

SHAre



Scottish
Huntington's
Association

Specialist support for Huntington's disease families

Winter 2023

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Scottish Huntington's Association
Issue No.101



Together we're reaching new heights for Huntington's families

Welcome from our Chief Executive

Earlier this year a major survey revealed a staffing crisis across the charity sector. It found that more than half (54%) of charities have vacancies and more than four in five (83%) are finding it difficult to recruit.



Such challenges are by no means unique to the charity sector, or to Scotland. They apply UK wide, and across all sectors. The manner

in which our entire community has galvanised and marched forward with steely determination in the face of such powerful headwinds should be a source of great pride for everyone.

The Family Gathering provides one perfect case study. Colleagues from all parts of the HD community, and from all over the country, rolled their sleeves up for the common weal. It was the



very definition of a team effort. The outcome: our best attended Family Gathering ever, with a family attendee rating of 9.8 out of 10. Quite a day!

Other examples are to be found throughout this newsletter: one of our HD Specialist teams being rightly recognised at prestigious national awards; action packed (if chilly looking!) youth activity days; the launch of an eye-catching winter fundraising campaign; a visitation and praise from a key figure from the US Huntington's community, to highlight only a few.

To top it all off we secured two of what were arguably our best pieces of national media exposure to date.

First came our wonderful ambassador, Robbie McNab, on BBC Scotland's *A View from The Terrace*. Then younger members of our community captured the hearts of the nation on ITV's *Tonight*, the most widely watched current affairs programme in the UK. Watch on STV Player, *Tonight - Young Carers A Hidden Crisis*.

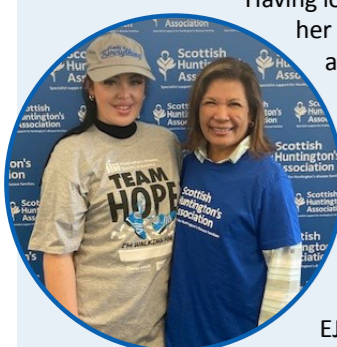
Read on for more inspirational stories from across your SHA community. One such item concludes with a plea to "stand tall together" for "our platinum standard charity." There is clearly no shortage of people doing the former, resulting in the latter becoming an increasingly accurate description.

As we head into our 35th anniversary year, we look forward with confidence to building upon the work of the previous 34 for the benefit of every Huntington's family throughout the country.

Alistair Haw, Chief Executive

US activist praises our work

Huntington's disease advocate EJ Gardner from Seattle visited our National Office to find out more about the specialist services provided by Scottish Huntington's Association.



Having lost her former husband and her son to Huntington's disease, and her grandson to Juvenile onset Huntington's disease, EJ's life mission is to support the Huntington's community by building awareness and raising funds to support education, family services, research and clinical trials.

EJ was in Scotland to take part in a fundraising walk of the West Highland Way in support of Huntington's Disease Society of America (HDSA). A member of the leadership team of HDSA Washington State Chapter, EJ also sits on the Executive Membership Committee with the Huntington's Study Group.

"I tell my story to anyone who will listen," she said. "I follow Scotland Huntington's Association on Facebook and see how active your community is, which is why I wanted to reach out."

Accolade for HD Care Team

Huge congratulations to the NHS Greater Glasgow and Clyde Huntington's Disease Integrated Care Team for reaching the finals of the Scottish Health Awards 2023.



As the most prestigious and recognised celebration of those working across NHS Scotland and its partners to deliver high quality health and social care services, the awards recognise those that go that extra mile.

With over 900 nominations received across all categories, the Huntington's Disease Integrated Care Team reached the final three in the Integrated Care Award.

Senior HD Specialist Sally Woolvine said: "This nomination helped me to reflect on the value of our commitment and development of the collaborative approach to our interdependent work with people with Huntington's disease.

"It underpins the importance of our ongoing work and the necessity of continuous improvement, and inspires us to keep pushing the boundaries of what we can achieve together for families living with Huntington's disease."

Robbie: "I know it will come for me eventually, but not this day"

Cowdenbeath FC Captain Robbie McNab has no regrets about opening up on TV about how he will one day develop Huntington's disease – in fact it's only fuelled his determination to do what he can for other families.



