

# SHAre

Spring 2022

scottish  
huntington's  
association

The Magazine of Scottish Huntington's Association  
Issue No.96



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Dance 100 brings everyone together in support of HD families

# So much has been achieved by trusting and empowering our amazing staff, trustees, families and supporters

**As I reach the milestone of my first year as CEO I thought it sensible to have a look back at the things I boldly claimed I would seek to do on taking on the post. To that end I somewhat nervously opened the slides I presented to the interview panel as I made my pitch for the role.**

I don't propose an excoriating self-analysis here (perhaps next time...), but I was reminded of an advisory quote that featured within my application: "The role of a CEO is not to have all the ideas. It's to create an environment where all ideas can be heard, and

to ensure the best ones win." As I look back on the many successes of the last 12 months I can see the wisdom of that quote in practice - for so much of what has been achieved has been through trusting and empowering the instincts, ideas and skills of our amazing staff, trustees, families and supporters.

Our record breaking Scottish Parliament motion calling for an expansion of specialist HD services was delivered by the determined lobbying of our supporters. Our highest ever annual income was achieved by all staff and supporters working together under the expert guidance of

our Income Generation Team. The introduction of new HD services came about as providers caved in under pressure to follow the examples of excellence provided by our existing services throughout the country. And you only have to survey the contents of this latest edition to see further examples of all the fantastic work being delivered to advance the cause of HD families throughout Scotland, ideas that came from our families and supporters themselves.

So as my second year as CEO gets under way, I thank you all for everything you have done to ensure my first ended with so many

successes to celebrate. I look forward to seeing this year's winning ideas as they develop, and to celebrating their successes as they work their magic for HD families.



Alistair Haw, Chief Executive

## Aarran joins our Board of Trustees

**Aarran Air, family member and Financial Controller at Cairn Energy, has been appointed as Treasurer on the Board of Trustees.**



Having worked in senior finance and commercial roles in the UK and internationally for more than 30 years, Aarran brings specialist finance knowledge in addition to personal insights and experiences of Huntington's disease and its impacts on family members.

Last year, Aarran helped our Income Generation Team to secure funding of more than £12,600 from Cairn Energy Trust, the charitable arm of his employer.

"Huntington's disease has impacted at least three generations of my family. I have seen the tremendously positive impact Scottish Huntington's Association can provide in support of those affected by the disease first hand, and also in trying to enhance understanding with the wider public," said Aarran.

"I'd like to bring my finance background and family experience to my role, raise further understanding about Huntington's disease and ensure necessary services are available to all who require them."

Our constitution requires that the Chair and at least 50% of Trustees are appointed from families whose lives are impacted by Huntington's disease. As a Board, they take collective legal responsibility for the direction and performance of the charity. Find out more at <https://hdscotland.org/our-trustees/>

# Logan sparks support from workforce



Apprentice steel fabricator Logan in action.

## Meet Logan Straub, a young apprentice who inspired his employers to help families living with Huntington's disease.

The 20-year-old from Falkirk spoke to his work colleagues at John Jenkins and Son Steel Fabricators about having Huntington's disease in his family. They were so moved by Logan's experiences that staff immediately began looking for ways to help – including by choosing Scottish Huntington's Association as the firm's first ever charity partner.



"It means a lot to me that people at my work are so driven to raising as much money and awareness as possible to help the charity and other families like mine. It's good to do something positive and give back to Scottish Huntington's Association for helping me and other young people who are struggling to cope," said Logan.

Logan and his two brothers lost their much-loved dad Mark in 2017 after watching his health deteriorate over the years as symptoms became more severe.

"It was hard growing up and knowing that my dad wasn't like my friends' dads but I didn't really know why," said Logan. "I started meeting Grant, my Scottish Huntington's Association Youth Advisor, when I was eight years old and for as long as I can remember the charity has changed my life completely.

"Mum was already dealing with so much and I had a lot of

thoughts and questions so it was amazing to have my Youth Advisor to talk to. He listened and helped me, even when something was bothering me that was nothing to do with Huntington's disease.

