



SHA warrior Alex Wilson battled his way through a 300-mile running challenge, often in full fancy dress, to raise funds for SHA and increase awareness about Huntington's disease. Full story on Page 5

Service expands to support families at risk of fuel poverty

Scottish Huntington's Association (SHA) is taking urgent action to help people keep their homes warm without running up bills they can't afford.

A specialist energy support service is being launched to reach those most at risk. It will also visit hundreds of households across Scotland to help families save money by looking at how they use gas and electricity.

This additional support comes after our financial wellbeing officers raised concerns about families facing fuel poverty. With £203,309 secured by the fundraising team through the Energy Industry Voluntary Redress Scheme, the charity is now working towards supporting 900 people by reducing fuel poverty and raising awareness about energy efficiencies.

The funding means SHA can bring in an energy advisor to join the team and provide specialist training for the charity's three financial wellbeing officers. It will also enable 700 home visits and 1-2-1 support for families across Scotland. The new officer is expected to be in place in the new year.

"People with Huntington's disease face incredible challenges every day because of the complexity of symptoms and how it affects the whole family," said Jo Baldock, Senior Financial Wellbeing Officer.

"Working lives are cut short, not just for the person with Huntington's disease but also for the loved ones who care for them. This has a major impact on household income and many of the families we work with are living well below the poverty line, in debt and unable to make ends meet."

"This winter, with the continuing challenges of the COVID-19 pandemic, there is real worry about turning on the heating and using electricity. This new specialist support will reduce this added hardship for families."

Raise a Cup O' Kindness with family members Pages 6 & 7

John Eden, SHA Chief Executive

I always enjoy receiving my preview copy of SHAre. In the hurly burly of day-to-day work, it is important to stop and reflect and the magazine provides a moment of perspective, particularly at the end of a challenging year.

I hope as you read through this edition you will see a charity that, despite the pandemic, has remained unswerving in its commitment to provide the best support we can to HD affected families. It always brings me joy to learn about how families are improving support for one another. Our new Youth Ambassadors, engaging in raising awareness about Huntington's disease are the perfect example. I really believe that tackling the lack of awareness of HD lies in your hands and I can see growing confidence, across the Huntington's community in Scotland, about sharing your stories. I visualise each one as a snowflake; unique and beautiful and when there are enough, they fill the sky and over time build deeper and deeper awareness.

I also see a charity that despite this year's formidable challenges has continued to move forward. The expansion of the invaluable Financial Wellbeing Service with another staff member and the addition of fuel advice is testimony to that. Our National Care Framework Lead, Alistair Haw has pressed on with its implementation, one result of which is the appointment of a Clinical Lead for Huntington's Disease and a new Specialist Nurse. These are core elements of a good service and I am delighted that families in the region will shortly have access to better specialist support.

Our staff have adapted quickly to the challenges of the pandemic and we are now using safe, digital platforms like Attend Anywhere across the organisation to provide alternative ways for families to access support. Necessity really is the mother of invention! Even when we emerge from this pandemic, we will retain these new facilities because for some individuals, especially those in rural areas they are a better way to access support.



Underpinning all of this, I see an organisation that has adapted smartly and efficiently to new fundraising challenges and our Fundraising Team are to be commended for continuing to innovate and support the work of the charity, but they cannot do that without your help, so I hope this Christmas you will join in me in raising a Cup O Kindness for all HD families and celebrate the accomplishments of the Scottish HD community.



A special message from our wonderful Patron, Sarah Winckless

I wanted to take the chance to write a brief hello in this winter magazine. At a time when the days are shorter and the climate harsher, it feels more important than ever to reach out and connect to each other.

I've thought about our community often – sometimes with joy as I am inspired by your determination, fundraising efforts and stories, at other times with sadness as it is the first year since I have been patron that I haven't personally been able to join for an event or camp, and I miss that deeply.

It's been such a strange year – the months passing without my usual milestones, however I wanted to share some wins – the seeds I bought at the beginning of lockdown, many survived and even thrived and my garden is now feeding both robins and squirrels.

I've managed to keep connected with a group of friends to do circuits twice a week since March using the House Party app – those of us who can stay on for a chat over breakfast, which has been fantastic.

And I'm now sharing my life with a labradoodle, Harlyn, who is growing at a great rate, and who makes me smile with her greeting every day.

I hope you have managed to look after yourselves and connect with the people and the things that give you energy during this extraordinary year.

My Christmas wish is that you feel the support of our community whenever you need it, and we keep taking one step in front of the next together into 2021.

Lots of love to each and every one of you,

Sarah

Virtual clinics rolled out to safeguard lifeline services

SHA is driving forward its use of digital platforms to provide lifeline support for families at times when face-to-face visits are not possible.