Robbie, 27, was in his early 20s when he tested positive for the hereditary faulty gene that causes Huntington's. He chose to share his story for the first time on the BBC's *A View From The Terrace* football show to raise awareness about the disease and the work of Scottish Huntington's Association.

Robbie even persuaded mum Amanda to appear alongside him and together they told a powerful and moving story about the impact of Huntington's, including the toll the disease has taken on Robbie's dad, Alan, over the years.

"Huntington's disease takes its toll on whole families and relationships. I see what's happening to my dad as his symptoms progress – he was always an 'up and at it' kind of person but it's becoming more difficult now," said Robbie.

Before the broadcast only those closest to Robbie had been told about his test result – none of his 'Blue Brazil' teammates, the club coach or fans knew anything. It sparked a massive swell of support for the player, his family and the Huntington's community on social media, in the press including the Daily Mail and The National, and on online news sites across the country.

"The reaction has been overwhelmingly positive," said Robbie. "Within days I had about 300 messages, including some from people whose lives are also affected by Huntington's disease."



The short film – which takes its title *Time Is Precious* from Robbie's outlook on life, also shows Robbie taking on skydiving and paragliding, and an incredible endurance challenge as he runs up the UK's highest peak Ben Nevis to raise money for Scottish Huntington's Association and spread awareness.

Super fit Robbie – who co-owns the OWNIT gym in Falkirk - took just one hour, 37 minutes to scale the 1,345 metres to the top – then only 53 minutes to get back down, raising more than £2,500.

He was delighted to learn that, just days after the film went out, a Cowdenbeath fan whose family is also impacted by Huntington's disease was so inspired that he donated a further £2,500.



Robbie's mum and dad, Alan and Amanda

Robbie said: "Since testing positive I haven't taken my mind or my body for granted. I enjoy myself but have a much healthier lifestyle to stay as fit and as strong as possible. Life's short and mine could be shorter in terms of quality. I also feel that exercise is a privilege and I want to make the most of it while I can.

"Sarah Winckless, Patron of Scottish Huntington's Association, is a big inspiration and after meeting her I'm more convinced than ever that having a healthy lifestyle can make a difference."

"Time isn't just precious for people with neurological diseases, it's precious for everybody. I know it will come for me eventually, but it's not this day."



Sarah and Robbie

Alistair Haw, Chief Executive Officer of Scottish Huntington's Association, said: "We are hugely grateful to Robbie who has made it clear that this is only the beginning. It is wonderful to know that he is keen to do even more for our community as he is a great ambassador for our cause.

"To see someone like Robbie talking on television about his own situation will inspire many people to learn more about this devastating condition, and that will make a huge difference to the families we support.

"The money he has raised is helping to ensure that every Huntington's family access to the specialist support provided by Scottish Huntington's Association. The awareness he is raising is priceless."

You can watch Robbie's film on the first episode of this season's *A View From The Terrace* on iPlayer or on the BBC website – or just search his name online and hit 'news'.

Lauren's glitzy SHA ball takes funds raised so far to more than £35,000

There's no stopping Lauren Boag when it comes to making sure Huntington's families, including her own, have access to the specialist services they need.



The 37-year-old volunteer fundraiser from Inch has raised more than £35,000 so far, boosting her total by a further £6,053 from her annual Scottish Huntington's Association fundraising ball which was held last month.

Lauren spends months organising the glitzy event, including gathering donations of amazing prizes which raise even more money.

Tickets sell out every year to guests including family members, locals, friends, work colleagues, and corporate supporters.

Married to Craig (35), Lauren tested positive for the Huntington's gene when she was expecting their first child Eva, who is now eight. The couple also has a second daughter, Sienna (5).

"My gran was diagnosed, my mum soon after, and I had started the testing process when I discovered I was pregnant," said Lauren.

"The positive result was like getting hit with a brick and it was very hard on Craig. But we look after one another, especially during the tough times when I wasn't in the best place mentally. It took time to turn things around and create something positive for us to hold on to."

Lauren began fundraising in 2018 – and since then the Boag family has been all in, from Kiltwalks to dinner-dances, sold-out psychic nights to bridge swing challenges.

