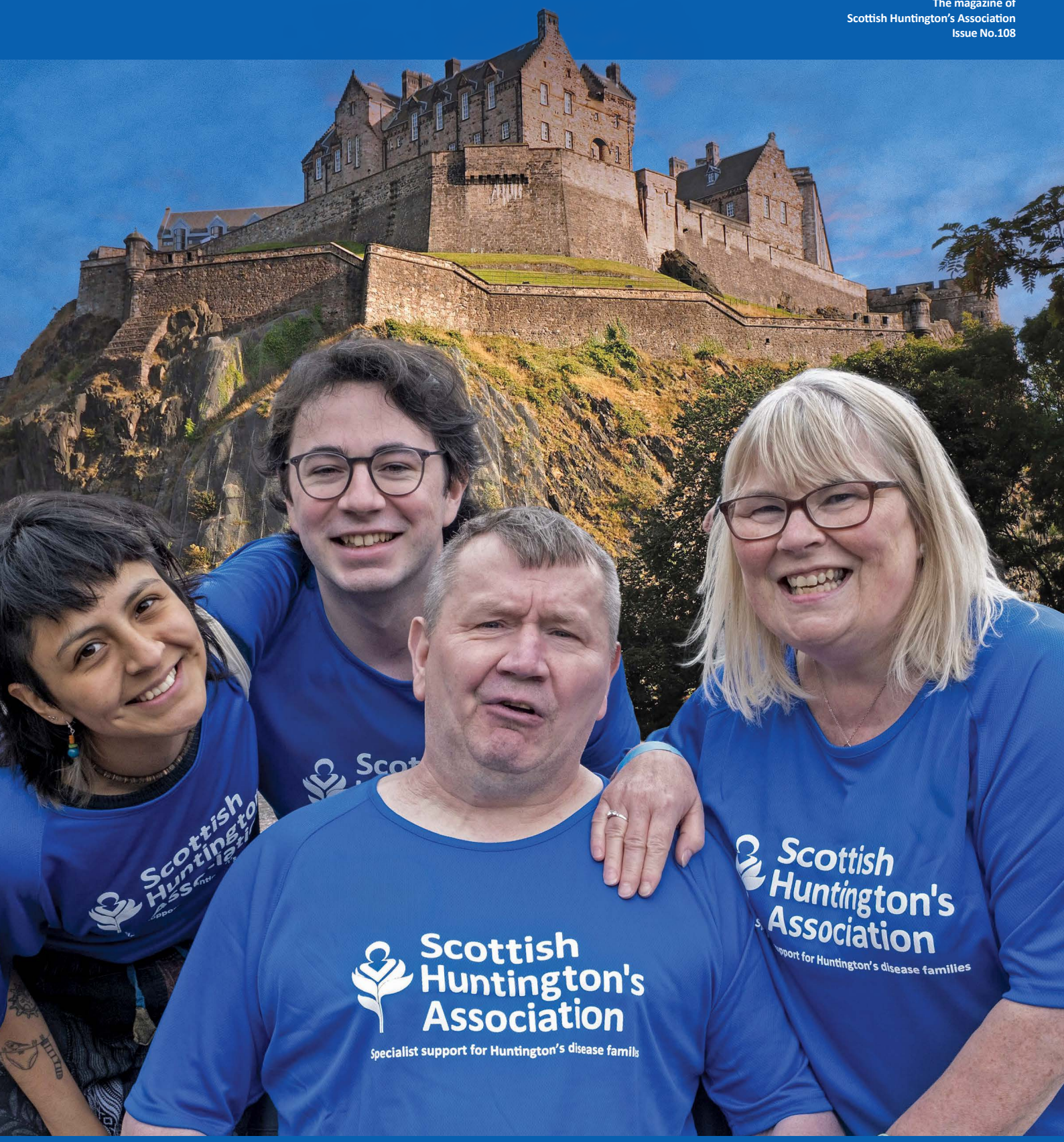
SHAre

Scottish Huntington's Association

Specialist support for Huntington's disease families

Summer 2026

The magazine of
Scottish Huntington's Association
Issue No.108



Inside: Dance 100, Family Gathering and more...

Welcome from our Chief Executive

My previous contribution in this space concluded: “the charity, of which we are all part, is being buffeted by a significant storm, and we need to unite regardless of department, region or designation to pull in one direction in pursuit of our nationwide vision. Let’s stick to our task and look forward to celebrating further achievements, regardless of the odds, in the year that lies ahead.” In this edition we see people across the country rising to this challenge.

On our front page, and within, we highlight the fundraising and awareness raising success of Dance 100 as Inverness passed the baton to this year’s host city Edinburgh. We celebrate partnerships with the universities of Glasgow, Stirling and Abertay; a Huntington’s first in the Borders; a charity of the year announcement from Tabletop Scotland; and work being done to train and educate health and social care staff throughout the country. Not to overlook fantastic and hugely appreciated individual and collective fundraising achievements, and new opportunities to get involved!

In addition to celebrating these achievements, this edition provides powerful reminders of what we are all about, and for whom we all do what we do, as we read powerful testimonies from Eddie, Nicole and family and also from Grace and her mum Cathryn.

We also read below of the appointment of a new member of our Board of Trustees, Liz Porterfield, who is also a member of a Huntington’s family, as is the majority of our Board, including our chair and two vice-chairs.

Families like these, and yours, remain our inspiration and guide for all the achievements highlighted and, with your support, all those to come.

Former government head of Strategic Planning and Clinical Priorities joins our Board of Trustees

Elizabeth (Liz) Porterfield MBE has joined the Board of Trustees at Scottish Huntington’s Association.

The role is especially meaningful for Liz, whose elder son died of complications associated with Huntington’s disease.

Speaking about her decision to join the charity’s board, Liz said: “Huntington’s disease is the absolute worst of all of the absolutely horrible neurological conditions. It doesn’t present until adulthood in the main but does also occur in very few children. The disease robs people of their cognitive and physical functions, including speech; it is rare, can take a long time to diagnose, and there is no cure.

“The services provided by Scottish Huntington’s Association are absolutely essential for people with Huntington’s and their families/carers. There are so few such services, more are needed, not fewer. These services are the only recourse for families affected by this genetic disease.”

Scottish Huntington’s Association is the only organisation in the country dedicated exclusively to providing specialist services and the personalised support that is needed by individuals and families.

Between 2016 and 2020, Liz and her colleagues on the Scottish Government Clinical Priorities Team worked with Scottish Huntington’s Association to develop the world’s first National Care Framework for Huntington’s Disease.

As Chair of Genetic Alliance UK since 2019 and Vice Chair of Sight Scotland/Sight Scotland Veterans since 2021, in addition to having held a number of key roles in the Scottish Government before her retirement, Liz’s appointment to Scottish Huntington’s Association brings additional extensive knowledge and experience to the organisation.

