

SHAre



Scottish
Huntington's
Association

Specialist support for Huntington's disease families

Winter 2022

The magazine of
Scottish Huntington's Association
Issue No.98



Bringing the
Huntington's
community
together to
drive change
for all families

Inside: Family Gathering 2022 brings new hope and friendships

Welcome from our Chief Executive

You may note that our first Family Gathering since the pandemic features somewhat heavily in this edition, and we make no apology for it!

As you'll see in our centre page spread feedback on the day was extremely positive. We are so pleased about the impact it had on families who were able to attend, which is what it's all about. Only today I heard from another family member who still feels "super-charged" by the event, and of another who was motivated to reach out



to a close family member they had not spoken to for years.

The contents of this edition perhaps help to explain why: powerful personal stories; the rolling out of new services; raising our profile in our parliaments; spreading the word at national and international conferences; raising funds and awareness by running marathons, cycling challenges, bake sales and ghostly gardens.

Reading about these things is inspirational enough. Getting the people behind these stories together in one place to share experiences, celebrate successes and plan

more for the future is what appears to have "super-charged" so many.

Whether you could make the day or not, let's commit now to using the energy created to deliver further strides forward for the Huntington's community throughout the country, and beyond.

Alistair Haw, Chief Executive

Momentum grows with Huntington's on the agenda at UK and Scottish parliaments

The move to increase awareness of our cause within our parliaments has taken another step forward since the last edition of SHAre.

At Westminster a motion tabled by the Rt. Hon. Hilary Benn MP calling for an expansion of specialist Huntington's services remains the most supported of the 22/23 parliamentary session, with 96 supporters from across all parties - including 51 Scottish MPs.

Furthermore, in November, Mr Benn secured and led a Westminster Hall debate on Huntington's disease, during which he made a powerful and emotional speech expressing his personal knowledge of the condition and asking a series of searching questions of the government minister in attendance, Helen Whately MP.



The debate included contributions from all corners of the UK, including from Gavin Newlands MP who spoke with knowledge and enthusiasm about the work and achievements of Scottish Huntington's Association. We will continue to work with supportive MPs and our friends at Huntington's charities for the rest of the UK to raise awareness and drive change at the UK Parliament.

The Westminster debate was swiftly followed by a Scottish Parliament debate on neurological conditions,

secured by our partners at the Neurological Alliance of Scotland. Again the debate included references about Huntington's disease.

Olympian turned MSP Brian Whittle spoke of his support for our National Care Framework for Huntington's Disease, which he helped to launch in the Scottish Parliament in May 2017, and tied his comments in with the UK Parliament debate from the week before.

Meanwhile Jackie Baillie MSP referenced her record breaking motion calling for an expansion of specialist Huntington's services, before pressing the minister to close service gaps in NHS Borders (no HD Specialists), NHS Forth Valley (no community based HD Specialists) and NHS Tayside (no formal HD Clinical Lead). In response the minister, Maree Todd MSP, referenced

Huntington's and SHA, but did not appear to provide a commitment to assist with the service gaps highlighted. Supportive MSPs have agreed to assist us to follow this up.

In closing his contribution at Westminster Hilary Benn said "we must unite in our resolve to ensure that the families and their loved ones who have this appalling disease visited upon them have the support they need and deserve, regardless of where they live in our United Kingdom."

Amen to that. Scottish Huntington's Association will work with all comers to deliver that outcome.

Read the full Hansard transcript of the Westminster Hall debate at <https://bit.ly/HansardHD> or watch at <https://bit.ly/WestHDdebate>



Stuart dedicates marathon triumph to his late father

"I ran for my dad. He was funny, fun-loving, generous, wise, loving and loved and we all miss him."

"I ran for my mum and for my family. And I ran so the wonderful people at Scottish Huntington's Association can continue to support families living with Huntington's disease."

"But most of all, I ran for my dad."

Stuart Oag (49) from Aberdeen recently completed his first London Marathon in support of Scottish Huntington's Association. He rallied his family, friends, work colleagues and networks and has so far raised an incredible £12,000.

