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step is filled
with love for
Granny Lorna

A message from our Chief Executive Officer

Something I've heard regularly during my five and a half years at Scottish Huntington's Association (SHA) is that Scotland has the best support for HD families anywhere in the world.

Of course that statement has more of an impact when said by someone who is not based in Scotland (for we would say that, wouldn't we?). Since my appointment as CEO earlier this year I've heard it from several such sources already. In fact the first person outside SHA to contact me after my appointment was the CEO of an HD Association in the southern hemisphere. He asked me to speak at their annual conference: "SHA has developed the best system in the world," he said "and we want to learn how you did it."

When I hear this I have mixed emotions. First there is a sense of pride - and gratitude - to the staff, trustees, families and supporters who have worked tirelessly to get us to where we are today. What could be better than being regarded as the best in the world? However, this pride is tinged with a great sense of sadness. Sadness that the services we in Scotland have come to take for granted - which remain *far* from



perfect - are but a pipe dream to families all over the world whose needs are just as great, and who matter just as much.

So let's remember how far we have come. It's right to be proud of that. But as we continue to fight to drive up standards (and continue to fight we must!) let's also remember it's not just families in Scotland who are depending on us to succeed. It's families throughout the world.

That's why the work we do matters so much. And why we are all so privileged to be part of this incredible organisation.

**Alistair Haw, Chief Executive Officer,
Scottish Huntington's Association**

We can help lower your energy costs

Our Financial Wellbeing Service is urging families to get set for winter with an Energy Health Check to see what savings can be made on gas and electricity bills.

Our specialist team can also help with applications for the Warm Home Discount scheme 2021/22, which has now opened with many household electricity suppliers. It can mean a saving of £140 off bills for individuals and families in receipt of qualifying benefits or on a low income.

When you book in for an Energy Health Check, your Financial Wellbeing Officer will work with you to explore a number of ways to save money on fuel bills. This includes helping you to switch suppliers for a better deal and sourcing grants subject to eligibility for upgrading an existing heating system or installing energy efficiency measures in your home.

To find out more just call our National Office on 0141 848 0308 or get in touch via our website.

In the words of one of our family members: "The service was fabulous. So much help, assistance and advice was given about different options that I would otherwise not have known about."

Sharp rise in HD diagnosis in northern Scotland

New findings reveal that diagnosed cases of Huntington's disease have risen by nearly 50% in northern Scotland over the past 30 years.

The study team at University of Aberdeen believe the increase in Grampian and Highland – an area that already has high prevalence rates - is due to the combination of underlying genetic susceptibility in the ancestral populations, increased awareness about the benefits of diagnosis and the region having one of the oldest specialist HD research clinics in the world.

Professor Zosia Miedzybrodzka, Consultant in charge of the NHS Grampian's North of Scotland Huntington's clinics, led the research. She said: "The emergence of the genetic

test which people, with or without symptoms, come forward to take is likely to have contributed to the increase in those diagnosed with Huntington's disease

"In the north of Scotland, an area known to have high levels of Huntington's disease, there has been a 46% increase over the last 30 years. Even in a country the size of Scotland, there is quite a variation in prevalence between health board regions. This could have major drug cost and service delivery implications, especially if expensive, complexly-administered therapies prove successful."

Commenting on the findings, SHA CEO Alistair Haw, said: "Whilst the increase in Huntington's diagnoses across

Grampian and Highland appears stark, what families in these areas have in their favour is access to a localised HD Care Framework backed by an HD Clinical Lead, an HD Specialist and specialist Financial Wellbeing and Youth Service staff.

However, in light of cases increasing by almost half over the period, local providers across the country may wish to reflect on the requirement to expand these services to meet significantly growing demand.

"Huntington's disease is a hugely complex, widely misunderstood and extremely difficult to manage condition - meaning specialist services are not some nice to have optional extra but an absolute necessity."

SHA appoints new Senior HD Specialist for Grampian

Sam Buckley has joined the Grampian team as Senior HD Specialist. Having worked as a Carer then Activities Coordinator in a Specialist HD Unit, Sam went on to study as a Mental Health Nurse.

She joins us from the NHS and brings experience of acute inpatient services (adult and elderly), Home Treatment Team, Community Mental Health Teams and Mental Health Triage Services. Welcome to SHA Sam!