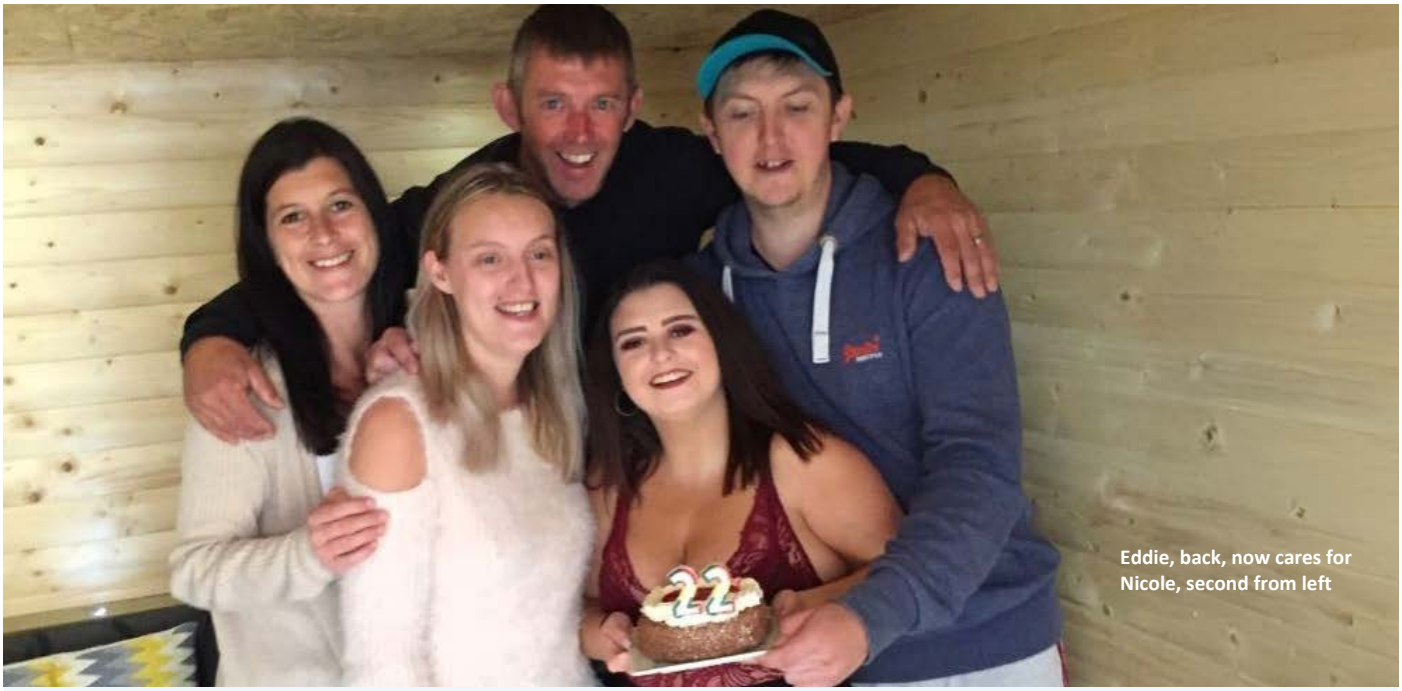
Genetic Alliance UK, which is a membership organisation of over 220 charities, works in the areas of genetic diseases/conditions, rare diseases/conditions and undiagnosed conditions. It provides secretariat support for UK and devolved Parliaments for their Cross Party and All Party Groups and is an influential member of all three governments’ policy delivery groups in the rare disease field, and particularly with reference to achieving a credible successor to the Rare Disease Framework, the extension to which ends in early 2027 and to which the UK, Welsh and Scottish governments have committed.

Sight Scotland (previously known as Royal Blind Scotland) was established 230 years ago and provides services in the community for people with visual impairment. It also runs the only dedicated school for children with sight loss/impairment as well as the Scottish Braille Press. Sight Scotland Veterans (previously known as Scottish War Blinded), which was founded in 1915, works to provide targeted services for veterans of all of the armed forces and supports, campaigns and enables research for people affected by visual impairment.

From 2008 to 2017, Liz was on permanent secondment from NHS National Services Scotland to the Scottish Government in key roles including Head of Strategic Planning and Clinical Priorities (2012 – 2017). Prior to this, she led the National Planning Team (2008-2012), and the Cancer Team (1999-2008). In 2016 Liz and her team produced the first national plan for rare diseases in the UK.

In 2024, for her contribution during her career and her continuing contribution to the community following retirement, Liz was recognised with an MBE for services to people with rare diseases.

Chair of Scottish Huntington’s Association Board of Trustees Aarran Air said: “We are delighted to welcome Liz to the Scottish Huntington’s Association Board of Trustees. Liz’s professional experience, network and personal perspective of Huntington’s disease will contribute greatly to our work as we continue to fight tirelessly to ensure that everyone impacted by Huntington’s disease in Scotland has access to the specialist care and support they need, regardless of where they live.”



Eddie, back, now cares for Nicole, second from left

“It was difficult to accept Nicole had symptoms at the beginning”

Eddie’s story is one of fierce love, resilience, and determination - not just to care for his daughter Nicole, but to make sure people truly understand the person behind the condition.

Nicole was only 18 when she chose to be tested for Huntington’s. The disease had already devastated her family; her grandfather died young, at just 44, and later her mother developed the disease too.

At the time, the family knew little about Huntington’s. “All I really understood was that it was caused by a faulty gene,” said Eddie.

But Nicole wanted answers about her own future.

“She had no symptoms then but wanted to know and understand what was ahead of her,” said Eddie.

When symptoms started in her early twenties, it was devastating for the family.

“I was trying to tell myself, ‘no, it’s not,’” Eddie recalled. “But eventually we had to accept it is what it is and prepare for what’s coming.”

Now 34, Nicole has lost many of the physical skills most people take for granted. Huntington’s has affected her movement, speech and swallowing, and for the past five years she has lived with Eddie and his wife, Tracey, who care for her full time.

Yet when Eddie talks about his daughter, it’s not the illness that defines her.

“Nicole’s attitude is great,” he says. “She’s made the most of everything and still loves shopping - honestly, every time we get out Nicole somehow manages to come home with trainers and tracksuits.”

At home, daily life revolves around careful routines and constant adaptation while also supporting Nicole to have as much independence as possible.

Eating has become one of the biggest challenges and at times mealtimes could stretch for hours.

“We were spending all day trying to get calories into her,” Eddie says. “Nicole was choking and struggling, but she was determined not to let it stop her. My wife Tracey is amazing, making sure Nicole’s fed properly, takes her medication and managing everything - she’s got it spot on.

“When we come back from work, it’s straight into helping with dinner, cleaning up, medication, tube feeding - there’s a lot involved and it can be exhausting. We don’t really have time for ourselves but we don’t mind putting things on hold.

“Scottish Huntington’s Association has helped us to learn about the disease. Anything we’ve struggled with, there’s always been someone from the charity to help us. Our Huntington’s Disease Specialist is amazing. Just having someone coming to see Nicole, noticing wee changes and helping us understand what’s happening, that means a lot.”

Eddie also wants more awareness of Huntington’s disease among the public because Nicole’s symptoms are often misunderstood by strangers and, for the family, respect and dignity matter enormously.

“When Nicole was out shopping and struggling with her balance, people thought she was drunk,” he says. “That’s not nice, especially when people think Nicole doesn’t understand because of how she looks or speaks. Mentally, she’s still Nicole. Up here,” he says, pointing to his head, “she’s the same as you or I, so people shouldn’t shout at her or talk down to her. There’s nothing wrong with Nicole’s hearing.”

