

SHAre



Scottish
Huntington's
Association

Specialist support for Huntington's disease families

Summer 2024

The magazine of
Scottish Huntington's Association
Issue No.103



Read more about our national award inside

Welcome from our Chief Executive



I recently met with a group of charity CEOs. The conversation was not what you might call uplifting. The economic, funding and staffing backdrop being increasingly challenging were among the common themes. When the facilitator encouraged attendees to lighten up and focus on the positives the conversation dried up and soon reverted to the aforementioned.

I relay this not as an invitation for you to start playing your tiny violins at the thought of charity CEO angst, but as a backdrop for the good news to be found within this latest edition of SHAre. Yes the climate is tough - but our staff, trustees and supporters continue to excel regardless. We have no shortage of positive news to share.

This month's cover story is emblematic of that – our triumph at the National Youth Work Awards. As our Youth Service Lead Grant Walker rightly observed, this is not just an accolade for him and his team (although it certainly is this!), it is an achievement borne of collaborative working with our children and young people, trustees and staff across all departments. Or, as Grant puts it: "This National Youth Work Award is a great achievement by the whole organisation." And so it is. Please read on to learn of many more.

Thank you – all of you - for your ongoing support, determination, resilience and dedication that produce the positive news to be found within this latest edition of SHAre. We could not be more grateful for all you are doing.

Alistair Haw, Chief Executive



Screen stars show support for our work

It's great to have the support of TV and film actors, writers and producers who attended this year's Scottish Screenwriting Festival.



Speakers and attendees included Maureen Carr (*Still Game, River City, Wild Rose*) and, pictured above, Shauna McDonald, known for her work in *The Scotts, Filth* and *The Descent*.

Scottish Huntington's Association hosted an information stand at the event and TV and film industry delegates were keen to find out more about our work and the impact Huntington's disease has on families.

"Most were unaware of Huntington's disease before speaking to us and were shocked by the severe impact the condition has on people of all ages. Everyone we spoke to was happy to show their support and recognised the importance of specialist services," said Senior Fundraiser Gemma Powell.

Scottish Huntington's Association scoops national youth work award

Our work with children and young people has been recognised with a major national award.

The YouthLink Scotland National Youth Work Awards – the 'Oscars' of the youth work sector – were held in Glasgow on 12 June 2024.

Scottish Huntington's Association beat stiff competition from across the sector to scoop the Health and Wellbeing Award, with the trophy being presented to Youth Service Lead Grant Walker and Youth Ambassador Jordan Barclay.

This huge achievement for our frontline Youth Service team also recognises the input and support of colleagues from across the organisation in addition to our volunteer fundraisers, our inspirational Youth Ambassadors, and the children and young people we support.

Grant Walker, Youth Service Lead, said: "I am delighted for Scottish Huntington's Association, the Youth Service team and the young people we support. It's amazing to be recognised at such a competitive level and to have the opportunity to tell more people about the work that we do and why it's so important.

"I am very proud of the Youth Service and how it has developed over the years thanks to the expertise and commitment of the Specialist Youth Advisors. The National Youth Work Award is also testament to our young people and the vital role they play in driving and shaping a service that's right for them.

"Thank you to colleagues in every department across Scottish Huntington's Association for their guidance, support and, crucially, access to the funding we need to continue this



important work. This National Youth Work Award is a great achievement by the whole organisation."

See our centre spread for photos and story about this year's summer camp

Would your expertise help Huntington's families?

Further to the recent appointment to our Board of Dr Tim Soane, HD Clinical Lead (Forth Valley Health Board), we are continuing to recruit volunteer trustees to play a vital role in the running and development of the charity.

Our Trustees contribute a wealth of skills and experience to the organisation including expertise in finance, education, healthcare, research, governance, business, operations and strategy, and our constitution requires that the Chair and at least 50% of Trustees are appointed from families whose lives are impacted by Huntington's disease.

This governance structure ensures that our mission and values – the

principles upon which the charity was founded – underpin all our work and meet the standards expected by donors, volunteers, partner organisations and the community we serve.

