

New CEO looks to future with great hope for HD community

Alistair Haw has been appointed as SHA's Chief Executive Officer following the retirement of John Eden, who has left the organisation after serving 11 years in the post.

Many family members, partner organisations and supporters already know Alistair through his work leading on the development of SHA's National Care Framework for HD, a key driver towards improving quality of care and support for families throughout Scotland.

Backed by the Scottish Government, the National Care Framework for Huntington's Disease is now being used by NHS Boards and Health and Social Care Partnerships throughout the country, empowering families and delivering improved services. It has attracted international attention from, amongst others, Norway, Australia, USA, New Zealand and Ireland, in addition to being endorsed by the European Huntington Association.

Prior to joining Scottish Huntington's Association in 2016 Alistair worked as a political and media advisor at both the UK and Scottish parliaments, and as an Account Director and Devolved Nations Lead at PR agency Kindred. He led award-winning teams as Campaigns and Media Manager, then Head of Media and PR, at Prostate Cancer UK. He is also Company Captain and Trustee of Glasgow 278 (Netherlee) Boys' Brigade, and has recently been appointed to the



Alistair, centre, with Emmy Award-winning TV journalist Charles Sabine and SHA Patron and Olympic medallist Sarah Winckless MBE. Charles and Sarah are both members of an HD family

Executive of the Neurological Alliance of Scotland. He takes up his new role as the global HD community continues the search for novel therapies and treatments.

Alistair said: "It has been an honour to have worked for SHA for the past five years - meeting and working with HD families, seeking to understand the challenges they face and fighting for solutions, both with them and on their behalf. I am hugely grateful to the Board for putting its faith in me to lead the charity. I look forward to working with it, our amazing staff, and inspirational HD family members

and supporters as we move forward together to ensure everyone in our community has access to the specialised care and support they need."

Catherine Martin, Chair of the Board of Trustees at Scottish Huntington's Association, said: "During a full external recruitment process, the Board was greatly excited by the vision Alistair set out for the future of the charity, and we look forward to working with him and all staff and supporters on this over the years ahead."

Be part of our Family Matters campaign P2

Families from across UK and Ireland join forces to drive major campaign

We're inviting families in Scotland to share their experiences of Huntington's disease or send a message of solidarity to the HD community as part of a ground-breaking UK and Ireland-wide awareness-raising media campaign.

Scottish Huntington's Association has joined with Huntington's Disease Association England and Wales, Huntington's Disease Association Northern Ireland, and Huntington's Disease Association of Ireland to create the Family Matters campaign, which will run from 1 May as part of Huntington's Disease Awareness Month. As the newly-formed Huntington's Disease Alliance, we are working together to highlight the experiences of families through stories in print and online news titles, short films, social media, and radio broadcasts.

Family members Jock Anderson, Gillian McNab; trustees Dina De Sousa and Dr Marie Short MBE and SHA youth ambassador Zoe Green – joined members of the HD community from over the UK and Ireland last month at virtual workshops to help develop the campaign.

Now we're calling on the wider HD community to get involved too by sharing messages of support, insights, photos and creative writing for inclusion in a unique living history online site.

"In this way, people and families affected by Huntington's disease will ensure that they – as the community at the very heart of the Family Matters campaign – have their voices heard and their stories told in a way that works for them," said Roisin Eadie, SHA Communications Officer.

"We hope as many families in Scotland as possible will support this exciting opportunity to bring the wider HD community together, build understanding about Huntington's disease, and highlight the resilience and strength of people and families whose lives are impacted."

Contributions to the Family Matters living history site, which can be published with or without names, could include:

- A poem about or a self-penned piece
- A selfie with family, friends or support bubble
- A message – or even just your family name and region as a show of support



From left, Marie Short, Gillian McNab and Zoe Green

- An inspirational or motivational quote
- A drawing or piece of art
- A picture of something that brings family or support networks to mind
- A quote from a favourite book
- An old or new family photo
- An image of footprints or handprints or something that is personal
- Extracts from a letter or note
- An anonymous message of support.

To find out more or to contribute, please email the M&F Health communications team at huntingtons@mandfhealth.com. The specialist health PR agency is working with us, as part of the Huntington's Disease Alliance, to develop the campaign and contributions for the living history site.