Despite everything Huntington’s has taken, family life still has moments of joy. Nicole loves television, relaxing in the garden on sunny days, and spending time together. And if Nicole was to give advice to anyone living with Huntington’s disease?

“Don’t lie down to it.”

We're getting ready for Family Gathering 2026

This year's Family Gathering will take place on Saturday 14 November 2026 at the Carnegie Conference Centre in Dunfermline.

We are lining up a fantastic programme of speakers and activities, including a look at the latest developments in research.

Our Patron Sarah Winckless MBE will once again join us for what promises to be a great day.

Registration will open later soon – please note that as part of our ongoing work to reduce overheads and make every penny go further for families, invitations will be sent by email rather than post.

The email will include the programme for the day, speakers, travel and transport information, accommodation suggestions, and any other information you may need.

Our Youth Service will also be running a fun activity off-site for children and young people, which will require to be booked in advance.

You will also be able to book place(s) via our website and social media. To sign up to our email list or to refresh your communication preferences to ensure you are on our list for future events, please click https://bit.ly/4uuL6D9 to complete the communications consent form.

It takes just a few ticks to tell us what emails you would like to receive, such as SHAre e-magazine and information about events and ways to get involved.

We are sincerely grateful to Family Gathering sponsors, with Skyhawk Therapeutics having confirmed as we finalise this edition

Registration opens for EHDN Congress (Krakow)

Registration is open for the EHDN Clinical Research Congress, which this year will be held in Krakow, Poland, from 22 to 24 October.

All sessions will be open to clinicians, scientists, advocates and family members impacted by Huntington's disease.

Full details of congress, including the preliminary programme and registration and how to apply to become an EHDN member, can be found at https://ehdn.org/ehdn2026/

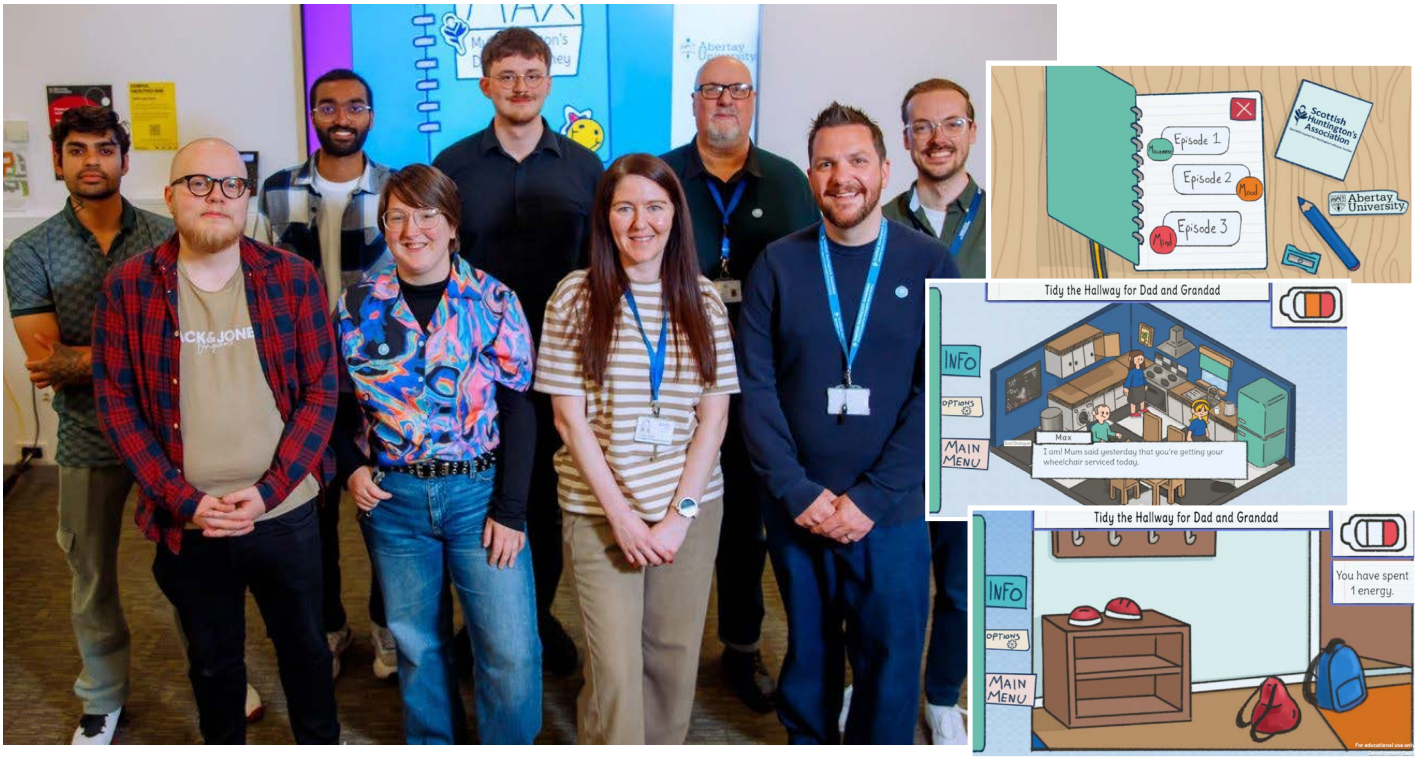
If you have any questions, please contact the EHDN Clinical Research Congress Organisation Team at krakow2026@ehdn.org.

Borders first HD Clinic

Our work is moving forward in the Borders with the establishment of the first Scottish Huntington's Association supported clinic for the area, which was held at Borders General Hospital.

Clients included new referrals from the area and the clinic also flagged two other local families who are currently unknown to Scottish Huntington's Association or HD Clinical Leads.

We hope to run the Huntington's disease clinics twice a year with support from local HD Clinical Leads.



University hits play on new video game resource for young people

Post grad students from Abertay University have teamed up with Scottish Huntington's Association to develop a computer game to help young people growing up in families impacted by Huntington's disease.

I Am Max – My Huntington's Disease Journey, inspired by the Scottish Huntington's Association story book for under eights, *New Things At Max's House*, was unveiled at the university's Applied Games Showcase in Dundee earlier this summer.

This new resource is aimed at an older age group – 14 to 18 – and will be incorporated into support provided by the charity's Youth Service. It will also be made available to parents and young people to use independently when it goes live online later this year.

Players will learn how the disease progresses and discover some of the different challenges that brings for the family. Its plotline also features additional characters living in the household, including parents and a younger sibling, and involves navigating three levels based on the physical, cognitive and mental health symptoms associated with Huntington's.

Lecturer in Games Production at Abertay University, Dr Andrew Reid, said: "The project was a collaboration between Scottish Huntington's Association and postgraduate game development students at Abertay University as part of an Applied Games and Research Practice module which runs between January and May each year.

"This involves a team of student game developers working with clients to produce games that address a creative brief set by the client. The result of this was *I Am Max*, a point-and-click browser game that tells the story of Max and her understanding of Huntington's disease through her father and grandfather's diagnoses."