"My dad, Les, was diagnosed about 15 years ago. I guess we were fairly lucky as his symptoms started quite late in life. However, things went downhill quickly in his last two years. He seemed very young at 65, he was fit, loved to socialise and go to the football and remained pretty active right up to around age 70. But when he died, he looked a very old and frail 72 year old," said Stuart.

"As the movements came on Dad began to have trouble swallowing and there was a risk he would choke or vomit. His walking was affected and he used a wheelchair in his later years. It could be quite upsetting as those symptoms became more severe."

"Having said that we did just learn how to manage and were able to have two family holidays and many nights out together even when Dad was quite ill."

"I never heard Dad complain but it was very hard on him and my mum, Hazel,

especially on those occasions when the disease affected Dad's personality. Mum did an amazing job as Dad's primary carer and only towards the very end did he have to go into a psychiatric ward and then to a home to be cared for."

Les and Hazel were supported by an HD Specialist and a Financial Wellbeing Officer from Scottish Huntington's Association.

"We wouldn't have known where to start but thanks to Scottish Huntington's Association we had the help we needed. This included practical things like finding out about Carers' Allowance, the blue badge, respite care and getting a wheelchair," said Stuart.

"There was also emotional support for mum. She would speak to the HD Specialist about Dad's symptoms and just as importantly, about how she was coping."

Stuart, who had previously completed the New York Marathon, decided to dedicate this past year to training for the London event and raising money.

With the help of the charity's Income Generation Team he secured his place - then began telling everyone what he was doing and why.

"After setting up my Justgiving page and emailing people to let them know it was there and why, things just took on a life of their own," he said.

"It was overwhelming to see so many friends and colleagues donating and leaving messages of support. I heard from people I'd not been in touch with

for a long time and it's been great to reconnect."

On the day of the marathon, Stuart's family including mum Hazel (pictured above with Stuart), his wife Glenda and children Kirsty and Campbell, and his sister Julie and her daughter Ailsa arrived in London to cheer him on.

"Every few miles I'd spot them in their blue SHA t-shirts waving big inflatable bananas so I wouldn't miss them," said Stuart.

"The atmosphere was unbelievable and I was flying until mile 21 when my legs started to cramp. Then and there my priorities changed. I wasn't going for my best time, it became about finishing the last part of the race and doing everything to get there successfully."

"That's how I feel about Huntington's disease. My dad's life was flying along for 65 years, but in that final stretch he had extremely difficult things to deal with - much more difficult than a bit of cramp for an hour in a marathon! But with the support of his family and friends and with help from Scottish Huntington's Association he acknowledged his condition, did what he could to manage it and lived the best life possible until at age 72 Huntington's disease finally overtook him."

*Stuart is already training for the 2023 London Marathon. We have a small number of charity places left - email linda.winters@hdscotland.org for more information.

Services on the up in Dumfries & Galloway and Borders

Work to expand specialist services in the south of Scotland has received a significant boost.

We are delighted to report that, for the first time ever, NHS Borders has appointed joint dedicated HD Clinical Leads.

Dr Niall Campbell, a consultant liaison psychiatrist, and Dr Myles Connor, a consultant neurologist, are working together and with SHA to develop a full specialist service in the borders.

We are further delighted to report that Dr Campbell and Dr Connor have held their first clinic for HD families at Borders General Hospital in Melrose, which constitutes a significant breakthrough for families in the area.

In an additional positive development, we now have a full staff team back in place for our new specialist service in Dumfries & Galloway.

Dr Sarah Pickstock, a consultant in palliative medicine, and Dr Alison McKendrick, a consultant in rehabilitation medicine, replace Dr John Higgon as HD Clinical Lead further to his retirement.

They are joined by Claire White, who joins SHA as the Senior HD Specialist for Dumfries & Galloway.

We wish all of these colleagues every success in their roles, and will continue to work with them to develop and further expand services to families in the south of Scotland.



