

SHAre



Scottish
Huntington's
Association

Specialist support for Huntington's disease families

Winter 2024

The magazine of
Scottish Huntington's Association
Issue No.104



A year of progress, partnership and special events

Welcome from our Chief Executive



Charity related news of late has made increasing reference to a “perfect storm” of recruitment challenges, rising costs and funding cuts. And that was before the UK Government budget, which landed charities with inflation-busting Living Wage increases and eye-watering National Insurance hikes which are pushing the charity sector to breaking point. Some charities have closed their doors, with more expected to follow. Yet, despite it all, I remain optimistic for Scottish Huntington’s Association.

For 35 years we have supported families – and they have supported us, whether that’s by organising fundraising events, getting involved in our activities or sharing their experiences to raise awareness. Right now we need your involvement more than ever. So please think about what you can do to help safeguard our services for everyone.

Maybe you have wealthy, famous or influential contacts who might want to support our cause? Or what about asking your employer or a local business to become a corporate partner? Could you take on one of our fundraising challenges or host an event, for example a bake sale or race night? Are you able to lobby for more services or shield us from the cuts coming down the road? How about sharing your expertise as a Trustee where we have gaps on the Board or joining the Association to help grow our membership and supporter base?

We know there are so many in our community already doing these things and so much more. Such work has taken us to where we are today and delivered so many of the incredible achievements you will read about within this latest issue of SHAre. Together we can and will weather this storm, but only with your help. And maybe you will become the star of a future SHAre magazine!

Alistair Haw, Chief Executive

Celebrating longest serving staff



Three members of staff were surprised with a special presentation from our Patron Sarah Winckless MBE during the Family Gathering in recognition of their long service to Scottish Huntington’s Association and the families we support.

From left, Jillian Foster, National Senior HD Specialist, has worked with Scottish Huntington’s

Association for 24 years; Fife Senior HD Specialist Nicola Johns has been with us for 20 years; and Paula McFadyen, Senior HD Specialist for Tayside has 21 years service.

We thank Paula, Nicola and Jillian for their commitment to the Huntington’s community and for the incredible value their insight, experience and knowledge brings to the organisation.

Chief Executive Alistair Haw said: “This is an incredible achievement from three incredible colleagues who have shown so much dedication to our community over many years.

“It was a real honour to have been there at our 35th anniversary Family Gathering to see Paula, Nicola and Jillian receive these greatly deserved accolades from our world champion Patron. We cannot thank them enough for all they have done and achieved

Raising profile in Lanarkshire

We attended a networking event organised by North Lanarkshire Health and Social Care to raise the profile of Scottish Huntington’s Association and explore potential partnership opportunities. Over 30 organisations and services took part to share what they do, the services offered, referral pathways, and partnership options. It was also attended by Health and Social care staff from across North Lanarkshire.

Board seeks to appoint new Trustees

Our Trustees contribute a wealth of knowledge and skills to the organisation, including expertise in finance, education, healthcare, research, governance, business, operations and strategy.

They ensure that the charity’s mission, vision and values - the principles upon which families founded the charity – underpin all our work and meet the standards expected by donors, volunteers, partner organisations and the community we serve.

We are currently recruiting for new Trustees to share their expertise for the benefit of the Huntington’s community, with a particular focus on professionals from a HR or communications/marketing backgrounds.

Full training will be provided. If you, or someone you know, is interested in getting involved, please get in touch for an informal chat at sha-admin@hdscotland.org

Saying hello in Highland

Senior HD Specialist Lorraine Watson held an awareness raising event at the Eastgate Centre, Inverness. She was joined by Cat Martin, Services Support, and members of a local dance school who performed for an hour and encouraged people to get involved.



First Minister responds to call for wider HD services

First Minister John Swinney MSP has invited Scottish Huntington’s Association to meet with the Health Minister following a call for the government to fulfil parliament’s commitment to increase specialist Huntington’s disease services.

We’re grateful to Fulton MacGregor MSP for raising the matter during First Minister’s Questions.