You can also get in touch with Roisin at roisin.eadie@hdscotland.org or find out more on the SHA website at <https://bit.ly/3q9iAFV>

Please complete survey about how HD impacts you

Another way you can support this important campaign is by completing a new survey which aims to capture the unique experiences of everyone whose life is impacted by Huntington's disease.

The survey can be accessed through SHA's Twitter and Facebook channels, and at <https://hdscotland.org/>





Striding out: Samantha is taking part in year-long challenge in support of other HD families

Sam takes big step for her family and others

Growing up, Early Years worker Samantha Murray knew nothing about Huntington's disease, how it impacted the people she loved, or that she is at risk of having inherited the faulty gene.

Samantha, 23, from Lanarkshire, said: "I've only known for about six years now because it was something nobody in our family ever spoke about. I found out that my mum Shauna has Huntington's disease, and her late sister also had it. It's inherited from my grandad's side of the family.

"I was only a teenager and I went to bed that night feeling as if my life was ending. Thankfully I found Scottish Huntington's Association and started speaking to people who understand that I need the right information. It's made such a difference to me, and my mum has had a lot of support from the charity too.

"I've spoken to an HD Specialist about having the test and I'm keen to go forward. My sister Claire, 21, has decided

that it's not for her just now, she doesn't see any benefit in finding out at the moment and I respect her decision. I'm also looking forward to meeting other young people from HD families through SHA's youth service.

"Mum has symptoms now, just small movements, but is doing OK. Sadly, we lost our gran to coronavirus last year, which is motivating us to live our lives as best we can, doing what we can to help one another and other people.

"I want more people to know about SHA and the work it does for families and I don't want Huntington's disease to be a taboo subject in my family any longer.

"That's why Claire and I have roped in my best friend Danielle to join us for our latest challenge, SHA's Big Walk 2021. It's really good, we need to do 10,000 steps a day to reach our target. For now, I'm focused on the positive, hoping for a good test result, and feeling optimistic that one day there will be a treatment or cure for Huntington's disease."

Finding silver linings in the GENERATION HD1 cloud

The decision to permanently stop dosing with the drug tominersen and placebo in the GENERATION HD1 study is bitterly disappointing for HD families, who have waited so long and so patiently for a treatment.

The aim of this phase III trial was to establish if tominersen was effective in lowering huntingtin protein in a larger group of patients, and if it helped improve signs of HD in patients already showing symptoms. Roche and Ionis have stated that they have stopped dosing on the advice of the Independent Data Monitoring Committee, an impartial body of experts whose role is to monitor and decide whether drugs trials should continue. At this early stage we do not yet know why.

Alistair Haw, SHA Chief Executive Officer, said: "Despite the overwhelming sense of sadness we share over this outcome, there are still positives to focus upon. Firstly, there appears to be no sign of worrying side effects for those involved in this trial.

"Secondly, when researchers come to search for another treatment option, they will not be starting from square one. Lessons have been learned that will take us closer to the success the global HD community so longs for.

"In the meantime, Scottish Huntington's Association is here for our families, supporting them through this difficult news – and accompanying them upwards and onwards to the day when Huntington's disease is finally conquered.

"When that day dawns the family members who volunteered for this trial and the staff who helped them, including those at sites in Glasgow and Aberdeen, will be remembered amongst the heroes of the global HD community."

HD Buzz has published an excellent article summarising the situation in layman's terms, co-authored by editor-in-chief Dr Jeff Carroll, who says: "This community – both HD families and HD scientists – have proven that they can do hard stuff together, so we'll shake ourselves off and do it again. And we'll keep doing it until HD is no longer a threat to ourselves and our loved ones."

Read more at <https://en.hdbuzz.net/300>

SHA Board looks for additional Trustees from within HD community and beyond

SHA's Board is seeking additional Trustees to help shape the future of the charity and the services it provides for families across Scotland.

This is an opportunity to join a family led grassroots organisation with an international reputation for advancing the care and support of the HD community. This includes dedicated services for young people growing up in HD families, a network of HD Specialists, Financial Wellbeing Advisors and the development of the world's first National Care Framework for Huntington's Disease.

Members of SHA's board of trustees come from a wide variety of professional backgrounds, with at least 50% being personally impacted by HD. The skill set of the trustees covers all aspects of the strategic management, growth and governance of SHA, ensuring that the charity remains faithful to the vision, mission



Opportunities: Chair Catherine Martin

and values upon which it was founded by families in 1989.

