

SHAre



Scottish
Huntington's
Association

Specialist support for Huntington's disease families

Spring 2025

The magazine of
Scottish Huntington's Association
Issue No.105



Bringing world champion energy to lunch - P3

Welcome from our Chief Executive



In a recent media article Lesslie Young OBE, CEO of Epilepsy Scotland, said: “I have worked for over 50 years in the sector. I can confidently say I have never experienced times as difficult as these.” “The need for funding,” she goes on, “vastly outweighs availability, while demand for the services we provide is rising at a phenomenal rate.” Her comments came as she was forced to close one of her charity’s much needed services. It’s becoming an increasingly and concerningly common narrative.

At the 2024 Family Gathering, and again in my previous introduction to this magazine, I thanked the Huntington’s community for everything it has achieved over the last 35 years and encouraged everyone to think about what support could be provided to steer us through these stormy economic waters. As you will see throughout this edition people are stepping up to that plate.

Of the many examples highlighted throughout this edition, I want to take a moment to reflect upon the particularly inspiring example of the Martin family from Lanarkshire. From an unexpected and devastating diagnosis in a family with no known history of the disease to launching straight into fundraising and awareness raising events, raising a five-figure sum. We can’t thank them enough for their incredible determination and achievements – read on for more detail on p5. And to our new friends at Women of Scotland Lunch (p3), thank you for such kindness and the opportunity to inspire hundreds of new people to our cause in such a profound way. In addition, we have also received an extremely generous and timely donation from another member of the community. They know who they are, and it could not be more appreciated.

We know how much the Huntington’s community needs Scottish Huntington’s Association at this time of all times. But be in no doubt that Scottish Huntington’s Association needs you too. Read on for inspiration about not only what Scottish Huntington’s Association does for you but also what you, our community of supporters, does for Scottish Huntington’s Association. We look forward to showcasing your latest successes in future editions.


Alistair Haw, Chief Executive

SAVE THE DATE!
Family Gathering 2025
Glasgow
Saturday 8
November 2025

We want you to continue enjoying SHAre – but can we ask for one small favour to cut costs?

By signing up to receive the magazine by email instead of through your letterbox you will reduce the charity’s production and delivery overheads.



Your digital SHAre will have all the same stories, news and opportunities to get involved – the only difference is that you will read it on our website instead.

Lots of people have already made the digital switch – it’s quick and easy to do. Simply scan the QR code or search <https://bit.ly/Digitalswitch> to update your preferences. This will only change how you hear from us about charity news and events - **it won’t affect letters you may receive from our HD Specialist, Financial Wellbeing or Youth Service teams relating to support provided or service delivery.**

Of course, if you prefer to continue receiving the print edition of SHAre, we will be happy to post it - with our sincere thanks for your interest and support for our work.



Lawyer Carrie-Anne joins our Board of Trustees



We have appointed Carrie-Anne Mackenzie to our Board of Trustees.

Carrie-Anne has a background in both civil and criminal law and her experience includes litigation, regulatory compliance and governance, including medico-legal work. Her appointment brings vital legal expertise to the Board.

Charity Trustees are the people in overall control and management of a charity. They are responsible for the charity’s governance and strategy, and making sure it is well-run.

They contribute a wealth of knowledge and skills to our organisation including expertise in youth work, finance, education, healthcare, research, governance, business, operations and strategy.

We are continuing to recruit voluntary Trustees and are especially interested in hearing from people who have worked at senior/director levels in communications/marketing and income generation.

Should you – or anyone in your professional network – be interested in finding out more about the role and responsibilities involved, please visit the Trustees page on our website at hdscotland.org or email sha-admin@hdscotland.org.

Olympic rowing stars Katherine and Sarah win new friends and support for our cause

The wonderful Women of Scotland Lunch has been a real highlight of the year so far, raising £25,000 for Scottish Huntington’s Association.

Hundreds of guests heard from three inspirational women, including our Patron Sarah Winckless MBE who delivered a powerful and moving speech about the impact of Huntington’s disease on families, including her own, and the need for specialist services.