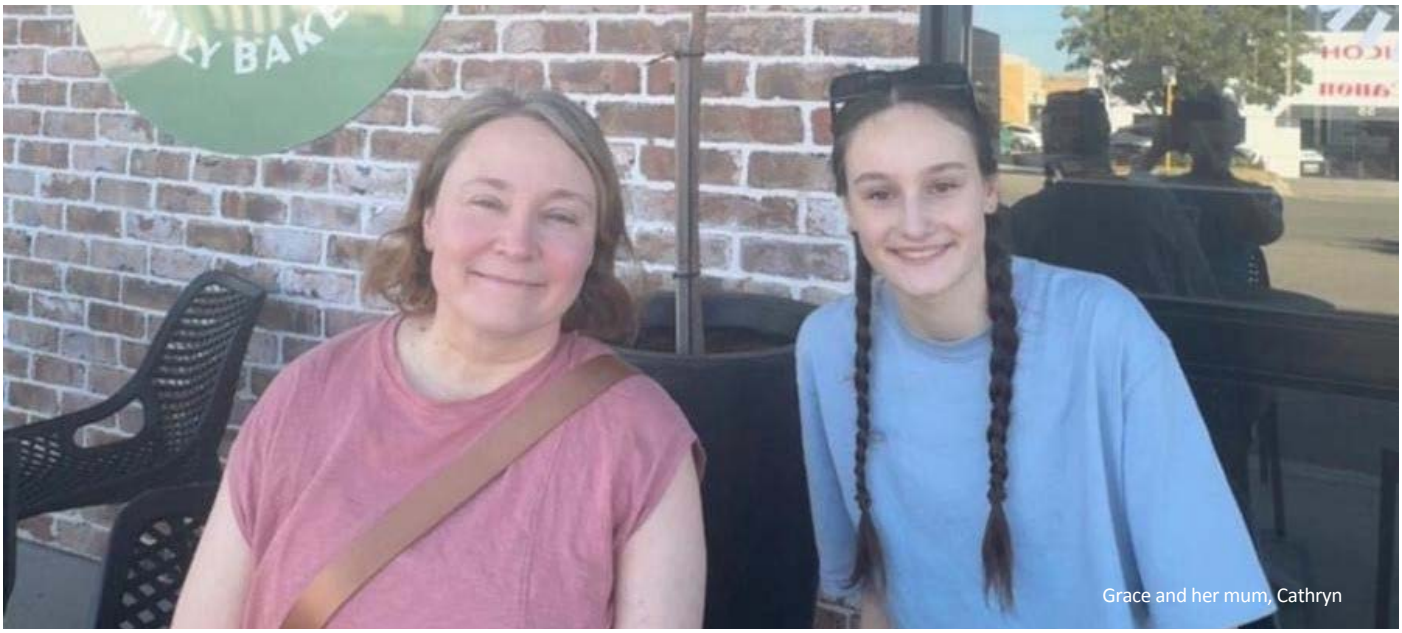
"*I Am Max* has serious potential to be a valuable resource for educating young people about Huntington's disease. Its delicate blend of humorous and emotionally charged moments, coupled with the simplicity and accessibility of its controls and visual presentation, stands as a solid example of what applied games are about: intentionally designing for a specific audience and a defined prosocial goal. I hope to continue working with the Scottish Huntington's Association team to ensure the game reaches its audience and achieves its desired impact."

With support from the charity's Youth Service, students undertook extensive research before development began. Youth Service Lead Grant Walker worked closely with them throughout the project to broaden their understanding of Huntington's disease, its impacts and challenges, and why specialist support for young people is so essential.

"Working with Scottish Huntington's Association has been something I have been keen to explore for a few years as my own research practice involves working with the third sector to address social and cultural challenges using applied games and game development," said Dr Reid.

"The student developers had to tread carefully with social and cultural sensitivities, such as age-appropriate content and ensuring *I Am Max* is playable for a wide array of game-playing skillsets. The narrative went through a lot of iteration and dialogue between Grant and the team.

"It has been incredibly valuable and the charity has been an excellent client for the students. I *Am Max* is a strong reflection of this collaborative effort and I'm really proud of what everyone has achieved. Observationally, it has been a partnership filled with insight and joy, and I am keen to continue to explore how the development and use of games can contribute towards the charity's goals in providing specialist support and care for families in Scotland."


Grace and her mum, Cathryn

“I felt more grown up than my friends because I had more responsibilities”

When speaking to Grace (17), it doesn’t take long to realise how much growing up she has had to do in her young life. She lives with her mum, Cathryn, who has Huntington’s disease.

As the symptoms have progressed, Grace has had to take on more caring responsibilities, from practical tasks including cooking and cleaning to more sensitive issues like reminding her mum about daily routines and providing emotional support when things become overwhelming.

It’s a lot for any young person, but for Grace it has simply become part of her day-to-day.

Research suggests that northern Scotland has one of the highest recorded rates of Huntington’s disease, with a prevalence of 14.5 cases per 100,000 people – over five times higher than the estimated worldwide rate. Another study confirmed that manifest Huntington’s in the region had reached 14.6 per 100,000 by 2020, indicating an upward trend in cases of this inherited disease.

The hereditary aspect compounds the challenges of coping with such a complex condition. It affects whole families and spans generations. And with each child of a person with Huntington’s disease at 50/50 risk of also inheriting the faulty gene that causes it, many young people are taking on a caring role while living with the uncertainty of knowing they may also develop the same disease.

Grace remembers her confusion when hearing for the first time about having Huntington’s in her family. Her mum didn’t have any symptoms, and she never knew her late grandmother, who also had the disease.

“Mum took me out to a restaurant to talk about it for the first time. I just felt awkward and didn’t know how to express myself about it then,” said Grace.

It was three years later when Grace started to see changes. Social interactions were becoming more challenging for her mum, especially when she was feeling overwhelmed or things were unpredictable. There were also memory issues, emotional sensitivities, and difficulties coping with changes to routine.

As Cathryn's symptoms increased, so did Grace’s caring role. She helps with cleaning around the house, cooking her mum’s favourite pasta meals, reminding her about personal care, and making sure important tasks are done, such as the weekly shop and paying bills.

“It’s always been similar tasks, like cooking,” she explained, “but now there’s more support with Mum’s emotions and trying to help keep her calm. That’s one thing that has become worse over the years.”

Such responsibilities had a huge impact on Grace’s teenage years in ways that most of her friends couldn’t understand.

“I felt a lot more grown up than my friends and I was dealing with things that they didn’t have to,” said Grace.

“I didn’t have any of my friends over after school because I was worried about what my mum would say to them or how they would react to her. I never really told them about Huntington’s disease.”

