered Face to Face, over the phone or via video sessions according to the service user's location, preference, mobility or availability. We have even been delivering Art Therapy to a service user in their home.

Our Holistic Therapy has again been more accessible to service users as restrictions have ended and we have been able to provide therapies such as massage and reflexology for those who would like a bit of relaxation and ease for their symptoms and to help with emotional stress. Again this has been offered in the service users home or at the therapists treatment rooms (again this can be dependent on the service users location).

This programme is designed as a time to destress, time out and time for themselves. Those with evidenced need can be referred into this by their Family Support Worker and we will do our very best to get a service according to their needs.

*We are continually developing our pool of therapists. Should we not have a therapist in your area we will attempt to source someone for you, or offer you an alternative.



In 2025 we provided

98

free
counselling sessions

to 19 people.

We also delivered

246

free
holistic therapy sessions like reflexology, reiki, massage, art therapy

to 50 people.

Policy Update

2025 policy responses

Help with Health Costs Consultation Response

HDANI has responded to a government consultation on financial support for health costs, highlighting the severe financial strain on Huntington's disease (HD) families. Many HD carers must give up work while facing high care costs and limited access to essential services like mental health support. HDANI calls for automatic free prescriptions, better financial assistance, easier access to disability benefits, and travel cost support for medical appointments. Without urgent policy changes, HD families will continue to struggle. HDANI urges decision-makers to act now to relieve this burden and ensure fair access to healthcare.

Caring for Carers Review Response

HDANI has engaged with the government's 'Caring for Carers' review to advocate for better support for HD carers, who face emotional, financial, and social challenges while often caring for multiple generations. Key issues include lack of mental health support, financial hardship, isolation, and the absence of a dedicated HD care pathway in Northern Ireland. HDANI calls for automatic mental health support, simplified benefit applications, expanded respite care, and a structured care pathway to ensure carers receive the help they need. These changes are essential to prevent carer burnout and improve quality of life.

Access to Mental Health Services

Over the years, it has been reported to us by families and professionals alike that there can be a difficulty in accessing mental health services for a patient when a diagnosis of HD has been made. There are reports that HD is considered a matter for neurology rather than mental health, when in fact it is a condition which requires multidisciplinary input.

Sorcha wrote to the Directors responsible for mental health in each of the five Trusts and gave them an overview of HD and the behavioural and mood symptoms which people can experience. She highlighted the need to ensure that there is consistency in the approach to the mental health response

to HD patients across the Trusts. Although health is a devolved matter the Trusts often look to England and Wales for guidance. Sorcha referred them to this statement by NHS England;

Access to services

Mental health services shouldn't exclude anyone because of any physical health diagnosis, neurodevelopmental condition (for example autism or ADHD) or neurological diagnosis ***(for example Huntington's Disease, Parkinson's or Dementia).*** *Services should be offered based on need and the likelihood of them being helpful, rather than determined by these diagnoses.*

Very often, adjustments to standard treatments can be made to adapt them if needed and services should bear in mind they ought to be making reasonable adjustments where necessary to support access to services and treatments.

In specific instances, some types of mental health treatment may not be possible to deliver or may not be helpful for some people because of particular communication, cognitive, or physical difficulties, and in this situation clinicians should advise on alternatives.

Full text available:
https://www.england.nhs.uk/mental-health/adults/

If you or your family members have been denied access to mental health services because of a HD diagnosis please reach out to us and we will advocate on your behalf. Although the primary duty to provide mental health services lies with the Trusts do remember that HDANI can offer access to free counselling to any HD family members and this could be availed of while you are waiting to see a Trust team or as a complement to any Trust-arranged supports or medication.

Welfare Reforms

The UK Government recently announced a series of proposals designed to cut the costs of the welfare bill and help get more people into work. Although many of these proposals are still in development, if implemented they could negatively impact people with neurological conditions like HD.

Social security is a devolved matter but in reality Northern Ireland tends to follow what happens at Westminster and in the current economic climate the Stormont government are not in a position to resist any cuts.