Chair of SHA's Board of Trustees, Catherine Martin, said: "We continue to look forward with hope for clinical advances in the treatment of Huntington's disease while working towards greater equality of services

for everyone in the HD community, all the while remembering and respecting the journey that got us to this point. Families are, and always will be, at the core of SHA and its governance."

Newly appointed CEO, Alistair Haw, added: "Our trustees share invaluable insights, ideas and knowledge. "While some have lived experience of Huntington's disease, others have joined ready to learn about the disease, the charity, the community we serve and our mission to transform the care of every family impacted."

Scottish Huntington's Association invites applications from all backgrounds, regardless of race, ethnicity, faith, disability, age, gender or sexuality. SHA is particularly interested in hearing from those with expertise in the legal or HR professions, and would also welcome applications from HD family members over the age of 16. Full training and induction will be provided – to find out more please contact alistair.haw@hdsotland.org

Applications now open for Scotland's only HD course

UNIVERSITY of STIRLING



Building the knowledge and skills of health and social care providers, and others who care for people with Huntington's disease and their families, is a vital aspect of SHA's mission towards improved services and support for all.

One of the ways we do this is through our ground-breaking collaboration with the University of Stirling to deliver the degree level module, 'Huntington's disease: an enabling approach to supporting families', which has been running since 2014.

The 15-week online programme, the first of its kind in Scotland, was created with input from the HD community. Its structure and content are specifically designed to highlight the diverse experiences of families and explore the different physical, emotional, psychological, and social impacts caused by Huntington's disease.

The award-winning module also draws on current research and practice to provide a deeper understanding about the complexities of HD, the needs of those impacted by it, and how best to support them.

Open to health and social care staff from all sectors and disciplines, family members of people with HD and others with an interest in learning more about the condition, past learners have joined from Scotland, the UK and around the world.

'Huntington's disease: an enabling approach to supporting families' launches for the 2021/22 session with a live one-day online introduction on 13 September. This will be followed by 14-weeks of supported online learning which can be accessed at a pace and times which suit individual learners.

Completion is worth 20 credits at SCQF level 10 following the assessment of a single written report. Fees are £675 and applications are open now.

To find out more and apply, visit <http://bit.ly/30UvSfn>

Should you, or someone you know wish to find out more, you can also contact Louise McCabe, SHA Trustee and senior lecturer (Dementia and Ageing) at the University of Stirling at louise.mccabe@stir.ac.uk



Family: Allyson and David Button

We know how much SHA helps

We recently received a message of support and a donation all the way from the USA.

Allyson and David Button, from Michigan, reached out to Scotland's HD community after seeing family members Kenny and Lorraine, from Dunbartonshire, sharing their story on our social media channels.

Allyson, who is Lorraine's sister, was diagnosed with Huntington's disease in 2012, two years after she married David. In recent years, the impact of the disease has been complicated further by additional serious health issues.

Allyson, who moved from Scotland to the States in the 1980s, said: "Our family here in Michigan know how important the support provided by Scottish Huntington's Association is for families back home."

David is helping Allyson to stay as strong as possible, physically and mentally.

"Huntington's disease is really tough to go through and Allyson has had some real highs and lows. Right now, thanks to good doctors and some medication changes, she is doing great and we just hope she keeps going the way she is," said David.

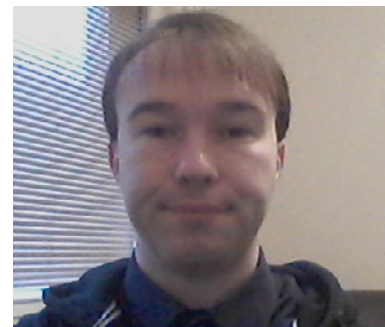
Fuel speed ahead for SHA's new energy advice service



SHA's Financial Wellbeing Service has expanded and is now delivering specialist energy advice to help families cut fuel bills and use energy more efficiently.

The service, which already supports families facing financial issues including debt management, access to benefits and money management, has also recruited a fourth specialist advisor to join its small but busy team.

Ben Peter, who has significant experience in welfare rights and working in the third sector, joined SHA in January, coinciding with the launch of the Energy Advice Project.



Welfare specialist: Ben Peter

He is working with families in Tayside, Forth Valley and Fife who are looking for advice and information relating to all aspects of financial wellbeing.

Funded by the Energy Industry Redress Scheme, the Energy Advice Project was introduced after the SHA team reported concerns from families at risk of fuel poverty.