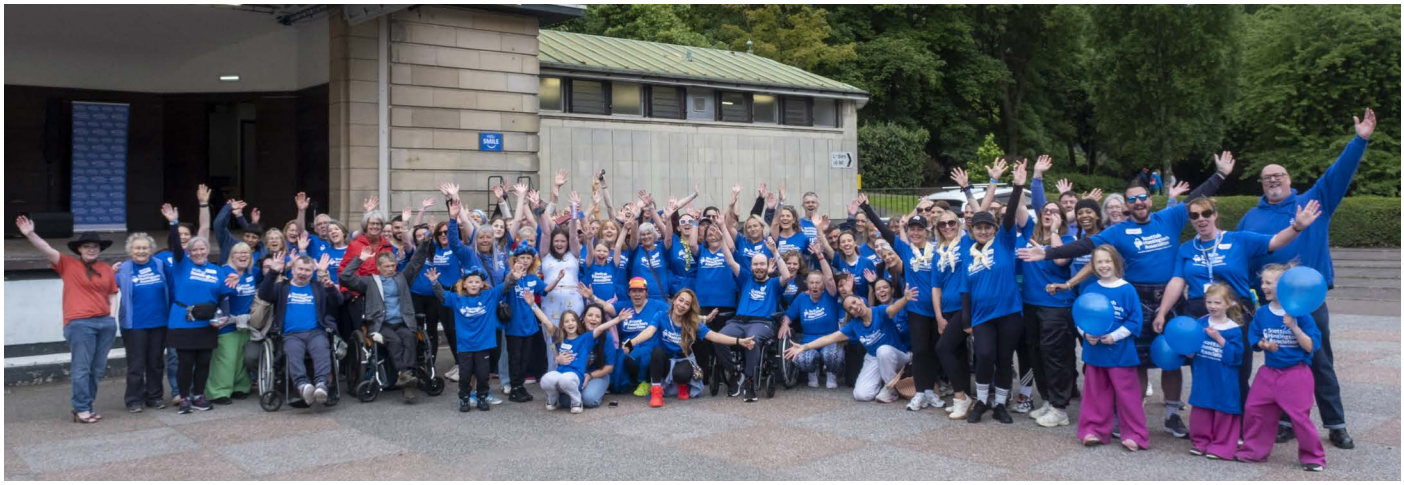
Having left school without qualifications, Grace feels now that having more parental guidance would have been a huge help, while living in a small, rural Highland community only increased her feelings of isolation.

Which is why the opportunity to meet other young people impacted by Huntington’s disease – including at the Scottish Huntington’s Association annual summer camp – has been such a rewarding and positive experience.

“They just get it,” said Grace. “We walk into that camp and everyone understands Huntington’s. We don’t always talk about it but we can if we want to.”

Grace has also benefited from regular meetings with her local Scottish Huntington’s Association Specialist Youth Advisor.

“Having support through one-to-one sessions is great; it’s really helpful to have someone who helps me to better understand Mum’s symptoms and who is so positive, even when I’m feeling down. It helps me to cope.”



What an unforgettable day!

Dance 100, our flagship community event, rolled into Scotland's capital city for the first time – and became our biggest event so far with record numbers of people taking part.

Together, more than 250 people joined us throughout the day at the Ross Bandstand in Princes Street Gardens to dance, celebrate, connect, and stand in solidarity with families affected by Huntington's disease across Scotland.

Thanks to such amazing support, Dance 100 has raised just under £16,000 for Scottish Huntington's Association so far.

While the fundraising total is fantastic, the impact of the day goes far beyond the money raised. Throughout the event, new friendships were formed, a community was brought together, and countless conversations helped raise awareness about Huntington's disease. From the incredible performances and non-stop dancing to the emotional moments of connection and support, Dance 100 showcased, once again, the very best of our community.

Our heartfelt thanks goes to everyone who helped make it such a memorable and meaningful day, including:

- Incredible headline sponsor, Skyhawk Therapeutics, whose support helped bring Dance 100 to Edinburgh for the very first time, and our fantastic song sponsor, Great Grog.
- Brilliant DJ and host, Steve McKenna, who kept the energy high and the dance floor moving from the first song to the 100th.
- The wonderful first aid team, Taylor and Ester from Remote Paramedics, for keeping everyone safe and supported throughout the day.
- Iconic venue, the Ross Bandstand, and Edinburgh City Council, for welcoming us to the heart of Scotland's capital and helping create such a spectacular setting for the event.
- All the talented performers – Rock Choir, Ceilidh Kids, MDA dance school, Zumba Scotland, and Phelan School of Dance – who brought so much energy, entertainment and joy to the day.
- Fantastic photographer, Peter Devlin, for capturing the smiles, special moments and memories we'll cherish for years to come.
- Talented videographer Alex Wright from Flying Mirrors for helping us tell the story of Dance 100 and share its impact far beyond the event itself.
- And Scottish Huntington's Association's dedicated volunteers, whose enthusiasm, commitment and hard work ensured everything ran smoothly from start to finish.
- And, finally, every single person who bought a ticket, donated, fundraised, cheered from the sidelines, or danced their heart out to help make it such a wonderful occasion.

Every conversation started, every song danced, and every pound raised helps Scottish Huntington's Association continue to be there for people across Scotland when they need us most.

Thank you for helping to show families impacted by Huntington's disease that they are not alone.

Looking ahead to next year's Dance 100

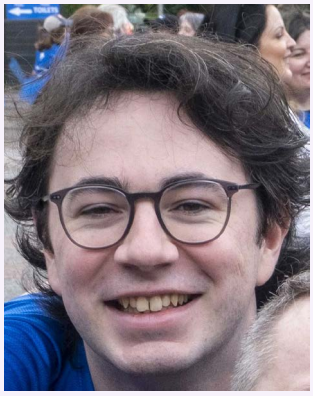
The success of Dance 100 Edinburgh has already got us excited for what comes next, and we can't wait to do it all again in 2027!

To help shape the future of the event, we'd love to establish a Dance 100 Family Committee, bringing together family members and supporters with lived experience of Huntington's disease to help influence, develop and grow the event in the years ahead.

If you'd be interested in volunteering your time and ideas, we'd love to hear from you. Please email fundraising@hdscotland.org for more information and to share your ideas for future events.


Scottish Huntington's Association
Thank you for your kind
Every pound ensures no one will face Huntington's

“I hope seeing this today inspires our newly elected MSPs to take action”

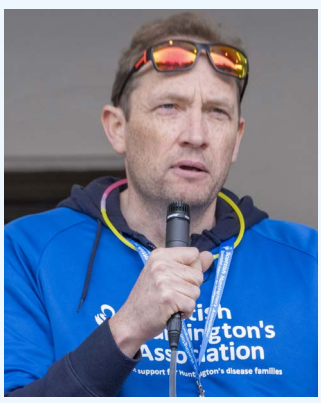


The Wilson family from Edinburgh, who feature on the cover of this month’s issue, joined this year's dancers to help raise crucial awareness.

Bruce was joined by his dad Graham, who has Huntington’s disease, his mum Lesley, and his partner Dav.

“Due to its hereditary nature and misunderstood symptoms, Huntington’s families have been shrouded in secrecy and stigma for too long,” said Bruce, who is a Youth Ambassador for Scottish Huntington's Association.