At the start of the pandemic, when restrictions were at their tightest, HD specialists and colleagues reached out over the phone and by email to reassure our HD community that all SHA's services would continue uninterrupted despite the challenges of lockdown.

Since then, a number of digital tools have been adopted by our Adult Clinical Services Team to enable assessments and consultations to go ahead.

One example is NHS Attend Anywhere, a web-based platform that helps health and social care providers offer video call access to their services. Apart from internet access, all people need to use Attend Anywhere are Chrome or Safari web browsers on a computer or mobile device. Computer users will also need a web camera (usually built into laptops) and a headset or speakers. Through the use of NHS Attend Anywhere, SHA hopes to mimic as closely as possible the in-person consultations preferred by our community, while eliminating the need for travel and safeguarding



against the spread of COVID-19. User confidentiality is assured, Attend Anywhere video consultations are secure and the user's privacy is protected; only authorised clinicians can enter the virtual consulting room.

Karen Sutherland, Operations Manager, Adult Clinical Services, said: "While SHA remains committed to its practice of home visits wherever possible, right now this just isn't always possible. We're listening to feedback from people and families, and we know that the services we provide are especially vital during these difficult times.

"Meeting up virtually is enabling the HD community to access our specialist services. For example, the Glasgow HD Specialist service has set up its HD Management clinic on the Attend Anywhere platform. Individuals will be offered a private space to meet with two of our HD specialists and participate in their assessment. The clinics are currently running weekly and the team will be in touch to offer appointments in due course/the coming months."

"Early indications are that the virtual clinics and consultations are working well, and it is interesting to note that some of our most confident digital platform users are our older clients, which has taught us never to make assumptions around people's abilities to learn new skills and stay connected."

SHA Attend Anywhere clinics are being rolled out in areas across Scotland, please contact your HD Specialist for more information. Telephone consultations are also available, for example in Fife most people have chosen to continue having calls with consultant Simon Rubidge, while in Grampian and Highland Professor Zosia Miedzybrodzka is using a mix of telephone and Attend Anywhere in response to client preference.

Working in partnership to reach clients

Ayrshire

Discussions have been taking place about when it will be safe to return to face-to-face clinic appointments. Until then, Dr Adrian Nitu, Consultant Psychiatrist with NHS Ayrshire and Arran, is carrying out home visits to people who have been assessed as urgent/essential.

Lanarkshire

Alison Gordon, Consultant Psychiatrist and HD Clinical Lead for NHS Lanarkshire, is continuing to work with the Lanarkshire HD Specialist team to offer HD Management Clinics on a choice of platforms. Appointments can be carried out by video or telephone.

Lothian

HD Management Clinic appointments with Dr Peter Foley, Consultant Neurologist and HD Clinical Lead for Lothian, are available to families in Lothian through Attend Anywhere. Again, consultations can be carried out over video or by telephone.

Tayside

The team has recently completed training in the use of Attend Anywhere, which will be available for client use in the near future.

Kiltwalk of kindness

Young people from Royston Youth Action (RYA) in Glasgow reached out to HD families as part of their 12 Months, 12 Acts of Kindness project, a year-long campaign to do what they can to support others. After learning about how Huntington's disease has affected the family of one of RYA's staff members, 10 young people completed the five-mile fundraising walk, each sporting their SHA t-shirts. SHA Fundraising officer Hannah Platt said: "During these uncertain times, it's great to see such a community spirit from RYA. We are incredibly grateful for their amazing fundraising and look forward to working with these inspiring young people again."

Family friend inspires Jamie

After losing her husband Colin to Huntington's disease in 2019, Brenda Elliot from Inverclyde has paid tribute to family friend Jamie

Coggins, pictured, for completing his second London marathon and raising more than £7000 for SHA. "Jamie is a true inspiration and he should indeed be very proud of himself," she said. Jamie, 47, went from a self-confessed couch potato to London marathon triumph in 2019. He was so inspired by the experience that he completed this year's virtual event too.



Bruce enjoys awards night

Bruce Wilson, family member and SHA youth ambassador, was shortlisted for the SCVO Scottish Charity Champion award and invited to attend the virtual ceremony hosted by television presenter Sally Magnusson. The event featured a message from First Minister Nicola Sturgeon and guest appearances from the likes of Simon Neil from Biffy Clyro and morning show queen Lorraine Kelly. While Bruce was pipped at the post for the award, he remained upbeat, saying: "I'm humbled to have even been given the chance to appear on the show and I had a lot of fun. Everyone in my category was incredible, they all deserved to win."