Key changes include tightening eligibility criteria for Personal Independence Payment (PIP), reducing the health element of Universal Credit for new claimants, and freezing the health element for existing claimants. Additionally, the government is considering a new Unemployment Insurance benefit and scrapping the Work Capability Assessment. This is only the start of a lengthy process of changes that are unlikely to begin until 2026/27. There is a green paper consultation at present, likely to be followed by a White Paper towards the end of eth year and then the process of new legislation needed to make the changes will begin.

Sorcha is working with colleagues in the HD community in the UK as well as other health sector charities in Northern Ireland, to respond to the proposed changes and lobby NI MPs and when the time comes, MLA's to mitigate the potential impact on our families.

Review of Neurological Services

Huntington's Disease Must Not Be Left Behind

HDANI recently submitted a formal response to the Department of Health's review of neurology services in Northern Ireland, strongly advocating for better recognition and support for those affected by Huntington's disease (HD).

Key points raised included:

- **Faster diagnosis & specialist referrals:** HD patients should be seen by a specialist within 6 weeks. This will require dedicated HD leads and clear referral pathways.
- **Improved access to genetic testing:** Testing should be timely, supported, and include emotional care before and after.
- **Multidisciplinary care:** A clear, regional HD care pathway is urgently needed, including neurologists, mental health professionals, and HDANI staff.
- **Family-focused support:** HD impacts the whole family. Early intervention, mental health support, and counselling must be built into services.
- **Recognising HDANI's role:** Our Family Support Workers are often the only consistent link families have to help, yet they are funded solely by charity. HDANI is calling for formal funding and recognition of this essential role.

- **Future planning:** Northern Ireland must prepare for emerging treatments, improve reproductive services, and support access to preimplantation genetic diagnosis (PGD) locally.

HDANI is committed to working in partnership with the Department to design a fair, expert-led care pathway that brings hope, dignity, and proper support to all HD families.

Lotteries for Communities Bill

HDANI has responded to the consultation on the Lotteries for Communities Bill, highlighting the urgent need for fairer funding opportunities for small charities in Northern Ireland. We stressed that restrictive current legislation excludes NI from many large-scale UK lottery funds, leaving charities like ours struggling to meet rising demand. Our response calls for the Bill to support sustainable funding, help us retain skilled staff, and ensure that vital services for families affected by Huntington's disease – some of the most vulnerable people in society – can continue to thrive.

In loving memory

Very sadly some people lost their fight against this dreadful disease and we would like to take a moment to remember them and think of their family, friends and loved ones.

Peter Byrne 27th October 1953 – 3rd February 2025

The Life of Peter Byrne - by Lauren Byrne

I would like to acknowledge the life of Peter Byrne, a man who was truly one of a kind. A real 'character,' as we like to say. Often described as a devilish rogue, in his younger days dad seemed to have a knack for getting into trouble and living life on his own terms. But beneath that mischievous exterior was a charming wit and a heart full of love for the many people he cared about.

Dad's life was rich with adventure and opportunity. Almost becoming a plumber at 17, his wild streak led him to the Royal Air Force (RAF). As an airport fireman, he was stationed in England and Oman, and he often spoke fondly of his time in the RAF, meeting people from all walks of life. When he returned home, he worked as a bread man, but that was just one stop along the way. He spent some time bringing Irish tradesmen over to rebuild Germany before starting work as a bin man when he returned.

But one of the most remarkable things about Dad was his ambition. He was a self-made man, from humble beginnings as son of a pig farmer in Ballykinler. His entrepreneurial spirit was influenced early on when he and his brothers—Tommy, Eamon, and Richard—spent days on Tyrella Beach, selling donkey rides with their beloved 'Limestone Rosie'. At the age of 30, while working as a bin man for the council, he saw another opportunity and took a bold step. He borrowed money to buy one bin lorry and started his own business, Waste Beater, which later became the first materials recycling facility in Northern Ireland, employing 50 people. His hard work and determination paid off, allowing him to sell the business and retire at 50.