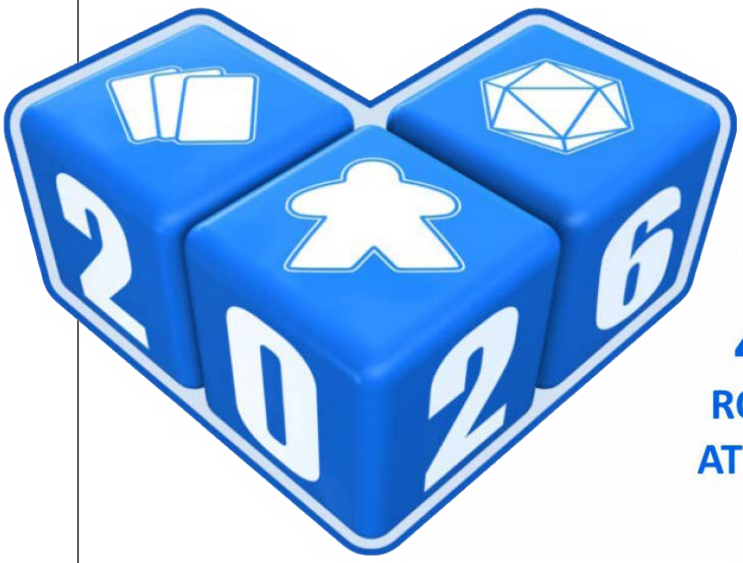
“Dance 100 is an amazing event which brings the cause out into the open to raise awareness of the condition and highlight the essential specialist services that our community both requires and deserves. I hope our newly elected MSPs and government were watching, and stand ready to act!”



Alistair Haw, Chief Executive of Scottish Huntington’s Association, added: “For many years, thanks to the work of our charity, Scotland has been recognised by the global Huntington’s community as a leader in the care and support of families living with this horrendous disease.

“That said, there’s absolutely no room for complacency. We increasingly find ourselves having to fight cuts to our services, and there’s still a long way to go to educate the public, medical, health and social care bodies and statutory funders about the dreadful toll of Huntington’s disease, its complex physical, mental health and cognitive symptoms - and why having specialist support is so essential for families.

“Having Dance 100 and all its participants there to support our cause, and being given such a fantastic welcome by the people of Edinburgh, was absolutely wonderful as together we continue to fight for the best possible outcomes for everyone impacted by Huntington’s disease throughout Scotland.”



TABLETOP SCOTLAND

4TH TO 6TH SEPTEMBER 2026

ROYAL HIGHLAND CENTRE, EDINBURGH

AT THE HEART OF GAMING IN SCOTLAND

www.tabletopscotland.co.uk

Gamer convention picks SHA as its charity partner of year

We are delighted to announce that Scottish Huntington's Association has been selected as Tabletop Scotland's Charity of the Year for 2026!

Tabletop Scotland is a board game, card game and roleplaying game convention. It is open to everyone, including those who are exploring the worlds of tabletop gaming for the first time and long term tabletop gamers looking to celebrate their hobby.

The event takes place at the Royal Highland Centre in Edinburgh from Friday 4 September to Sunday 6 September.

Gemma Harper, from Tabletop Scotland, said: "We picked Scottish Huntington's Association as our charity partner this year for several reasons.

"Personally, we have family and friends affected by Huntington's so we want to raise awareness and funds that help not only those with the disease but their support networks as well. We also hope to provide a space where the games community can be educated about Huntington's and give support for this important cause through donations.

"At Tabletop Scotland, we believe there is a game for everyone. Whether you're discovering the worlds of board games, card games, and roleplaying games for the first time, or you're a long-time tabletop enthusiast, our convention is the place to celebrate and connect.

"We are proud to support the incredible work of Scottish Huntington's Association and looks forward to making a positive impact together with our amazing tabletop gaming community."

*Will you volunteer at the Scottish Huntington's Association stall? If you'd like to support Scottish Huntington's Association and help create a welcoming and inclusive experience for attendees, we'd love to hear from you.

If you can spare a few hours or more, your support will make a real difference.

Contact us at fundraising@hdscotland.org.

Welfare Grant Fund opens for applications

The 2026/27 Welfare Grant fund is now open to support individuals and families facing financial hardship or, for example, to help with the cost of equipment that will improve quality of life or assist care.

The maximum award is £300 and applications can be submitted by, or on behalf of, a person living with Huntington's disease, a carer of a person living with Huntington's disease, or a young person (up to 25) living in a family impacted by Huntington's disease.

Further criteria stipulates that the applicant's household savings must not exceed £8000 and that no one living in the household has received a Welfare Grant in the past 12 months.

Applications should be made on the Welfare Grants digital Beacon form and can be submitted with a supporting letter included. Completed forms will be sent to the Welfare Grants Committee for consideration.

The total budget for this year is £10,000. Please note that as Welfare Grants are being prioritised we will not be offering short break funding at present.

Please get in touch with your HD Specialist or Specialist Youth Advisor, or email sha-admin@hdscotland.org

Building the skills and knowledge of hundreds of healthcare workers

Did you know that Scottish Huntington's Association trains hundreds of medical, health and social care practitioners each year?

Since January, we have delivered sessions in Tayside, Lothian, Greater Glasgow and Clyde, Tayside, Grampian, Ayrshire and Arran, Fife, and Dumfries and Galloway.

Our HD Specialists provide vital knowledge and skills to care home staff, nurses, occupational therapists, physios, third sector organisations, and others to raise the standard of care for Huntington's families.

For example, in Tayside we've worked with more than 50 care home staff members while in Lothian more than 50 medical, health and social care professionals signed up for the May workshop, with another 50 registered for the September date and a further 18 in December. This is in addition to 59 care staff from nine agencies across Lothian in May.

The most recent session in Dumfries and Galloway was tailored to local professionals in community mental health teams, while in Lanarkshire it was aimed at members of the Equal Say advocacy charity organisation.

Staff working for care homes in Fife accessed palliative, end-of-life and more general Huntington's disease training, some of which will continue weekly until the end of this year.

Feedback from attendees continues to be overwhelmingly positive, highlighting a significant increase in understanding about how the disease impacts behaviour, communication and mental health, and strategies to improve their own practice moving forward.

"Training is a fundamental aspect of our work to ensure the best possible care and support for everyone impacted by Huntington's disease in Scotland," said Cat Martin, Head of Specialist Services and Income Generation.

*Our online learning module, *A Multidisciplinary Approach To Understanding Huntington's Disease,* delivered in partnership with University of Stirling for medical, health and social care practitioners, will be relaunched early in 2027.

This follows an extensive review to ensure the focus and learning continues to meet the needs of professionals and reflects the changes in the health and social care landscape.

It will also include new multimedia elements such as podcasts, video and client case studies.

Our fabulous fundraisers

From the streets of London and Edinburgh to the historic roads of Rome, our incredible community of runners has gone the extra mile for Scottish Huntington's Association. Taking on some of the world's most iconic marathons, they dedicated months of training, determination and commitment to cross the finish line knowing they have made a real difference!