“As a child without Scottish Huntington’s Association I was isolated, I was caring for my mum but I couldn’t cope. We didn’t know what was happening to her; we didn’t have the language we needed, we just knew she was different,” said Sarah, who tested positive for the faulty gene that causes Huntington’s disease in her final year at Cambridge University.



The second speaker was Sarah Davidson, Chief Executive Officer of Carnegie UK. She previously had a 25-year career in the civil service, latterly as Director General for Organisational Development and Operations at the Scottish Government.

The final talk was by Dame Katherine Grainger, Sarah’s good friend and one of the most successful Olympians, recently appointed to the British Olympic Association. Sarah and Katherine competed together as part of the invincible Team GB World Champion rowing squad of 2005 and 2006.

“I cheered for Sarah when she won her Olympic medal but I’m never prouder than when I hear her speaking about something so important,” said Katherine.

Hosted by TV presenter Jackie Bird, guests at the lunch included Scottish Huntington’s Association Trustees Professor Lorna Milne, Dr Marie Short MBE, Margaret Moncrieff and

Gillian McNab; Highland Clinical Lead Professor Zosia Miedzybrodzka; and family members Sharon Marshall and Aiva Martin.

The Women of Scotland Lunch was founded in 1958 to celebrate women who have made a difference in their community in Scotland.

“Our 66th lunch was a huge success, raising vital funds for Scottish Huntington’s Association and raising awareness of this devastating illness. The 365 women who attended were inspired by the incredible speakers and enjoyed networking with friends old and new, whilst donating generously for this worthwhile cause,” said Chair Barbara Allison.

With donations still coming in, the final total raised will be announced on our social media channels soon. In the meantime, we thank the Women of Scotland Lunch committee for welcoming Scottish Huntington’s Association as its 2025 charity of choice and to guests for such incredible generosity.

CEO of Scottish Huntington’s Association, Alistair Haw, said: “The Women of Scotland Lunch was an incredibly meaningful event for our community and those who attended, and we thank its committee for choosing to support our work.

“It is important to raise awareness about Huntington’s disease, a hugely complex, widely misunderstood and extremely difficult to manage condition, so there is more understanding about why the specialist services we provide are not some ‘nice to have’ option. They are an absolute necessity for families throughout Scotland.

“We’re also hugely grateful to Sarah and Katherine – it’s difficult to think of a more powerful double act advocating for the Huntington’s community.”



New university study strengthens calls for expanded specialist Huntington’s services

Scottish Huntington’s Association has joined Scotland’s longest serving HD Clinical Lead in renewing the call for expanding specialist Huntington’s services, following news that Scotland has some of the highest rates of the disease in the world.

The number of people who have the faulty gene that causes Huntington’s disease in the north of the country has been more accurately counted by researchers from the University of Aberdeen.

Analysis of NHS family-based records indicated that there are more than 160 adults living in the north of Scotland who have the faulty gene but have not been tested. However, researchers behind the project believe the figure will be even higher as not all people with Huntington’s disease symptoms seek diagnosis.

Scottish Huntington’s Association is clear that this is not a call for more people to seek a predictive test to establish if they have the faulty gene that causes Huntington’s disease. This is a complex personal decision which requires significant counselling and consideration.

The study, published in Neuroepidemiology, confirmed that Northern Scotland has one of the highest rates of Huntington’s disease in the world at 14.5 per 100,000 people, more than five times the estimated worldwide rate of 2.71 per 100,000 people.

Chief Executive Officer of Scottish Huntington’s Association, Alistair Haw, said: “Specialist services are not some nice to have optional extra but an absolute necessity to prevent patients reaching crisis point and presenting to acute emergency statutory services. Specialist Huntington’s services need to be expanded urgently – a message further reinforced by this new and clear evidence which has major implications for health and social care providers throughout Scotland and beyond.

“Despite this we see evidence of a small minority of Health and Social Care Partnerships hatching plans to pull the plug on specialist support. With a study in the Journal of Huntington’s Disease showing that Huntington’s Disease Specialists reduce hospital admissions by over 50%, it’s difficult to think of a more glaring false economy. The evidence could not be clearer that specialist support needs to be expanded, not abolished. Along with our cross party political supporters we will continue to fight tirelessly to ensure that everyone impacted by Huntington’s disease has access to the specialist care and support they need, when they need it.”