We are especially interested in hearing from professionals from the following backgrounds

- Law
- Communications/Marketing
- Contracts/Procurement
- Human Resources
- Income Generation

If you or someone you know is interested in joining us, please get in touch by emailing sha-admin@hdscotland.org to find out more.

Giving support

Our Grampian HD Specialist Service has established two support groups in Aberdeenshire – one in Aberdeen and, for the first time, a group in Fraserburgh in response to feedback from families.

Stella Sihlabela, NHS HD Research Nurse, joined the first Fraserburgh meeting to talk about latest research and clinical trials. This was followed by volunteers from St Andrew's First Aid who presented on choking and falls.

In Aberdeen, HD Research Nurse Resifina Seyara shared her insights into research. This was followed by a presentation about developments at Scottish Huntington's Association including fundraising opportunities and Standing Tall: A Strategy For Growth 2023 - 28.

Thank you Dina!

Former trustee Dina de Sousa and husband Paul are continuing to champion our work after their move to Portugal last year.

Dina, who served on our board for five years until 2023, is well known to the Huntington's community through her activism with both Scottish Huntington's Association and the European Huntington Association.

Now a member of the Portuguese association - Associação Portuguesa dos Doentes de Huntington (APDH) – Dina and Paul took part in the country's national Huntington's Disease Day by speaking at an APDH event about the European Huntington Association and the services and support provided by Scottish Huntington Association.



Meet our new ambassadors

We're delighted to have welcomed two new voluntary Youth Ambassadors.



Natalie Hall (17), above, and Aleece Sinclair (17) below, will provide peer support, help at events, and raise awareness about Huntington's disease. This includes speaking to the media, giving presentations and featuring in our communications work.



"My family has been involved with Scottish Huntington's Association for a long time, including the Youth Service which has provided me and my siblings with support and days out. The charity has also supported my mum and my gran. I spoke at last year's Family Conference which has given me the confidence to become more involved," said Natalie.

"I have joined the Youth Ambassador Scheme as I've received incredible support for many years and I'm eager to give something back to the charity," added Aleece.

Find out more at hdscotland.org/youth-service/

Lauren continues to inspire others at 2024 Scottish Charity Awards



We are so proud of volunteer fundraiser Lauren Boag whose incredible support for Huntington's families was recognised at this year's Scottish Charity Awards.



Lauren was presented with a Highly Commended Award in the Volunteer of the Year category – one of only two special such awards announced by broadcaster Sally Magnusson MBE.

It's an amazing achievement – over 500 applicants were whittled down to just 39 finalists across all categories.

"I had a brilliant time – it has been such an amazing experience to be nominated and I am delighted to have been Highly Commended by the judging panel," said Lauren.

"Thank you to everyone who has supported me and who wished me luck."

Lauren, who is facing the onset of Huntington's disease, is an outstanding volunteer fundraiser - there's no stopping her when it comes to making sure Huntington's families have the specialist support they need.

In January 2023 she set out to raise £5000 in 12 months to bring her total so far to £38,500. Lauren is now heading for £45,000 by the end of 2024. The working mum of two raises awareness by speaking at events and in the media, inspiring people to get involved while creating valuable opportunities for Scottish Huntington's Association to develop new relationships and expand its supporter base.



In this year alone, Lauren has braved a nippy dip in freezing January temperatures, hosted a Taylor Swift tribute night and smashed the Kiltwalk in Aberdeen – all while organising her annual gala ball which will take place in November in her home village of Insh.

"I can't think of anyone more deserving to be recognised in this way – we are extremely grateful to Lauren for all she does for Huntington's families and for Scottish Huntington's Association," said Chief Executive Alistair Haw.



New funding will help researchers to engage and promote findings



Scottish Huntington's Association is now offering funding to support the impact of research that seeks to improve the lives of families impacted by Huntington's disease in Scotland and beyond.

The charity's Impact and Engagement Fund has been made possible through a generous legacy donation in support of the charity's commitment to sharing knowledge about Huntington's disease and the services and care that individuals and families need. It is open to academic and practitioner researchers across all disciplines and at any career stage who are studying or working in an associated education, healthcare or third sector setting in Scotland.

Grants of up to £2000 will be awarded to each successful applicant to help promote findings from innovative and high quality studies through, for

example, workshops, training, or the development of creative and engaging outputs to share research findings.