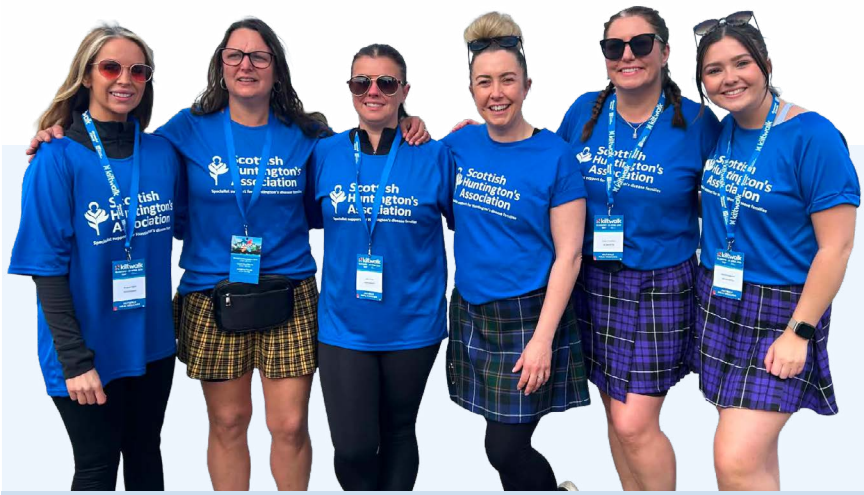
Fundraising total: £62,000

Huge thanks goes to our Branches for their support.

They organise invaluable social events such as day trips, get togethers and lunches which help to facilitate support networks, forge friendships and share experiences. Our branches also distribute welfare grants to local individuals and families impacted by the disease.

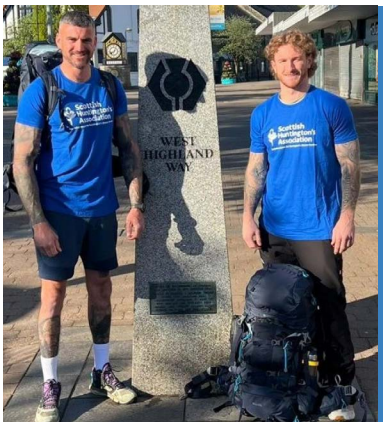
The Tayside Branch, for example, raised a total of £10,707 for Scottish Huntington's Association in 2025/26, of which £7153 was spent by the branch locally supporting families and £3400 was transferred to the national organisation to support frontline services provided by the charity in the area.

Meanwhile, the Fife branch raised £6047 during the same period, of which £5708 was spent by the branch locally supporting families and £400 was transferred to the national organisation, again to support the delivery of services including the HD Specialist team and the Specialist Youth Service.



Our fantastic team of Kiltwalkers laced up their boots and proudly donned their tartan to take on both the Glasgow and Aberdeen Kiltwalks. From city streets to scenic routes, they embraced every mile with enthusiasm, determination and plenty of team spirit.

Fundraising total: £10,900

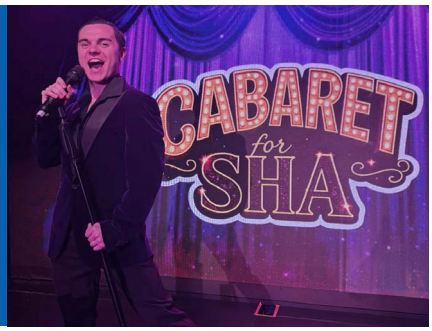


Footballer and gym owner Robbie McNab from Falkirk smashed his latest fundraising challenge in support of families, including his own. While it typically takes between eight and 10 days, the 29-year-old Stirling Albion midfielder and his long-time pal, Scot Buist, completed the West Highland Way in just four. That meant averaging around 25 miles and up to 10 hours each day to do the 96-miles from Milngavie to Fort William.

Fundraising total: £3110

William Hillhouse, a talented singer and performer, recently hosted a fantastic 'Cabaret for SHA' night at Phoenix Arts Club in London. It was a brilliantly run evening filled with music, energy and the support of William's friends and wider community.

Funds raised: £1195



Inspired by their childhood friend living with Huntington's disease, Christine and friends organised their own dance event in Alexandria, bringing their community together for a fantastic day of fun, music and fundraising.

Fundraising total: £2200

We also want to celebrate the fantastic effort of Abbie Forbes and her coursemates at Dundee College, who chose to support our Specialist Youth Service as part of their enterprise project. The group organised a children's book stall on campus,

Fundraising total: £156

Polmont Scottish Women's Institute selected Scottish Huntington's Association as its charity of the year and invited us to deliver an awareness talk during Huntington's Disease Awareness Month. It also hosted a raffle and donated the tea money collected throughout the year.

Fundraising total: £216

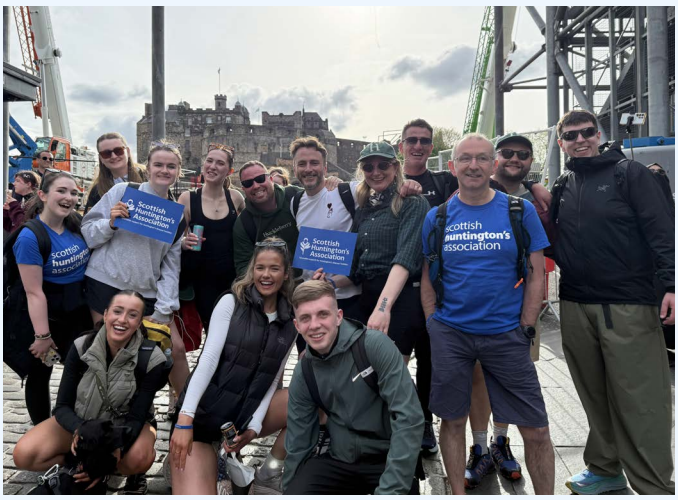
The Martin family – Philip, Joanne, Aiva, Faye and Beth - held gala ball in a local hotel, complete with a live band and an amazing auction, followed by a grand finale raffle for a £2500 diamond necklace donated by a family friend. Following the success of last year's event, tickets sold out in days and the family was overwhelmed by the support and generosity of guests, before, during and afterwards. In addition to raising thousands of pounds, the annual event is helping to increase awareness and grow a committed community of people who want to help.

Funds raised: over £16,500

Businesses making a difference: The power of workplace fundraising

Across Scotland, businesses are discovering that fundraising is about much more than raising money. It is an opportunity to bring employees together, build team spirit, increase awareness about important causes, and create change for communities and society.

At Scottish Huntington's Association, we are incredibly grateful to organisations that choose to support us. If your workplace is looking for a team challenge, fundraising event or community activity, we'd love to hear from you too.



Huck takes team building to new heights on the 7 Hills

For employees at the marketing agency Huck, fundraising began with a simple idea: organise a fun out of the office activity while supporting a worthwhile cause. The team decided to take on the Edinburgh Seven Hills Challenge then set about choosing a charity.

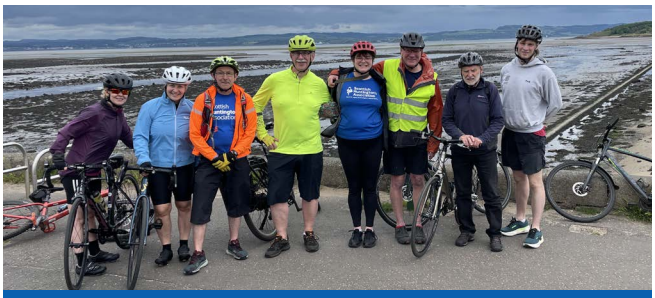
“When we started discussing charities, Heather shared her family’s connection to Huntington’s disease,” said the Huck team. “It was really meaningful to learn more about Scottish Huntington’s Association and the support it has provided to Heather’s family over the years, and it felt like a special cause for us to get behind.”

