

# SHAre



Scottish  
Huntington's  
Association

Specialist support for Huntington's disease families

Spring 2023

The magazine of  
Scottish Huntington's Association  
Issue No.99



**Dance 100: Join us to drive change for all Huntington's families**

## Working together to influence for change across UK

In the last edition we shared news of our joint working with the Huntington's Disease Association (England & Wales) and the Huntington's Disease Association of Northern Ireland to raise the profile of Huntington's disease at Westminster.

We are hugely fortunate to have the support of the Rt. Hon. Hilary Benn MP, who secured a debate on the topic during which he confirmed that he knew someone who is impacted by the disease and he spoke passionately on their behalf and for the community as a whole.

In May 2022 Mr Benn also tabled a motion calling for an expansion of specialist Huntington's services throughout the UK, which remained the most supported of the 2022/23 session into March. At the time of going to print 1038 motions have been tabled so far during this session. Mr Benn's motion on Huntington's disease is one of only three to have secured in excess of 100 supporters.

Further to these events the Westminster Department of Health and Social Care, which is responsible for these issues south of the border, is preparing a paper on potential National Institute for Health and Care Excellence (NICE) guidelines for Huntington's disease. NICE is the independent body that develops evidence-based guidance for the NHS in England, Wales and Northern Ireland.

Although these guidelines would therefore not directly apply north of the border this would still be a hugely welcome development by helping families in the rest of the UK who, unlike ourselves, don't have a National Care Framework for HD. NICE Guidelines could also have the potential to act as a reference point and stepping stone to further improvements in Scotland.

These developments therefore provide yet further evidence of the benefit of the UK's Huntington's charities working together to influence for the community throughout these islands.



## Welcome from our Chief Executive

As you can read elsewhere in this edition, we welcomed the Huntington's Disease Youth Organisation (HDYO) International Congress to Glasgow in March.

A main focus of my time at congress was soaking up knowledge from the numerous informative sessions – including those expertly led by our Youth Service staff and our inimitable Chair Cat Martin – as well as meeting new faces and seeking to forge new relationships for SHA. HDYO Executive Director, Jenna Heilman (pictured), among them.

When introducing myself to new faces it was not uncommon for people to claim to be “privileged” or “honoured” to meet me. I am not, as far as I know at least, a member of the Royal Family – so am generally unaccustomed to such sentiments being expressed in my direction. Of course these sentiments were not really directed at me at all. Instead they speak of SHA's formidable international reputation built up by families and staff over almost three and a half decades. One of my final encounters at congress tells the tale.

Having sat in on an “ask the experts” plenary session, I shortly thereafter elected to attend a breakout session led by one of the internationally renowned experts from the panel. No sooner had I done so than I found myself being approached by said expert, informing me that they had seen me in their workshop and were “honoured” that I had chosen to attend it. They then went on to say what a “privilege” it was to meet, as SHA is known as the “gold

standard” throughout the world that all other countries and Associations look up to, aspire to learn from and be like. Despite being from a different continent this person knew all our services inside out, and advocated that all countries follow our lead.

This person was not viewing the services that Scottish families and staff have developed through rose tinted spectacles. They were fully aware that our system is no panacea, and room for considerable improvement continues to exist. We are all acutely aware of that too. But as we continue our ongoing collective fight for the best for our families here at home, let's not be daunted by how far we still have to travel. Instead let's remember how far we have come, and how much our work inspires others who in some cases have only a fraction of the support experienced by families in Scotland and, in all too many more, find themselves abandoned with no specialist support whatsoever.

A wristband I received at congress from the International Huntington's Association reads “We Are a Global Community.” And so we are. The work of Scottish Huntington's Association is clearly global in its impact. Thank you for everything you do for the hope it provides to families not only here at home, but throughout our global community.

Alistair Haw, Chief Executive

## Findings of PROOF-HD on the way

As this edition of Share magazine was going to print, we received encouraging news from Prilenia about the PROOF-HD clinical trial.

It is reported that the final planned visit of the blinded treatment period has taken place, marking the completion of the main study.