We thank all our friends in Tayside for their support

A special mention for the Tayside Family Branch, and Couper Angus Shop volunteers including Mary Cunningham and Jessie Smith whose fundraising and support is making a real difference to local families.

Despite the restrictions that were in place over the past 18 months, fundraising by this dedicated group of volunteers resulted in an amazing donation of more than £22,000 to Scottish Huntington's Association. This vital funding has helped sustain our HD Specialist Service, Youth Service and Financial Wellbeing Service within the Tayside area.

In addition, Tayside Family Branch has also provided funding to buy equipment, including items for the sensory room at Rumbling Bridge, for use by clients, sent wellbeing packages to families to help reduce feelings of isolation as a result of lockdown, and organised the distribution of Christmas gifts last December. Thank you!



David and Teri keep on running!

Good luck to our marvellous My Zen Runners who are taking part in our virtual challenge throughout September.

Our Team SHA includes neurology nurse David Thomson and his wife Teri who were inspired to join in by one of David's patients, SHA Trustee Marie Short MBE.

Find out more about My Zen Run by contacting linda.winters@hdscotland.org

Family Time for carers

Families, trustees and staff are working together on the continuing series of Family Time webinars to be held throughout the remainder of this year and into 2022.

The live online events bring together our community to connect, learn from one another, be inspired and access latest information and news from Scottish Huntington's Association. You will hear from family members, specialists from across the charity and guest speakers. And, importantly, the one-hour gatherings are a chance to chat with friends old and new, have fun and enjoy some entertainment too!

The next Family Time session takes place on Tuesday, 21 September at 3pm. This session will focus on the amazing carers in our community and explore ways to assist them to look after their own health and wellbeing too.

Karen Sutherland, SHA's Deputy Chief Executive Officer, said: "We all look forward to SHA's annual conferences, bringing everyone together is a real

highlight and, crucially, it's a vital aspect of our work to reduce the isolation that is a reality for all too many of our family members".

"Unfortunately, due to the COVID-19 restrictions that continued throughout 2021, we've been unable to plan events this year with any degree of certainty. We explored holding online conferences, however feedback suggested there is little appetite for a day-long virtual events. So, with that in mind, the Family Time online get-togethers offer a chance to get together every six weeks or so until we are all able to meet face-to-face once more."

You can also keep an eye on our social media channels – Facebook, Twitter and Instagram - for upcoming Family Time dates and topics, or we can send you an invitation via email. If you haven't signed up to receive our emails, which include important updates and upcoming events, let us know by visiting hdscotland.org/stay-in-touch, or by calling 0141 848 0308.

Register for Family Time: A Focus on Carers on Tuesday, 21 September at 3pm, by emailing FamilyTime@hdscotland.org. This email address is also available for you to send questions, feedback or suggestions for future themes and speakers. Please let us know if you need support to access the Zoom app and join the meeting and we'll get right back to you.



Bringing our young people back together

At last we've been able to bring our young people back together for the first time since the onset of the pandemic last year.

The easing of restrictions earlier this summer meant the Youth Service was able to hold three outdoor activity days in July for children and young people aged from 8 to 25 years old.

Young people from Edinburgh and Fife had a fun day out at Broomlee Activity Centre where they enjoyed archery, clambering over low ropes and the highly terrifying 'catwalk' treetop and plunge challenge.

For those living in the west of Scotland, a visit to Pinkston Activity Centre in Glasgow for kayaking, paddle boarding and 10-pin bowling. And in Aberdeen, at Lochter Activity Centre, there was a segway assault course to conquer, go-karting, digger driving and navigating a 4x4 with a blindfolded driver at the wheel. At the time of writing, the Youth Service was also organising an activity sessions for young people in Orkney and Caithness.

Specialist Youth Advisor Grant Walker said:

"It was great to see the smiles on all the faces and to welcome some young people who until then we'd only met virtually because of COVID-19 restrictions.

"Many of the young people we support are carers who can feel very isolated, especially during the long summer break. Hopefully as things move forward we can begin planning our annual camps and residential trips. Until then the activity days have been a great way for everyone to catch up with one another and have fun together."

The feedback from families has been hugely positive – in the words of one of the mums: "I can't thank you all enough, William had an amazing day. He was buzzing when I collected him, what a great day out for everyone!"