The challenge itself brought plenty of memorable moments.

“One of the biggest highlights was getting to spend a full day together outside of the office, learning more about each other’s lives beyond work - and everyone’s choice of motivational snacks!” the team said. “It was also valuable being able to talk about Huntington’s disease during the walk because some of the team hadn’t come across it before.”

The experience also sparked conversations beyond the workplace. One of the agency’s clients also has a family connection to Huntington’s disease so was delighted Huck had chosen to support Scottish Huntington’s Association.

For businesses considering fundraising, the Huck team has a clear message: “Go for it. Scottish Huntington’s Association does such important work and every fundraiser, donation and conversation helps raise awareness and hopefully moves us closer towards better support for families.”



Pedalling with purpose: Great Grog’s charity cycle

Another fantastic example of workplace fundraising came from Great Grog Wine Merchants, whose team hosted a charity cycle.

The bike ride from the Great Grog warehouse in Leith to Cramond Beach raised an impressive £762.50 (including Gift Aid.) The super cyclists finished the journey with well-earned pizzas and beers – ending the day on a high.

Richard Meadows, owner of Great Grog ,said: “It was great to join some cyclists and pedal with them on Edinburgh’s beautiful, and often secret, cycle paths. All in a good cause.”

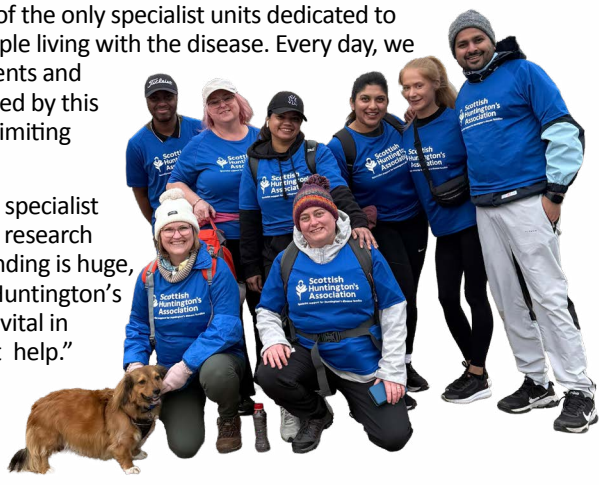
The event was a wonderful example of colleagues coming together, getting active and supporting families impacted by Huntington's disease.

Rumbling Bridge makes a ‘loch’ of difference with sponsored walk

At Rumbling Bridge Nursing Home, where residents are cared for in a dedicated Huntington’s disease unit, staff completed a 20km sponsored walk at Loch Leven, raising an incredible £1000 (including Gift Aid) for Scottish Huntington’s Association.

Cathryn Steer, Deputy Manager, said: “[Rumbling Bridge] is home to one of the only specialist units dedicated to caring for people living with the disease. Every day, we support residents and families affected by this complex, life-limiting condition.

“The need for specialist care, support, research and understanding is huge, and Scottish Huntington’s Association is vital in providing that help.”



Partnering with university for event

Around 50 people, including family members, Scottish Huntington's Association staff, academics, researchers and medics, attended the *Changing The Course of Huntington's Disease: Somatic Expansion and Emerging Therapeutic Targets* event at University of Glasgow.

The interactive patient engagement day, designed to share knowledge about the latest research and treatment developments for patients and carers, was held with support from the Scottish Huntington's Association Impact and Engagement Fund.

Presenters included Dr James Herron, Consultant Psychiatrist in HD Psychiatry/Research, Enroll-HD and HD Clarity Principal Investigator, and HD Clinical Lead for Greater Glasgow and Clyde; Professor Darren Monckton, Professor of Human Genetics at University of Glasgow; Dr Caroline Benn, Chief Scientific Officer at LoQus23 Therapeutics; Dr Madeleine Wakeling, Chief Operating Officer at Harness Therapeutics; and Dr Mena Farag, Specialist Registrar in Neurology, King's College Hospital.

Scottish Huntington's Association was represented by Chief Executive Alistair Haw; Head of Services and Income Generation Cat Martin; Greater Glasgow and Clyde Senior HD Specialist Pauline Donaldson; Youth Service Lead Grant Walker; and Senior Fundraising Officer Gemma Powell.

"Most attendees were family members, and it was an inspiring, uplifting and incredibly helpful event," said Cat.

Connecting at long term conditions day

Senior HD Specialist Pauline Donaldson and Financial Wellbeing Service Lead Caitlin Daly joined healthcare charities and organisations at the West Dunbartonshire Long Term Conditions Self Management Assembly in Clydebank Town Hall.

Other organisations taking part included Breast Cancer Now, Stepping Stones, RNIB, Spinal Injuries Scotland, Epilepsy Connections, British Liver Trust and Greater Glasgow and Clyde NHS.

The annual event offers an opportunity for people with a range of long term conditions to connect with support, advice and resources. It also helps to raise the profile of participating organisations and fosters links and potential partnership working opportunities between them.

"We connected with Breathing Space and carer centres, and found about the fantastic service provided by Dumbarton Community Transport which takes local residents to any health-related appointments free of charge," said Pauline.

Check out our full events calendar below and scan the QR code to find out more and sign up.

Alternatively, you can call us on 0141 848 0308 or email events@hdscotland.org

2026/27 EVENTS CALENDAR

August

Dundee Kiltwalk 16 August 2026
Scottish Half Marathon (Edinburgh) 16 August 2026
Scottish 10K (Edinburgh) 16 August 2026
Zipslide Challenge Aviemore 22 August 2026

September

Edinburgh Kiltwalk 13 September 2026
Men's and Women's 10K (Edinburgh) 20 September 2026
Loch Ness Festival of Running Events 27 September 2026

October

Great Scottish Run 10K & Half (Glasgow) 5 October 2026
Halloween Bungee Jump 16 October 2026
Three Peaks Challenge (Ben Nevis/Scotland; Scafell Pike/England; and Snowdon/Wales) Various Dates

November

Supernova 5K (Forth Road Bridge) 7 November 2026

March

Supernova Kelpies 5K 11 and 12 March 2027

April

Glasgow Kiltwalk Date TBC
London Marathon 25 April 2027

May

White Water Rafting 1 May 2027
Edinburgh Marathon Festival 29 and 30 May 2027

June

Tough Mudder 5 June 2027
Aberdeen Kiltwalk Date TBC

July

Skydive Challenge 24 July 2027

GOT AN EVENT IDEA? GET IN TOUCH!






EXCITING EVENT PLANS FOR 2026 – 2027 ARE STILL TO COME!

Keep an eye on our website and Facebook page for the latest updates, event details, and booking information.

To make sure you don't miss out, scan the QR code to receive our emails and be the first to hear about upcoming events, special activities, and seasonal celebrations.

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Registered Office: Business First, Burnbrae Road, Paisley, PA1 2FB