The invitation follows a motion tabled by Jackie Baillie MSP, calling for increased specialist services which secured cross party support and became the most supported in the history of the Scottish Parliament.

Health Minister Jenni Minto signed the motion before she was appointed to the Scottish Government as Minister for Public Health and Women’s Health.

We look forward to this meeting and hope it leads to meaningful progress. Watch the clip on our Facebook page at <https://bit.ly/FMQSHA>

Staying in touch

Don’t miss an exciting event, latest research or breaking news from Scottish Huntington’s Association ever again.

It’s easy to stay connected – simply scan the QR code and tell us how you would like to hear from us.



Zoë leaps at chance to tackle triple challenge

For Zoë, supporting Scottish Huntington’s Association is more than just a good cause - it’s a way to give back to the charity that has been there for her for over 15 years, since her late father George was diagnosed with Huntington’s disease.

Driven by her family’s experiences, she already volunteers as a Scottish Huntington’s Association Youth Ambassador and supports the charity by raising funds and awareness whenever she can.

“The one-to-one support I have had over the years from the Youth Service has been priceless and I think it’s really beneficial for young people to see and hear from someone who’s been through it,” said Zoë.

In 2024 the talented artist decided to set her sights higher than ever – quite literally – by taking part in our thrilling Tri-Challenge, three adrenaline packed activities, a zipline across the Clyde, a skydive from 10,000ft, and an abseil off the Falkirk Wheel.

Zoë’s adventurous spirit shines out in everything she does. “Years ago, I did the charity’s Shark Dive at Deep Sea World and since then I’ve wanted to do more,” she said. “I saw a post on Facebook for the Tri-Challenge and immediately thought ‘that’s the one for me!’”

Having already completed the zipline and skydive, Zoë is now preparing for the abseil in March 2025.

However, Zoë’s passion for supporting the charity doesn’t end with the Tri-Challenge. Always on the lookout for new ways to get involved, she’s now considering taking on the SHA Firewalk too!

“I think me and my sister will do that. It’s now a quad-challenge!” she said. Beyond these daring physical challenges, Zoë is also planning to end her fundraising year with a creative twist. As an artist, she is considering organising a silent auction of her artwork next year, with all proceeds going to the charity.

If you’ve been inspired by Zoë’s journey there are plenty of ways to get involved. Whether it’s joining the Tri-Challenge, braving the Firewalk, or hosting a fundraiser of your own, every donation makes a difference. Visit [hdscotland.org/events](https://www.justgiving.com/page/zoe-green-shafundraising). You can also donate in support of Zoë’s Tri-challenge at https://www.justgiving.com/page/zoe-green-shafundraising



A milestone year of progress for families

From using jelly babies to explain genetics to young people, to providing Huntington's disease training sessions to 650 medical, health and social care practitioners, 2024 has been a year focused on advancing care and support today while strengthening and safeguarding services for tomorrow.

We marked the 35th anniversary of Scottish Huntington's Association by delivering on the five key aims of **Standing Tall: A Strategy for Growth 2023 – 2028**.

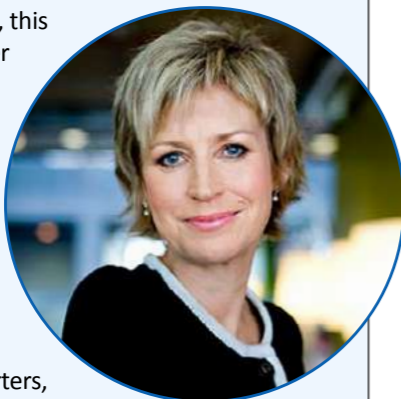
We will increase awareness of Scottish Huntington's Association

We created our most successful social media campaign for Huntington's Disease Awareness Month. The *Who Do You Think We Are?* films have reached over 60,000 people so far. In June, our expertise was recognised with a top award at the National Youth Work Awards.



Weeks later

it was highlighted again, this time by BBC broadcaster Sally Magnusson who commended volunteer fundraiser Lauren Boag at the Scottish Charity Awards.



In September, Dance 100 rolled into Inverness for the first time, inspiring families, businesses, new supporters, and the city (full story and pics on P8).