And what did the young people think? We've had a great response from them all with only one negative comment – and that was about not liking the sausage rolls served for lunch!

Visit hdscotland.org/shayp for information about the Youth Service.



Radio chat recording archived for future

Did you know that a conversation with one of our family members is being archived in the British Library so future generations can learn from it? Katie took part in the BBC Radio 4 Listening Project Broadcast to talk about the challenges of Huntington's disease. If you missed it, catch up now at <https://bbc.co.uk/sounds/play/m000ydpc>.

The conversation is one of 1000 that are being stored in the British Library to give a snapshot of what life is like today for people from all backgrounds and walks of life.

Robert inspires work colleagues to drive new charity partnership



Thoughtful: Elaine is thrilled to have a reply from the Queen.

Queen writes back to Elaine after receiving kind message

When Elaine Dowds sent her condolences to Buckingham Palace following the death of Prince Philip, she never expected to hear back from the Queen.

But a few weeks later a card from the royal residence arrived, addressed to Elaine at the Robert Allan Unit of Benore Care Centre in Fife.

Nurse Gillian Blackadder said: "Elaine was very upset when news broke that the Duke of Edinburgh had sadly passed away. She asked if someone would go and buy her a sympathy card to send to the queen."

"She told us what to write then we sent it off to be posted. None of us expected to hear anything but then a very official and royal card arrived for Elaine. It was from the Queen to thank Elaine for writing to her and for such kind words."

Elaine (57) is delighted to have received such a wonderful reply and the card is framed and in pride of place in her room.

Scottish Huntington's Association HD Specialist Nicola Johns, who works with families in Fife, said: "Elaine is such a thoughtful lady who deserved acknowledgement for her kindness, so I was absolutely thrilled when I heard she had received a reply from the Queen."

Our new charity partnership with Grant Thornton is going from strength to strength since its launch earlier this summer.

Scotland-based employees of the global financial firm are raising funds for lifeline services, increasing awareness about Huntington's disease and creating opportunities for our young people.



Support: Robert Hannah

It comes after we were nominated by Grant Thornton employee Robert Hannah, whose wife has Huntington's disease. SHA went on to win the staff vote and it hasn't taken long for work to begin on a number of innovative projects.

"We're using our skillsets to benefit the Youth Service, working to provide a range of access and employability support for young people who access these services," said Robert.

"We're also building local awareness and creating a national set of materials to support staff and people managers to provide the best quality of support to any staff member dealing directly or indirectly with the challenges of Huntington's disease."

Alistair Haw, CEO of SHA, thanked Grant Thornton employees for their support.

"This innovative partnership brings great opportunities to change lives and attitudes, especially in relation to young people who are often turned into carers for their parents whilst also dealing with the reality that they too are at risk of inheriting the devastating condition that's unfolding in front of their eyes," he said.

* To find out more about the ways we can work with business and employers, please email gemma.powell@hdscotland.org*

Empowering families with Tailored Talks

New carers' resources and a Huntington's disease toolkit are being developed by our Adult Clinical Services, Financial Wellbeing Service and Youth Service teams for inclusion in the Tailored Talks platform, a new digital resource that supports shared decision-making in healthcare.

Scottish Huntington's Association is one of the first organisations in Scotland to be invited to create a condition-specific space on the site, which will support clinicians to provide more personalised support for clients.

"Tailored Talks is funded by the Scottish Government's Neurological Framework. The aim is to improve the quality and delivery of information for patients with neurological conditions and to support health and social care professionals and people working in third sector organisations to provide information that is specific to each individual patient's needs," explained Karen Sutherland, SHA's Deputy Chief Executive Officer.

"This information can be shared on screen during face-to-face meetings/consultations, on paper for people who aren't using technology, or remotely by emailed pdf or via web links so that patients and their carers can access the information on their mobile devices, PC or laptop." Recipients then have the opportunity to share this individualised information with other people (e.g. family members) wherever they are in the world.

Unlike traditional paper-based patient information leaflets, the content is readily updated to ensure it is current, relevant and accurate.

We will keep families updated with more information when our Tailored Talks space goes live.



Family: Olesja and Mark are coming to terms with his diagnosis last year.