"I spoke to Grant a lot after our dad died and before I decided to get tested for the HD gene last year. I'm negative but my younger brother hasn't had the test so it doesn't feel like we can be happy about it yet."

Employees at John Jenkins & Son are already planning a string of fundraising activities including running the Edinburgh Marathon, entering a team for this year's Tough Mudder and organising a race night.

Managing Director Jonny Jenkins said: "When Logan spoke to me about Huntington's disease and how it has affected his family, then explained how the charity is helping families like his, I knew it was something we want to get behind.

When we proposed the idea to the staff everyone was really on board and now we're looking forward to getting together to do something positive for this worthy cause."

Lee Johnstone, Head of Income Generation and Administration, said: "We're hugely grateful to John Jenkins & Son for the commitment they have made to our families by choosing Scottish Huntington's Association as their charity partner. It's great to see a team rally behind one of their young apprentices like this and we can't wait to get started!"





# We're doubling every donation!

We're celebrating Huntington's Disease Awareness Month with the launch of our first ever match funding opportunity for donors.

Every £1 you give through our crowdfunding appeal page will instantly generate another £1 for Scottish Huntington's Association from the National Emergencies Trust - meaning your kindness will go twice as far. All donations received from 1 May to 14 June 2022 are eligible.

Your donation will help us to:

1. Expand our HD Specialist network to areas where there are currently no services available for families struggling to cope with the condition.
2. Sustain levels of support for all HD families during this time of increased need across all our services.
3. Raise awareness about the impact of Huntington's disease on families, including carers and young people, in communities across Scotland.



Scan here to visit our appeal and turn £1 into £2



Or visit [bit.ly/SHAdouble](https://bit.ly/SHAdouble) for more information



Scottish Huntington's Association  
 Business First | Burnbrae Road | Paisley | PA1 2FB  
 Phone: 0141 848 0308 Charity No: SC010985



# Group gives £10,000 and joins forces with SHA in new charity partnership

Westerleigh Group has chosen Scottish Huntington's Association as its new corporate charity partner, kicking off support with a £10,000 donation.

The Group, which has 36 sites in England, Scotland, and Wales, is also partnering with the Huntington's Disease Association England and Wales for the year.

Earlier this year, Westerleigh Group Chief Executive Officer Roger McLaughlan stepped down after learning he has inherited the faulty gene that leads to Huntington's disease.

His successor, Debbie Smith, said: "Choosing Scottish Huntington's Association and HDA England & Wales 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.

"We wanted to make an initial donation to mark the start of our year of partnership with the two charities but this is just the beginning. Over the coming months, our colleagues at Borders, Stirlingshire and West Lothian Crematoria will be looking at other ways of supporting and raising money for Scottish Huntington's Association."

Funds are raised through the Group's metal recycling scheme. With the consent of families, metals recovered during cremation are recycled and money raised is donated to charities and local causes. In 2021, Westerleigh Group raised almost £500,000 through its recycling scheme for the benefit of charities and community projects. In addition, a small share of the funds raised is sent to group headquarters to enable corporate donations to be made, while staff get involved further by holding fundraising activities and events.

Scottish Huntington's Association Deputy Chief Executive and Head of Services Karen Sutherland said: "Specialist services are an absolute necessity for families whose lives are



impacted by Huntington's disease and we are committed to ensuring that the right support is available when and where it's needed.

"Given the rise in cases over recent years, our HD Specialists, Youth Advisors and Financial Wellbeing Officers are reaching more families than ever, despite the funding challenges we face.

"For that reason, we are profoundly grateful to Westerleigh Group and its staff for choosing to support Huntington's disease families who are often overlooked because they are impacted by a rare disease that even today is widely misunderstood by the general public."

In March, Scottish Huntington's Association was invited by Westerleigh Group to participate in a special service streamed to sites across Scotland, England and Wales to celebrate Mother's Day. Scottish Huntington's Association Chief Executive Alistair Haw spoke about the work of the charity and read a poignant poem, My Mum, which was written by member of the HD community.