"The girls love doing the Kiltwalk every year, and Eva says she enjoys doing something to help her grandma," said Lauren.

"We're open with them about the disease but right now we're living our best lives and having fun. That doesn't mean I don't worry.

Thinking about the symptoms can keep me awake at night. I dread losing my spirit or precious memories and it's upsetting knowing what people in our family go through because of Huntington's.



"Sometimes I have a cry to try to get it out of my system. Then I put myself back together and focus on the positive; I have hope that there will be a breakthrough by researchers to find a treatment."

"Dad says he'd be lost without Scottish Huntington's Association, especially as Mum's symptoms have progressed.

"People ask why I put so much energy and time into the ball and other fundraising events. I think it's because Huntington's disease takes things out of my control, while doing what I can puts some control back into my life."



Team heads over the sea to Skye

Huntington's families, health and social care professionals, and members of the wider public were invited to an information session organised by our Highland services in Portree on the Isle of Skye.

The event was hosted by Lorraine Watson, Senior HD Specialist; Emma Pollard, Financial Wellbeing Officer; Jenny Bruce, Specialist Youth Advisor; and Patricia Cattrell, Team Lead.

"There are several families living with Huntington's disease on the Isle of Skye and we held the session to bring those families together in an informal and supportive setting to meet all the members of the Highland service," said Lorraine.

"We encouraged questions and suggestions as to how we can best support people living in this rural community. The invitation was extended to the wider community including professionals as an opportunity to raise awareness, answer any questions and offer informal education."

Join #TeamSHA Kiltwalk stars

Our 52 #TeamSHA Kiltwalkers clocked up the miles all over Scotland this year and raised over £14,000 between them. Thank you!

The 2024 dates have been announced – and you can sign up for the Glasgow and Aberdeen Kiltwalks now.

- Glasgow – 28 April 2024
- Aberdeen – 2 June 2024
- Dundee – 11 August 2024
- Edinburgh – 15 September 2024

Get started by emailing fundraising@hdscotland.org for your Team SHA fundraising pack and your code for 25% off the registration fee!



Help Huntington's Families For Generations...

You have the power to help families living with Huntington's disease this winter.

You can help Scottish Huntington's Association to provide the essential specialist services that people need to cope with the challenges of Huntington's disease in 2024. For those without support, the realities of living with Huntington's disease can devastate the wellbeing of everyone in their family, for generations.

At Scottish Huntington's Association, we understand the challenges our families face every day. Our expertise has been trusted by generations of families for over 30 years who rely on the long-term support of our HD Specialists, Specialist Youth Advisors, and Financial Wellbeing Officers.

We're supporting people with the condition who may be losing their ability to walk, talk, eat, drink and care for themselves. We're supporting their family members who care for them and may struggle to help their loved ones manage the complex and severe symptoms they experience. We're supporting young people who are growing up around Huntington's disease while knowing they have a 50% risk of inheriting the condition.

Every member of the family deserves our support when coping with Huntington's disease and we simply wouldn't be able to do the work we do without the support of incredible people like you.

By donating to this appeal...

- You can ensure we are there to provide expert and personalised support for everyone in Scotland impacted by Huntington's disease.
- You can help alleviate wellbeing risks to children and young people living in Huntington's families.
- You can assist the Huntington's community to connect through events such as our free annual Family Gathering.
- You have the power to help improve the lives of families impacted by Huntington's disease today and the days to come.



"Scottish Huntington's Association has been in my life since I was 12 years old. My Specialist Youth Advisor helped me through the testing process, before and after, and I'm still in touch with Pete who works with young people in Fife and Lothian. He's been my rock over the years

and supported me last year when I was struggling with Dad's death.

"I went to camps, family gatherings and days out, and have shared my experiences one-on-one with people about the HD testing process. The charity has been a constant in our lives and I hope for it to continue that way."