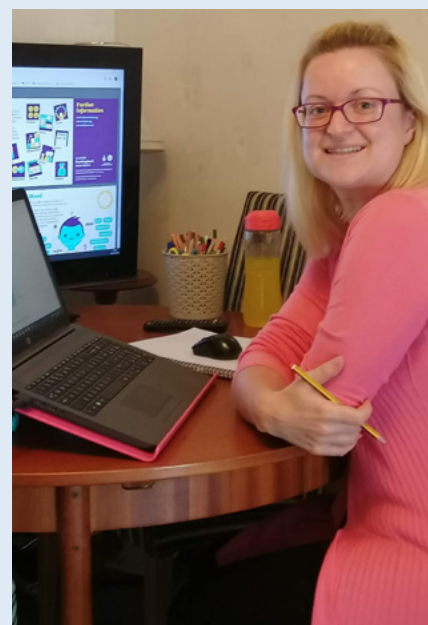
With more young people struggling right now, our youth service is more vital than ever

Kirsten Walker, SHA Youth Service Manager, looks at the impact of the coronavirus restrictions on children and young people, and why the work of the youth service is increasingly vital during these challenging times.

SHA's youth service staff are frequently overawed by how resilient and capable our young people are. Although they face many difficulties in their day-to-day lives, including the more 'typical' young people issues, there are challenges which are more specific to growing up in families impacted by Huntington's disease.

Yet it never ceases to amaze us how the young people face things head on and find a solution, and this has never been more apparent than during the Covid-19 lockdown and continuing restrictions. Whilst we were unable to do face to face visits, many young people continued with support via phone or video calls, and initially we were reassured by how well they were coping. However, as time goes on, we are now seeing a more negative impact of the ongoing changes in restrictions.

Over the past three months, the team is reporting the need for more intensive support, in stark contrast to the early days of lockdown. For many of our young people, it is the growing pressure of managing issues and difficulties over an extended period of time, which are starting to become more contentious. There is a real concern that the struggle to find



solutions is – or will – have an impact on their mental health.

As one young person told us: 'I could manage during lockdown, because there was no choice. I had to be in the house as I couldn't go to school and although it was boring, actually a lot of pressure was taken away from me by being there all the time. Now I'm back at school, I'm expected to keep caring for my mum. Dad lives in a different area so his restrictions are different to mine.'

"We're constantly told that young people are carriers and tend to get milder symptoms of Covid-19, so it's a worry that I'll bring it into my house and make Mum ill. Her depression and anxiety are worse and swallowing is becoming an issue. After she started choking, all I wanted was to see someone face-to-face to talk about this."

"Then, when I did have a socially-distanced chat with my specialist youth advisor in the park, I felt as if everything I'd been keeping hold of for eight months spilled out in one go. I actually didn't realise how much I was struggling until I saw that familiar face in person."

The experience of this young person, and of others, reinforces our determination to be here for each and every one of our young people. It may not be possible to meet face-to-face in this world of Zoom and social distancing, but that doesn't stop us reaching out, strengthening relationships, and providing the vital support they need.



Alex hits his 300th mile with a smile

SHAre cover star and family member Alex Wilson, 57, from Edinburgh, tells us why he decided to take on SHA's month-long My Zen Run challenge.

"My youngest brother Graham and I are close, we've always shared interests, including football and running. We did the Edinburgh marathon together in the early '80s for a Huntington's disease charity, I don't think Graham was even 18 then," says Alex.

"I remember dragging him over the line at Meadowbank Stadium to finish together in front of our family. I was very proud of Graham that day, as I am very proud of him today. He's done so much for his family and managed his joinery business for over 20 years before medically retiring in his 40s due to Huntington's disease. He has good and bad days with the symptoms, but noticeably to all the family, Graham is funnier now than ever. He's determined to get out and see the people he loves, and faces life with a positivity that inspires us all.

"Our Dad, Alex, had Huntington's disease. I was 14 when I found out about HD and it was difficult to watch the disease overtake Dad. He became more reclusive in nature and had significant mental and physical health symptoms. As the oldest of four children, I felt it was my responsibility to help Mum care for my dad and my siblings. She faced extremely challenging times, working full time in social work while caring for Dad and the rest of the family. But Mum stayed strong and did an incredible job overall! Unfortunately, Dad was only 47 when he passed away.

"Now I'm the proud dad of two beautiful girls, Kate (26) and Chloe (22) and I do all I can to maintain positive health and wellbeing.

"I haven't been tested for HD, I was going to have the test about five years ago but just as I received my appointment, I discovered I required a major operation to have a complete knee replacement. That was enough to deal with and I decided to have surgery and leave the test. Now I have a titanium knee, and I can run and keep fit without being in pain.



"I know how much Scottish Huntington's Association supports Graham, his wife Lesley and their son Bruce. Having support to ensure the appropriate care is in place, and being able to talk to their HD Specialist and youth advisor, makes a huge difference.