We took the case for wider Huntington's disease training to the EHDN/Enroll-HD Congress in Strasbourg, where we also highlighted the impact of our National HD Specialist Service. In November, at First Minister's Questions in the Scottish Parliament, First Minister John Swinney

MSP confirmed a meeting will take place between Health Minister Jenni Minto and Scottish Huntington's Association. It followed calls from Fulton MacGregor MSP for the government to meet its commitment to increase specialist services for families impacted by Huntington's disease.



We will raise awareness about Huntington's disease

Media coverage included a radio interview about Dance 100, publication of letters in The Scotsman and The Herald, and features in national and regional news titles.



In Tayside, Fife and Moray, Family Branch members played a key role in building wider understanding in their communities while providing local support and raising funds.

Families in Greater Glasgow and Clyde, Fife, Lothian and Dundee took part in a new photography and video project while sharing their experiences.

650 medical, health and social care practitioners accessed Scottish Huntington's Association training through an expanded programme including one hour taster options, full day multi-disciplinary events, and individualised sessions tailored to client needs.

In November, the Family Gathering 2024 secured the highest number of registrations to date and a score of 9.5/10 by attendees. Full story and pics on P6/7



We will grow our charity to meet the needs of the future

We increased capacity in the Finance Department and invested in IT, HR and employment law services.

Employee development included management training for all team leads and online learning modules for every member of staff.

Dr Tim Soane, HD Clinical Lead for Forth Valley, joined the Board of Trustees.

The Income Generation team unveiled new fundraising opportunities and ways to get involved, including the £50 Workplace Challenge and the Firewalk 2025.

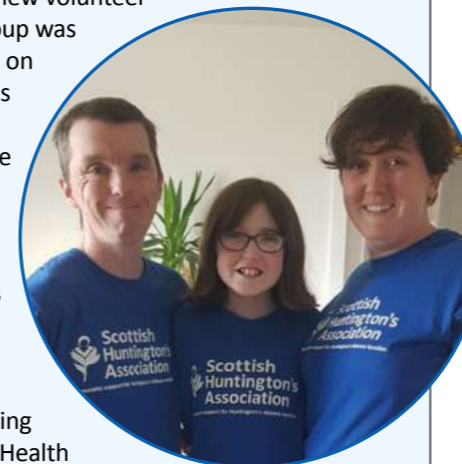


All while inspiring hundreds of volunteers across the country to skydive, dance, run, abseil, walk, bake, organise events and share their talents in support of the Huntington's disease families.



In Highland, a new volunteer fundraising group was formed to lead on local campaigns and activities, including Dance 100.

We engaged with key commissioners throughout Scotland and lobbied for increased funding from the NHS, Health and Social Care Partnerships, and local authorities.



We will expand access to specialist care and support

Following the success of the pilot scheme, the Senior National HD Specialist post became permanent.

This was soon followed by the appointment of a second National HD Specialist to expand the service.

More families than ever are now able to access support groups, active in Greater Glasgow & Clyde, Lothian, Fife, Highland, Grampian and Tayside.

We developed new community partnerships, including with St Columba's Palliative Care, Equal Say, Turning Point, Carers' Trust and young carers' groups.

In October, the rollout of the restructured Financial Wellbeing Service began.

We will ensure strong participation in global research activities

We developed our Board of Trustees' Research Sub-Group and created a dedicated research webpage: <https://hdscotland.org/research/>

The innovative Impact and Engagement Fund was launched at a national conference, followed by the award of its first grant.

Meanwhile the Staff Research Sub-Group led the way to increase the number of Scottish Huntington's Association representatives on European Huntington's Disease Network Research Working Groups.

All the while we were working with Enroll-HD to roll out its new programme across Scotland.

And building new relationships and partnerships with pharmaceutical companies working on treatments, therapies and clinical trial protocols.



"I look back with pride at all Scottish Huntington's Association has achieved this year," said Aarran Air, Chair of the Board of Trustees.