## Youth Service bounces back with spring activities

**The Youth Service is holding a one-day group work session for young people aged 13+ in Edinburgh on Tuesday, 12 April.**

It will look at the symptoms of Huntington's disease and the testing process and will be followed by a visit to an ice cream parlour where the young people can enjoy catching up with one another.

The next day, the Youth Service will host a two-day group residential trip for eight to 12 year olds on Wednesday, 13 and Thursday, 14 April at Craggan Outdoors Centre, Grantown-on-Spey. Sixteen young people will take part in a series of activities including raft building, mini Highland games and Laser Quest. Group work will look at ways of coping better with Huntington's disease.

The April sessions follow a day of trampoline fun and mini golf, which took place in Edinburgh in February and was attended by nearly 40 young people from across Scotland.

Grant Walker, Youth Service Lead, said: "It was so nice to see all the young people back enjoying each other's company. After the disappointment of missing out on our panto because of Covid restrictions, we wasted no time in meeting up as soon as we could."

Grant has recently been appointed to the role of Youth Service Lead following the departure of Kirsten Walker who has taken up a new position outwith SHA.

Many family members will already know Grant from activity days, summer camps and residential trips and through his work supporting young people as Specialist Youth Advisor for Greater Glasgow & Clyde, Forth Valley and Lanarkshire.

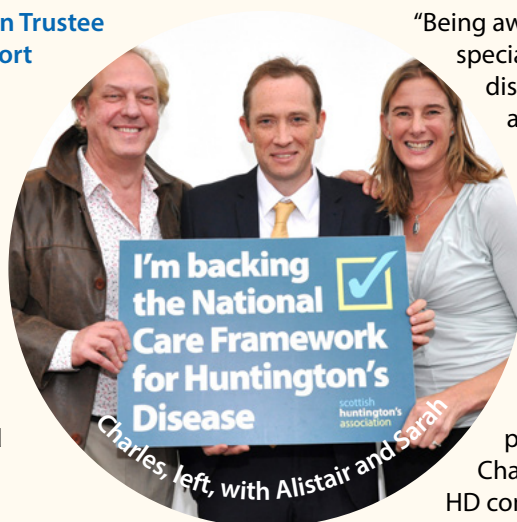


# Community celebrates with activist Charles Sabine OBE

Scottish Huntington's Association Trustee and family member, Dr Marie Short MBE, has welcomed the news of the award of OBE to global HD advocate Charles Sabine in the 2022 New Year's Honours list.

It's the second year in a row that The Queen has included an advocate for the Huntington's disease community in the list – in 2021 Matt Ellison, founder of HDYO (Huntington's Disease Youth Organisation) was awarded an MBE.

Marie, who was presented with her own MBE by the Duke of Cambridge at Buckingham Palace in 2019 for services to Scottish Huntington's Association, believes this growing recognition is vital to raise awareness about the disease, how it impacts families and the need for specialist services in Scotland, the UK and beyond.



"Being awarded an MBE offered me a very special opportunity to have a brief discussion with the Duke of Cambridge about the work of Scottish Huntington's Association and how we strive to improve services for all families, regardless of where they are in Scotland.

"It also meant reaching new audiences through media and social media coverage, to raise the profile of our community and highlight how people can support the work of SHA.

Charles' OBE is very exciting news for the HD community and I hope it will give people the courage to start lots of new conversations about HD and join him in being 'Hidden No More.'"

On receiving news of his award, Charles said: "This is far from an honour awarded to me alone. It must be shared with the hundreds of thousands of courageous Huntington's disease patients and their carers whose brave struggles have, for generations, remained in the shadows of recognition beyond our community, because their plight has been so hidden.

"I pledge to use this honour to further my mission, encouraging ever greater numbers to join the global collaboration with researchers and scientists so we can further enact a paradigm shift for all of us affected by Huntington's disease and to empower ourselves with the resolve that we should be 'Hidden No More'.