Olesja: Helping Mark to cope with his diagnosis is most important thing

Mark who lives in Glasgow, was diagnosed with Huntington's disease last year after years of health problems, tests and hospital stays. Mum Olesja tells us about their shock at the diagnosis, the changes she sees in her son and how they made both their birthdays extra special this year.

"Before Mark was diagnosed, I couldn't understand why we were being asked about Mark's family history in relation to a hereditary genetic disease we knew nothing about," said Olesja.

"Afterwards I was offered a test and I said no because Mark's result was too much to take in. I've spoken to both sides of the family and we've decided to leave it there for now. The most important thing is Mark, what this means for him and how he's coping. He's changed during the past five years, especially over the past two to three. His balance, speech and ability to complete tasks becoming more and more affected and he's lost quite a bit of weight too.

"My son is a strong man with a lovely nature and he never argues or complains. I'm very proud of him but it can be frustrating because that can mean he doesn't tell me when he's not feeling well."

Olesja, a professional wedding photographer, organised an outdoor shoot by one of her work colleagues to celebrate Mark's 26th birthday earlier this summer. Their beloved kitten got in on the action too by getting dressed up and photographed for the special day too!

To mark her own birthday, Olesja chose to support the wider Huntington's disease community by inviting friends and family to donate to Scottish Huntington's Association instead of sending gifts.

"We've a lot of contact with Helen, our HD specialist. She checks in regularly to see how we're doing, answer our questions and make sure we have what we need. Helen helps us to understand the disease and what to expect, and we know we can contact her at any time. That makes a huge difference to both of us. My birthday fundraiser was a way to say thank you and help to make sure other families have that support too," said Olesja.

*Find out more about how to set up a birthday fundraiser at <https://www.facebook.com/fund/ScottishHuntingtonsAssociation/>.



Catching up with Katrina as service marks £5m milestone

Since 2015, the Financial Wellbeing Service has generated £5million in financial gain for family members facing hardship or being supported to maximise, future proof and plan their finances. We meet Financial Wellbeing Officer Katrina Lovie, who works with families in the north of Scotland.

Tell us about your journey to Scottish Huntington's Association

My first sojourn into advice work was as a student volunteer with the Citizens' Advice Bureau. I loved my degree course in Scottish Ethnology and Scottish History and went on to do a post grad in Rural Land Economy. It was geared towards becoming a rural surveyor or estate factor to look after the interests of landowners but I soon realised I'd rather be helping estate tenants who were often living in poor housing. This led to my first job in a local authority homelessness team. I continued in the sector, working to bring empty homes back into use and latterly was involved in strategic policy roles. But I missed direct contact with people and came full circle in 2014 when I joined Citizens' Advice Bureau and the following year I started at SHA.

What most inspires you about your role with SHA?

The love and commitment our family members show their loved ones and their ability to maintain a sense of humour, despite living with this most difficult of illnesses. Witnessing the challenges families can encounter when it comes to securing and sustaining a decent income makes me feel sad about the impact this has, angry at the injustice and keen to do all I can to support and empower them to get their financial situation on a good footing. I want families to be free to concentrate on having the best quality of life without worrying about money.

How does the Financial Wellbeing Service support families?

There are three main strands to our work. The first is income maximisation, which is primarily checking for social security entitlement and supporting with claims. Secondly, we support with debt problems which can involve negotiation with creditors to agree



Expertise: Katrina's support reduces financial pressure on families.

debt arrangement schemes. And, thirdly, there's everything else! Future planning (power of attorney, guardianship, planning for care costs and estate and will planning); helping people access pensions early on ill health grounds, employment issues, housing issues, insurance issues, energy advice – anything at all that touches on financial wellbeing.

We work alongside SHA's HD Specialists and Youth Service, and with external clinical services such as genetic counsellors for people considering predictive testing, researchers and consultants. Families have a one-stop shop for all financial wellbeing issues and we also engage with other financial specialists. For example, if someone is retiring early on ill health grounds there are a whole range of issues to be considered, from tax to social security eligibility. I'll bring in an Independent Financial Advisor (IFA) pension specialist and I'll look at how pension payments will interact with present or future social security payments to maximise income. Our service is unique, holistic and joined up and families tell us they find this helpful. It saves them having to go to many different advisers for advice on specific aspects.

What do you enjoy outside of your work?