"I took part in the My Zen Run to help more families receive that support. I set myself a challenge of running 10 miles every day, with the aim of completing 300 miles in one month. Sometimes I wore fancy dress for a laugh and posted videos on Facebook, and I actually managed to exceed my 300-mile target because I was having so much fun.

"The response has been great, and I'm grateful to everyone for such incredible donations to Scottish Huntington's Association and for their encouragement.

"I've taken early retirement from my post as a survey/valuer after 40 years with the Lothian Joint Valuation Board, and the last day of My Zen Run coincided with my final day at work. So, I ran by the office to wave farewell to colleagues – wearing my warrior costume and SHA t-shirt."



Shelly Waterson



Lorraine and Kenny Crichton



Sandy Patience



Join us by raising your **#CupOKindness** and donating to support families impacted by Huntington's disease

Visit www.hdscotland.org/cup-o-kindness



Sandy is supporting Cup O' Kindness in memory of Helen, a beloved sister to both him and their brother David.



Loving family: Helen, David, Sandy and their dad.

For Sandy Patience, Huntington's disease has robbed him of too many close family members, including his older sister Helen. Her death earlier this year is heartbreaking for Sandy and his brother David, and came at a time when Sandy was already adjusting to big changes in his life.

"I had just taken ill health retirement from a job that I loved, but now I feel blessed that I was able to be at Helen's side during her final few weeks and when she died," says Sandy, from Inverness.

"She had the symptoms of this dreadful disease for 30 years, it overwhelmed her in every way yet she managed to keep a great spirit for life. Helen never wanted to live in a care home but she wasn't able to look after herself. Even though we did everything we could, it was the best place for her to be.

"Helen, David and I grew up in a loving family but so many of my memories are linked to this disease. It has taken my mother, my gran, great aunts, numerous cousins, friends and now

Helen. Seeing family members suffer, and understanding that might also be your future, is a very difficult thing to deal with.

"When we found out that my daughter Kimberley is clear, it was the best moment of my life. I know Huntington's disease stops with me and she and her children are safe."

Now Sandy, who tested positive in 2017, is determined to make the most of his retirement.

"As a railway signaller, I had to make decisions in an instant, the job is so safety critical that either I'm fit or I'm not. A cognitive test before lockdown showed that I'm a wee bit slower than I was, I'm still sharp but not sharp enough to do that high-pressure job now.

"I have plenty to keep me busy with the Roche trial, staying fit, and spending time with my wife Laura, Kimberley, my stepchildren, and our grandchildren. And, of course, Rollo, my labradoodle and soulmate!



"I'm looking after my health, getting fit and building muscles, and that's helping my mental health too. I feel stronger than I have for years. I'm ready for this next stage in my life, I'm busier than ever. It's not what I'd hoped for but I have a wonderful family, friends and Scottish Huntington's Association to support me in whatever comes next."

Every gift to Cup O' Kindness will make an am

Life has changed for everybody as a result of the Coronavirus pandemic – and for families with Huntington's disease it means they are relying on SHA more than ever.

Your kindness will help protect the lifeline services relied upon by our families, including our nationwide network of HD Specialists across Scotland, our expert Financial Wellbeing team and our world-leading youth advisors supporting young carers.

Inspired by Rabbie Burns' Auld Lang Syne and building on our strong Scottish grassroots, the Cup O' Kindness appeal is led by family members who are sharing their stories as a message of friendship and support to all families whose lives are impacted by Huntington's disease.

To find out more about the appeal and to donate, please visit www.hdscotland.org/cup-o-kindness

Kenny and Lorraine are raising their Cup O' Kindness for everyone whose life is affected by HD

Lorraine turned 50 knowing she was in the early stages of Huntington's disease, and in the five years since she has lost control over movement and her speech is now affected.

Sometimes the struggle to get the words out is too frustrating so, even though she has plenty to say, Lorraine often turns to husband Kenny, 54, to do the talking for them both.

Their determined spirit make for a formidable team as they face the impact of Huntington's disease together. It was more than 30 years ago when they first met in a local pub. Lorraine liked the look of Kenny straight away – "He was just back from Ibiza so he had a really good tan!" she says.

They went on a date a week later, and the following year as Lorraine was coming to terms with her test result, Kenny was by her side.

He's been there ever since. In 1996, daughter Ashleigh was born and soon after the couple surprised guests at her christening by announcing they were getting married that day too.

Kenny says: "We got on with life and hoped it would be a long time before any symptoms started, but now it seems

to be progressing fairly quickly. When we meet friends who haven't seen us for a while they can be quite shocked by the changes in Lorraine."

Lorraine has given up the job she loved working in their local bowling club, and now uses a wheelchair when she goes out.