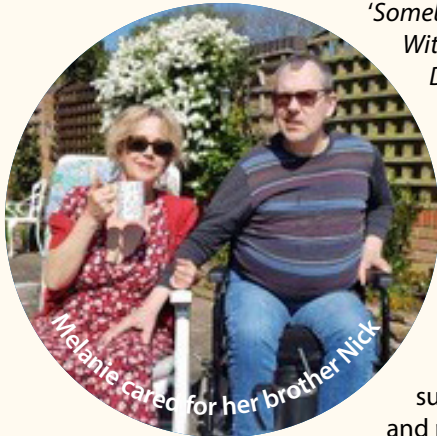
"Huntington's disease had been misunderstood or not even known about by many health professionals, and the wider public, for too long," said Marie.

"The amazing work that Charles does to increase awareness about research and clinical trials, and the challenges and stigma that too many families face on a daily basis, is making a real difference improve the lives of families in the UK and internationally too.



# Carer turned author will share powerful story of life and love

**"If you thought that unbreakable family curses only happened in fairy tales, think again."**



The words of Melanie Pearson, author of *'Somebody Up There Likes Me: Living With The Threat of Huntington's Disease'* and the first guest speaker in a new series of Family Voices webinars hosted by the HD Alliance (SHA, HDA England and Wales, HDA Northern Ireland and HDA of Ireland).

All family members are invited to join us for what is sure to be an inspiring, uplifting and moving conversation on Wednesday, 16 May at 7pm.

Melanie will share her experiences of growing up in a family impacted by Huntington's disease and explain why writing her first book was so important to her and for others.

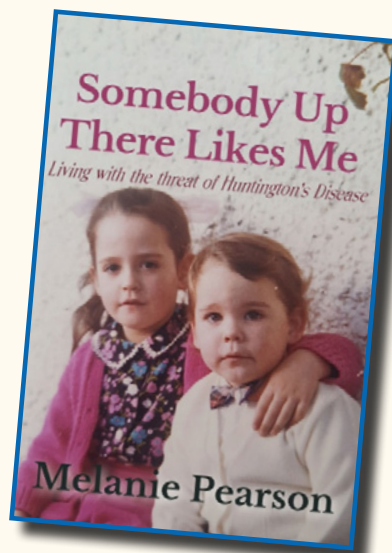
"It's my personal account of growing up in the shadow of a hereditary illness with no remission," says Melanie.

"I wouldn't wish Huntington's on anyone but its impact on my mother and my brother Nick has shaped my family over the years and taught me so much about courage and finding happiness against all the odds. You also learn what's truly important in life, which mostly boils down to love.

"Having grown up around family illness and worked in social care, it was still a shock to find myself looking after my brother when he became ill with an incurable disease - but also a great privilege. Writing my first book was a way of sharing this experience with love and humour, but also as a way of raising awareness of a little known condition."

*'Somebody Up There Likes Me: Living With The Shadow of Huntington's Disease'* has been met with five star reviews and acclaim by the HD community and beyond.

Please watch our social media channels or contact your HD Specialist for details about how to join the webinar.



## SHA's big welcome to Nathan



We're delighted to welcome Nathan Charles to our Income Generation team as a Fundraising Officer.

Nathan has significant experience of fundraising and events, having worked previously with a charity in Leeds that supports homeless people and those living with addictions.

"I always wanted to create as many opportunities as possible for people to get involved and support the charity, and that's something I'm keen to continue at Scottish Huntington's Association," he said.

"I started my career as a fundraiser a few years ago, working with the homeless and those with addiction. I began running small community fundraising stalls and supermarket collections but I was keen to introduce new events and opportunities to fundraise, such as Total Warrior, online auctions and text donations."

## Worried about rising fuel bills?

Did you know our Financial Wellbeing Service offers support to help you explore ways of making your home more energy efficient and reduce the impact of increased fuel costs?

Our Energy Advice Service launched in January last year in response to concerns from families about rising household bills. The team of four Financial Wellbeing Officers has since provided support to more than 80 individuals and families, including by providing an energy health check and signposting/advocating for improved insulation or boiler upgrades.