PROOF-HD is a Phase 3 study conducted by the Huntington Study Group and Prilenia. The clinical results are expected to be announced in the coming weeks – you can read the full update at <https://bit.ly/PROOFHDpressrelease>

We are looking forward to learning about the trial findings and what is next in research, and send a huge thank you to all the participants and the researchers who worked on this study.

## HD Specialist appointed for Highland

**Our new Senior HD Specialist for Highland, Lorraine Watson, joined SHA at the end of March.**

With a background in mental health nursing and working with people who have learning disabilities, Lorraine has spent most of her career in Highland. Her most recent post focused on dementia care in the community, care homes and hospitals.

With a passion for supporting people who present with stress or distress, Lorraine has wide experience of using psychological approaches to support clients and in 2020 became a nurse prescriber. She is also studying for the advanced nurse practitioner certificate.

Outside of work, Lorraine is a mother of two, a very proud grandmother of two, and enjoys adventures in the family motorhome with her husband and their dog.

# Hugh's ready for a giant leap of faith

'Bionic man' Hugh Heath from Dunfermline, Fife – who has two metal replacement knees – is set to climb to the top of a 100-foot-tall crane for a high-speed zipwire along and across the River Clyde to help families with Huntington's disease.

The daredevil experience is the latest in a series of fundraisers by the 80-year-old grandfather who has collected thousands of pounds for Scottish Huntington's Association over the years.

Even the Covid pandemic couldn't stop this retired salesman - when social distancing prevented most fundraising events he clocked up 2600 kilometres over 12 months as part of our Big Walk campaign, smashing the 2000-kilometre target and collecting more than £3000 along the way.

Hugh's support began after he met his second wife Rose whose four children inherited the faulty gene that causes Huntington's disease from their late father. Rose's son Hunter and her daughter Kathleen have since passed away and another daughter, Janet, is in the late stages of the disease and receives 24-hour care in a care home.



The fourth sibling, Dr Marie Short MBE, pictured left at Buckingham Palace, is a Trustee at Scottish Huntington's Association and a passionate advocate and campaigner for improved specialist services for all Huntington's families, regardless of where in Scotland they live.

"I didn't know anything about Huntington's disease before I met Rose back in the 1970s, none of us did. Then after her ex-husband was diagnosed, we discovered what that could mean for each of their children," said Hugh.

Hugh says he is inspired by stepdaughter Marie's determination to do all she can to support the Huntington's community. Marie's commitment to volunteering, raising awareness and fundraising was recognised with an MBE in 2019.

Hugh, who is originally from Glasgow and has three grown-up children and grandchildren from his first marriage, says the zipline challenge will be his final fundraiser - and he's making sure he bows out on a real high!

"I wanted to do a skydive but my replacement knees ruled that out so a zipslide is the next best thing. I'm terrified of heights and it's quite a climb to the top of the crane but I keep myself fit by going to the gym and I walked 15,000 steps every day in March," he said.

"I'm only 80, I feel strong, and I have new knees so there's nothing to slow me down!" said Hugh.

To find out how you can join Hugh at the zipline challenge or – knees permitting – visit <https://hdscotland.org/events/>



## Get ready Glasgow, we're coming back!

Join #TeamSHA in Glasgow city centre for Scottish Huntington's Association's 100-song sponsored dance challenge - Dance 100!

**Date:** Sunday 14 May

**Location:** George Square, Glasgow

**Time:** Check in opens 11.30am

**Challenge:** Dance for 100-songs back-to-back. All dancing abilities welcome from dad dancers to pro dancers!

**Entry fee:** £5 registration fee

**Minimum sponsorship:** You don't have to fundraise to take part in Dance 100, but if you do, there is no minimum sponsorship – just raise as much as you can!

In 2022 Dance 100 marked a real step change for the charity and the Huntington's community as we joined forces to take our message straight to the heart of Scotland's largest city.

It was big, it was bold, it was brilliant - everything we need to be as a community as we work towards the day when Huntington's families have all the care and support it needs.