"We are excited to offer this support to researchers and students across Scotland to share their work more widely, to engage with the Huntington's community, and to increase the impact of their research," said Professor Louise McCabe, Chair of the Scottish Huntington's Association Board Research Sub-Group and Professor in Dementia Studies at University of Stirling.

The Scottish Huntington's Association Board Research Sub-Group was formed in 2023 to raise the charity's profile as a partner in research by developing national and international networks in the research community. It helps to ensure relevant research is communicated effectively, gives guidance and information to families

who want to get involved in research, and disseminates research projects in which the charity has been involved.

In addition to Professor Louise McCabe, trustees on the sub-group include palliative care nurse and Huntington's disease ambassador Gillian McNab, Dr Marie Short MBE who also sits on the European Huntington's Disease Network Scientific and Bioethics Advisory Committee (SBAC), and Dr Tim Soane, Consultant Neurologist and HD Clinical Lead for NHS Forth Valley.

Visit <https://hdscotland.org/research/> for more information, including award criteria and how to apply.

The fund was officially launched at this year's NDN/SDRC/Brain Health Arc Conference in Dundee. Pictured above, Professor McCabe was joined by fellow trustees and sub group members Dr Marie Short MBE and Gillian McNab.

Deadlines for 2024/25 applications

The application portal at <https://hdscotland.org/research/> remains open at all times and applications will be considered in October and April each year with the first 2024 and 2025 deadlines as set out below. Projects should be scheduled to begin with the results deadline in mind; awards must be taken up and work initiated within six months of the date of the award. Retroactive applications will not be accepted.

Submission deadlines	Result published
30 September 2024	31 March 2025
31 October 2024	30 April 2025

Fun, friendship and learning from each other



“We pretend summer camp is primarily for our young people but for me it’s a massive privilege to see the communities that we’re creating, to hear from the young people, and to listen to what’s really important to them right now.”

The words of our Patron, Sarah Winckless MBE, as this year’s summer camp at Lagganlia, near Aviemore, drew to a close.

The five-day trip brought together 47 young people from across Scotland to enjoy a packed programme of fun activities and take part in workshops and discussion sessions.

Sarah, Cowdenbeath FC Captain Robbie McNab, and Chief Executive Alistair Haw joined the Youth Service team and volunteers.

“I had a great session with the 18+ group. We just had a conversation, just to help them think. I always say to them: ‘follow that thought, tell us more. I’d love to understand your thinking on that.’ And the young people were brilliant; I learned loads,” said Sarah.

For Robbie, it was his first time at the camp and he was keen to learn more about it, take part in activities, and meet the young people and staff.

Over the past year he has become increasingly involved in supporting the work of Scottish Huntington’s Association to raise awareness and funds. This year Robbie brought a team of friends together to conquer the Three Peaks Challenge. Together they raised more than £6,300 by scaling

the UK’s three highest mountains in under 24 hours – Ben Nevis in Scotland, Scafell Pike in England, and Snowdon in Wales.

Robbie tested positive for the HD gene when he was in his early 20s and began speaking publicly about his experiences last year.

“Before summer camp I had probably never been in a room where there were so many people who have a touch point with Huntington’s. It was amazing to hear different stories, different experiences, and to talk about what the young people wanted to talk about. I was speechless at times but it was a really positive experience. I learned a lot and have taken so much from it,” said Robbie.



£50 Workplace Challenge

Our new £50 Workplace Challenge is off and running and we are reaching out to employers who may be interested in getting involved.

Having strong networks and support in the corporate sector is essential to the growth of Scottish Huntington’s Association.

The [£50 Workplace Challenge](#) is a simple first step to getting involved – we’re giving 25 businesses £50 and until February 2025 to turn the money into as much as possible.

Whether a team of two working together or 200 colleagues working remotely, their support will help to change the lives of families living with Huntington’s disease.

To find out more, or to suggest an employer we can approach, email fundraising@hdscotland.org

Top marks For Megan



A huge “well done!” to Megan Gilroy who gave a presentation to her PSE (Personal and Social Education) class and Guidance Teacher about Huntington’s disease.