Suzanne Armit, 30, Rosyth

Ways to donate

Online:
Through our website at <https://hdscotland.org/winter-appeal/> or our JustGiving page at <https://bit.ly/SHAWinterappeal>

Phone:
0141 848 0308 (Mon to Fri between 9.30am & 3.30pm)

Bank Transfer:
Scottish Huntington's Association
Bank of Scotland
Sort code: 80-16-53
Account number: 10056968

Cheque:
Please make your cheque payable to: 'Scottish Huntington's Association' and send to:
Scottish Huntington's Association, Business First, Burnbrae Road, Paisley PA1 2FB
Please use the reference Winter Appeal

Hitting the right note with Family Gathering



Sarah and family members share their experiences

What an amazing day! Our Family Gathering brought together 150 family members, trustees and staff to be inspired, meet friends old and new, share experiences and sing!

Our wonderful Patron Sarah Winckless MBE set the tone by telling her story and why she feels compelled to use her voice to raise as much awareness as possible. Opening up about what it was like to grow up watching her mum's behaviour change as symptoms progressed, Sarah spoke about the difficulties it caused in their relationship. It was only when she started at university that Sarah really began to understand what was going on.

"I was studying psychology when I heard the words Huntington's disease. It was a huge relief to really know what was happening to mum's brain, it all made sense. We were able to repair our relationship because of that knowledge and I was able to be more patient and understanding," said Sarah.

"Before then I wasn't grateful for her or for all she was doing for me. I didn't have the language, the understanding, or a community like this to help me understand."

It was later – after the glory of the Olympic Games – that Sarah found her voice to really talk to people about the disease,



Sparking conversations amongst families

including those close to her. With her family's support, she chose to use her profile as a Double World Champion and Olympic medal-winning rower in support of the Huntington's community.

It was the first step in a journey that led Sarah to become one of the world's leading ambassadors in our community – and our Patron following her retirement from rowing in 2009.

"Finding my voice and allowing others to speak to me and with me has made a huge difference. It is hard but we are stronger together and that can only amplify our voices," said Sarah.

Sarah was joined on stage by trustees Margaret Moncrieff and Derek Brady, and Youth Ambassadors Natalie Hall and Zoë Green for a frank and emotional discussion about how Huntington's disease has impacted their lives and why it's important to talk about it.

After lunch, which included plenty of time for people to catch up and have their own conversations, family members attended interactive workshops.

Caring For Carers was led by Senior National HD Specialist Jillian Foster with Carley O'Hare and Keri Moore from Stirling Carers Centre; Telling People About Huntington's Disease by Senior HD Specialist Paula McFadyen, HD Specialist Lindsay Wilson, and Communications Lead Roisin Eadie; and the hugely popular singing session, Let's Make Some Noise by choir director Jonny Graham.

This year's Family Gathering scored a near-perfect 9.8 out of 10 from families in their feedback. Thank you to all who responded – your responses are already helping us to plan the next Family Gathering, which will mark our 35th anniversary year.



Pitch perfect workshops



Let's Make Some Noise



Having fun with friends



"As always, amazing! I had a brilliant, emotional day - it hits home! But honestly SHA, from the depths of my heart - THANK YOU xx"

"LOVED the choir. After a morning of talks, it was great to feel the power of doing something as a community."

"What a beautiful event. As always you guys think of the details that matter, like the snack packs and sweeties on the table. I just love those details. Thanks again."

"Excellent conference as always, thanks to all involved."

"The conference was amazing. I chatted to lots of new people and met new friends. Well done to all the staff."

"Workshops were a great addition - great discussions were had."

"I took a lot from other people's personal experiences."

"I really appreciate the opportunity to speak to staff and family members on an informal level."

"Workshops were different class especially the singing class - X Factor here I come!"

"Make Some Noise - brilliant, just what people needed to the end of the day. Great to see more people involved. Meals well thought out. So good to meet new members, family stories, brings back so many memories. Thanks to all the staff for their dedication each year."

"Good workshop topics and a great way of sharing stories. Well directed by the team. Really enjoyed the new format to allow mixing and discussion."

"Overall I thought it was one of the best SHA events I have been to."

"These events just keep getting better and better every year."

“Julia is a very strong woman and her smile gives me the strength I need”

During our Family Gathering, trustee and family member Derek Brady shared his experience of caring for Julia Stronza, his partner of 36 years and adored mum to their three children. Here he tells us about changes in their relationship as Julia’s symptoms progressed, the impact on their family, and how love endures nearly 40 years after falling head over heels on the dance floor.