To mark Huntington's Disease Awareness Month in May, we need YOU to help us make this year's event in George Square, Glasgow, even BIGGER and BETTER. By taking part you will meet other families, you will increase understanding about the disease, and you will raise funds to provide the vital services that Huntington's families rely upon.

Join us and be part of the largest gathering of Huntington's families and supporters the city has ever seen.

## How do people sign up?

To make sure we can look after all our dancers and volunteers on the day, we need to know who is coming along. Please sign up using our Eventbrite form via [hdscotland.org/dance100](https://hdscotland.org/dance100). There are two ticket options, each costing £5 which will be added to the total raised at the event:

1. Dance 100 Sponsored Challenge – For those looking to complete the 100-song dance challenge and raise funds to provide vital services for Huntington's families.
2. Dance 100 (no-fundraising) – For those looking to join in with our fantastic community without fundraising – everyone is needed to make our message louder!



## Meet our Dance 100 headline sponsor!



"At Benson Wood & Co, we feel lucky and privileged to be given the opportunity to support Huntington's families by partnering with Scottish Huntington's Association including sponsoring Dance 100. We feel that our organisations are a really good fit with each other, and we couldn't think of a better charity for our business to partner with.

"We have been inspired by Gillian McNab's story including her amazing fundraising, flying and dancing exploits over the past few years and can't wait to help out in any way we can. All of the team are particularly looking forward to taking part in Dance 100, and despite our Directors John and Chris being the worst dancers ever, they promise to try very hard on the day!"

# Dina steps down from SHA Board

**Global advocate Dina De Sousa has stepped down as a Scottish Huntington's Association Trustee after serving for five years on our Board.**

Dina (59), who inherited the faulty gene that causes the disease from her late father, is moving later this year to Portugal where she and her husband Paul both have family roots. She is also facing treatment for breast cancer, which was detected during a routine check shortly after her decision to step back from the Board.

Following treatment, Dina intends to continue her involvement with the Huntington's community by volunteering with the Portuguese organisation, serving on the European Huntington Association Board, and as a member of the Executive Committee with the European Huntington's Disease Network (EHDN).

"Scottish Huntington's Association is one of the strongest in the world and it's been a privilege to serve as a Trustee," said Dina. "I've learned a lot from how the charity is run and the quality of access to services it provides for families, including the work of HD Specialists, the Financial Wellbeing Service and the Youth Service, and the development of the National Care Framework for Huntington's Disease.

"Organisations in other parts of the world are always impressed when I tell them about the services in Scotland and what Scottish Huntington's Association does for families."



Dina first contacted Scottish Huntington's Association ten years ago while taking part in a fundraising trek in Peru. Since then she has become increasingly active locally, nationally and internationally on behalf of the Huntington's community.

As Chair of the Lothian Family Branch from 2015 to 2022, Dina brought together families to support and learn from one another, enjoy activities and social events, and fundraise. She also sat on our Welfare Grants Committee to provide emergency financial support for families and our Short Breaks Committee to enable families to enjoy some time away together or for much-needed respite.

A keen advocate of research, Dina has participated in the Predict and HD Clarity studies and sat on the influential EHDN Scientific and Bioethics Advisory Committee until 2022. Her global network includes key decision makers, scientists, campaigners, clinicians and family members and she has taken part in international conferences including in Poland, Brazil, Italy and, most recently, the HDYO Congress in Glasgow.

"There's a lot more we can do – every family, regardless of where they live, needs specialist care and support to cope with this dreadful disease," said Dina. "There is always hope and I'll keep doing what I can by getting involved, speaking out about the disease, and raising awareness."

**"Dina has made an incredible contribution to our work and to the lives of Huntington's families in Scotland and far beyond. We have benefited greatly from her expertise, friendship and the gentle yet determined approach she takes in all that she does for our community. We wish her the very best with her treatment and will, of course, be staying in touch. Dina means so much to the SHA family and will always be made enormously welcome at any of our events and get together whenever she is able to attend."**

**Chief Executive Alistair Haw**

## Derek and Margaret join SHA as trustees

**Derek Brady, who is semi-retired, brings a range of skills and experience to the Board having enjoyed a 30+ year career in procurement, supply chain and strategic sourcing in a variety of manufacturing environments.**



"My life partner of 35 years was diagnosed as being positive for Huntington's disease in 2008. Since then my partner, myself and our three children have been

afforded exceptional support from Fife HD Specialists and staff who have steered us through some difficult times," said Derek.