Sharing our knowledge at home and internationally

Our staff, trustees and family members have been sharing their insights, innovation and expertise at key conferences in Scotland and across the world.

Scottish Huntington's Association was represented at the Neuroprogressive and Dementia Network Annual Conference in Edinburgh in addition to meetings and events in Bologna, Prague and Florida.

In Edinburgh, Consultant Neurologist and HD Clinical Lead for Lothian Dr Peter Foley, Trustee Professor Louise McCabe and family member Trustee Gillian McNab presented to families, clinicians and researchers alongside delegates focusing on Multiple Sclerosis, Parkinson's, MND and dementia. On the same day, our Chief Executive Alistair Haw, Senior HD Specialist for Greater Glasgow and Clyde Sally Woolvine and National HD Specialist Jillian Foster were in Bologna at the European Huntington's Disease Network 2022 meeting where they caught up with trustees Dr Marie Short, Carolyn Craig and Dina De Sousa. Marie and Carolyn travelled to Bologna after accessing funding from the EHDN and met the remainder of costs themselves, while Dina was there on behalf of the European Huntington Association as a guest speaker.

"I was soon aware of how popular Scottish Huntington's Association is across the whole European network," said Sally. "People were very complimentary, even more so after seeing posters highlighting the impact of

the National Care Framework, our work to build support from parliamentarians for improved specialist services, and the value of our National HD Specialist role."

In Prague, SHA HD Specialist for Lothian Julie Wilson, student Rebecca Fleming, who is studying for an MSC in occupational therapy, and Edinburgh Napier University Professor Alison Porter-Armstrong were invited to speak at the European Pressure Ulcer Advisory Panel Annual Meeting.



Julie Wilson and Rebecca Fleming in Prague

Their presentation explored current evidence in terms of postural care and guidelines for seating and positioning in Huntington's disease.

Then just last month we were invited to showcase our work at the Huntington's Study Group meeting in Florida. Our posters were displayed at the venue while a short video and further information was shared via the conference app.

Free online postural care training is now available

Family members and carers are invited to a free Zoom 'coffee and chat' to find out how postural care can improve the lives of people with Huntington's disease.



People with Huntington's disease can experience changes in their body shape which may lead to pain and discomfort when lying or sitting down. It can also increase the risk of muscle contractures and reduce ability to have a safe position for eating and drinking.

By learning about 24-hour postural care, carers can help to improve comfort, reduce pain, aid sleep and improve the quality of life of someone with difficulties moving around or who has involuntary movements.

The 'coffee and chat' takes place on Tuesday 17 January at 7.30pm when you can also find out about new free online training in postural care. The four-week course will run each Tuesday morning for four weeks from 31 January, 10.30am to 1.30pm. Tutors include a specialist occupational therapist and carer consultants.

To register for the 'coffee and chat' or the online course – or both – email Leanne.Colston@pamis.org.uk. To have an informal chat to find out more, contact SHA HD Specialist Julie Wilson on 0141 848 0308.

"There are times when I feel like I'm drowning, I can't see a way forward"

In this article we meet John, whose wife Gillian is in the later stages of Huntington's disease. Together for more than 25 years, John has supported Gillian through the loss of her father and her sister and is now her full-time carer while also working from home.

We thank John for sharing, in his own words, what it is like to be a 24-hour carer at home, including the impact on his own health and wellbeing.

"A tiny bit of what was Gillian is lost every day as brain cells die. Occasionally she will say something funny or insightful which evokes memories of how she used to be.

"I am, essentially, mourning someone before they are dead. It's horrible. I have been, at times, exasperated, angry, upset and fearful, often all in the same day. I constantly think of my own worth - am I doing the best I can? Am I doing things correctly?"

"I have had illnesses on several occasions and become run down. I comfort eat all the wrong foods because at the time it helps, but only for that moment.

"I never consider going to the hospital when I'm ill because there's no one here for Gillian while I'm away. Social services, care providers and charities are of limited help if you have chest pains at 3am on a Sunday. I feel I have to beg and plead for help from care organisations.