The new analysis showed that, on average, every person who has been diagnosed with Huntington’s disease will have at least another 2.2 relatives who have the faulty gene.

The research was led by University of Aberdeen’s Professor Zosia Miedzybrodzka who is also Clinical Lead for Huntington’s Disease in North of Scotland (covering Grampian, Highland, Orkney, Shetland, and the Western Isles), based in NHS Grampian, alongside Heather Cruickshank, Genetic Counsellor in NHS Grampian.

Professor Miedzybrodzka said: “Previous work looked at how many people in the area have been tested for Huntington’s disease, that is people diagnosed with Huntington’s disease signs and those with a gene alteration that will develop the condition in later life. However, no one has properly counted just how many people who haven’t been tested yet must have the gene.

“It is crucial that we know this number so that health boards can properly plan now for care, and for treatments when they become available in the future.”



Sylvia and her husband David

Community speaks out in UK media to increase awareness

News of this important research hit the headlines across the UK and beyond including BBC, STV and GB News online, The Times, The Independent, The Herald, The Scotsman, Daily Record, The National and The Press and Journal, with Scottish Huntington’s Association Chief Executive Alistair Haw driving home the need for improved care and support for families.

It also ran on BBC Reporting Scotland, the STV national and regional news, and BBC Radio Scotland. In total, more than 200 titles featured the story, with many also incorporating interviews from family members including with Moray Branch member Brian Watt and long-time Huntington’s advocate Sandy Patience from Inverness. David Johnston, from Shetland, also spoke to BBC Radio Shetland about his wife’s Sylvia’s severe symptoms and the impact of the disease on their family.

“Huntington’s is devastating, it really is. It has been hard on Sylvia, especially when she had mood swings and a lot of other different things involved with this illness. It’s a gradual descent that has played a terrible part in our lives,” said David.

“Sylvia has a little bit of speech left and she still has a tremendous spirit but we worry for our children and our grandchildren. This research tells us there’s going to a lot more people diagnosed with Huntington’s disease so the authorities need to provide more help.”

We are hugely grateful to Professor Miedzybrodzka and her team, and to Brian, Sandy, David and others for speaking out to help the wider public understand Huntington’s disease and what families need from our medical, health and social care providers.



Friends, family and a star guest rally for family with unexpected diagnosis

When the Martin family decides to support Scottish Huntington’s Association, they really go for it!

Their first gala ball at the Georgian Hotel in Coatbridge, Lanarkshire, brought over 130 family, friends, and friends-of-friends together – including TV comic Susie McCabe – to raise funds and spread awareness about Huntington’s disease.

Dad Philip and daughter Aiva worked tirelessly for months to organise the event as a thank you to Scottish Huntington’s Association.

And what a magical evening it was, filled with emotion, hope, laughter, dancing, games, prizes and a live auction. So far it has raised an incredible £18,000.

“We’ll never forget that night; the love and support in the room was overwhelming. I thought we were pushing it by aiming for £10,000 but people were very generous when they heard about Huntington’s disease and its impact on families, including our own.”

It was a special moment the family needed after two difficult years coming to terms with mum Joanne’s unexpected diagnosis.

They had no idea there was any family history of the disease – and it was only a chance remark by a friend that led them to discuss the possibility with their GP.

Joanne said: “I thought I was quietly going insane. I knew something wasn’t right and kept going to the doctor but it was always put down to depression and anxiety.”

Philip added: “For a long time Joanne wasn’t well but we just couldn’t get an

answer, It was draining and Joanne gave up work to try to get a bit of peace of mind but things didn’t get any better.”

When it was confirmed that Joanne has Huntington’s disease, the couple was confronted with the reality that daughter Aiva and her two younger sisters are also at risk of the disease.

“The hardest thing was talking to them about it but then a weight lifted and we began to think about how we could raise funds and spread awareness,” said Philip.

Joanne added: “We have to be strong and I have good days and bad days, like everyone else. I need to be positive because of our girls.”

Philip and Joanne are supported by an HD Specialist from Scottish Huntington’s Association while Aiva and their other two daughters Beth and Faye meet regularly with a Specialist Youth Advisor.