"Lorraine never complains, I really admire how she deals with things," says Kenny,

"He moans more than I do!" says Lorraine. "That's true," agrees Kenny. "I get frustrated, for example if Lorraine drops something. I have to remind myself that the mess doesn't matter, we



can always tidy it up. It's never easy but the pandemic has made it harder. I was furloughed until recently and Lorraine misses meeting up with her friends.

"The HD Specialists from Scottish Huntington's Association really help. They understand what families are going through and make sure all the support and information is there for them."

Looking to the future, Kenny and Lorraine worry about Ashleigh, 24, who is at 50% risk of having the same faulty gene.

"Ashleigh's test has been delayed because of the pandemic, which is difficult as she's ready to know. We hope that Lorraine is where the disease stops for our family."

Making a difference for families across Scotland

Helping families to manage their household finances

Our Financial Wellbeing Service works with individuals and families across Scotland to ensure they receive the right package of financial support and are able to manage their household budget.

In addition to providing specialist advice about benefits and allowances, including the most up-to-date changes as a result of the Coronavirus pandemic and the new Scottish Child Payment, our financial wellbeing officers can also help with tackling debt-related issues and filling in forms.

To contact your local officer visit <https://hdscotland.org/services/getting-specialist-financial-advice/> In the meantime, Senior Financial Wellbeing Officer Jo Baldock shares the latest information relating to energy bills, families and young people, carers and pandemic-related support.



Energy

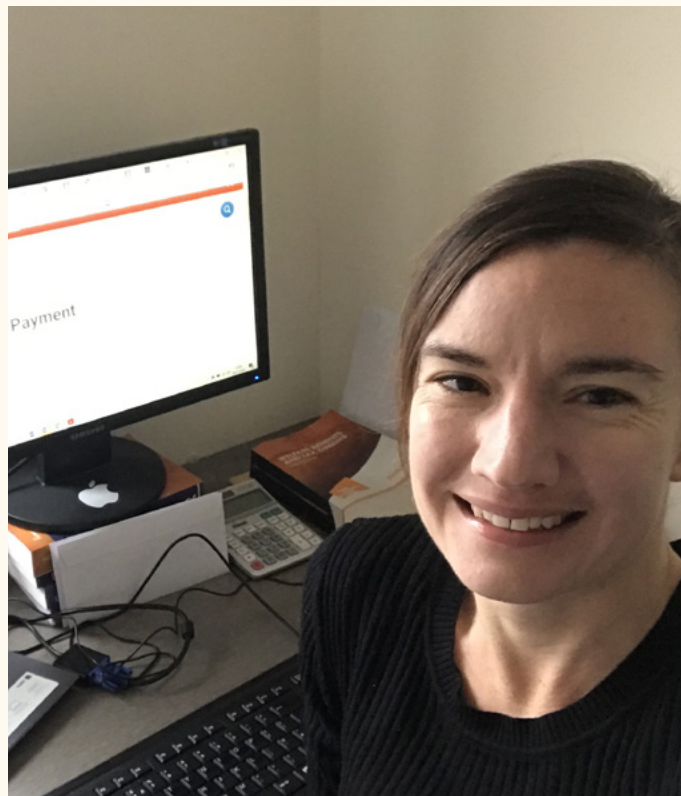
- **Warm Home Discount** applications are now open from most energy suppliers. Claim **£140** off your electricity bill if you are on a low income and receive certain benefits. Get in touch with the Financial Wellbeing Team if you are unsure or would like help with an application.
- **Watch Out** for our new Energy Advice Service to be launched in January 2021 which will enable us to provide even more advice on energy issues.



Families and young people

- **Scottish Child Payment** is a new Scottish benefit for low-income families with children under six years old. Eligible families will receive **£10 per week per child**. Applications are open now with payments scheduled to begin from the end of February 2021.
- A **Job Start Payment** of up to **£250** is available for young people aged between 16 and 25 who start a new job, after being out of work and on certain benefits for six months beforehand. (this time period does not apply to care-leavers).
- The **Young Carers Grant** is a yearly payment of **£305.10** for young carers in Scotland. You must be 16, 17 or 18 to apply and care for someone for over 16 hours a week who is in receipt of certain benefits. You cannot also be claiming Carers Allowance yourself but it does not affect the Carers Allowance that someone else may also be claiming for the person.

More information about all of these benefits can be found on <https://www.socialsecurity.gov.scot/benefits>, or speak to the Financial Wellbeing Team or your Youth Specialist.



Disability benefits and carers

- **PIP renewals** were suspended earlier in the year due to the Coronavirus pandemic and many people received notification of an extension to their award. However, this has ended in some cases, and if your PIP is due to end in the next six months and you have not been sent a renewal form, we suggest you contact PIP on **0800 121 4433** for an update.
- This year's second **Carers Allowance Supplement**, paid to carers in Scotland who were in receipt of Carers Allowance on 12/10/20, will be **£230.10** and paid automatically in December.