I've joined Oor Vyce, a campaign for the legal recognition of the Scots language. While it shares the same linguistic roots as English, Scots has developed

differently; it has a rich literary history and presence and is an important part of the speaker's identity.

I also play the bagpipes. I started on the chanter aged 11 and played at agricultural shows and Highland games with Towie & District Pipe band. I've competed with the Grampian Police Pipe Band and played unusual venues from a boat docked at Maloy harbour, Norway, to a music festival at Herring, Denmark. Now I enjoy teaching, playing for pleasure and getting inveigled in musical collaborations.



During lockdown I learned to play the accordion through online lessons. I was inspired by Phil Cunningham – he and Aly Bain played our community hall a few years ago and dazzled us all with their playing. They also tell a dashed good story!

* Visit <https://hdscotland.org/services/getting-specialist-financial-advice/> to access support or contact your local Financial Wellbeing Officer.*

£80k boost for life-changing youth support

The life-changing work of our Youth Service has been recognised with an £80,000 award from the National Lottery Community Fund's Young Start Award.

The funding is helping to provide 1-2-1 and group sessions, activity days and workshops to improve mental and emotional wellbeing, build confidence, reduce social isolation and offer a break from caring responsibilities.

Youth Service Lead Kirsten Walker said: "Children growing up in families impacted by Huntington's disease experience significant and often devastating ongoing losses and challenges, which no child should have to face unsupported.

"Often children have to become the main carer for their parent which has a significant impact upon their mental and physical health, education, social experiences and future.

"Additionally, the children are living with the knowledge that they are at risk of developing the disease which has a tremendous impact on their wellbeing. We can empower our young people to manage their HD journey, support them with the challenges they face and provide much-needed peer support and respite. For many young people this is life changing."

Jillian to speak at key research event

Senior HD Specialist Jillian Foster, who works alongside families in Fife, is to speak at the strategy launch of the Neuroprogressive and Dementia NHS Research launch at University of Strathclyde in December. Jillian will be focusing on the importance of including people from the HD community in such research.

The invitation comes after Jillian gave an address at the Huntington's Disease Youth Organisation International Conference earlier this year about how we can help families and practitioners to manage difficult behaviours.

If somebody throws us a lifeline, families are going to grab it



Moray Family Branch Chair Jock Anderson made the news this summer when he appeared on BBC Scotland to talk about the impact of Huntington's disease on his family.

Jock is a founder member of Moray Family Branch and his involvement with Scottish Huntington's Association goes back to when he cared for his late wife Maureen. Two of their three daughters – Lynn and Jude – are now symptomatic, while Jackie has tested negative. Jude participated in the Roche trial so Jock is well placed to understand the disappointment of families when dosing of the trial drug tominersen was halted earlier this year, effectively concluding the trial.

Speaking to Reporting Scotland, Jock said: "When you have a condition like Huntington's disease, and somebody throws you a lifeline, you're going to grab it. Thirty years ago I had to find a permanent nursing home to care for my wife. About four weeks ago I had to do the same for my middle daughter Lynn. Thirty years down the line and we're in exactly the same position."

He was joined by Scottish Huntington's Association CEO Alistair Haw, who used the interview as an opportunity to reassure families that there are a number of medical trials that continue to offer hope for the community. He also reinforced the call for improved services and support for everyone whose life is impacted by Huntington's disease.

*We are grateful to Moray Family Branch, including former Chair Brian Watt, for its support for SHA and local HD families. The group's fundraising includes work with local employer Johnstons of Elgin which has extended its charity partnership with Moray Family Branch.

Branch member and Johnstons employee of 38 years Fran Gardiner said: "Johnstons of Elgin has been especially supportive, including by donating cashmere scarves with the Huntington's disease amaryllis and supporting staff to donate through payroll giving."

The scarves, which cost £30 for the pastel shades and £45 for the larger navy style, plus P&P, can be ordered by emailing d.brebner@johnstonsofelgin.com or calling 01343 554099.



Share memories of your loved ones

Scottish Huntington's Association has a new partnership with MuchLoved.com to allow our community to create their own special memorial websites in tribute to loved ones.

It's free to set up a site and collect donations in your loved one's name, organise events, celebrate anniversaries – and much more.