Megan had already spoken to a couple of her classmates about how Huntington’s impacts her mum and was keen to talk to her whole class about the disease and the support she receives from our Youth Service.

Megan was supported by Specialist Youth Advisor Pete Carruthers to put together the presentation and on the day when she gave her talk.

“I was really nervous but my classmates made it easy for me to talk about my mum and Huntington’s disease,” said Megan.



Ian and Jennifer with Tayside HD Specialist Lindsay

Families take the lead on new film series to raise awareness

Our families and staff joined together to create a powerful digital campaign for Huntington's Disease Awareness Month.

The Who Do You Think We Are? series helped May 2024 to become our best month ever on social media, reaching record numbers of users on Facebook, X, Instagram and LinkedIn with stories from the Huntington's community and information about the disease, the specialist support that is needed, and the importance of research.

We shared a collection of short videos featuring family members Josh Marshall from Lothian, Ian Hardie from Tayside, Robbie McNab from Falkirk and Lauren Boag from Aberdeenshire. Staff members Jenny Bruce (Specialist Youth Advisor) and Cat Martin (Services Support) highlighted the work of Scottish Huntington's Association and ways to get involved in research. Josh, who launched the series, shared



his experience of being diagnosed with Juvenile onset Huntington's disease and the progression of symptoms, including how it has changed his mobility and ability to care for himself. He spoke movingly about his determination to raise awareness for the benefit of the wider Huntington's community.

Our top performing post featured Ian, who was diagnosed 10 years ago. He and his wife Jennifer are supported by our HD Specialist team in Tayside.

Ian shared special memories of the day he managed footballing legend George Best during a centenary match in 1982 between his club Arbroath Vics and the local senior side Arbroath FC. His uplifting and entertaining story touched thousands of people, generating record numbers of shares, comments and reactions from far beyond the Huntington's community. So far it has appeared on nearly 11,000 social media accounts.

Working with families directly meant we were able to share powerful experiences of Huntington's disease in a way that resonated with thousands of people, well beyond the Huntington's community.

*Fancy getting involved in future Who Do You Think We Are? films or other communications work to raise awareness about Huntington's disease? Please contact our Communications Lead Roisin Eadie at roisin.eadie@hdscotland.org.

Gavin appointed as committee chair

Family member Gavin Keith has been appointed to Chair our Welfare Grants and Short Breaks Committee.

He brings experience in strategic planning, research skills, monitoring and evaluation, knowledge and fundraising to the role, and is currently employed as Health and Wellbeing Co-ordinator with Fife Sports and Leisure Trust.

"Having dedicated much of my life to healthcare and social welfare, and having family connections to Huntington's through parents and grandparents, I am excited about the prospect of contributing my skills and experience to a cause as crucial as Scottish Huntington's Association," he said. "I am also looking forward to working alongside like-minded individuals dedicated to making a meaningful impact on the lives of those affected by this disease."



We love sharing your photos too! This great shot captures the Fife Family Branch day out in July to Pitlochry for a lovely lunch at the local hydro hotel followed by a bit of shopping in the town. "A great day was had by all," said Nicola Johns, Senior HD Specialist (Fife).

Great response as places snapped up for Family Gathering and 35th Anniversary celebration dinner

Families have responded quickly to book places at this year's Family Gathering and 35th Anniversary Dinner.

The event will take place on Saturday 9 November at the Apex City Quay Hotel, Dundee and we have lined up a superb programme of speakers and activities while also ensuring there will be plenty of free time for family members to relax and socialise.

Our Patron Sarah Winckless MBE is joining us once again. In the morning session Sarah will share personal insights before leading a discussion with a panel of family members and Scottish Huntington's Association Youth Ambassadors.

In the afternoon people there will be a choice of interactive workshops designed to suit the varying needs of family members, after which our great friend Professor Ed Wild (Associate Director of UCL Huntington's Disease Centre) will deliver – in his own unique style – an update on global Huntington's research.



Professor Ed Wild



Our Patron Sarah Winckless MBE.

The daytime event will be brought to a close by the Chair of Trustees Aarran Air who will share his reflections on both the event and the past year.