Coronavirus-related issues

- For those who are impacted financially by the current pandemic, for instance due to loss or changes to employment, or periods of self-isolation and sickness, there is a complex and ever-changing system of support in place. For more information on where to find up to date information please see our website <https://hdscotland.org/covid-19-financial-advice/> or get in touch with the team.

Kenny's love for his dad leads to double challenge

Kenny Train lives with the knowledge that he is at risk of developing Huntington's disease in later years – however for now he prefers to look to the future with hope and focus on the positives.

"Because HD is hereditary, there's a 50% chance that I have the gene too but I haven't been tested as I'm an optimist and like to look on the bright side," said Kenny.

"My dad Bob was diagnosed with Huntington's disease more than 20 years ago after a car accident. Thankfully no one was injured, however since then he's gradually lost the ability to do what we take for granted, like eating, walking and talking. Nowadays, it's really hard to understand what he's trying to communicate.

"On good days, Dad is up in his big chair watching TV but that's quite rare now. Most days, he's in his bed asleep for long periods."

This year, Kenny set himself a massive double challenge in tribute to his dad and to help other families whose lives are affected by Huntington's disease. He signed up for SHA's My Zen Run during his

training for the Great North Solo Run.

"I hope to raise as much as possible for SHA as a thank you for supporting my dad, our family, and our friends. I also

want to raise awareness because HD is not well known or understood by most people," said Kenny.

He set himself a personal target of 300 miles and hoped to average around four miles a day to raise as much as he can for Scottish Huntington's Association.

Kenny joins people from all over Scotland who chose to run for somebody they love this year by joining the My Zen Run challenge or taking on the virtual London Marathon to raise funds for Scottish Huntington's Association;

Every mile covered by our SHA runners is already making a real difference to the families we support, and we are truly grateful to them for helping to safeguard lifeline services, especially during these difficult times when so many fundraising events have been cancelled.

HD Specialist appointed for D&G families

The Care Framework for HD has secured another significant advance for families impacted by the condition in the south of Scotland.

For the first time families in Dumfries and Galloway are to have access to an HD Specialist, who was recently appointed and is scheduled to start work in January 2021. The post holder – who will be introduced in the next edition of SHAre - will work with SHA and HD Clinical Lead for Dumfries and Galloway Dr John Higgon, who was appointed earlier this year.

The development means that, for the first time, Dumfries and Galloway will have access to a specialist HD service in line with that experienced in other areas of Scotland. The appointments followed work to develop a localised Care Framework for HD in the area, which is now online and is due to be formally launched once the new specialist team is fully in place.

Elsewhere, the Care Framework is continuing to be used to influence change on behalf of HD families. NHS Tayside is in talks with SHA with a view to providing more dedicated time for HD Clinical Leads in the area.

NHS Forth Valley is in discussions with SHA around providing more community-based HD Specialist Support. And NHS Borders, the last area not to have an HD Framework, is committed to putting one in place, with one already having been drafted.