“In 1987, when I was working in Kent, I went to a new club and there was Julia on a nurses’ night out. I saw this beautiful vision with Cindi Lauper big hair bopping about like a daft thing, my heart went boom and that was it. We fell in love, moved back up to Fife and started our life together.

“Julia was a bank nurse at the Western General for a while then moved on to work in a care home in Kirkcaldy. We have three children – Jordan, a mum of two wonderful children who has followed in her mum’s footsteps by becoming a nurse and who has her own aesthetics clinic; Clara who is mum to a gorgeous wee one-year-old girl and a regional manager with the Nationwide; and our free spirit Cameron who is taking life by the horns, travelling and working all over the world. He’s very sporty, entrepreneurial and is settled in the French Alps with his wife.

“I’m extremely proud of them – they have real strength, caring natures and a work ethic that comes from Julia. They had a great childhood; Julia welcomed all their friends to our home and was always great fun and very sociable.

“But around 2006 I began to see changes - Julia was so gregarious, very active and good at getting people together. Always dancing, we called her the dancing queen. But she was losing some of her grace; her poise was going and I could see what was happening. Julia knew too because we’d seen it happening to three of her brothers.

“In 2008 Julia tested positive for Huntington’s disease and that was when we first engaged with Scottish Huntington’s Association. Senior HD Specialist Jillian Foster came into our lives, a wonder woman warrior who stopped at nothing to make sure we always had the information and support we needed.

“We didn’t talk about the diagnosis to the children for a long time, and that’s something I regret. They wish we had pointed them in the right direction sooner, especially as they had seen the road their three uncles had gone down. But it seemed too difficult for them to know their beloved mum faced the same.

“Julia decided to stop working in the care home and that set her back psychologically, but never one to give up she went to work in Asda on the tills. She enjoyed that because she was using one of her great skills, the ability to speak to people and connect with them.



Julie and Derek met at a nightclub in the late 80s

“Julia was adamant that she didn’t want anybody to know. There were times when people in the village would talk about her because they thought she was drunk and that wasn’t very nice to deal with. Then a neighbour with a professional background in mental health asked me straight out if Julia had Huntington’s disease. I said yes – and it was one of the worst things I ever did. It wasn’t my place to tell people, it was Julia’s.

“When Julia found out the confidence was breached, our relationship deteriorated badly. I became the sole focus of her anger, but Jillian explained to me that it was the disease, not Julia, and reassured me that it may pass. Jillian was right, it did pass, and she was still my Julia from 1987.

“There was the stubbornness so often associated with Huntington’s disease, for example a real resistance over having to stop driving, and OCD developed. I’d be dragged out of bed at 2am to check the gas rings and electric sockets or the doors were locked. This could take two hours a night. I can laugh about it now but at the time it was very hard.

“When it’s someone you love and have spent most of your adult life with, it’s extraordinarily hard to help them with personal care and feeding. But throughout that period Julia maintained her chirpiness and continued smiling her beautiful smile. Julia’s symptoms progressed, and we had council appointed carers in four times a day but there was a high turnover of staff and many were badly trained or not used to working with people with Huntington’s disease.

“Then when Julia developed a series of UTIs she became so dehydrated that delirium kicked in. One evening Julia kept demanding and demanding water, she was obviously uncomfortable, and I just lost it and swore at her. That stuck with me for ages, there’s a great deal of shame felt by carers.

“Julia’s base line had dropped dramatically, and this led to the most difficult day for our family when we had an arranged call with the Scottish Huntington’s Association Fife HD Specialist team, our social worker, and the HD Consultant. We had resisted the idea of a care home and were doing our best to look after Julia at home. But it wasn’t to be, Julia had to be safe at night and needed to be looked after by a team.



Enjoying a family day out

“Jillian helped us through it and was a great comfort to all the family. I was ashamed because I believed I’d let everyone down and was in a dark place, despite great support from my family and close friends. We are all very close, but I know that isn’t the case in every Huntington’s family. It’s the support from both my immediate and Julia’s extended family that gets me through a lot of stuff.