The Service covers all of Scotland – to find out more and for contact details of your local Financial Wellbeing Officer, visit <https://hdscotland.org/services/getting-specialist-financial-advice/>



# Stars rally round to help out

We're delighted that news of Dance 100 has reached the stars of BBC's Casualty and River City actor Leah MacRae, who have all been in touch to send messages of support.

The cast of Casualty, led by HDA England & Wales Patron George Rainsford - who plays Dr Ethan Hardy in the hospital drama - recorded an amazing short dance video to inspire as many people as possible to join us on 12 June.



## Are you ready for some strictly fun dancing...?

**SHA's Dance 100 event is bringing people together to take on our 100 song challenge in support of families impacted by Huntington's disease.**

You can join us at George Square, Glasgow on Sunday, 12 June or take part virtually anywhere to raise vital funds. This new event is inspired by family member and trustee, Gillian McNab, and her wonderful neighbours who danced in the street for 100 days in a row to stay connected during the first days of the 2020 lockdown. They followed that up by doing an amazing 100 dances in one day on Gillian's 51st birthday, raising more than £5000 for Scottish Huntington's Association.

Gillian said: "Dancing has always been important to me and my daughters. We dance to celebrate the good times and we dance to lift our spirits when life gets tough.

"Dance100 will bring us all together to dance joyfully and with purpose. I'd love to see an army of dancers in their #TeamSHA t-shirts, taking over George Square in Glasgow.

"Together we'll spread the word about Huntington's disease and how Scottish

Huntington's Association is helping families all over the country."

Gillian tested positive for the faulty gene that leads to Huntington's disease soon after her 40th birthday.

"I'm determined to do all that I can to build awareness, and to fundraise, for as long as my health allows. Once the symptoms start, I'll no longer be able to live my life the way I want to. I also live with the knowledge that each of my three daughters may also have the faulty gene. I can't change that but I try my best to stay positive and do what I can to help other families who are also affected by this terrible disease," added Gillian. Senior Fundraising Officer Gemma Powell said: "Please join us at Dance 100 - every person who puts on an SHA t-shirt and fundraises will help to increase vital awareness and make sure Scottish Huntington's Association is able to reach everyone who needs our specialist support.

"You don't have to be a good dancer - just coming along and having a go will make a real difference."

To find out more about how to get involved, please visit <https://hdscotland.org/Dance100/>

And Leah, a familiar face in theatre and television, shared a short video on social media urging her followers to go along too. Leah met co-organiser Gillian McNab at the Sunday Mail Scotland's Champions Awards last year, pictured above. Leah was one of the first people to congratulate Gillian on being named the 2021 Caring Champion for her work in support of the Huntington's disease community.

"Gillian is the most incredible and inspiring woman," said Leah. "I send all my love to everyone heading to George Square in Glasgow.

"Here's to everyone who is supporting Gillian and to everybody who is going through this terrible disease. I hope people dance their socks off!"

Another well-known Scot showing his support is Clyde 1 presenter and Sunday Mail columnist Garry Spence. He agreed immediately to help with promotion when Gillian reached out to him about Dance 100.

We thank George and his friends in the Casualty cast, Leah and Garry for all they are doing to raise awareness and help HD families.



# Aidan powers on in fabulous 500 challenge

Amazing Aidan Macgruer has embarked on an awesome challenge for 2022 – a 500 mile cycle to raise £500 in support of families impacted by Huntington’s disease.

The eight year old has powered his way well past the 100 mile mark already. Not even coronavirus can stop this cycling superstar – after testing positive for the virus a couple of weeks in, Aidan battled on without missing a mile after mum Debbie set up his bike indoors!



His fundraising is going great guns too - he’s already smashed his £500 target!

“Last year I did a 50 mile cycle with my mum running alongside to raise money for

Maggie’s Cancer Centre and this time around I wanted to help families who have Huntington’s disease, which is a rarer disease that not so many people know about,” said Aidan.

“Cycling is my best sport so I decided to go even bigger by setting myself a target of 500 miles.”

Aidan has mapped out the North Coast (NC) 500 route - a 516-mile scenic journey around the north coast of Scotland, starting and ending at Inverness Castle. It takes in Caithness, Sunderland, Wester Ross and the Black Isle and Aidan is plotting his virtual progress around the route to keep his sponsors updated on Facebook.