"I can't relax even when I get some respite; the fear is always there that something will happen when I am away. There's also guilt at taking some time out for me.

"I never sleep deeply, I'm on constant alert in case Gillian needs help through the night. I'm constantly tired, which can make me irritable.

"When things go wrong, for example Gillian may have a toilet accident, a choking incident or a small series of little dramas, I can feel like I'm drowning because I'm not able to see a way forward.

"Knowing that others could be suffering as badly, or worse, isn't a comfort in those circumstances.

"I get annoyed, unfairly, at other carers who have a bigger support network, or those who are later in life when their partner's Huntington's disease kicks in. I feel they have had a major part of their life untroubled by the disease, at least in their own lives.

"That said, there is a countside, although sometimes it's hard to enjoy those times as they can be fleeting. When Gillian says something funny or when she hears something that makes her laugh with joy, temporarily relieving the 'Huntington's face' that is so common amongst people with the disease.

"When she is sleeping I see how peaceful and calm she looks. I remember her genuinely good nature and stories about her family, especially her dad, and the fun we had with our dog. There are many of these good times to remember and they can help balance things out, at least to a degree."

*Our HD Specialists provide practical and emotional support for carers. To find out about the help we provide please visit hdscotland.org

It's just brilliant to be back together!

“I felt like my heart was going to burst with pride at what we are doing!”

“Well that was quite a day! Thank you!”

“Past meetings have been great. This one has been the greatest. We go from strength to strength.”

“I got in the car and cried all the way home! We have hope again and no Christmas present will come near to that feeling after today. I am so, so grateful to be part of the SHA Family. Thank you, thank you, thank you!”

“Looking forward to the next Family Gathering! Fantastic day, I met and spoke to many new people.”

“Best conference ever!”



We received many, many wonderful messages after last month's Family Gathering which was attended by nearly 150 family members from across Scotland, trustees and staff.

It was truly wonderful day filled with hope, confidence, friendship and community, with attendees giving the event an overall rating of 9.8 out of 10.

Internationally-renowned speakers included global ambassador and former Emmy-winning NBC war correspondent Charles Sabine OBE who inspired families to be 'hidden no more' with his powerful address.

Professor Ed Wild, Associate Director of

University College London Huntington's Disease Centre and Editor in Chief of HD Buzz, blasted out the Star Wars movie theme before going on to explain how the search for a treatment can be likened to the sci-fi blockbusters, beginning with Star Wars: A New Hope and concluding with the wonderfully re-imagined Return of the Jedi.

Chief Executive Alistair Haw shared news about how we have gained the overwhelming support of MSPs at Holyrood for better services and the success of the joint campaign with HDA England and Wales and HDA Northern Ireland at the Westminster parliament. This includes an Early Day Motion and a key debate led by Hilary Benn MP in Westminster Hall.

He also unveiled Scottish Huntington's Association's ambitious five-year strategy and families were quick to share their ideas as we work together to increase awareness, expand specialist services across Scotland and create new opportunities to engage with, and influence, research.

Our final talk came from Sarah Mitchell, one of our Youth Ambassadors. Sarah, who lost her mum June in 2020, spoke movingly about her determination to raise awareness about Huntington's and how support from our Youth Service is helping her to cope with her loss while knowing she is at risk of developing the disease.

“Wonderful days like The Family

Gathering don't happen by accident. They happen because of the hard work, dedication and expertise of a fantastically talented team of people and the commitment and friendship of our trustees and family members,” said Chief Executive Alistair Haw.

“Our next trick is to build on this for next year. Improving on 9.8 out of 10 is a tough ask – but we're going to give it our best shot because we know how important it is to our families.”