“It also helps to listen to people who are in similar situations, whether it be Huntington’s or those whose loved ones have other conditions. And you need specialist support, which is where Scottish Huntington’s Association comes in.

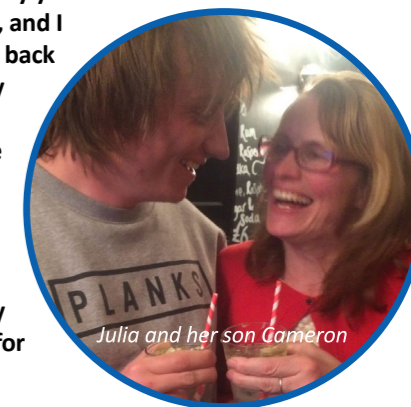
“Scottish Huntington’s Association has been outstanding for us as a family. Fate brought us to Fife because I know that Julia’s brothers and their families didn’t have nearly the same level of support and care in other regions of the UK as we have in Scotland. The charity has steered us through everything, including when Cameron was supported by the Youth Service and help from the Financial Wellbeing Service with filling in forms related to the care home.



Julia and her daughters

“I’m semi-retired now and spend most afternoons with Julia. She loves it when the grandchildren visit and when we take her out for the day. I know she is well looked after and settled, so life is calmer.

“For the first time in many years I have time on my hands, and I want to give something back to help make sure every family has the support they need. So I became a Scottish Huntington’s Association trustee last year and am so proud to be part of this organisation, to play my part and do what I can for the community.



Julia and her son Cameron

“We can trace Huntington’s disease in Julia’s family back to the 1930s, to her grandad Cecil who died in a traffic accident during World War 2 in occupied Jersey.

“Our family story is full of strong women, including Julia’s grandma who brought up four children during the German occupation of the Channel Isles in WW2. Julia’s mum, Eileen, brought six kids back to the UK from Puerto Rico after the breakup of her marriage to Julia’s dad and raised them brilliantly before succumbing to Huntington’s disease. My sisters-in-law Julie, Ginny and Tonita who battled on caring for their husbands and brothers. My daughters and daughter-in-law, Jordan, Clara and Laurane who inspire me every day. The superb HD Specialist team in Fife. The strongest women I share my life with and ... Jools... whose beaming smile gives us all strength and resilience.

“I have worked in the medical device industry for many years and fully understand all the regulatory challenges the research and development communities need to overcome. I truly believe there will be a day when Huntington’s disease is a footnote in medical journals.

“Until that day we need to continue to raise awareness of Huntington’s disease, Scottish Huntington’s Association, our platinum standard charity, and STAND TALL together.”



Derek and Julia are together every day

Moray branch helps families by growing support amongst locals

Members of our Moray Family Branch have been raising awareness in their community and helping local Huntington's families by campaigning and raising funds, while supporting families, including carers.

It recently received a donation of £500 from Baxters of Fochabers after being nominated by employee Lindsay Dewar.

"A huge thanks to Lindsay and all the staff at Baxters for their hard work collecting for local charities – well done to everyone involved, you are a credit to the company," said Jock Anderson, Chair of the Family Branch.

"Our collection tins also continue to bring in much needed funds and we are grateful to local businesses Decora, Hopeman Post Office, Spynie Stores and Lhanbryde Store for their continued support."

Funds raised help the Branch to support local families, which includes the offer of a new free First Aid training course for carers and loved ones of people with the disease.

"Earlier this year one of our members was faced with a very scary incident when caring for her sister who has Huntington's disease. Her sister choked really badly while eating her lunch and this was as you can imagine a traumatic experience for both of them," explained Jock.



"Luckily someone with First Aid training stepped in and came to the rescue. When this was brought up at one of our meetings it was then decided to offer any carers the opportunity to take up a First Aid training course, funded by the group.

"Jackie Lewis, our secretary, has now organised the course. We have a number of members booked up. It will take place in Lossiemouth in January 2024. People can find out more on our Facebook page." Search Moray Huntingtons Disease Support Group on Facebook.



Youth Service blends learning with fun activities

It's been an extra busy time for the Youth Service which held a group activity day for young people 8 – 12 years old followed by a residential trip for those aged 13 – 17 during the October week school holiday.