"Now that I am semi-retired I thought it was time to give something back by supporting families such as mine and doing my level best to spread awareness in Scotland and beyond."

**Margaret Moncrieff has a long relationship with the charity as a family member and as a volunteer fundraiser and speaker.**



She qualified as a Chartered Accountant in 1969 and has worked in professional CA offices, with a short career gap for children. Since 2011 she has worked part-time for a firm of solicitors in Paisley.

"Huntington's disease was not known in my family until 2005 when my younger sister was diagnosed. I did some fundraising after I retired in 2008 then volunteered at National Office where I saw how much the funds raised were appreciated," said Margaret.

"I have also seen the support provided to my sister through HD Specialists. I have been fortunate to have had a negative test. In the past 15 years I have raised funds annually for Scottish Huntington's Association and the condition is at least known about in my community."



# Beinn breaks his silence with gruelling challenge

Beinn Burroughs, from Banff, who tested positive for the gene that causes Huntington's disease when he was 18 and studying at university, is taking on a unique and gruelling challenge in support of other families impacted by the devastating condition.

Having graduated earlier this year, Beinn (21) is now living and working in Ayrshire.

He is also training hard for an incredible triple challenge for Scottish Huntington's Association- the London Marathon, the Stafford Half Ironman and the Bolton Ironman challenges within a few weeks of one another.

At the London Marathon in April, Beinn will face 26.2 mile run. For the Half Iron Marathon in June he will swim for 1.2 miles, cycle for 56 miles and finish off with a 13.1 mile run. And finally Beinn will take on the Bolton Ironman a few weeks later – a 2.4 mile swim, 112 mile cycle and a full 26.2 mile marathon.

"Three years ago I discovered I have the faulty gene," said Beinn. "It wasn't a huge shock as I always knew there was a risk because my dad has Huntington's disease. It also helped that I was well supported by the Scottish Huntington's Association Youth Service from when I was 10 years old.

"Even so, it was difficult to talk about and during my first year at university I just cracked on with life and kept myself to myself. In fact until a few months ago only five people outside my family knew.

"But now the time feels right to start speaking about how Huntington's affects me and my family. A couple of people have since told me that people close to them are also impacted by the disease."

Beinn is inspiring people around him and friends, work colleagues and family have already donated more than £2700 through his Justgiving page at <https://www.justgiving.com/fundraising/beinn-burroughsxsha1> and you can follow his progress at <https://bit.ly/BeinnYouTube>

"I'm training hard because it's going to be extremely tough but I'm up for the challenge because Scottish Huntington's Association is so important to families impacted by Huntington's disease," said Beinn.

## Foundation grants £136k to Youth Service

We're grateful to Bank of Scotland Foundation for £135,920 in support of our work with young people growing up in families impacted by Huntington's disease.

The funding is a share of nearly £1.5 million being shared amongst 12 charities as part of it's foundation's Change Programme.

Our Youth Service supports children and young people across Scotland to help them cope with being a young carer, managing changes to a parent's physical and mental health, dealing with loss, bereavement, and the impact of being at 50/50 genetic risk of the disease.

100% of children and young people we support have reported improved emotional wellbeing after seeing their SHA Specialist Youth Advisor.

In addition to 1-2-1 support, the Youth Service also provides group work, activity days, an annual summer camp, residential trips, and bursaries to support education and employability.

The Service also provides access to information materials including financial management digital resources developed in collaboration with our young people and SHA's Financial Wellbeing Service.

# Gavin's bold shortcut for his Mum and other HD families

**PT instructor Gavin Keith had his long hair shaved off to raise money for two charities close to his heart – and his mum couldn't be prouder of his kindness.**

The 32 year old raised £1400 from family, friends and work colleagues which was shared between Maggie's cancer support charity and Scottish Huntington's Association, the only charity in the country dedicated exclusively to supporting people impacted by Huntington's disease.