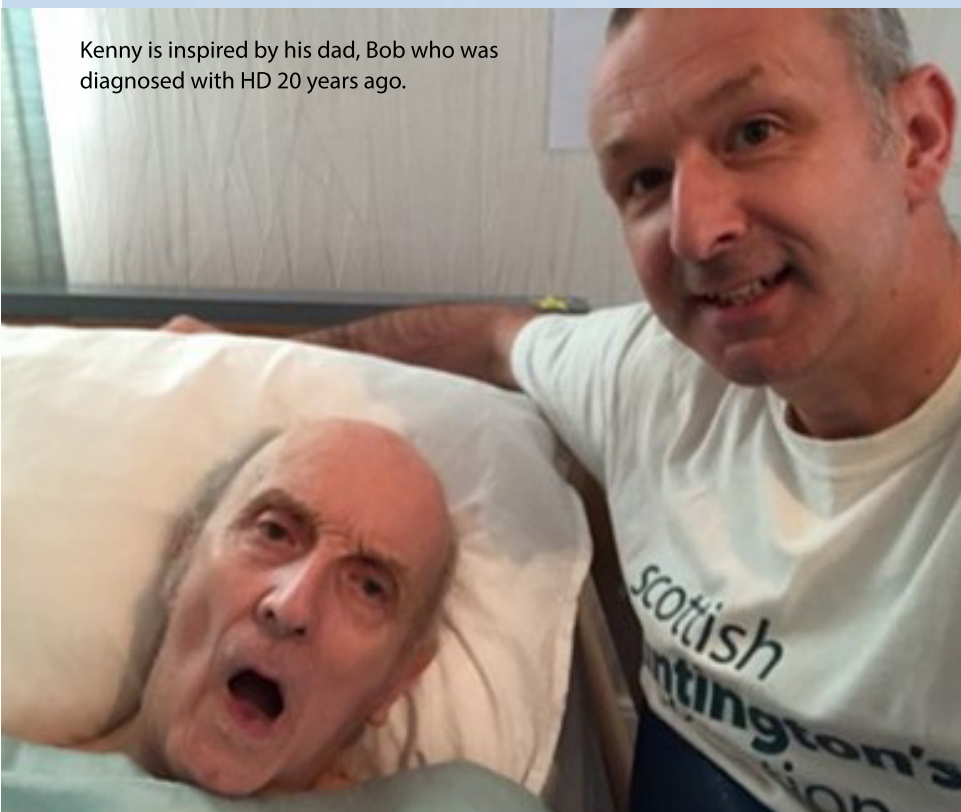
SHA National Care Framework

Lead, Alistair Haw, said: "The Framework has had a significant role to play in introducing new services for HD families throughout the country, with the appointment of an HD Clinical Lead and now HD Specialist for Dumfries and Galloway being two recent examples.

"It is proving to be the useful influencing tool we always hoped it would be, and SHA is determined to continue using it to drive up standards for HD families wherever this is required."

The National Care Framework for HD can be viewed at: <http://care.hdscotland.org/>

Kenny is inspired by his dad, Bob who was diagnosed with HD 20 years ago.



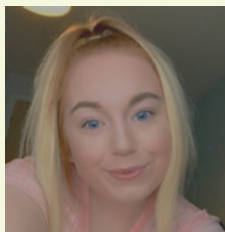
Four new youth ambassadors join team to provide support and raise awareness

SHA has welcomed four additional young people to its Youth Ambassador Peer Support (YAPS) team.

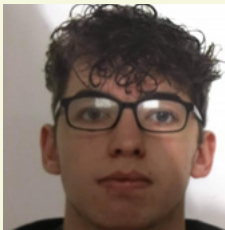
Run by SHAYP, SHA's youth service, the YAPS programme aims to empower its volunteer ambassadors, who are aged from 16 to 30, to provide support to children and other young people growing up in HD families.

They also help to raise awareness about Huntington's disease, fundraise and promote the work of SHA and SHAYP. In return, the programme offers the chance to develop new skills, including public speaking, to help youth ambassadors to grow in confidence and boost CVs or college/university applications.

Joining the six YAPS already in place are:



Jodi Queen, 18, who said: "I'm happy to become a SHAYP Youth Ambassador because I can help others with their understanding about Huntington's disease and be there to support all my peers."



For Declan Newport, 17, it offers the chance to give back to the charity. "I decided to become a Youth Ambassador because the charity has helped me so much and I want to do my bit and help raise awareness about the disease," he said.



Fellow YAP Keir Straub, 17, said: "I joined the Youth Ambassadors programme because SHAYP means a lot to me and I'm glad to help them out in any way I can."



And Kayi Birnie, 17, added: "I am a youth ambassador for SHA because I want to give something back for all the people who have supported me growing up and to help others understand what Huntington's disease is."

The four new YAPS have already taken part in an induction/training session, delivered virtually by Kirsten Walker, Youth Services Manager, and Pete Carruthers, Specialist Youth Advisor.

"We're always impressed by the willingness of our young people to become involved as youth ambassadors. By sharing their knowledge and experiences, our YAPS make a big difference to the lives of other young people because they understand what it means to grow up in a family impacted by Huntington's disease," said Pete.



Feedback from young people shapes project

One of the first tasks for our new recruits to the YAPS programme is to help with the development of a project to provide information about financial matters for young people in the HD community.

With funding from the Scottish Government Debt Advice Levy Fund, accessed through Advice UK, SHAYP is working in partnership with SHA's Financial Wellbeing Service and the YAPS to develop a suite of resources.

All 10 youth ambassadors took part in an early project consultation, with some participating in the online focus group while others contributed ideas directly to the organiser, Grant Walker, Specialist Youth Advisor.

"The input of the YAPS is invaluable, and they are very aware that the resources have to work for all our young people, not just those in the 16+ age bracket," said Grant.

"Nevertheless, it's good to understand more about the top areas of interest among our YAPS, which include mortgages, life insurance, student finances and benefits. There were some surprises, for example we assumed that information about allowances such as the Young Carers' Grant would be a priority but it was actually further down the list.

"Following our discussion with the YAPS, we're also considering how best to share the resources with our young people. There's little interest in printed materials and much more of a focus on digital, including animated videos."

I cried in the car today. This is why.

I cried in the car today. I fixed my mascara in the rear-view mirror before afternoon surgery, so I'm almost sure I got away with it.

When I arrived at the nursing home, the paramedics were wearily checking their kit in the back of the van. Rain dripped down the back of my neck as I leaned in to thank them for trying.