Aiva said: “My friends have known from the beginning and been very supportive. They ran the 5k Supernova at the Kelpies with me and two aunts to raise money, helped at the gala ball, and one of them, Jasmin, even did the Kiltwalk for Scottish Huntington’s Association.”

After dipping their toes into fundraising, the family began to aim for something bigger – and the Martin family annual gala ball was born.

All the tickets were snapped up within two days – “We could have sold twice as many,” says Philip – and Aiva hit social media to find sponsors and donations for raffle prizes and auction lots, which including signed football strips and an Aviemore short break.

And TV comic Susie McCabe, an old school friend of the couple, flew back from London where she was recording a podcast with Allan Carr to show her support family and entertain guests.



With friend and TV comic Susie McCabe

“It was overwhelming; we’re just finding out about the disease and it’s all new but people have been interested and keen to help,” said Philip.

“I’d say 75% of guests at the ball had never heard of Huntington’s which was the whole point of the night. To raise awareness, get people talking about the disease, and bring them into the community as supportive and informed friends.

“I’m always thinking about ways to get the word out there; I wear my Scottish Huntington’s Association lanyard and pin badge at work and speak to everyone I can about the disease.

“The support we’ve had from Scottish Huntington’s Association lifts us up and the advice and guidance has been brilliant.

“Families rely on that specialist care so we have to make sure it’s there for everyone who needs it.”

Founded by families, for families across Scotland



Scottish Huntington's Association has Branches in Tayside, Fife and Moray, run by volunteer members who have personal experience of Huntington's disease.

Branches had an instrumental role in establishing Scottish Huntington's Association and fighting to secure services for families throughout the country. Each continues to play an important role in providing help and support at a local level, including offering a significant source of interaction for people with Huntington's disease, their families, carers, and friends. They are an integral part of, and form a vital link with, the national organisation.

In this edition we meet Tayside Branch secretary Ian Balfour. A member for over 30 years, Ian shares - in his own words - his experiences of Huntington's disease and the journey, influence and continuing impact of the Branch.

"Dad was ill for most, if not all, of my childhood"

"When I was born in 1968 my mum was 42 and my dad was turning 55. My brother was nearly 14 and my sister was 11. I like to think I was a pleasant surprise!

"Because he was around the same age as my friends' grandparents, I didn't think it strange that my dad spent a lot of time in bed. He was diagnosed in the mid-1970s but little was known about Huntington's then, other than it was hereditary and had no cure.

"I was in my early teens when I first heard the term Huntington's Chorea. There was no support and no internet so I searched articles at the local libraries. Back then even some GPs had little experience of Huntington's and there was a lot of misinformation, including that it could only be passed down the male side of families.

"Dad passed away peacefully at home in 1985, having been cared for by my mum with no outside support. Around then

we learned about the Association to Combat Huntington's Chorea, a UK-wide charity, and we donated Dad's funeral collection. A few years later I did a sponsored half-marathon and started to have regular contact with them.

"I was hugely impacted by a TV medical series"

"I remember an episode of Where There's Life, presented by Dr Miriam Stoppard in the 80s. It featured US scientist Dr Nancy Wexler studying a remote community in Venezuela with a high incidence of Huntington's, and she was confident that finding the cause could lead to a cure.

"I can't explain how significant and emotional this was for me. The families' living conditions were poor and there were so many people with the chorea movements, mannerisms and facial expressions that I had only seen with my dad."



Dr Nancy Wexler

"It all began with Branches."

"Scottish Huntington's Association was founded in 1989 and Branch campaigning enabled the charity to grow and employ specialist staff. Branches were the local support for families, providing help, advice and friendship. In 1990 there were meetings in Aberdeen, Edinburgh, Strathclyde, Fraserburgh and Ayr."

"So how did I become involved?"

"In the early 90s I went to a Family Conference in Dundee with Bill Husband, my sister's father-in-law. We didn't know anyone and sat next to a lady who introduced herself as Sheila Simpson. Little did we know that day the role Dr Simpson was to play in our family's life, and how grateful we would be.

"Then, along with my brother-in-law David, we joined the Branch. Bill was a great asset – a retired TSB bank manager, he became Branch treasurer, and for a while was also honorary treasurer for the Association. His contribution was invaluable.