*You can watch the presentations by Professor Ed Wild and Charles Sabine on our YouTube channel at https://www.youtube.com/channel/UCFhJ_Q5qLLsnrSWz95oKAKA



Charles Sabine OBE
Former NBC war correspondent and global Huntington's ambassador

“After 25 years of watching men kill each other I have seen how human beings lose their moral compass and social equilibrium when you take away dignity and hope. The HD community has survived because the very best of humanity surrounds it. It is in the darkest moments that the greatest quality of human spirit shines brightest and in doing so they give us all hope.”



Professor Ed Wild
Associate Director of University College London Huntington's Disease Centre, Editor in Chief of HD Buzz

“We're starting to see incredible scientific discoveries that we only know about because so many families are taking part in research. It is entirely possible that there are people walking around with gene therapy in their nervous system and that one of those people is experiencing the effects in their body of the first effective treatment for Huntington's disease.”



Sarah Mitchell
Scottish Huntington's Association Youth Ambassador

“I encourage more people to talk about Huntington's and how it affects them and their families. I know I can't miraculously raise worldwide awareness but no matter how big or small, if people put in a bit of effort, like taking part in a news article or chatting to someone about Huntington's, that really helps.”

With grateful thanks to our event sponsors:





Newly-weds Rachael and Graham face the future together after test result

It was when she first began to think about being tested for Huntington's disease that data analyst Rachael Steele realised she'd met the love of her life.



The 33-year-old from Hamilton wanted to plan for her future with Graham Cameron (37) but her fear was realised when the result came back positive for the faulty gene that causes the incurable condition.

"That was back in 2018 but I am still healthy and have no symptoms," said Rachael.

"One of the hardest things was telling my mum, June, who has Huntington's disease. It was devastating, much worse than when she found out about herself. It does take a toll on Mum but now we're getting on with things."

IT Specialist Graham added: "My heart sank when the test came back positive. I felt helpless because there was nothing I could do to change it, all I knew was that I have to be here for Rachael for whatever she needs."

Right from the start, the couple have been open with friends, family and work colleagues.

And when they tied the knot last year they ditched traditional favours and gave a Scottish Huntington's Association pin badge to every guest instead. Now Rachael has become more involved with the work of Scottish Huntington's Association as voluntary Chair of the recently formed Lanarkshire Fundraising Group. Its fundraising will go towards our HD Specialist, Financial Wellbeing and Youth Services.

"We're determined to raise as much money and awareness as possible and have regular online meetings. Our first event was a big Christmas fayre in Rutherglen," said Rachael.

"Mum and I both have Scottish Huntington's Association HD Specialists, and every group member has a connection with Huntington's disease, which means we all know how much families depend on the charity's services."

Trustee Marie takes on family role with EHDN

Family member and Trustee Dr Marie Short MBE has joined an influential European Huntington's Disease Network (EHDN) body that considers proposed research projects.

The EHDN Scientific and Bioethics Advisory Committee (SBAC) reviews research submissions, clinical trial protocols and applications for seed funding. Its members are drawn from across Europe and specialise in the fields of research, statistics, science, neurology and psychiatry.

Marie has a key responsibility as the only family member representative for Europe.

"My role is to ask 'how would a family member feel about this?' and to consider submissions from the perspective of the Huntington's community," said Marie, who has a background in science and regulatory affairs.

"It's a big responsibility and submissions are highly confidential. But it's important that the voice of family members is heard and I am excited to be part of the process."

Marie is following in the footsteps of fellow SHA Trustee Dina De Sousa who is stepping down from SBAC after six years. Dina, who was the first family/patient representative on the SBAC committee, has recently been co-opted to the EHDN Executive committee as the European Huntington Association representative.

"As a family member I thank Dina for her significant contribution to the work of SBAC and as a new SBAC committee member I am grateful to have had Dina's support and insights. I wish her all the best in her new role with the EHDN Executive," added Marie.

Carolyn: "I'm most proud of the support families now have"

Family member Trustee Carolyn Craig stepped down from our Board at the AGM in November after more than 14 years of dedicated voluntary service.



It was in 1979, when she was 18 and living away from home, that Carolyn found out her mum Christine had been diagnosed with Huntington's disease. As a family they set out to discover what, if anything, they could do.