"My dad had lung cancer and passed away six years ago," said Gavin, who lives with his partner Richard in Leven.

"Now I run specific sessions for cancer, cardiac and long term health condition patients, and deliver classes for Maggie's through my work at Fife Sports & Leisure Trust.

"But it was also very important to me that the donations were shared with Scottish Huntington's Association as a thank you for supporting my mum Lesley who has Huntington's disease."

Huntington's disease, which is caused by an inherited faulty gene, changes the brain and causes physical, mental health and cognitive symptoms. These can leave people unable to walk, talk, eat, drink, make rational decisions and care for themselves.

The devastating toll on families is compounded further by the reality that each child of a parent with Huntington's is also at 50/50 risk of developing the disease.

"My late grandma and my great aunt both had Huntington's and their symptoms were severe," said Gavin. "My grandma could barely speak, she constantly twitched and her hands would wave about. Then when I was 21 my feet were fidgeting a lot and I remembered my grandma's movements. I was worried it was the disease starting for me so I decided to be tested.

"When it came back negative we had real hope that Mum was clear too, which made it even harder to deal with when her result was positive."

Mum Lesley Currie is visited regularly by a Huntington's Disease Specialist for emotional and symptom management support. She was also referred to the charity's Financial Wellbeing Service after losing her job in a jewelers shop during the Covid pandemic.

"I'm proud of Gavin and was very moved when he told me how much money was being donated to Scottish Huntington's Association," said Lesley.

"It was Gavin who noticed the changes in me, especially my mood swings, before I was tested. Now my symptoms are more obvious. I drop cups of tea, my balance is affected and I've fallen down the stairs a few times. But the biggest change is to my mental health and my HD Specialist is very good at knowing when I need help with that."



## Jenny joins our Youth Service

**Jenny Bruce has joined us as the new Specialist Youth Advisor for Highland, Grampian and Tayside.**

With a background in support work, education and psychology, Jenny previously worked at PKAVS, a charity that supports the wellbeing of people and communities throughout Perth & Kinross. Her previous roles include Carer Training & Development Co-ordinator and managing a young adult carer service.

## Another year of bursary funding

**We have secured funding from the Hyman Robertson Foundation to extend our young people's bursary scheme for a third year.**

In 21/22 we made 33 awards and last year that increased to 37, totalling £4800 in 22/23. All recipients access our Youth Service and are aged between 16 and 25 years old.

This year's bursary scheme reflects the ongoing impact of the cost of living crisis and increased energy costs. It is aimed at young carers living in a low income household.

Applications have been coordinated by the Youth Service with a view to awarding up to £200 per applicant.

In agreement with Hyman Robertson, the bursaries can be used for food and care packages, clothing and utility bills.



Lesley and her son Gavin



# Introducing 24 hour postural management to your routine

**24 hour postural management - a programme of supported positioning - can help to reduce pain, maintain body shape and improve comfort.**

It can be especially beneficial for people with Huntington's disease who may have limitations in their independent mobility and level of activity, putting them at risk of developing spinal problems.

These in turn can lead to pain, discomfort and potential agitation while sitting, eating and drinking, showering, sleeping, and engaging in activities. It can also cause difficulties with breathing, digestion, eating, drinking, swallowing, temperature control, toileting, circulation, pressure sores and personal care.

Research suggests that 24 hour postural management can help to prevent or reduce the impact of these difficulties and improve comfort if applied throughout the day and night.



## When to start 24 hour postural management

Ideally when the person with Huntington's disease is showing signs that their condition is changing and their ability to mobilise is beginning to be affected.

Early intervention is key to establishing if a person's mobility and movement is changing.

Supportive seating should be pursued if the person with Huntington's is beginning to lose their sitting balance, falling to one side in their chair, having difficulty supporting their head or upper body or is less able to support their body weight through their feet and legs.