Daddy had a real zest for life. Anything he set his mind to, he threw himself into wholeheartedly, with a passion bordering on obsession—whether it was becoming the East Down Darts Champion, studying the mechanics of a golf swing, or starting and sponsoring a Byrne family pool competition. Dad never saw himself as particularly academic, having never gone to university, but he deeply researched whatever he was into at the time, buying all the books he could find on the subject. He would say he attended the 'school of life'—and what a high-level education he had from his diverse experiences.

Family was everything to Dad. There was nothing he was prouder of than being a Byrne. As children, my siblings and I would join him in visiting our extended family—from his aunts and uncles to cousins—all of whom shared their deep fondness for him over the years. During his time in the RAF, he was not granted compassionate leave when his uncle died. In true Peter Byrne fashion, he went AWOL to attend the funeral; despite knowing he would be put into solitary confinement upon his return. This is an example of his devotion to family and the type of man that he was.

At 24, my dad met my mum, Roisin, whom he often described as his best friend. His sisters, Roisin and Geraldine, often marveled at my mum's ability to handle my dad's unique personality—a testament to their strong and loving partnership. They married in 1980 and built a beautiful family together. My brother Kyle was born in 1983, my sister Jodie in 1985, and I came along in 1992. Dad was deeply proud of his children—boasting about Kyle's technical prowess with computers, sharing business tips with Jodie when she took up his mantle and started her own business, and

especially delighting in the fact that I became Dr. Byrne. But we never needed to achieve anything to feel my dad's love—he told us openly and regularly that he loved us. This love extended as our family grew to include his son-in-law and daughter-in-law—Conor and Sinead—and his four grandchildren—Leon, Tom, Jack and Sophia. In his later years, he got great pleasure from spending time with his grandkids.

My dad always said he wouldn't have been able to achieve what he did without the support of my mum, Roisin. She was not only his life partner but also his business partner, playing a vital role in the success of Waste Beater. Her dedication to the Huntington's Disease Association—acting as chair of the board and attending annual conferences in Europe—was a testament to her commitment to understanding and managing the disease. The knowledge and understanding she gained helped us as we grew up, allowing us to comprehend Dad's behavioural changes. It also contributed greatly to his ability to stay positive and well cared for at home over the last 20 years.

Dad's life was a testament to living fully and finding joy in the everyday. He was a man who gave everything to his current passion, and his enthusiasm was infectious. He may no longer be with us, but his spirit will always be a part of the Byrne family. He is now reunited with his loved ones, including his mother, Isa; his father, Peter; his brothers, Tommy and Eamon; his sister, Maureen; his nephew, Kieran; his cousin, James; and his close friend, Tommy Grant—to name just a few of those who had a big part in his life. We are comforted knowing that he is up there now, looking out for us.

To my daddy, with love from all your family, "Do you know we love ya?"

Maggie Fee

Maggie Fee (née Murphy) passed away peacefully on Tuesday, December 31, surrounded by her loving family. She was a resident of Glenwood Gardens, Enniskillen, and formerly of Moorfield, Trillick.She was the devoted wife of Brian and loving mother of Barry (Caitriona) and Claire (Pete). She was a cherished nanny of Maeve, Oisin, Ayden, Eimear, Efan, Leah, and Jack, and a sister of Larry, John, Arlene, Bronagh, and Jimmy.Maggie will be loved & missed by her husband, son, daughter, grandchildren, brothers, sisters, extended family circle, friends & neighbours.

Maggie was not impacted by HD herself, but cared for her husband Brian Fee who has HD and was a huge advocate.

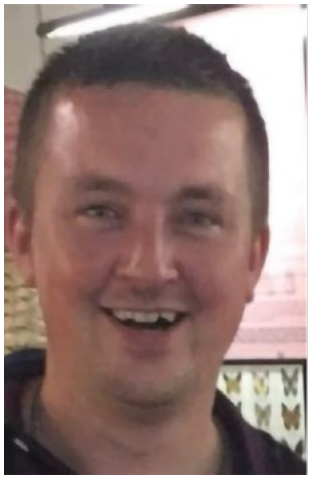
Fermanagh family's joy at medical breakthrough

By Annie Flynn, Oct 3rd 2025

A LOCAL man living with Huntington's has said a recent breakthrough in the fight against the disease has given him hope for his children and grandchildren's futures.