Her room was stuffy, lingering sweat and panic in the air. Hastily discarded plastic wrapping, defibrillator pads and bag and mask surrounded her on the floor. Someone had sliced the front of her T-shirt raggedly, leaving her chest exposed, waxy and pale. Her nails were painted bright pink.

Fiona, a kind senior nurse I knew well, held back tears as she told the story. She had been having lunch, helped by a carer. Her neurological condition had stolen away most of her swallow, but she still loved the childhood comfort of sweet puddings and ice cream.

Suddenly, quietly, her heart had forgotten to take a next beat, and not even those expert life-savers in green jumpsuits had been able to convince it to start again.

It was a far quicker end than we would have predicted. A monstrous disease, hidden in her genetic code, had been eating away at her for years. Bite after cruel bite.

The first signs were the jerks and twists of her limbs, making it impossible to hold a cup of tea. The genetic clinic dealt the blow, and relentlessly the illness took her job, voice, sanity and finally, her overwhelmed family. Now home was this room, nurses and

daytime TV for company and some framed photos to remind her of what was lost.

We had spent a difficult morning together, trying to understand her ideas about the future. What should we do when her swallow stopped working? Would she want us to form a tube into her stomach for liquid feed? If her heart stopped suddenly, should we try and revive her? How tight was her grip on what was left of her devastated life?

Not easy questions for anyone, never mind someone whose vocabulary had shrunk to a handful of mumbled words. I hope we did our best. I hope I gave her the dignity and time she deserved.

Her choices (no tube feeding, but yes please to CPR) had been noted in all the right paperwork and so when her heart stopped, two spoonfuls of custard into her lunch, the staff phoned 999.

I performed my ritual checking for signs of life, stethoscope on her silent chest. It was a strangely holy moment. She lay, still and grey as a carved queen on a tomb, finally resting after years of incessant movement. The nurse and I were quiet pilgrims on our knees beside her, as though in silent prayer. I felt strangely reluctant to leave her side.

The tears started as soon as I left the carpark.

Pulling into a layby under some tall pines, I closed my eyes and rested my forehead on the coolness of the steering wheel. She wasn't my first sudden death, not even the first death

I had certified that week. Why was this one hitting so hard?

She had been less than five years older than me. Too young. The children in those framed photos were only a little older than mine, and who could blame them for finding visiting days too sad to endure?

Perhaps that proximity drove home the monstrous unfairness of a life so destroyed by a tiny faulty gene. Perhaps it was the heartbreaking silence of her wasted body on that floor.

Perhaps the teaspoon still resting against the rim of the abandoned bowl of custard on her table.

Rain continued streaming over the windscreen, as steadily as the tears on my cheeks. The beat and whoosh of wipers and tick of hazard warning lights kept time, reminding me that my afternoon was far from over.

Turning the key in the ignition, I wiped mascara from cheeks and chin with my sleeve, and pointed the car back towards the health centre.

I gave myself three minutes in the car park to let my red eyes settle, then straightening my shoulders, headed through the waiting room with a watery smile for its irritable occupants. I thought I had pulled it off but as I closed my office door I heard a loudly stage-whispered complaint.

'She's always bloody running late, that one!'

*We thank Dr Meeten for her permission to share this article with our readers.

SHA's Fundraising Calendar of Events January – October 2021



January

The BIG Sponsored Walking Challenge

Friday 1st January – Friday 31st December – Virtual Event

March

SHArk Dive

Date TBC North Queensferry

Supernova Kelpies 5K

Friday 19th – Sunday 21st March – Falkirk



April

Go! Festival Ayr

Saturday 24 April – Ayr

Kilomathon

11th April Edinburgh

ZipSlide Across the Clyde

Date TBC – Glasgow

May

Glasgow Kiltwalk

Date TBC – Glasgow

SHA SkyDive

Date TBC – Perthshire

Stirling Marathon

Sunday 9th May – Stirling

Edinburgh Marathon Festival

Saturday 29th and Sunday 30th May – Edinburgh

Inverness Half Marathon

Sunday 16th May – Inverness



June

Beast Race Loch Ore

Saturday 12th June – Fife

Great Scottish Tattie Run

Sunday 27th June – Edinburgh



July

Tough Mudder

Saturday 3rd – Sunday 4th July – Edinburgh

Ride the North

Saturday 24th July – Aberdeen

August

Dundee Kiltwalk

Date TBC – Dundee



September

Edinburgh Kiltwalk

Date TBC – Edinburgh

Scottish Half Marathon

Sunday 19th September – Edinburgh

My Zen Run

Month of September – Virtual Event

October

Virgin London Marathon

Sunday 3rd October – London

Great Scottish Run

Sunday 3rd October – Glasgow



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We will not pass on your details to any other organisations. Your data will be treated in accordance
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