All Financial Wellbeing Offices have completed specialist energy advice training to support with issues including:

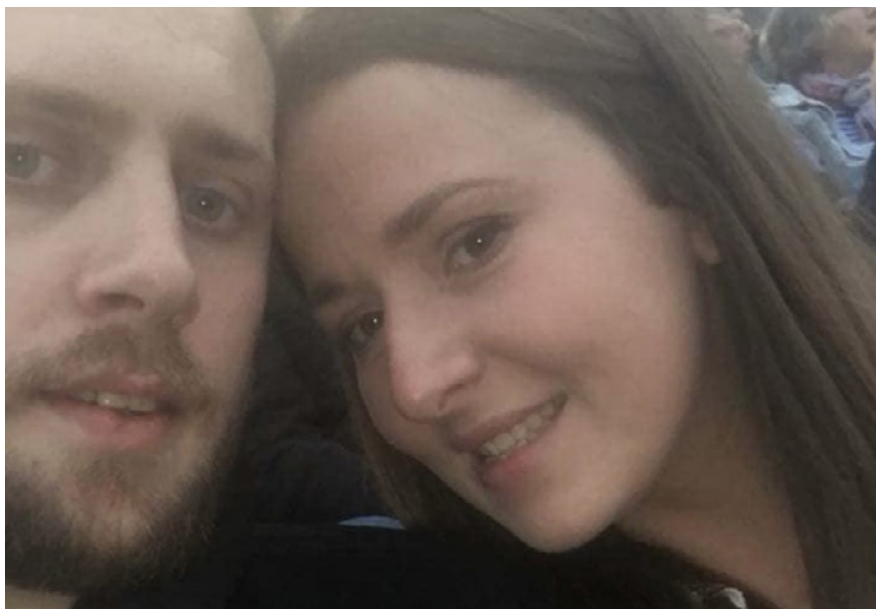
- Energy bills and payments.
- Reducing costs, including tariffs and switching suppliers.
- How to use your heating system effectively.
- Dealing with problems such as damp and mould.
- Accessing grants and schemes, including for installation of insulation or new heating systems.

SHA introduced its Financial Wellbeing Service in 2015 to help people and families living in hardship as a result of Huntington's disease. Since then, the expert team has helped to generate nearly £4.5million in unclaimed benefits, allowances, grants and financial products for individuals, carers and family members. To find out more about the Financial Wellbeing Service and its portfolio of support, including energy advice, visit <http://bit.ly/3eSQnkP>

Care Framework secures appointment of HD Specialist in Dumfries & Galloway

As reported in a previous edition of SHAre, a Care Framework for HD is now in place in Dumfries & Galloway. This led to the appointment of an HD Clinical Lead, Dr John Higgon, and we are delighted that an HD Specialist is now in place too. Miriam Procter has recently taken on the role and will be based at Gardenhill Primary Care Centre, Castle Douglas. We welcome Miriam into the team and look forward to working with her and Dr Higgon as we develop our services to families throughout Dumfries & Galloway.

To view the Care Framework for your area visit: care.hdscotland.org



Keri and Daniel, who were married in 2018, continue to support SHA by fundraising on their birthdays.

There's a moment with Keri and Daniel when he leans in and, speaking softly, says: "I always wonder if I pushed you to have the test."

"You didn't at all," Keri responds firmly. "I'd made up my mind. Anyway, when have you ever convinced me to do something I don't want to?"

"It's a very personal decision. For years I didn't think it would make any difference; a test result wasn't going to change what job I was going for or me finding a partner. Then, after we married and had our own home, I didn't want the uncertainty any longer."

Daniel, 31, was by Keri's side as she had the test, and he was with her when the results confirmed that she has the faulty gene that leads to the disease.

"I was down for a few days, then it was a case of, 'well that's it, we've got to make the most of it,'" says Keri, who works at an ASN school supporting teachers and pupils.

"I have wonderful friends and a close family around me, and Daniel is so supportive. He's always Team Keri. I had great support from my SHA HD Specialist and counselling to make sure I was comfortable with my choice and prepared for the result."

The discussion about Huntington's disease came up early on in the relationship.

"I could see Keri's gran wasn't well," says Daniel, a

Keri and Daniel talk about test decision and why they give back every birthday

customer services assistant. "Then when I first met Keri's family, her sister Jen was fundraising for SHA and her younger siblings were involved with the Youth Service."