## Possible benefits for health and comfort

- Improves functional ability.
- Facilitates safer eating and drinking.
- Aids communication/social interaction.
- Enables access to environments and social opportunities.
- Reduces fatigue.
- Improves attention and concentration.
- Promotes comfort to minimise anxiety and agitation.
- Promotes the sustenance of normal movement patterns.
- Encourages active movement to maintain muscle length.
- Maintains bone and joint alignment to reduce the progression of deformity/body asymmetry.
- Manages pressure and helps maintain skin condition.
- Health benefits are maximised by the positive impact on the autonomic nervous system functions such as breathing, swallowing, digestion, cardiac function and circulation.

## Support for families and carers

As postural management is a 24 hour approach, some families and carers may find this a bit daunting, especially in the initial stages.

Your physiotherapist and occupational therapist should work with you to identify and explain the appropriate equipment for the needs of the person you are for.

You should also be provided with a Care Plan, Manual Handling Plan and Risk Assessment, if needed, ideally including pictures, explaining how to use any equipment provided and how best to position the person you are working with to meet their postural needs. This is also designed to keep you safe and minimise any risk to you, as a handler, whilst carrying out tasks to support and position the individual you work with.

The plans above should include the best positions for day-to-day activities such as eating and drinking, sleeping, bathing, showering, hoisting and relief of pressure.

## Accessing training and information to help with controlled positioning

Families, carers and the team working with the person with Huntington's disease need to be given the right information, support and training to ensure they are able to apply effective postural management to the person they are caring for. This means training for families and carers is essential to enable 24 hour postural management to be effective.

**To find out more about 24 hour postural management, training and its benefits, please contact HD Specialist Julie Wilson at [julie.wilson@hdscotland.org](mailto:julie.wilson@hdscotland.org)**



# HDYO Congress brings global community together

Scotland welcomed family members, researchers and clinicians from across the world to the Huntington's Disease Youth Organization (HDYO) Congress in Glasgow.

Grant was invited to share his insights and expertise in supporting young people and ways to build effective services and programmes.

It was fantastic to see so many representatives from Scottish Huntington's Association and Scotland's Huntington's disease community, including many of our young people, at the event in Glasgow.



"We are so unbelievably proud of this fantastic group of young people, our incredible Youth Service Team, colleagues from Scottish Huntington's Association and friends from across the globe, especially Huntington's Disease Youth Organization (HDYO) for an amazing weekend of love, laughter, tears, sharing, growing, learning and creating friendships," said Scottish Huntington's Association Youth Service Lead Grant Walker.

Further speakers over the three days included young people and families in addition to representatives from pharmaceutical companies, genetic counsellors, neurologists, researchers, Huntington's disease associations and medical professionals.

Sessions focused on the power of social media to raise awareness, the impact of Huntington's disease on families, talking to kids about Huntington's disease, coping with grief and loss, taking part in research, advocating on behalf of the international community, and juvenile onset Huntington's disease.

## "It's important to talk about Huntington's disease"

**After losing her much-loved father-in-law to Huntington's disease, Amanda Birnie recognised the start of similar symptoms in her husband before tests confirmed that he had inherited the incurable condition.**

Now, as she comes to terms with 53-year-old Clark's diagnosis, Amanda is determined to make the most of the time they have for as long as possible.

"Even though we expected the diagnosis it was still a shock. Until then there was always the hope that Clark wouldn't have it," said Amanda, 47, from Falkirk.

"But I'd seen changes in his movements and noticed that on the sofa he'd sit on his hands to stop his arms moving. And his moods were different. Clark is mild mannered and very chilled out but he'd started flying off the handle and getting very upset.

"One minute he was happy as Larry, the next he was losing it. Clark knew himself that wasn't like him and that it was affecting our relationship.

"When Clark was diagnosed with Huntington's disease it was very difficult, especially for our son Kayi. It helps that he has been supported by the Scottish Huntington's Association Youth Service since he was very young. For years he's been meeting

up with Grant, his Specialist Youth Advisor, and he takes part in Youth Service activities including annual summer camps.

"It's important to talk about it, to be open and honest about what's happening. Clark's employers and colleagues have been brilliant and our friends check in to see how we're doing and to see we're alright."