"We focused on support, fundraising and reducing the isolation felt by families. We also invited speakers including welfare benefit advisors, speech and language therapists, and occupational therapists, and campaigned to persuade local health authorities that families needed specialist support.

"In the early 2000s our Tayside HD Specialist, Paula McFayden, was appointed. We've been so fortunate in the calibre of people who have become involved and the long service of staff, including Paula, shows just how dedicated they are.

"Back then Branches also organised local Family Conferences and members sat on Association committees. I was on the Executive Committee and later, as Chair of the Tayside Branch, the Scottish Huntington's Association Council.

"Working – and cycling – together!"



Ian on ferry to Millport

"Our original Branch covered a large area then Chair Brian McKechnie moved on to form the Fife Branch, which still runs today. We all worked together, including the annual fundraising trip to Millport. Glasgow and Ayr hosted while Tayside and Fife hired a bus to take families to Great Cumbrae for a sponsored cycle.

"The coach left Forfar at 7.15am, picking up in Dundee and Fife. Always a stop at the chippy in Millport before the ferry back to Largs and the long bus journey home. We took part in many activities but it was when Mary Cunningham and her volunteers got involved that the serious fundraising took off.

"A couple of personal highlights"

"I attended the European Huntington's Conference in Norway in 1996 and two years later it was the turn of Scottish Huntington's Association to host the event. It was held at Stirling's Management Centre in 1998, with the spectacular Wallace Monument as a backdrop.

"Another favourite memory is of our West Highland Way walk. I can't confirm or deny whether alcohol at our 1996 dinner dance was involved, but before the night was out I had my first volunteers. A few work colleagues and police officers joined us and TV detective Blythe Duff of Taggart fame came along to 'arrest' Huntington's disease.



Telly 'tec Blythe Duff and the fundraising squad

"It cost just £90 for seven nights' accommodation and we 'rehydrated' in the pubs each night. But everyone was always ready the following morning, and together we raised £10,000.

"Looking to the future"

"The charity's growth has been amazing; families now have local HD Specialists in most of Scotland and we have the world's first National Care Framework for Huntington's Disease.

"While only three Branches remain, it's important to recognise what they provide as part of the wider Association. We're looking for new members and ideas about what we can do differently to attract support, ensure we provide what families need, and be fit for the future."

Learn more about our Branches at hdsotland.org

SUPPORTED BY
BBC
CHILDREN IN NEED

£100k award for Youth Service work in Highland

Fantastic news! We have been awarded £100,000 over three years from BBC Children in Need to reach young people aged 18 and under in Highland.

This vital funding will help our Specialist Youth Advisors to deliver:

- One-to-one meetings
- Group and peer support sessions
- Residential breaks such as Summer Camps
- Resources, such as digital and print

Scottish Huntington's Association is the only charity in the country dedicated exclusively to the Huntington's community, including young people growing up in families impacted by the disease.

This grant will help to make a real difference in their lives, while it also recognises the impact of our work with individuals and families across Scotland.

Representing our community at UK and Ireland event

Chief Executive Alistair Haw, Cat Martin (Services Support), Senior HD Specialist Nicola Johns and Youth Service Lead Grant Walker attended the UK & Ireland HD Network Meeting in Birmingham.

The two-day conference at the city's Queen Elizabeth Hospital brought together Huntington's organisations including Scottish Huntington's Association and the Huntington's Disease Association (England and Wales), scientists, clinicians and pharmaceutical companies.

The event offered excellent networking opportunities and the chance to highlight progress achieved by Scottish Huntington's Association.



Abseil-utely fabulous!

What a fantastic day! #TeamSHA turned out in force for this year's abseil off the Falkirk Wheel, with people travelling from as far as Aberdeen to be part of the fun.

We were delighted to welcome staff teams from Carrickstone Care Home and from Avondale Care Scotland who were taking part for the first time, along with supporters and family members who access our services.

Together they smashed our fundraising target, reaching a grand total of £7886.

Feedback has been overwhelmingly positive, with people asking to return next year or expressing interest in our other fundraising challenges (See our events calendar on P12).