Keri credits the support of SHA's Youth Service for helping her cope when she was younger.

"I went to summer camps and getting to know other young people was great. I'm so grateful to the Youth Service advisors who made finding out about such a horrible disease so much easier," she says.

The couple married in 2018 and settled in Fife. Since then, they've both supported SHA by swapping birthday gifts for donations to the charity.

"Having a birthday fundraiser is an easy way to help fund services for everyone who needs them," said Keri. "We have a great group of friends and family who support us every year – I turn 30 this summer so I'm hoping for lots of donations because this one's a bit special!"

Insurance: Finding the right policy

We've developed four short videos in partnership with Specialist Insurance Adviser, Kathryn Knowles, of Cura, to provide a brief summary of the key issues around insurance, genetic testing and Huntington's disease. They can be viewed on our website <https://bit.ly/3uUAdx5>. The videos are designed to provide information only, and SHA is not recommending the use of any specific specialist insurance advisor over any other – so for more information, please contact our Financial Wellbeing Service in the first instance.

Summer Camp put on hold



This year's Summer Camp, which usually takes place in July, is unable to go ahead due to the uncertainty around the pandemic and changing levels of restrictions.

Even if lockdown eases, it is very unlikely that residential camps for large numbers of young people in shared accommodation will be allowed to go ahead.

Knowing how disappointing this is for the young people we support, the Youth Service team is working hard on a programme of virtual activities for 'camp week' to make sure it's still a time to remember. We'll be in touch with our plans soon!

Dipping into Tip Jar for money info



Work on online resources to support young people with financial information is nearing completion.

The suite of digital worksheets will include information that answers questions such as: Can I get a mortgage if I have the gene? Can I get life insurance if I'm at risk of HD? How can I afford to go to University if my family is on benefits?

The Youth Service is working with SHA's Volunteer Youth Ambassadors and the Financial Wellbeing Service to produce the new resources, with the support of funding from the Scottish Government's Debt Advice Levy Fund.

Welcome our new Ambassadors

SHA's Youth Ambassador team continues to grow as we welcome three more young people to the ranks.

Pictured from left, Phoebe Lipp, Emily Wright and Emily Hillis have joined the volunteer programme, which now has 13 ambassadors in place.

They are given the opportunity to share their knowledge and insights to raise awareness about Huntington's disease and the work of SHA.

After training and in line with agreed guidelines, Youth Ambassadors may also be asked to share their experiences to support other young people, and contribute to key projects.



Phoebe Lipp



Emily Wright



Emily Hillis

Can you support our young people to develop crucial work skills and experience?

Have you been looking for a volunteering opportunity which directly benefits families living with Huntington's disease? We are looking to work with members of our HD community to offer workplace mentoring and visits for our young people across Scotland and we hope this could be you.

Supported by funding from The Gannochy Trust over three years, our aim is to help young people growing up in HD families to develop their employability skills and gain additional certified qualifications. This will include workshops on, for example, CV writing, interview techniques, digital skills.

It also aims to highlight how young people can transfer to the workplace their existing skills, including those they have developed as a result of growing up in an HD family, with our Youth Service providing opportunities to study for additional qualifications in, for example, First Aid and Food Hygiene.

We aim to match our young people with a member of the HD community working in their field of interest. As a mentor you would have a chat with a small group of young people about your own career, giving an insight into your industry and the paths our young people could take to a fulfilling career of their own.

Initially due to coronavirus restrictions, we would expect all meetings and visits to take place virtually. If you are a person who:

- Believes in our young people and wants to help them towards a brighter future.
- Has an understanding what it's like to grow up around Huntington's disease.
- Is keen to volunteer your time to help this project.
- Has an employer that will support you taking part in this project.

Then please email your details to Gemma Powell at gemma.powell@hdscotland.org and we will be in touch to have an initial chat with you about your volunteering. We are keen to give our young people a flavour of different industries and occupations, so please include in your email your name, job title, employer and industry.

Team welcomes Helen and Ann



Joining team: Helen Maginnis

New HD Specialists Helen Maginnis and Ann Waugh have joined SHA and are now working with families as part of the Greater Glasgow and Clyde team.

Helen, who spent three years with the NHS, dedicated a year to the study of genetics while at university and graduated from medical school in 2017.