Share memories, thoughts and stories with family and friends as well as:

- Light virtual candles
- Add music, photos and videos
- Create funeral notices
- Add fundraising pages from JustGiving.



For more information on how to set up a Family Forever Memorial Site please visit <https://hdscotland.org/in-memori-iam/> or email fundraising@hdscotland.org

In memory of Jim – Anne's story

I've set up my Family Forever Memorial Site in memory of my husband Jim. He passed away in 2014 after living with Huntington's disease for nine or so years.

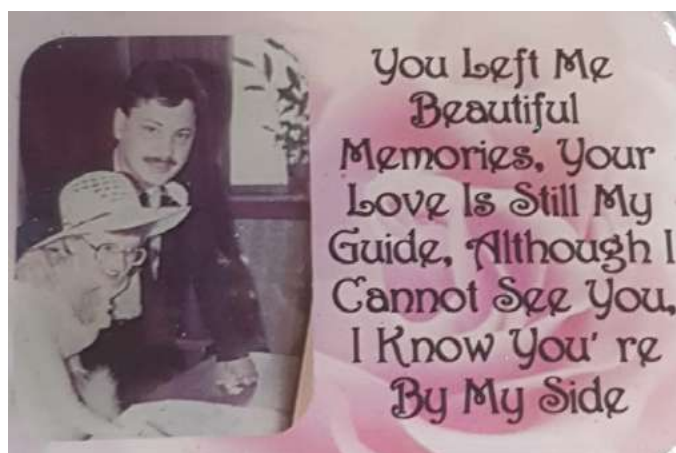
We were everything to each other. We got chatting after meeting in a pub in Stirling when I was on holiday. I was gutted when I had to go home to Halifax in England. My Mum and Dad didn't have a phone so I would go to the payphone at the end of my street every Friday at 7pm to talk to Jim. I'd be running down the street praying no one else was using the phone at the time. One particular Friday, I answered the call to Jim asking me about the ABC – that was the cinema in my home town. He was standing outside it! I got on a bus quick as a flash to go get him and we were together ever after. He met my mum and dad the next day and that was it really!



Huntington's disease really changed him. Jim was a caring, loving person so when he started going through his angry stage I knew something was wrong. I remember him getting his diagnosis in 2005, and seeing the words there written on paper clear as day. We all knew there was something going on but it was almost overwhelming seeing it in writing. After that Jim started to deteriorate until he had to go into full time care in 2010. I visited him every day for the first year he was in there. I had to. I needed him to know I was there for him.

Living with Huntington's disease is really hard. I see on the Facebook groups, and through Scottish Huntington's Association events, the support families give each other and I wish I knew that was around when Jim was going through it. I do think it's amazing though and that's why I started fundraising for the charity in Jim's memory. My first ever event was a firewalk and since then I've done an abseil, two skydives and a wing walk. My friends think I'm mad but they've always supported me.

My memorial site for Jim celebrates his life and what he means to me. It's for me but I'll share with family so they can also share photos and memories as well. I like looking back and thinking about the amazing times we all had with Jim.





Close: Aidan, Max, Guy and Carolyn have talked about Carolyn’s positive test and what it means for them as a family.

Nurse’s unexpected question was first time Huntington’s disease had been mentioned

Carolyn and Guy Jenner spent the first few years of married life completely unaware that Carolyn was even at risk of inheriting Huntington’s disease. It was a disease they knew little about because, to their knowledge, no one in the family had it.

Then, after 10 years of physical and mental health problems including balance issues, mood swings and behaviour changes, Carolyn’s mum Margaret was diagnosed during a long-term hospital stay.

“A nurse looked at Mum when she was admitted then asked if we had Huntington’s disease in the family,” recalls Carolyn.

“We didn’t know anything about it so I Googled when we got home. We were in total disbelief but we started to ask doctors and psychiatrists until eventually Mum had a CT scan and was tested.

“When the result came back, it answered a lot of our questions about how



Caring: Carolyn and mum Margaret

much Mum had changed and deteriorated over time. She was an incredible woman, we all loved her very much. We took her home and I was privileged to look after her until she passed away. That’s what Mum wanted and we wanted that for her.”

For 12 years, Carolyn poured her energies into caring for Margaret, pushing thoughts about her own health to the back of her mind. Then, after her mum passed away four years ago, Carolyn decided it was time be tested herself.