Credits: Photo of Woody Guthrie by Lester Balog; Photo of Woody Guthrie by Robin Carson; Photo of Anna Canoni by Scott Canoni

Venue: Online
Date: 19 June 2025
Time: 7pm - 8:30pm
All welcome

When Bob Dylan Met Woody Guthrie – a very special evening for our families and beyond

Scottish Huntington's Association is co-hosting a unique webinar presented by Woody's granddaughter Anna Canoni, President of Woody Guthrie Publications.

As part of the ongoing Huntington's Disease Family Voices series, Anna will delve into the personal and professional relationship between Woody Guthrie and Bob Dylan, exploring the deeper creative impact Woody had on Bob Dylan's writing in his early days.



She will also share personal insights into the Guthrie's family story and Woody's illness with Huntington's disease, which he was symptomatic with when first meeting Bob.

When speaking about Woody's songwriting, Bob Dylan said: "You could listen to his songs and actually learn how to live. The songs themselves had the infinite sweep of humanity in them." What did Dylan mean by that? Through the sharing of the

Guthrie's personal family collection, photographs, home tapes, archival images, and rare releases you'll find some answers!

This inspiring and uplifting presentation is open to everyone and will be of particular interest to those whose lives have been impacted by Huntington's disease, fans of Woody Guthrie and Bob Dylan, folk and other music lovers.



The webinar will last approximately 90 minutes and places can be booked now via the Huntington's Disease Association website Events page.

Huntington's Disease Family Voices is brought to you by the UK and Ireland Huntington's Disease Alliance – Scottish Huntington's Association, Huntington's Disease Association, Huntington's Disease Association Ireland and Huntington's Disease Association Northern Ireland.

Your National Care Framework

The National Care Framework for Huntington's Disease and its localised versions are vital tools for individuals, families and professionals involved in the care and support of people impacted by Huntington's disease.

Developed by Scottish Huntington's Association and funded by the Scottish Government, it was created in partnership with the Huntington's community and medical, health and social care practitioners. Visit our website to find out more.

Building knowledge and skills

Applications are now open for this year's intake to the *Huntington's disease: an enabling approach to supporting families* module delivered in partnership with the University of Stirling.

The 12-week online course offers the opportunity learn about Huntington's disease and its impact on the people and families who live with it, while enhancing the skills, knowledge and capacity needed to provide support. Search 'Huntington's disease Stirling University' to find out more.

Short Breaks
Fund distributes
£8k to Families

A total of £7800 has been allocated in the 2025/26 round of funding for short breaks to be taken before 31 March 2026.

The Short Breaks Fund remains open for applications throughout the year, which will be considered by the committee in February 2026. Visit the Short Breaks Fund page on our website for more information.

Trustee joins
call for more
neuro research

Trustee Dr Marie Short MBE worked with us to create a powerful short video highlighting the importance of research into neurological conditions.

It was shared on our social media channels as part of the Neurological Alliance of Scotland campaign during this year’s Brain Awareness Week from 10 – 16 March.

HDYO welcomes
Scottish delegates
to 2025 congress

It was great to have so many family members from Scotland taking part in the HDYO Congress in Prague.

More than 350 young people, researchers and practitioners from around the world travelled to the event.

Scottish Huntington’s Association was represented by Youth Service Lead Grant Walker and a number of Scottish Huntington’s Association Youth Ambassadors attended, along with other family members.



Baked with love by Connie

A huge thank you to Connie Daly, who turned her love of cake making into an amazing event in aid of Scottish Huntington’s Association.

A keen amateur baker, Connie raised more than £1300 by teaming up with Pillow Partners, encouraged by her husband Holden who works there.

The one-day bake sale at the property company’s Glasgow HQ was a huge success and Connie is delighted that she was able to turn her talents to supporting other Huntington’s families.

“I wanted to raise awareness and funds for the charity because Huntington’s disease has been in my life for as long as I can remember,” she said.

“We can trace it back to my great grandmother. I never knew my gran but I remember Uncle Gary developing symptoms, including the jerky movements that he couldn’t control.

“As a child I didn’t understand what was happening to Uncle Gary but I was used to being around people with symptoms so it never scared me. Looking back, I realise now that I was shielded from the worst by my mum and dad. But I was still heartbroken when I lost my favourite cousin Laura; she was so full of fun and had a great spirit. I still miss her now.