Ten young people took part in the group activity day in on Monday 16 October. The morning session focused learning about the lobes of the brain and linking these to symptoms that develop in people with Huntington's disease. In the afternoon the young people enjoyed a pizza lunch and 10-pin bowling.

The residential trip to Dunbar from Tuesday 17 to Thursday 19 October was attended by 12 young people. Group work concentrated on mental health and wellbeing, using a fun balloon bursting game to promote sharing of coping strategies. Activities included trampolining and a visit to Foxlake inflatables for a high speed Ringo session.

The team received great feedback, including: "It helped me with ways in which to improve my mental health. We learned how it can be changed by doing simple things such as walking and self-care, and getting support such as this trip."



Margaret and her friends complete 12th Walk of Hope

Congratulations to family member and trustee Margaret Moncrieff on the success of the 2023 Walk of Hope.

This year Margaret was joined by supporters from Erskine, Langbank and Wales, with Gemma Powell and Linda Winters from our Income Generation team also taking part. Together the walkers have raised more than £1,250.

"This is a great result. The funds go to support the HD Specialist services which provide visits to families in their own home. With this long running condition the service of HD Specialists is vital," said Margaret.

"We are immensely grateful for all contributions."

Sky's no limit for #TeamSHA

High adrenalin challenges delivered by our Income Generation team have boosted funds by more than £8,000.

Our super-brave volunteer fundraisers took part in a skydive in Fife and a thrilling zipline ride over the Clyde, raising funds and awareness along the way.

Special congratulations to our most senior zipliner Hugh Heath who dedicated his 80th year to fundraising for Scottish Huntington's Association.

*Are you up for a turbo charged challenge in support of Scottish Huntington's Association? Email fundraising@hdscotland.org for more information.



Zipline superstar Hugh Heath

SHA backs Changing Places Toilets campaign



Scottish Huntington's Association has signed an open letter from TIG (Tyndrum Infrastructure Group) to the First Minister of Scotland, Humza Yousaf.

It is calling on the Scottish Government to meet the commitment (£10 million pledged in 2021) to increase the number of Changing Places Toilets in Scotland and support mobile Changing Places Toilets to enable people with disabilities the dignity to go to the toilet when accessing events, outdoor venues or having a day out around the country.

The charity was inspired to get involved by campaigner and SHA Admin Assistant Kim Kemp, pictured left.

Changing Places Toilets are larger fully accessible toilets for people with disabilities who cannot transfer from wheelchair to toilet. They have equipment, such as ceiling track hoists, shower facilities, rise and fall sinks, modesty screens, adult-sized changing benches, a mirror and adequate space for powerchairs, and carers.

The letter from TIG was also co-signed by national and local charities across the country. These include Parkinson's UK, Scottish Autism, Neurological Alliance of Scotland, Cerebral Palsy Scotland, MND Scotland, My Name's Dottie Foundation and Capability Scotland.

Find your fundraising event challenge

March

Supernova Kelpies Run

Friday 15 - Saturday 16 March 2024, Falkirk

April

Glasgow Kiltwalk

Sunday 28 April 2024

May

Edinburgh Marathon Festival

Saturday 25 and Sunday 26 May 2024

- › Edinburgh Marathon
- › Edinburgh Half Marathon
- › EMF Hairy Haggis Team Relay
- › EMF 5K & EMF 10K
- › EMF Junior 1.5K & EMF Junior 2K
- › EMF Kids Kilometre

June

Aberdeen Kiltwalk

Sunday 2 June 2024

Three Peaks Challenge

Friday 12 June 2024, Scotland, England and Wales

Tough Mudder

Saturday 15 June 2024, Dumfriesshire

#TeamSHA Skydive Challenge

Saturday 29 June, Fife

August

Dundee Kiltwalk

Sunday 11 August 2024

Scottish Half Marathon

Sunday 18 August, Edinburgh

September

#TeamSHA Zipline Across The Clyde

Sunday 15 September, Glasgow

Edinburgh Kiltwalk

Sunday 15 September 2024




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

Your communication preferences

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

Scottish Charity No: SC010985

Patron: Sarah Winckless MBE, Olympic Medallist

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