“I wanted to get in front of it before any symptoms started,” said Carolyn, who works part-time in a supermarket. “It came



Determined: Guy and Aidan completed challenge

back positive, I have no symptoms but our sons understand what might be ahead. I don’t worry about me nearly as much as I worry about Aidan and Max, but for now we’re all doing OK.”

The family is thankful to know there is help from Scottish Huntington’s Association should they need it and are keen to help ensure all families are able to access support.

For Guy, a police officer, and son Aidan that meant taking on a gruelling mission – the Virtual Special Forces Inverse 360 Challenge.

“My brother Robert Henry suggested it and we decided to raise money

for Scottish Huntington’s Association at the same time,” said Guy.

“We had to walk 300km in 360 hours, all while carrying a 45lb backpack. We were out for at least five hours a day and we finished well ahead of schedule. It’s such a tough challenge that loads of people drop out but we were amongst the fastest finishers.

“At the last count, nearly £4000 has been donated, our friends, family and work colleagues are brilliant. Carolyn and I are very proud of Aidan too, there were days when the weather was horrendous and it was tough going. But he never gave in.”



Brilliant: Struan conquered the Seven Hills of Edinburgh in support of HD families

Super schoolboy scales Seven Hills in one day

Struan Waddell, from Edinburgh, raised more than £2500 in one day to help provide lifeline support for families across Scotland who are impacted by Huntington's disease.

The dedicated young man took on the Seven Hills of Edinburgh and, accompanied by his dad Scott, took just over five hours to conquer Castle Rock, Corstorphine Hill, Craiglockhart Hill, Braid Hill, Blackford Hill, Arthur's Seat and Calton Hill.

Every step was fuelled by love for his Granny Lorna (68) who was diagnosed with Huntington's disease in 2013.

Struan said: "Granny can struggle with talking, eating, movement, balance and thinking, and I know Scottish Huntington's Association does a lot for people who have this illness by making life easier for them and their families."

His mum Karen said: "Struan did so well to complete his challenge and raise so much to help other families. When Mum was diagnosed it was a shock for all of us because we have no family history of the illness.

"Since then, she has had terrific support from the Scottish Huntington's Association and also from the SHA Edinburgh and Lothian Family Branch support group run by Dina de Sousa."



Proud: Lorna and her grandson Struan.



Volunteers appeal for donations

Volunteers raised nearly £1400 for the Fife Family Branch by opening a pop-up shop in Methil for one week.

Staffed by family members, carers and Senior HD Specialist Jillian Foster, it also helped to generate vital awareness.

"It's a great way for us to reach people who might otherwise never know that there are families in their own community who are impacted by Huntington's disease," said Jillian.

Jillian and her band of helpers are now looking forward to re-opening for a week from Saturday, 20 November to the following Friday. They are appealing for donations of new and second-hand items to sell and smaller items such as bottles of wine, sweets, tins of food or jars of coffee for use as tombola prizes.

Call 01592 647993 to arrange for goods to be picked up. For transportation purposes, the team can accept items that fit into a car only.

SHA's Fundraising Calendar of Events September 2021 – October 2022



September

Scottish Half Marathon
Sunday, 19 September 2021

My Zen Run
Month of September - Virtual Event

The Glasgow Kiltwalk
Sunday, 26 September 2021



January

The BIG Sponsored Walking Challenge

Saturday, 1 January to
Saturday, 31 December 2022



October

Virgin London Marathon
Sunday, 3 October 2021

Great Scottish Run
Sunday, 3 October 2021

SHA Hallowe'en Zipline
Sunday, 31 October 2021



March

Inverness Half Marathon and 5k
Sunday, 13 March 2022



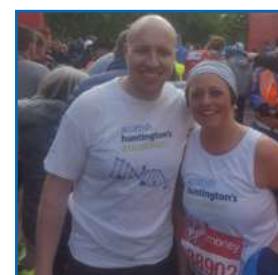
November:

Supernova 5k
Friday, 12 November to Sunday,
14 November 2021 – Falkirk



October

Virgin London Marathon
Sunday, 2 October 2022



December:

SHA's Christmas campaign
We'll be announcing details soon so keep an eye on our social media channels to find out how to get involved.



Your preferences

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