More than 1000 invitations were sent

out by post and a further 170 by email in August to ensure we reached as many people as possible with news of the event. Places are limited to 150 and a waiting list will be opened beyond this number.

Places at the evening celebration dinner are also filling up quickly and we are looking forward to celebrating our 35th Anniversary together with Huntington's families and friends of Scottish Huntington's Association.

Watch out for a full round-up of the events on our social media channels and in your next edition of SHAre magazine.

Alex inspires employers to help foot the bill

A huge thank you to Alex Hall from Pavers Shoes in Dundee. Alex nominated Scottish Huntington's Association to receive a donation of £500 through the Pavers Foundation, the company's charity arm.

"I've lost two close family friends to Huntington's disease so I understand how difficult and devastating the disease is," said Alex.

"It's a pleasure to support Scottish Huntington's Association and I'm delighted the funds will help other families impacted by this disease."

The kindness of individuals like Alex and organisations such as Pavers Foundation make it possible for us to continue to provide personalised support to people of all ages through our specialist services. We are truly grateful for their support.



Putting SHA on the map at major events

Through their collective efforts, our supporters have been bringing much-needed attention to the cause by taking part in national running events to ensure that Scottish Huntington's Association can continue supporting individuals and families across the country. This year our #TeamSHA runners have raised an incredible £26,000 between them so far.

While running the iconic London Marathon, Andrew Freeland managed to meet up with a participant running for HDA amidst the bustling crowds!



Staying the distance, long-term supporter Steven Henderson was back at the London Marathon this year too.



At the Edinburgh Marathon Festival, Gregor Scotland kept going thanks to the fantastic support from his adorable cheer squad.



Fabulous Four hit incredible heights

They reached for the sky – and smashed it by raising £6301.25, including Gift Aid.

Huge thanks to Margaret McCafferty, Amanda McNab, Charlene Currie and Zoë Green for taking part in the Scottish Huntington's Association tandem skydive in Glenrothes, Fife.

Jumping from a plane at 10,000 feet then reaching adrenalin-pumping speeds of up to 120mph before gliding back to land – that's a sure-fire way to get the adrenalin pumping in support of our work!



Scottish Huntington's Association

Specialist support for Huntington's disease families

To sign up for any of these events or view our full Events Calendar, please visit www.hdscotland.org/events
Alternatively, you can contact us on 0141 848 0308 or email fundraising@hdscotland.org

2024/5 Find your fundraising event challenge

September

Loch Ness & Festival of Events
29 September 2024

October

Great Scottish Run 10K & Half Marathon (Glasgow)
6 October 2024
Three Peaks Challenge Ben Nevis, Scotland; Scafell Pike, England; and Snowdon, Wales

February 2025

Firewalk (East of Scotland)
The Hub at Friockheim, Eastgate, Arbroath
22 February 2025
SuperNova 5K (Forth Road Bridge)
22 February 2025

March 2025

Firewalk (West of Scotland)
Helensburgh and Lomond Civic Centre
8 March 2025
SuperNova Kelpies 5K (Falkirk)
14 March 2025
Falkirk Wheel Abseil
16 March 2025

April 2025

London Marathon 27 April 2025
Glasgow Kiltwalk (Date TBC)

May 2025

Edinburgh Marathon Festival 2025

June 2025

Aberdeen Kiltwalk (Date TBC)
Women's 10K Glasgow 15 June 2025
Men's 10K Glasgow 15 June 2025
Tough Mudder (Date TBC)



No matter how you choose to support Scottish Huntington's Association we're here to help you to do something amazing for the Huntington's community. Get in touch with your ideas at fundraising@hdscotland.org or call 0141 848 0308 to speak to a member of the team.



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



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?

No prior training is necessary for the firewalk; if you're over 18 and can walk ten paces at a regular pace, you can participate. You'll spend 90 minutes developing the mental strength required to tap into your potential and courage before taking on the firewalk challenge.

What we ask of you

Secure one of our limited firewalk challenge places for only £25 and pledge to raise a minimum of £125 in aid of Scottish Huntington's Association, the only charity in the country exclusively dedicated to providing expert and personalised support for those impacted by Huntington's disease.



[Angus Firewalk
Registration](#)



[Helensburgh Firewalk
Registration](#)