Dad Kenny and step-dad Steven are delighted with Aidan’s efforts – “I couldn’t be prouder of the wee man,” said Kenny – while mum Debbie is so inspired that she’s joining Aidan on his outdoor cycles.

“Aidan gets his love of cycling from me and he’s been on a bike since he was tiny,” said Debbie. “He got a real buzz out of fundraising for the Maggie’s Centre so I wasn’t surprised when he asked me what he could do this year.

“He’s doing really well and has lots of family and friends cheering him on all the way.”

## Family members invited to support group meetings

**Support groups for carers and people who are symptomatic have now resumed in Greater Glasgow and Clyde for the first time since the onset of the pandemic two years ago.**

They take place at Hyndland Community Hall, 24 Novar Drive, Glasgow, G12 9RU from 2pm to 4pm on the following dates:

- Thursday, 19 May - Carers
- Thursday, 23 June - Symptomatic
- Thursday, 18 August - Carers
- Thursday, 15 September - Symptomatic
- Thursday, 27 October - Carers
- Thursday, 8 December - Symptomatic

“Over the past few years it has understandably been difficult for people to get together, so we’re delighted

that our Huntington’s disease support groups are now able to resume face-to-face for those living in Greater Glasgow and Clyde,” said HD Specialist Helen Maginnis.

“Whether you want to share your own experiences of life with Huntington’s disease, hear from some of our guest speakers, or simply have a cup of tea and a chat, we’d love to have you along.”

To find out more, please call the Greater and Glasgow and Clyde HD Specialist team on 0141 556 4100 / 0141 556 2136.



## Disability benefits changes rolled out

**Our Financial Wellbeing Service can provide information about new benefits in Scotland, including Child Disability Payment and Adult Disability Payment.**

Child Disability Payment is a new payment that was launched in November 2021 by Social Security Scotland to replace Child DLA. New claims can be made for someone under 16 who has a disability.

Children under 16 who already receive Child DLA will continue to receive their existing benefit until it is next reviewed, at which point they will be moved across to the new one.

Last month Adult Disability Payment was rolled out in specific council areas (Dundee City, Perth and Kinross, and the Western Isles). Adult Disability Payment replaces PIP for adults with a disability. Again, people currently on PIP do not need to do anything just now as they will be moved over to the new benefit when their PIP is next due for review.

For more information, please get in touch with your local SHA Financial Wellbeing Service officer at [hdscotland.org](https://www.hdscotland.org).

## Jillian and Dina speak at annual conference



**Jillian Foster, Senior HD Specialist, and Trustee Dina De Sousa, pictured above, addressed the recent Neuroprogressive and Dementia Network conference in Glasgow.**

Jillian spoke about the involvement of Fife families in HD Clarity, and Dina shared her experiences of a number of studies including HD Clarity, Enroll, Redirect and Brain Train. Dina stressed the critical importance of research and explained why she feels compelled to participate.

The event marked the launch of the new Neuroprogressive and Dementia Network strategy which includes contributions from Scottish Huntington's Association and HD families.

## Looking back as we drive mission forward

**Expanding HD Specialist services, delivering a ground-breaking awareness-raising campaign and making history at the Scottish Parliament are just a few highlights of the past year.**

Against a backdrop of changing Covid restrictions and fundraising challenges in 2021, the charity continued to reach families across Scotland with lifeline support, adopting new ways of working and sourcing fresh income streams to protect and grow our specialist services.



"HD families need face to face support provided by specialist staff and the continued impact of Covid-19 made this extremely difficult in many cases, and impossible in others," said Scottish Huntington's Association Chief Executive Alistair Haw.

"Our staff repeatedly rose to these challenges by finding innovative ways to support patients, carers and young people. At a time when this support was most needed, many of our traditional fundraising activities continued to be limited by the pandemic. This meant we had to think differently and find new ways to generate funding to safeguard services."