"This is thanks to our community, our trustees, our staff, our funders, and our supporters for advancing our vital work despite the many challenges that have been visited upon the sector. We look forward to the coming year and beyond as together we strive to deliver the best possible care and support for everyone impacted by Huntington's disease in Scotland."



Families come together to learn, support and get involved



Sparking conversations amongst families

We are grateful for the support of our Family Gathering sponsors, below



"Let's make some noise was really good fun!"
"Genetic Testing - Our Journey was extremely moving and a fantastic example of the work the youth group do."
"Updates on research were very important and incredibly helpful. Overall an amazing and insightful day!"
"First time here – will be back next year. Fantastic and very enlightening. So nice to converse with likeminded people."

Our Family Gathering 2024 will go down as day to remember!

We marked the charity's 35th year with 160 family members, staff and trustees, most of whom stayed on to join us and their friends at an anniversary celebration dinner.



It also marked a shift towards an increasingly interactive event, with people answering questions from the stage in real time using a digital polling platform, drumming and singing together, and working as a group to map out the genetic testing journey.

Our Patron Sarah Winckless MBE was joined on stage by family members Tiffany Newport, Keri Finlay



and Kris King for a frank discussion about how Huntington's disease has impacted their lives and why it's so important to build the resilience needed to cope.



After lunch, which included plenty of time for people to catch up and have their own conversations, family members were free to attend their choice of four workshops – Let's Make Some Noise with Drum Fun, Caring for Carers, Research and My Genetic Testing Journey.

We were also delighted to hear from Professor Anne Rosser from the University of Cardiff. Professor Rosser was attending a Family Gathering for the first time and families welcomed her insights into the latest research and her optimism that there will be a breakthrough in the search for an effective treatment.

"We had a great response from family members at the Family Gathering, which was given an overall rating of 9.5/10 by those who attended," said Chief Executive Alistair Haw.

"It's a highlight of the Scottish Huntington's Association calendar and we work hard to make sure families have an



enjoyable, informative and meaningful experience. We thank those who took the time to share feedback comments which is being reviewed and considered as planning begins for next year's Family Gathering."



"Great to learn all the new research coming out about Huntington's disease. Listening to different families going through the same experiences."

"The sessions were great and very informative, especially for people new to the conference. Great to meet others and find out all stories and how similar they are although different."

"The drumming session was unbelievable!"

"I found today really informative and felt more positive about upcoming trials and medications."

"This is my first year and I am leaving feeling uplifted and hopeful. Thank you x"

"We had a great day at the Family Gathering – looking forward to the next one."

"Really informative day. I will be looking into joining Enroll HD in 2025."

"Research update from Prof. Anne Rosser was awesome - really made the trip worthwhile."

"A real tonic and bringing together of fellow Huntington's disease warriors."



Dance 100 – a wonderful day of friendship, fun and fundraising

Wow – what a day it was when families hit Inverness city centre to bring Dance 100 to the city for the first time.

The event inspired families, supporters, spectators and the city itself as we smashed the five-hour dance marathon to a 100-song live DJ set.

Amongst those taking part were people with Huntington's and those who are at risk of developing disease. There were also carers, family members of all ages, supporters, a Highland pipe band, local dance schools, and members of the public who joined in the fun.

By the end of song 100 more than £13,000 had been raised – with a further £3000 coming in over the following days, smashing the fundraising target and paving the way for a potential return to Inverness in 2025.

The Inverness event was organised and led by local families in our Highland Fundraising Group in partnership with Scottish Huntington's Association following

its success in Glasgow in 2022 and 2023.

Scottish Huntington's Association Chief Executive Officer Alistair Haw said: "Dance 100 is an amazing example of how the Huntington's community comes together in support of one another and to raise awareness about Huntington's disease."

"By dancing together in the city centre families have helped to smash through the stigma that has surrounded Huntington's disease for too long. Our families will be hidden no more and we as a charity are going nowhere until every Huntington's family in Scotland has the specialist support they need."

"We are hugely grateful to our families in the Highlands who worked so hard to bring Dance 100 to Inverness and to the businesses who supported the event. And we thank the people of Inverness who came along to watch or dance with us. We received many donations on the day and were genuinely overwhelmed by such generosity."