Brian Fee was diagnosed with Huntington's disease 10 years ago at age 53, following a fall at work. Since then, he has experienced mobility issues, slurred speech, and short-term memory loss.

full article: https://fermanaghherald.com/2025/10/fermanagh-familys-joy-at-medical-breakthrough/



Martin Byrne

Martin RIP

Died 18th March 2025 peacefully at Thompson House surrounded by his loving family.

Late of 10 Cumber Drive.

Loving husband of Carly. Adored Daddy of Katie, Peter and Cora.

Beloved son of Marie and the late Eamon.
Dear brother of Paul, Stephen and Declan.
Cherished brother-in- law of Tracey, Sinead and Hannah.
Much loved nephew, uncle and cousin.
Son-in-law of Barry and Marion.
Brother-in-law of Gareth, Steven and Marc.

Martin Smyth

Smyth Martin peacefully at hospital surrounded by his loving family 14th September 2025. Loving son of the late Daniel and Betty, devoted brother of the late Eilish, beloved husband of Nuala, devoted dad to Sam. R.I.P.

Ann Boyd

Peacefully at hospital surrounded by her loving family 16th September 2025. (late of Rossnareen Avenue)
Beloved Wife of the late Daithí. Much loved Mother of Ciarán, Feidhlim, Domhnall, Mary and the late Niamh. Mother-in-law of Kathleen, Ciara and Neil. Loving Granny of Daniel, Hannah, Conal, Sheá and Rionagh. R.I.P.

Patrick Joeseph Farry

FARRY Patrick Joseph, (Manchester) and formerly Trillick, Co Tyrone, died peacefully in Manchester Royal Infirmary, on Thursday 17th July 2025. Beloved eldest son of the late Patrick & Sara-Ellen (Kilnock, Trillick). Treasured brother of James (Trillick), Marie Devane (Richard) Manchester, Dessie (Gretta) Kilnock, Trillick, Dympna (Pat) Enniskillen, Stephen (Bernie) Trillick, Ursula Dolan, Bellanaleck and pre-deceased by his sisters Catherine (Micky McCann) Tattymoyle,Fintona, Noreen (late Sean McCann) Fintona and Rosetta Donnelly, Mountfield.

The recent loss of our much loved Pat-Joe has left a deep void in the lives and hearts of all who knew and loved him. Pat-Joe was a widely respected, hard-working gentleman, but primarily he was a devoted family man, loving son of the late Patrick and Sara-Ellen. Much loved brother of James, Marie, Dessie, Dympna, Stephen,
Ursula and the late Catherine, Noreen and Rosetta. Brother in law of Richard,
Gretta, Bernie, Mickey, Pat and the late Sean.

HDANI - In loving memory.

HDANI have a space for those who wish to share photos and memories of those they have lost through HD on Facebook, album, "In Loving Memory." You can also include birthdays/anniversary dates you would like us to remember.

We want to ensure everyone is given the opportunity to share their own memories. I understand this can be difficult and don't want to upset anyone. It may not be something you would like to do so publicly and we respect that, please get in touch with any questions.
If you would like to share memories, please get in touch via email **info@hdani.org.uk**
or via Facebook
www.facebook.com/HDANorthernIreland
with photos, messages, dates and we can add these to the album but it won't be shared as a public post on the newsfeed.

If you require any support from HDANI please do not hesitate to get in touch.

Finanace and Grants

As we move forward into 2025, we want to share some incredibly positive news regarding our recent funding efforts. Thanks to the tireless work of our team and the compelling case studies provided by our families, we have secured a total of **£567,668** in grant funding during our 2024/2025 financial year!

Significant Victories

This total is a transformative win for our organisation and is largely anchored by a major grant of £500,000 from the Lottery Community Fund towards vital 3-year project costs. This secured funding provides a strong foundation and a degree of stability we have long sought, allowing us to plan strategically and expand our reach.

In addition to this flagship grant, we have also successfully secured significant funds towards core operations and specific support areas:

- **Garfield Weston:** A generous £20,000 has been secured for core running costs, supporting the crucial infrastructure of HDANI.