### The charity's highlights of 2021 include:

- Strengthening our Board with the appointment of three new Trustees.
- Working with NHS Dumfries & Galloway to deliver an HD Specialist and an HD Clinical Lead for the first time.
- Working with NHS Borders to secure the area's first HD Clinical Lead.
- Securing the support of 99 out of 101 eligible MSPs for a Holyrood motion calling for the expansion of HD Specialist services, making it the most supported motion in Scottish Parliament history.
- Expanding our Financial Wellbeing Service and launching an Energy Advice Service in response to concerns over rising fuel costs.
- Delivering Family Matters, the first UK & Ireland-wide campaign which reached more than six million people during HD Awareness Month.
- Spreading news of our work, including gaining international recognition at the Australian HDA conference and global HDYO conference.
- Producing digital resources to provide money advice to young people.
- Training 16 volunteer Youth Ambassadors from HD families to provide peer support and promote the work of Scottish Huntington's Association.

"Despite the pandemic, Scottish Huntington's Association is continuing to advance its mission to ensure every family has access to the care and support they need. The progress achieved in the past year is testament to our families, staff and Trustees," said Alistair.

"We are also deeply grateful to our charity partners and volunteer fundraisers whose support makes so much of our work possible."

# Working together to drive up the standard of care for every family

**Scottish Huntington's Association is pushing forward its call for equality of care for all HD families, regardless of where they live, while raising awareness about Huntington's disease.**

Having secured the support of 98% of MSPs at the Scottish Parliament in 2021, we are now joining forces with HDA England & Wales and HDA Northern Ireland to target MPs at Westminster.

For Huntington's Disease Awareness Month in May, we are working to ensure that a parliamentary motion calling for improved specialist services across the UK will be lodged on behalf of the three HD charities. MPs across all parties will be encouraged to show their support by signing the motion.

While support for motions at Holyrood and Westminster are in themselves no guarantee that

action will be taken, the heightened awareness and endorsement of parliamentarians adds strength to our cause at national level while offering opportunities to further discussions with constituency MPs at local level.

This work will be accompanied by a UK and Ireland wide public survey carried out on behalf of the HD Alliance (Scottish Huntington's Association, HDA England & Wales, HDA Northern Ireland and HDA of Ireland). In this way, we will be able to gauge the level of awareness amongst the general public about Huntington's disease and how it impacts families.

The results will be shared with the Huntington's disease community, supporters and decision makers including funders, partners and the media. It also offers an opportunity for Scottish Huntington's Association to better understand

what the wider public needs to know – and how best we can share that information.

"Last year we raised our profile significantly in the Scottish Parliament, which had a role to play in growing our services to families.

"By working with our friends in other Huntington's disease charities across the UK and Ireland, we can combine our resources and skills to help deliver a change for all families in these islands," said Chief Executive Alistair Haw.



# It's all going swimmingly for Paula and Jacqui

**BRRR-illiant Scottish Huntington's Association staff member Paula Hepburn and her sister Jacqui braved wind, snow and sleet to do 'a dip a day for SHA' in freezing waters in support of families impacted by Huntington's disease.**

The hardy duo took on the month-long challenge - without wetsuits - and smashed their fundraising target, going on to raise nearly £2000. Paula, the admin and resource worker with our Grampian HD Specialist team, said: "I see every day how much Scottish Huntington's Association supports HD families in Grampian and around Scotland so I wanted to do something to help raise the funds that the charity needs. I live near



the sea in Aberdeen and Jacqui volunteered to join me by doing a sponsored dip a day. We chose February because it's the coldest month of the year and we wanted to make it as challenging as possible.

"We swam every day, either at Aberdeen beach, Stonehaven harbour or Catterline harbour. Fortunately



the weather was kind to us with sunshine most days. The wind was a bit mean at times, and there was some sleet and snow, but that's what we get on the north east coast.

"Each day we shrieked a little less and pretty soon we began to feel the benefits. We had great support from family and friends who helped us to raise more than £1800. After we completed the challenge Jacqui and I both realised how much we had come to enjoy it, so we've no plans to give up wild swimming any time soon."