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

2025/26 Events Calendar

February

Angus Firewalk 22 February 2025

March

Helensburgh Firewalk 8 March 2025
 Supernova Kelpies 5K 14 March 2025
 Falkirk Wheel Abseil 16 March 2025

April

Glasgow Kiltwalk 26 & 27 April 2025
 London Marathon 27 April 2025

May

Edinburgh Marathon Festival 24 and 25 May 2025

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
 Skydive Challenge (Glenrothes) Date TBC

August

Dundee Kiltwalk 17 August 2025
 Scottish Half Marathon (Edinburgh) 17 August 2025
 Scottish 10K (Edinburgh) 17 August 2025

September

Dance 100 (Inverness) 13 September 2025
 Zipline Across the Clyde (Glasgow) Date TBC 2025
 Kiltwalk (Edinburgh) 14 September 2025
 Men's 10K (Edinburgh) 21 September 2025
 Women's 10K (Edinburgh) 21 September 2025
 Loch Ness Festival of Running Events 28 September 2025

October

Great Scottish Run 10K & Half Marathon (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

No matter how you choose to support Scottish Huntington's Association we are here to help and support you in any way we can.



Follow us on [f scottishhuntingtonsassociation](https://www.facebook.com/scottishhuntingtonsassociation) [i scottishhuntingtons](https://www.instagram.com/scottishhuntingtons) [\(formerly Twitter\)@scottishhd](https://twitter.com/scottishhd)



Pictured above, from left to right, are Jock Anderson (Moray Chair), Gavin Keith (Fife Chair), David Husband (Tayside Chair), Ian Balfour (Tayside Secretary), Carolyn Craig (Fife Treasurer), Allan Barker (Tayside member) and Andy Whyte (Fife Secretary).

Welcoming new office bearers

Fife Family Branch's new office bearers were given a warm welcome by members of the Moray and Tayside branches at this year's Family Gathering.

Chair Gavin Keith works with the Health and Wellbeing team at Fife Sports & Leisure Trust, teaching classes for people with long term health concerns including cardiac conditions, cancer and postural stability. Former mechanic and sales advisor Andy Whyte has been elected secretary. He has accepted this new role following his retirement while also caring full time for his wife Sally.

They are joined by former trustee Carolyn Craig as treasurer. A member of the Scottish Huntington's Association Board for 14 years, Carolyn was a teenager when her mum was diagnosed with Huntington's. Carolyn and her husband Neil were also guardians for her brother Hugh.

A huge thank you to former Fife office bearers, including outgoing co-chairs Claire McKechnie and her sister Heather McKechnie, for their hard work and dedication over many years to supporting families in Fife, the wider Huntington's community, and Scottish Huntington's Association.



Pop-up shop opens in time for Christmas

Fife families opened the Branch's regular pop up shop in Methil in the run up to Christmas, offering shoppers the chance to snap up some bargains while raising money to help support local families and the wider Huntington's community across Scotland. A huge thank you to all the volunteers, donors and shoppers for their support.



Michelle's legacy of kindness

Moray Family Branch accepted with thanks a cheque for £7250 from Wilma Wilson, on behalf of her late stepdaughter Michelle who passed away earlier this year.

Following the success of its coffee morning earlier this year, the Moray Family Branch's successful fundraising streak continued when member Val Watt received a cheque from Asda in Elgin, where she works. Val applied to the company for match funding and her employers boosted the total raised by a further £250.



Tayside branch celebrates big day with Dennis

Tayside Family Branch has been busy fundraising and bringing its local community together, including to mark milestone birthdays.

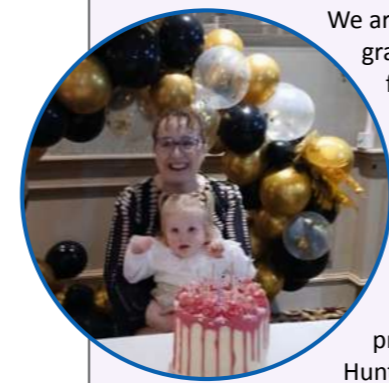
Members organised a meal in Forfar for families, including people who are new to group to help them to get to know everyone.