Keen to raise awareness and help other young people growing up in Huntington's families, Kayi (19) has fundraised for SHA and is now a volunteer Youth Ambassador.

While studying at college in Aberdeen he still does his bit to raise awareness, provide peer support to other young people growing up Huntington's families, and help out at activities and events when he can.

Most recently he took part in a big fundraiser for the charity organised by his parents. The Neil Diamond tribute night with disco and dinner at the Three Kings in Falkirk raised £3380 - all 132 tickets were snapped up and the family was overwhelmed with donations of raffle prizes from the local community and beyond.

"We've asked for half of the money to go specifically towards the Youth Service as a thank you for its amazing support and the remainder will go towards the charity's other services for families," said Amanda.

# “My beautiful, bright daughter deserved the whole world”

**In this poignant piece, David shares memories of his only child, Stephanie, who lived life to the full and built a successful career before the advance of Huntington’s disease which meant she was no longer able to look after herself.**

My daughter Stephanie was really special. I know most fathers would say that, but she really was. From a young age, she knew her own mind and exactly what she wanted to do.



For example, Stephanie had ulcerative colitis as a child which led to her being in and out of hospital over five years and missing a couple of years at school. We had a tutor but when she was ready to go back the teachers suggested going into first year when

her friends were in third year. “Absolutely not,” said Stephanie. “If they won’t put me in third year, I’m not going to that school.” So off she went to third year with the teachers keeping a close eye to make sure she was coping. And cope she did – ending up as deputy head girl and showing everyone exactly how capable she was.

Her mother Ann started showing symptoms of Huntington’s disease when Stephanie was at university studying clinical psychology. It was learning about Huntington’s disease in her course that triggered Stephanie to encourage her mum to see her doctor about the symptoms and that was when Ann got her diagnosis. Because Ann’s cognitive reasoning was impacted, she in part blamed Stephanie for her diagnosis although, of course, logically it was nobody’s fault. We were divorced by this point but I couldn’t stand seeing Ann going through it alone so I brought her to live with me and cared for her (with lots of help) until she passed.

Stephanie had an incredible life until Huntington’s started to take hold. While at university she modelled for Bliss magazine and worked for Express Newspapers as the assistant to the editor. After graduating she was offered a full-time post in advertising and this is where Stephanie thrived. She travelled all over for her job, was very generous with the money she was making, and was always well dressed! I remember the women who work at the local chemist saying to me that they loved to see what Stephanie was wearing every time she went in to pick up a prescription. So they could get outfit inspiration!

She was a beautiful girl but didn’t take much stock in the attention she got from guys. We were at a wedding in Canada when a handsome young man approached and asked to take Stephanie out on a date. He was quickly shot down and when I asked why, Stephanie said: “Oh Dad, I’m fresh meat to the market here. No thanks.”

There were some lovely boyfriends though – in fact one got in touch after seeing Dame Deborah James on TV because she reminded him of Stephanie. It was strange as I had literally said the same thing to my partner Ronnie! It was nice to catch up and hear his fond memories.

I was Stephanie’s go-to guy, she could talk to me about anything and was always, always there for me. There was never a point in her life when Stephanie would have doubted the love I had for her, how proud I was of the person she had become and how she handled everything in life. Watching the impact of Huntington’s disease on my beautiful, bright and kind girl was the hardest thing I’ll ever go through. She deserved everything the world had to offer. I struggled seeing her friends from childhood grow up, start their lives and their families when I knew Stephanie would never have that.

Nevertheless, Stephanie was selfless and kind right until the end. She even asked me not to visit her because it would be too hard for me after caring for her mum. I had to tell her: “I can’t not see you, I just can’t do that,” and would visit every morning and sit with her a while.

It broke my heart that she died alone. Until I realised that more than likely she chose that for herself, like she did everything, always wanting to make it easier on everyone else. Just before she passed, she told me, “Dad don’t worry about me, I’ve had a wonderful life.”

Our HD Specialist Sally is a wonderful woman. Straight down the line and tells it like it is. She has got to know us really well over the years and she cares deeply. She came to Stephanie’s funeral and has been checking in on me since. It means a lot.