## Helping young people to feel more connected

**Specialist Youth Advisor Pete Carruthers works with young people from Fife, Lothian and the Borders. He reflects on the impact of the pandemic and social isolation and how Scottish Huntington's Association is ensuring children and young people have access to the support they need.**

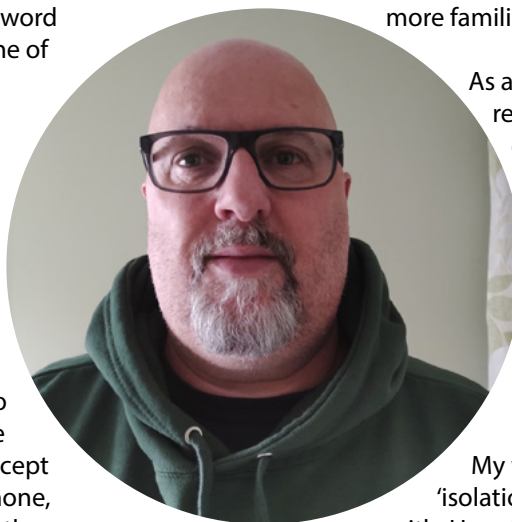
Before the pandemic, when I heard the word 'isolation' my thoughts would turn to one of my favourite songs by Joy Division. But the past two years have changed that. Isolation became a word that I kept hearing over and over. From children, from teenagers and from young adults. Not loneliness - that was part of it - but isolation. They felt cut off, disconnected, set adrift; the list goes on.

The worry is that the young people who talk to me about feeling isolated are the ones who are able to reach out. They accept my invitation to meet up, talk on the phone, text or video call. The ones who can are the ones we hear from.

We know what some of the effects of social isolation can be on our mental health, sleep patterns, diet and wider health issues. Add in the fact that the children and young people we support live in a family impacted by Huntington's disease, how does social isolation affect them on top of all

the issues that may already exist for them?

Of course, there are many who have coped. There are wonderful stories of individuals and families doing everything they can to maintain their mental and physical health and inspire others. But even those least affected by the pandemic are looking to get back to the world they are more familiar with.



As a Specialist Youth Advisor, I am now rebuilding bridges in person with our children, young people and their families once again. We are helping them back into a world where they can look for and receive the support they need. Our activity days, groups and residential trips that have taken place since restrictions have eased have shown how much our young people want and need our support.

My wish for 2022 is to hear the word 'isolation' less from the people we all work with. Hopefully through the Youth Service's face-to-face work, groups and residential trips, we will help those living in a family impacted by Huntington's disease to feel connected again.

Visit <https://hdscotland.org/youth-service/> to find out more about the work of our Youth Service and the support it provides.

## SHA's Fundraising Calendar of Events 2022



### Running Events

#### Edinburgh Marathon Festival

Sunday, 29 May 2022

#### Stirling Marathon

Sunday, 15 May 2022

#### My Zen Run

1 - 30 September 2022

#### Great Scottish Run

Sunday, 2 October 2022

#### London Virgin Marathon

Sunday, 2 October 2022



### Something different

#### Tough Mudder

Saturday, 2 July to Sunday 3 July 2022

#### Glasgow Zipline across the Clyde

Date TBC

#### Skydive, Wingwalk or Sharkdive Challenge

Choose your own date!

#### Great Wilderness Challenge

Saturday 13 August 2022



### Walking events

#### SHA's Big Walk

1 January to 31 December 2022

#### Glasgow Kiltwalk

Sunday 24 April 2022

#### Aberdeen Kiltwalk

Sunday 29 May 2022

#### Dundee Kiltwalk

Sunday 21 August 2022

#### Edinburgh Kiltwalk

Sunday 18 September 2022

#### Scotland's Virtual Kiltwalk

Saturday 7 October to  
Sunday 9 October 2022



## Go your own way!

Why not organise your own fundraiser with the help of your friends and family? Whether it's a Walk of Hope, bake sale, shaving off your beard or hosting a bingo night, our Income Generation Team is on hand to help you every step of the way.



### 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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