"I've been interested in working in the third sector for a number of years so I'm very excited to be joining SHA. I've really appreciated the warm welcome and look forward to getting to know everyone," said Helen.



Direct support: Ann Waugh

Ann takes on her new role after working in the NHS for more than 30 years. Her varied nursing career includes providing specialist support to parents of premature babies and working as part of a community health team. Ann has also recently completed a counselling diploma and continues to provide volunteer support for people struggling with bereavement.

"What strikes me most about Huntington's disease is the ripple effect it has on families," said Ann. "In this role, I'll be providing direct support to people who are going through difficult periods, which is what attracted me to SHA."

There have been staffing changes in the Tayside team too, with the appointment of HD Specialist Alison Tonner, while her colleague, Lindsay Wilson, has expanded her role to include support for clients in Rumbling Bridge Care Home. To find HD Specialist support in your area, visit www.hdscotland.org/services/specialists/

Senior HD Specialist: "My clients inspire me to make a difference."

As Senior HD Specialist Alan McGill marks his fifth year with Scottish Huntington's Association, he reflects on the ways the families he meets and the work of the charity inspire him.



"For 15 years, I've been a registered nurse specialising in mental health, and before joining Scottish Huntington's Association, I worked within a community mental health team. During that time I met two young men who were symptomatic with Huntington's disease. They had a profound effect on me and I started to look for a change of direction so I could focus specifically on working with clients in the HD community.

"My first year with SHA's Ayrshire HD Specialist team was a steep learning curve. But being busy, getting to know family members and getting stuck in was the best way to begin to

understand the complex and unique challenges being faced every day by those affected by Huntington's disease.

"SHA's HD Specialist support can mean the difference between coping and not coping for many families. This includes 1-2-1 meetings, assessing need, coordinating care with health and social care providers, advocating on behalf of family members, and training clinical and social care professionals to raise awareness and understanding.

"I feel extremely proud to work alongside the HD community, it's a privilege to share in their experiences and be part of their lives. I do all I can to make things better for family members. That can be something as simple as meeting up for a coffee and a chat to helping with more serious, lifechanging issues, such as coping with a positive test result, looking for the right care home or coming to terms with the loss of a loved one.

"I work with a client group that shows the bravery of a frontline soldier every day. I know how devastating this disease is, and how it affects whole families in every aspect of their lives. I've seen strong relationships break down, careers lost, and families separated as the symptoms become increasingly difficult to manage at home.

"But I also see the determination, courage and love shining out from families, who do everything they can for the people they love in the most difficult of situations. That's why I'll continue to support and advocate for the HD community every day. Just like our clients, I won't give in."

Helping families access best care

The National Care Framework and its regionalised versions help families, carers and professionals to find out more about the specialised support, including HD Specialists, the Youth team and Financial Wellbeing support delivered by SHA across Scotland.

The online resource also provides information about services offered by other agencies, including health and social care providers, to help families access the care that's right for them.

Visit care.hdscotland.org for details.

Staying positive? Retired nurse Cath has that down to a fine art



"When my shakes are bad all day, my neck gets very sore and it's impossible to read or watch TV. But painting is something I can always do."

Retired nurse Cath, 60, was diagnosed with Huntington's disease in 2018. Since then, she has faced other serious health issues, including surgery and a condition that caused the loss of 75% of her vision. Now, as she adjusts to a new reality of sight loss combined with Huntington's disease, Cath tells us how her changing health led her to unlock a hidden talent.



"Over six months I was diagnosed with HD, had bowel surgery and went blind," said Cath, a mum and grandmother from Dunbartonshire. "I'd had balance problems for a few years before then but it was a shock because we didn't know HD affected our family. Soon after, my mum, 90, and my brother, who passed away last year from cancer, were also diagnosed."

"I lost power in my legs and couldn't stand for more than 30 seconds. I could walk for miles but stopping and starting was difficult, and after a 10-minute walk I would shake for 20 minutes. I also had anxiety made worse by a lack of sleep and not eating enough."

"Sally, my SHA HD Specialist, helped me come to terms with my new disability and not being able to continue in my nursing career. When I needed counselling, Sally arranged it and she continues to be a great encouragement to me. We've also received help from SHA's Financial Wellbeing Service."

"My whole family, including my daughters, my son, and Al, my partner, are a wonderful support to me. When my sister suggested that I should incorporate joy into my life, I decided to do something positive every month so there's always something to look forward to. I went travelling but when I came back, I was more affected and needed a walking frame."