"To try to find out about Huntington's Chorea, as it was called then, we wrote to the London Combat office in 1987. They forwarded the letter to Brian Smith, the Family Support Officer of the Association to Combat Huntington's Chorea in Glasgow," recalls Carolyn. "He posted out all the information he had. There wasn't much, it fitted into one envelope and there were no services to offer support."

"Then we heard that a branch of Combat was being set up in Elgin so a number of families met up to help each other and share ideas. It was a far cry from the Scottish Huntington's Association of today with HD Specialists serving most of Scotland, and its many other vital services."

After their mum passed away, Carolyn and her brother Hugh were both tested for the faulty gene that causes the disease. Hugh's result was positive and Carolyn, who tested negative, helped to care for him until his death in 2015.

As a Trustee, Carolyn's responsibilities included chairing our Short Breaks and National Welfare Grant committees and sitting on the National Care Framework for Huntington's Disease steering group. She also helped to strengthen our networks by attending EHDN conferences in Vienna and Bologna, accessing funding from EHDN as a family member and meeting the remainder of costs herself.

As Carolyn steps back from her formal role, she reflects on how far the charity has come in the past 20 years and the growing impact of our work. "We're the only Huntington's charity to support the whole family and we're at the forefront of innovative services, including the National Care Framework and the first National HD Specialist covering gaps in services. I'm most proud of the support Scottish Huntington's Association provides and its communication with families," says Carolyn.



Carolyn and Charles Sabine

"I might have left the Board but that doesn't mean I've left Scottish Huntington's Association. You won't see the last of me by any means and if anyone thinks I can help in any way, just get in touch."



Aidan clocks up 500 miles then celebrates with a free ice cream

Schoolboy Aidan Macgruer has smashed his 516 mile bike ride in support of families affected by Huntington's disease.

Back in January 2022 the eight year old challenged himself to complete a virtual North Coast 500 by cycling through Thurso and surrounding countryside. He gave himself a year to do it - then powered to the finish line five months early, collecting a whopping £1800 for Scottish Huntington's Association along the way.

Friends and families gathered to cheer Aidan on to the finishing line, which was conveniently set outside an ice cream shop where he was presented with his favourite ice cream treat.

"I've loved it," said Aidan. "Everyone was very supportive and I got plenty of waves and cheers when I was out on my bike. They all knew I was raising money for Scottish Huntington's Association and I received loads of donations from people I've never even met."

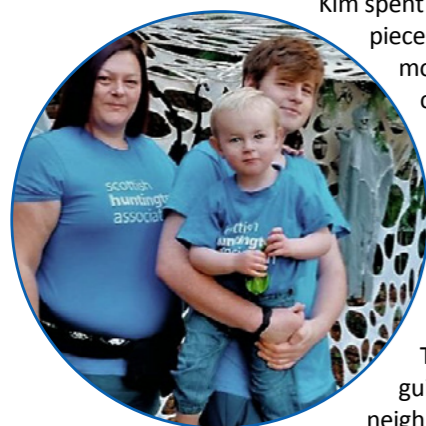
"There were days when the weather was bad and I wasn't keen on going out but I was determined to keep going. I was stung by a wasp one day and another time I fell off my bike on a dirt track. But my mum, dad and stepdad all encouraged me by coming out on their bikes too."

Mum Debbie said: "Aidan has really enjoyed having people cheering him over the past eight months. It's been an adventure for the whole family and we're all incredibly proud of him."

Family's ghostly garden is a hit with 500 visitors

The Herkes family went all out on the spookiest night of the year to raise money in support of families affected by Huntington's disease.

Mum Kim (35), dad Colin (39) and Aaron (17), Jayden (14), Logan (5) and Jaxon (2) turned their back garden into a haunted horror fest with zombies, vampires, skulls, pumpkins and scary skeletons lurking in the shadows.