## Student Felix is inspired by families to do his bit at event

The Lanarkshire Fundraising Group, which was formed by family members and supporters only last year, is already planning ways to follow up its hugely successful first event.

The Christmas Extravaganza held in Rutherglen raised more than £3300 – and increased much needed awareness amongst the local community.

And it also inspired new people to get involved with our work, including Glasgow Caledonian University post grad student Felix Olowokere who spotted one of our fliers on campus and got in touch to see how he could help.



He was invited to volunteer at the event and the day spent with staff, supporters and family members had a big impact on him.

“Learning about Huntington’s disease was quite an emotional experience for me. Prior to volunteering, I knew very little about the disease and was just eager to participate,” said Felix, who came to Scotland from Nigeria last year to continue his studies in human resource management.

“I must applaud Scottish Huntington’s Association for its good work to raise funds and awareness while also helping those whose lives are affected by this disease. I absolutely hope to do more volunteering with the charity in the future.”

If you would like to find out more about volunteering and fundraising for SHA, please email [sha-admin@hdscotland.org](mailto:sha-admin@hdscotland.org)



## Westerleigh rounds off fantastic year of support for families

Westerleigh Group has celebrated its year-long charity partnership by increasing its total given to more than £20,000.

A final cheque for £11,000 was presented at West Lothian Crematorium to round off a year of fundraising by the UK’s largest independent owner and operator of crematoria and cemeteries, which includes sites in Borders, Stirlingshire and West Lothian crematoria.

At the end of 2021, Roger Mclaughlan stepped down as Westerleigh Group’s Chief Executive Officer after learning he had inherited the faulty gene that leads to Huntington’s disease.

His successor Debbie Smith said: “Choosing Scottish Huntington’s Association and the Huntington’s Disease Association as our corporate charity partners seemed to be a fitting way for Westerleigh Group to honour, thank and pay tribute to Roger for his leadership.

“Our colleagues across the country got behind our fundraising challenge and found lots of different ways to raise money for the charity and bring together local communities in support.”

With the consent of families, metals recovered during cremation are recycled and the funds raised from this are donated to charities and other organisations which serve the communities surrounding Westerleigh Group’s sites all over the country.

Donations were also invited for Scottish Huntington’s Association during community events at Westerleigh’s Scottish sites and last September a team from West Lothian Crematorium took part in the Edinburgh Kiltwalk.

# SHA's Fundraising Calendar of Events 2023/24



## Running events

**Edinburgh Marathon Festival**

27-28 May 2023

**Scottish 10K**

Sunday 24 September 2023

**London Marathon**

Sunday 24 April 2024



## Adrenaline challenges



**SHA Ziplide the Clyde**

Friday 8 September 2023

**SHA Annual Skydive**

Saturday 9 September 2023

Interested in a shark dive or wingwalk?  
Get in touch!

## Dance 100 2023!

Register your interest today. Dance 100 will take place on Sunday 14 May as part of Huntington's Disease Awareness Month. This sponsored dance challenge is the highlight of our fundraising year as it brings families together from across Scotland to raise vital funds and huge amounts of awareness from George Square in Glasgow city centre. Email: [fundraising@hdscotland.org](mailto:fundraising@hdscotland.org)

Registration is now open – check out page 3 for more information



## Walking events

**West Highland Way Challenge**

6 May – 14 May 2023

**Three Peaks Challenge**

Friday 29 Sep to Sun 1 October 2023

**Kilkwalks**

Glasgow - April 2023

Aberdeen - May 2023

Dundee - August 2023

Edinburgh - September 2023



## Overseas trek

Fancy challenging yourself by taking on one of the world's greatest treks while helping families right here at home in your own community? From Machu Picchu to Kilimanjaro we can help make your dreams come true!




## Your preferences

You can update your preferences or choose not to receive post from us at any time, just let our team know on 0141 848 0308 or at [sha-admin@hdscotland.org](mailto: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](http://hdscotland.org)

Scottish Charity No: SC010985

Patron: Sarah Winckless MBE, Olympic Medallist

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