And there was also a very special dinner for Dennis Mcritchie who celebrated his 80th birthday. Congratulations to Dennis who hailed it as "his best birthday ever!", surrounded by friends from the Tayside.



Special gifts that help so many others

A huge thank you to all those who choose to ask for donations in lieu of gifts for special occasions, including Dave Smith, above, who celebrated his 70th birthday and raised nearly £500, and Karen Robertson, pictured below, who donated over £400 from her joint birthday/early retirement party.



We are also hugely grateful to volunteer fundraisers Mary Cunningham, Jessie Smith and their helpers in Tayside who dedicate so much time, creativity and effort to help provide support for Huntington's families.

WoSL inspired to support us at annual event

We are delighted to have been chosen as the charity for the Women of Scotland Lunch, an annual event that attracts around 350 guests to celebrate the great achievements of women in Scotland.

Held on 25 April 2025 at the Radisson Blu Hotel in Glasgow, this fun day out welcomes women of all ages to meet with friends old and new, be inspired by amazing speakers, and raise money for charity.

Our Patron Sarah Winckless MBE will be amongst the inspirational speakers at the event, and she will share her experiences of winning world championship and Olympic medals as part of the Team GB rowing team, her choice to speak publicly about facing the onset of Huntington's disease, why she feels so driven to advocate on behalf of our community, and the personal impact of becoming involved with Scottish Huntington's Association.

The Women of Scotland Lunch aims to raise at least £20,000 to help ensure families have access to the specialist services delivered by Scottish Huntington's Association.

Barbara Allison, this year's Chair of the Lunch, said: "We are delighted to be supporting the work of Scottish Huntington's Association. The committee was so impressed with the work the charity is doing to help those people affected by such a terrible condition and we were keen to help.

"It is hoped that what we raise will help more families benefit from more specialist services that they need and reduce unnecessary hospital admissions, support carers and alleviate wellbeing risks to children across Scotland."

As well as a two-course lunch there is a prestigious prize draw with exceptional prizes. Tickets are priced around £60, which includes lunch, a welcome drink and wine at the table. Attendees can buy individual seats or tables of 10 when places go on sale mid-February. To be included in the mailout please email: hello@wosl.co.uk

For more information contact us at sha-admin@hdsotland.org or visit www.wosl.co.uk.

We need your help!

Can you spare 10 minutes to share your feedback about our services? Your experiences are vital in helping us secure the funding we need to continue providing essential support for families impacted by Huntington's disease.

Scan the QR code and explain how our services make a difference to you or your loved ones. Your input will help us report back to our funders and raise money in an increasingly challenging funding environment. Plus, as a thank you, you'll be entered into a prize draw to win a £50 Amazon gift voucher!





**Scottish
Huntington's
Association**

Specialist support for Huntington's disease families



FIREWALK

Firewalk, Angus, 22 February 2025

Firewalk, Helensburgh, 8 March 2025

Reveal your superpowers and walk barefoot on fiery coals at a whopping 650°C!

WHAT'S INVOLVED?

To participate in the firewalk, no prior training is needed; just be over 18 and able to walk ten paces. You'll spend 90 minutes building mental strength before your firewalk challenge begins.

Angus Firewalk



WHAT WE ASK OF YOU

Secure your spot for £25 and commit to raising at least £125 in aid of Scottish Huntington's Association, the only charity in the country dedicated to providing expert and personalised support for those impacted by Huntington's disease.

Helensburgh Firewalk



Your communication preferences: You can update your communication preferences at any time, just let our team know on 0141 848 0308 or at sha-admin@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](https://www.hdscotland.org)

Registered with and regulated by the Office of the Scottish Charity Regulator No: SC010985. Scottish Huntington's Association is a wholly Scottish charity and is registered in Scotland as 121496. Registered Office: Business First, Burnbrae Road, Paisley PA1 2FB