"So my other sister took me to a healer and I was symptomless for three weeks. When they did come back, my shakes didn't seem as bad."

"Then my son invited me to visit him in Brazil. He said, 'get yourself on a plane and we'll get you off at the other side'. In December 2019, I flew out but soon started to ask myself, 'what do I do

next?' I signed up for a painting class advertised on Facebook, and now I paint every day."

"I'd never picked up a paintbrush before. My brother and sister are artists and my other sister is a writer, but I thought I was more practical than creative. I started with acrylics, now I love pastel work. Painting is something I can always do, even if I don't always hit the page where I want to, and swapping to my left hand helps settle my shakes."



"I've had exhibitions and last year sold my first painting. I spent the money on an earthing sheet, a remedy rooted in connecting with the earth. I've also tried reiki, and I meditate and do yoga. Right now, I feel well and strong. I listen to my body then try things to help myself."

"Huntington's disease makes me stop and think about life, to use all my senses and focus on nice moments every day. Watching and listening to the birds in the garden, the smell of hot toast with butter, it all brings joy."

Thank you Cairn Energy Trust

"We've had invaluable support and guidance since my sister Jane was diagnosed with Huntington's disease. Without SHA's help, we would have a much harder road to travel."

Knowing the difference the charity's services make, Aarran Air advocated on the SHA's behalf for funding from Cairn Energy Trust, the charitable giving arm of Cairn Energy, the company where he works.

His support helped the charity achieve an award of £12,652, which is now helping SHA to reach other HD families, carers and young people in Edinburgh and Lothian with HD Specialists, Financial Wellbeing advisors and the Youth Service team.

"Huntington's disease has been in my family for at least three generations and has affected my grandfather, my mother, and several aunts and uncles and cousins," says Aarran.

"My sister Jane was diagnosed around 10 years ago, when she was in her early 40s. Jane was a lively and popular person and she worked in a local hospital before being medically retired due to the disease. Since then, her health has worsened significantly and in 2019, after a short illness, Jane was transferred to a local residential care home with 24-hour support.



Loving mum: Jane

"Our HD Specialist, Lindsay Wilson, was of great assistance to Jane and myself during this time, explaining things to us and having very difficult conversations with Jane about end-of-life care and moving into long-term residential care.

"Lindsay also put me in touch with SHA Financial Wellbeing Officer Katrina, who assisted me with Power of Attorney and resolving certain financial matters relating to my sister.

"Jane has three children and one granddaughter. My younger nephew and niece have received publications from SHA's Youth Service which explains Huntington's disease in a

straightforward way for young people. This helps them to understand the disease that their mother has and how it could potentially impact them.

"The support from SHA helps all of us. The team is professional, knowledgeable and caring, they listen to questions and concerns, and provide explanations about medical and non-medical issues. They meet up with Jane and other family members, and keep us up to date with medical research advances.

"We are part of a larger group of people impacted by Huntington's disease, and want to do what we can to help make sure that SHA services are there for anybody and everybody who needs them."

Cairn Energy Trust supports causes across a number of categories including young people, communities, health, environment, arts and culture, and education and learning.

We applaud the fantastic work they do with charities in Edinburgh and Lothians and thank them deeply for their generous support of our work with families in this area.

To find out more about the ways we can work with business and employers, please email

gemma.powell@hdscotland.org

Vital boost from Zurich Community Trust

Since the beginning of the COVID-19 crisis, Zurich Community Trust has stepped up its support for the HD community in Scotland. In this past year alone, the organisation has donated £30,000 towards our work with families in Glasgow and Lanarkshire.

This continued support comes at a time when SHA, like many charities, has been hit by the cancellation of key fundraising events and activities as a result of pandemic restrictions. In addition, Zurich Community Trust is sharing its expertise with partner charities through a series of online workshops and webinars aimed at helping third sector organisations to survive and thrive during these difficult times.

We thank Karen, Black, family member and Zurich employee, who first nominated SHA to Zurich Community Trust in 2017 and inspired work colleagues to volunteer and fundraise for us. We're also grateful to Stephanie Clark,

who is also a family member and Zurich employee, for encouraging staff to support us through raffles and other activities.

Since that first grant of £15,000 over three years for our Financial Wellbeing Service, the relationship with Zurich Community Trust continues to go from strength to strength.