Kim spent months creating the models out of bits and pieces found around the house, paper mache and modelling clay. Then after she had brought the creepy characters to life, Colin and the boys got stuck in to display them around the garden. On the night things were made even more terrifying with added smoke, scary music, and spiders' webs along with nice surprises including sweetie stations, a juice bar and hot drinks for the grown-ups.

The family was hoping for around 100 guisers but news spread far and wide through neighbouring streets and across Edinburgh – and more than 500 people turned up!

"It was fantastic," said Kim. "One group of kids who had been out trick or treating had me close to tears - they had made a few pounds each from other houses and they came to us and donated it all. I hoped to raise £500 but we ended up collecting more than £2500. We had lots of people asking why we chose Scottish Huntington's Association and we explained that Huntington's is in our family. Some folk had never heard of Huntington's before but now they know all about it."



Kim's gran, who was diagnosed with Huntington's around 10 years ago, is supported by a Scottish Huntington's Association HD Specialist.

"We first began to notice changes when Gran's behaviour changed. She would become very angry, very quickly and be quite aggressive. She thought there was nothing wrong but her arms were jerking and her speech was affected. Now it's becoming more difficult for her to talk and her memory is deteriorating," said Kim.

"My mum tested negative, which means I'm not at risk and neither are our boys, but our wider family is affected. It must be terrifying to have the disease and to know that you're losing yourself, and it's awful to watch that happening to someone you love."



Shona Cumming, Pete Carruthers and Julie Wilson from SHA

Charity partner hosts World of Work day

We had a wonderful World of Work day with charity partners Grant Thornton Scotland who are helping to boost the employability skills of our young people.

After a fun quiz and a tour of the Glasgow office building to break the ice, five young people got down to the serious business of taking part in mock interviews, client meetings and working together as a team to design a new product – the wonderfully named Starbot.

Thanks so much to staff at Grant Thornton Scotland for their support.



Elise holds her first 'book and bake'

Ten-year-old Elise Harris – niece of Senior HD Specialist for Tayside Paula McFadyen – put her talents to good use by setting up a bracelet, book and bake stand in front of her house. In no time at all Elise had raised £15 for SHA and lots of awareness with passers-by. Thank you Elise!

37 young people awarded bursaries

The Scottish Huntington's Association Bursary Scheme has granted awards to 37 young people since the summer to help with employment, training and education.

The Hyman-Robertson-funded grants are running for the second year and aim to support young people growing up in Huntington's families to reach their full potential.

This year's awards of between £100 and £250 have been distributed through our Youth Service.

Every gift helps to change lives

Leave a message under our tree this Christmas

This festive season you're all invited to leave a gift with a personal message under the Scottish Huntington's Association tree!

Many people choose to donate to charity at Christmas and we'd be grateful if you would consider giving to Scottish Huntington's Association.

Every donation helps to make happen the work you've been reading about in this magazine. Our HD Specialists, Youth Advisors and Financial Wellbeing Officers are here for all Huntington's families, supporting carers struggling to cope with their loved one's illness, easing the concerns of young people and helping families to manage household bills and other money worries.

Only Scottish Huntington's Association has the expertise, networks and commitment needed to make every day better for families facing the challenges of this devastating and incurable disease.

Simply make your donation, leave a message and we'll do the rest! You'll receive an email to let you know when your gift is in place.

Thank you!



Visit hdscotland.org/christmas to leave your donation and message

SHA's Fundraising Calendar of Events 2022/23



Running events

London Marathon
Sunday 23 April 2023

**Edinburgh Marathon
Festival**
27-28 May 2023



Take on an adrenalin challenge

Skydive
St Andrews
Saturday 9 September

Wingwalk
Yorkshire

Sharkdive
Queensferry



Dance 100 2023!

Register your interest today. Dance 100 will take place during Huntington's Disease Awareness Month 2023. 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

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. 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

Walking events

Winter Ben Nevis Weekend
11 March – 13 March 2023

**West Highland Way
Challenge**
6 May – 14 May 2023

Three Peaks Challenge
Multiple dates

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!