- **Halifax Foundation:** A successful bid of £10,250 will be dedicated to a 1-year counselling project, ensuring our families and young people have access to the specialist mental health support they desperately need.

- **Targeted Support:** We also received fantastic support from funders like **James Tudor Foundation, Jeans for Genes, Cash for Kids**, and **Hedley Foundation**, which will fund essential services like youth events, camps, and support groups, ensuring no one in our community feels isolated.

The Need for Your Continued Support

While these grant successes are monumental, they primarily cover specific project costs over a set term. As we expand our services—offering more dedicated and holistic to support for entire families —our overall operating costs are naturally rising.
We are committed to doing everything in our power to get the best value with every penny we spend, ensuring every pound has the maximum impact on the lives of those affected by Huntington's Disease in Northern Ireland.

This is why the need for continued, consistent fundraising remains absolutely critical.
We urge our members and supporters to help us bridge the gap between project funding and essential day-to-day operations. Building strong relationships with local businesses and corporate connections is key to securing unrestricted funds that allow us to respond flexibly to the immediate and emerging needs of our community.

Your donations, big or small, are the fuel that keeps our life-changing work running. Thank you for standing with us. Together, we can ensure the future of HDANI is stable, strong, and able to meet every challenge ahead.

NOTES TO THE ACCOUNTS

1 Accounting policies

Charity information

Huntingson's Disease Association Northern Ireland is a private company limited by guarantee incorporated in Northern Ireland. The registered office is: 53 Andersonstown Road, Belfast, BT11 9AG

1.1 Accounting convention

The accounts have been prepared in accordance with the charity's governing document, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2019). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.
The financial statements have been prepared under the historical cost convention, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Restricted funds are subject to specific conditions by donors as to how they may be used.

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Fundraising heroes

Thanks as always to those who take the time and energy to create fundraising events and or take on challenges to raise much needed funds for HDANI. Please see below some of those who have helped us this year.
We are always happy to share your event with our followers and love to be able to let everyone know how people have got on so please do let us know if you are having an event / taking on a challenge.

Lauren B - father passing away - donations in Lieu

Brian Fee - wife Maggie passing away - donations in Lieu

Bill Cardwell held a fundraiser on his birthday at Crusaders Football Club

Trevor Lamont raised money for HDANI and took the opportunity to talk about HD and spread awareness at the Cooke RFC pre match lunch

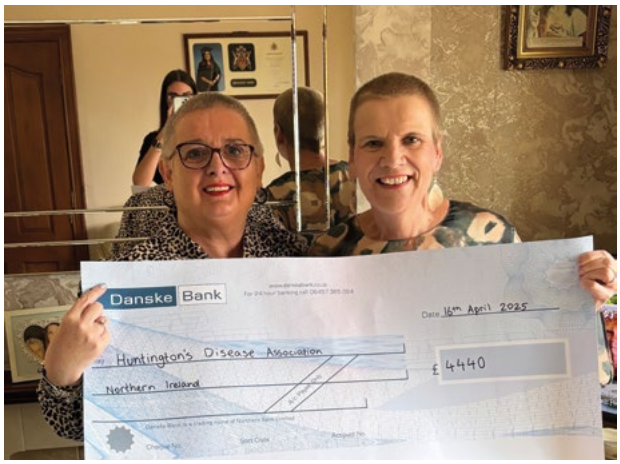
Orba Yoga Spa and Retreat have had numerous fundraisers for HDANI in the last year or so including jumble sales.

Virginia O'Kane from Hotel and Catering Society organised a fundraising event for HDANI

Iris Burrows from Braeside Bar & Restaurant did fundraising for HDNAI

Rachel Smith from Moyola Park Golf Club fundraised for HDANI

Mairead and Mary braved the shave and had a fundraising event at Corrs Corner.



Lee Orman who ran the Belfast Marathon and chose HDANI as his charity in honour of his cousin Kirsty.

Steven, Denver and friends who completed the Ultimate Road trip driving from Belfast to Benidorm and chose to support HDANI.

Thanks to **Ross, Ruair, Izzy, Erin and Mariee** who ran the relay marathon in honour of Ross' Mum.