Steve Grimmett, Head of Zurich Community Trust, said: "As part of our COVID-19 Response Plan, we quickly made the decision that we would focus our financial support this year to the existing charity partnerships we had throughout the UK to play our part in supporting charities through such difficult times. As such, we're pleased to be supporting the excellent work of Scottish Huntington's Association both financially and through the skills-based non-financial offerings available for our partners."



You're changing the odds for our young people

As of the 1 April 2021, our Lucky Lotto players will be delighted to know that all the money raised by our monthly lottery will go directly to help fund our world-leading Youth Service.

Funds raised by Lucky Lotto will help provide 1-2-1 and group support that reduces isolation, helps young carers, promotes mental health and wellbeing, and makes sure young people have the information and resilience they need

to cope with the challenges of today and prepare for what's to come.

Our ambition is for Lucky Lotto to grow its number of subscribers and contribute sustainable funding towards our youth service.

And for our Lucky Lotto players to know that their kindness is helping to change young lives every day.

£3 a month = £36 a year

- Funds a dedicated youth advisor to take a young person out for coffee to offer emotional support and advice on how to cope with any challenges the young person is facing.
- Gives a young person a training opportunity to boost confidence, skills and their CV - helping to make up for opportunities missed due to their caring responsibilities.

£15 a month = £180 a year

- Provides a group session to help young people cope with the changes in a parent's condition, deal with loss, bereavement and the impact of being at genetic risk of the disease.
- Provides opportunities for a young person to attend Youth Service get-togethers where they can meet other people their age from HD families and form important friendships - reducing isolation and improving their resilience.

How to play

Purchase at least one stake in Lucky Lotto to be in with a chance of winning each month.

Sign up at hdscotland.org/lucky-lotto, email gemma.powell@hdscotland.org or phone 07423 680741.

The winners will be drawn at the beginning of each month and notified by one of our fundraising officers so you don't need to worry about checking your number.

Important information

- All players must be aged 16 and over.
- Play the Lucky Lotto Responsibly.
- Scottish Huntington's Association is registered with Renfrewshire Council under the Gambling Act 2005 (www.gamblingcommission.gov.uk).

Further support can also be found at the Gamble Aware website (<http://www.gambleaware.co.uk/>).



One more exciting change!

Players can now win a top prize of £250, or a second-place prize of £100 every month. Plus, to thank our Lucky Lotto players for committing to helping our young people, we will increase the top prize by £50 for every new 100 players who join in.





Keir, pictured with his brothers and their late dad, Mark, volunteers as an SHA Youth Ambassador.

‘I didn’t understand Dad was very ill or how hard it was on our mum’

SHA youth ambassador Keir, from Falkirk, shares his story to support other families – and to say thank you to his mum Mary.

“Mum cared for our dad, Mark, really well at home for as long as possible. At the same time, she was raising me and my older brothers, Logan and Morgan, while working as a nurse and studying for a degree,” said Keir, 17.

Mark, a university environmental research assistant who enjoyed boxing to keep fit, was diagnosed with Huntington’s disease soon after Keir was born, and the three boys watched as their dad lost his ability to walk, talk and swallow.

“When I was younger, I didn’t really understand that he was very ill,” said Keir. “We had carers coming in but eventually Dad went to live in a care home. By then I knew that we wouldn’t have him for long.”

Mark passed away in 2017 aged just 42, and Keir credits his family and SHA’s Youth Service for helping him to cope.

“I was about eight years old when I met Grant, my youth

advisor,” said Keir. “I’m at 50% risk of having the faulty gene that causes Huntington’s so it’s good to have him to reassure me and to be there when I have questions.

“He’s helped me to learn more about the disease, I’ve been to seven youth service summer camps, and I’ve signed up as a Youth Ambassador to help other young people.

“I’m very open about it with my friends; many of them remember Dad from when he would pick me up from primary school.”

Keir treasures the time he had with his dad, and his fondest memory is of a family holiday when Mark’s quick-fire sense of humour had them in stitches.

“We were queuing at the Atomium in Brussels and it was going to take hours to get in. An orderly noticed Dad, asked where we were from then led us to the top of the queue.

As he left, Dad turned around and said, ‘That’s good of them to let us go to the front just cos we’re Scottish!’”

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Scottish Charity No: SC010985 Patron: Sarah Winckless, Olympic Medallist

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