“Dad has tested negative for the faulty Huntington’s gene, which means we don’t need to worry about either of us developing the disease. But we still live with the loss of too many loved ones. In that respect, Huntington’s will always be with us.”

Bake sale customers included Scottish Huntington’s Association Chief Executive Alistair Haw and Head of Income Generation Andrea McIntyre.



“We are truly grateful to Connie and Pillow Partners for their support in this way. Our charity is reliant on the generosity of individuals, groups, and businesses to help make a positive impact in the lives of those impacted by Huntington’s disease. Connie’s contributions highlight the strength of community and the difference one person can make when they blend their talents with a desire to help others,” said Andrea.



We’re growing our membership to
deliver best outcomes for families

Did you know you can become a member of Scottish Huntington’s Association and have your say in key decisions for the charity?

Our membership is made up of people who have accessed, or continue to access, Scottish Huntington’s Association services; those who have joined in a professional capacity; and people who have chosen to support our charity, for example through partnership working or fundraising.

This community of likeminded individuals is helping to engage with, and further, our mission on behalf of all Huntington’s families, while also supporting vital work to ensure the sustainability and good governance of the charity.

You will have voting rights at the charity’s AGM and help to uphold its transparency and effective governance. Further benefits include eligibility to become an office bearer with

a local branch; regular news updates; and opportunities to deepen your involvement in our work through volunteer fundraising and advocacy.

Membership of Scottish Huntington’s Association is free.* Once registered, your membership will continue until you notify us that you wish to cancel. To keep our records up to date, we may also contact you from time to time to ascertain whether you wish to remain a member.

To find out more about membership categories and how to join, visit the Branch, Support Group and Membership page on our website at hdscotland.org or call 0141 848 0308.

*Please note that because Scottish Huntington’s Association is a company limited by guarantee, in the very unlikely event that it should ever be wound up members would be legally liable to contribute no more than £1 each towards the costs of winding up.

The Dance
100 roadshow
is heading
back to
Inverness on
Saturday 13
September –
and we want
you to join us!



Last year’s event in the city’s Falcon Square was a huge success, raising over £16,000 and inspiring hundreds of members of the public with a positive message of hope and friendship from the Huntington’s community.

So if you fancy a fun day out dancing to 100 songs over five hours, meeting up with friends old and new, led by a top DJ and special guest dancers, don’t miss out on our early bird offer. Just scan the QR code above.

All abilities and ages are welcome – it’s going to be a wonderful day out for all the family!

Your communication preferences: You can update your communication preferences at any time, just let our team know on 0141 848 0308 or at data@hdscotland.org. We will not pass on your details to any other organisations. Your data will be treated in accordance with our Privacy Policy which you can view at hdscotland.org

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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](tel:01418480308) or email events@hdscotland.org



2025 EVENTS CALENDAR

June

Aberdeen Kiltwalk 1 June 2025
Tough Mudder (Drumlanrig) 7 June 2025
Men's 10K (Glasgow) 15 June 2025
Women's 10K (Glasgow) 15 June 2025

August

Dundee Kiltwalk 17 August 2025
Scottish Half Marathon (Edinburgh) 17 August 2025
Scottish 10K (Edinburgh) 17 August 2025
Zipslide Across the Clyde (Glasgow) 29 August 2025

September

Dance 100 (Inverness) 13 September 2025
Kiltwalk (Edinburgh) 14 September 2025
Men's 10K (Edinburgh) 21 September 2025
Women's 10K (Edinburgh) 21 September 2025
Firewalk (Helensburgh) 27 September 2025
Loch Ness Festival of Running Events 28 September 2025

October

Firewalk (Carnoustie) 4 October 2025
Great Scottish Run 10K & Half (Glasgow) 5 October 2025
Three Peaks Challenge (Ben Nevis/Scotland; Scafell Pike/England; and Snowdon/Wales) Various dates

November

SuperNova 5K (Forth Road Bridge) 1 November 2025

If you can't find an event that appeals to you, why not organise your own and invite friends, family and colleagues to join the fun!



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