Clanabogan actor, Gerry McDermott, who is also chair of Huntington's Disease Association of Northern Ireland, accepts a cheque for £1,750 from members of Clanabogan Drama Circle. JasMc2

Drama group raises £3,500 for two charities

BY VICTORIA HOUSDEN

AS well as reliably making their patrons laugh with glee and smile with joy, a popular Clanabogan drama group have helped to £3,500 for two charities following a sold-out comedy play in Omagh.

In early May, Clanabogan Drama Circle (CDC) staged their final performance of Jimmy Keary's hilarious 'Fortunes and Misfortunes' to a packed house, while also raising funds on the night for The Saturday Club and Huntington's Disease Association of Northern Ireland (HDANI).

And it was a happy meeting on a sunny June evening at the Strule Arts Centre, as members of CDC joined with representatives from their two chosen charities to hand over the much-needed donations, with both organisations receiving exactly £1,750 each.

A spokesperson from CDC expressed their thanks to everyone who donated towards the well-supported fundraiser.

"Each charity is truly deserving of the funds," they said. "The Saturday Club will use their much-appreciated donation to provide activities for local children with learning disabilities, whilst the HDANI will use theirs to continue to provide support for local people who live with this awful disease and for their families.

Laura Quinn, Alasdair Patrick and Margaret Wilkinson from The Saturday Club accept a cheque for £1,750 from Clanabogan Drama Circle. Laura is a dedicated member of both The Saturday Club and CDC. JasMc1

"Alasdair Patrick and Margaret Wilkinson from The Saturday Club were most expressive in their appreciation to the drama group, stating that such significant donation with provide a huge boost to the children who will benefit from the activities which be funded by this much needed money."

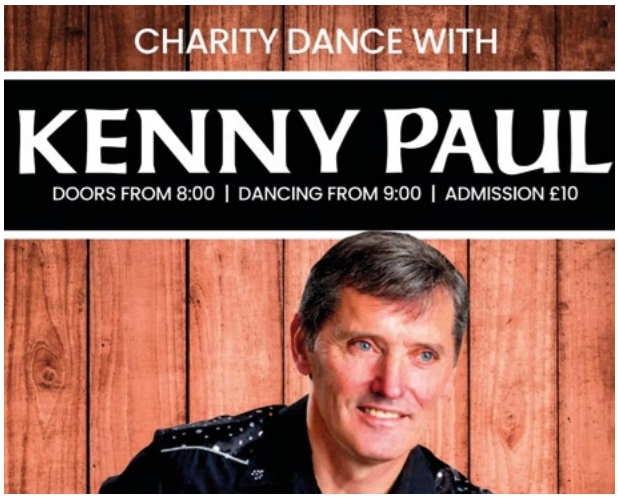
The spokesperson added, "Gerry McDermott who is chair or HDANI and also a valued actor with CDC was delighted that the group selected the charity as a recipient of this year's charity performance, and highlighted that other sources of funding are no longer accessible so the group is extremely grateful to CDC for both the financial donation, but also highlighting awareness of this cruel illness and the effects it has on entire families."

Clanabogan Drama Circle look forward to planning for 2025 and incorporating another charity performance into their busy schedule for next year.

Lisa and Stephen who chose HDANI as their charity in hour of their friend who has the disease. Lisa's work the Cooneen Group also made a donation to support them as they completed their 8 mile walk.

Thank you so much to **Ballyrea Boyne Defenders** who recently paraded through Armagh wearing pink t shirts with the HDANI logo and the words raising awareness for Huntingtons Disease

Millbrook Lodge Hotel who had a charity dance with Kenny Paul



Carnglen Credit Union Limited who very kindly made another donation to HDANI.

Thank you to all others - some prefer not to be on social media / named directly so:

our heartfelt thanks to everyone who has participated in events/ arranged events, donated to events in honour of all those who live with HD, it is very much appreciated.

Contact Us:
Sorcha McPhillips/Chief Executive, 07982843907 sorcha@hdani.org.uk

Contact our Family Support Team Mon-Fri 9-5pm
Katie McClean, 07341963264 katie@hdani.org.uk
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