SHAre
Winter 2021

scottish
huntington's
association

The Magazine of Scottish Huntington's Association
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Annabelle Ewing MSP
Deputy Presiding Officer &
Scottish National Party

Douglas Ross MSP
Leader, Scottish
Conservative & Unionist
Party

Anas Sarwar MSP
Leader, Scottish Labour
Party

Gillian Mackay MSP
Health Spokesperson,
Scottish Green Party

Alex Cole Hamilton MSP
Leader, Scottish Liberal
Democrats

HD families make history in parliament!

ALSO INSIDE: WILL YOU SHARE A CUP O' KINDNESS?

Together we're bringing real hope for families

They say that good news comes in threes, but reading through this edition of SHAre makes me think that number must be a lot higher - for it's just packed with inspiring stories and successes from across the organisation.

Our Board has been strengthened with two new Trustees who bring skills that will be a huge asset to the charity. Our Youth Service is back to full strength with the appointment of a new specialist youth advisor, and plans are well under way for a return to summer camp in 2022. We've celebrated with a family member who won a prestigious national award and used it to raise awareness about HD amongst high profile influencers.

And there's a whole host of amazing fundraising feats to catch up on.

However, there are three distinct developments that you can read more about in this edition that give us particular cause for encouragement as we look ahead to 2022.

First, we are recruiting for our first National HD Specialist. Our hope is that this will be a huge boost to our families.

Second, we have secured record backing in parliament for a motion calling for the expansion of HD Specialist services. Let's use this as a springboard to make it happen.

Third, we have won our highest ever corporate partnership, which we intend to leverage in our quest to further improve services for families.

Individually, each is a crucial advance in our mission towards better care and support for all HD families. Collectively, and combined with our other successes, they tell a story of a movement going from strength to strength. Read on to find out more.

And thank you for helping to make it all happen this year, and in the years that lie ahead.

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

MSPs give record support for improved HD specialist services

The call to expand specialist services for families impacted by Huntington's disease (HD) has received unprecedented cross party support from Scotland's parliamentarians.

It secured near universal backing after families, SHA staff, trustees and supporters joined forces to contact their MSPs, urging each of them to sign a parliamentary motion calling for more HD specialist services across Scotland. It was tabled by Labour Deputy Leader and Shadow Health Secretary Jackie Baillie MSP.

Jackie Baillie MSP

Our initial target was to gain the support of 50% of all eligible MSPs from across all political parties.

In the end we secured 98% support – making the motion the most supported of its kind in the history of the Scottish Parliament. Influential supporters include Conservative leader Douglas Ross, Labour Leader Anas Sarwar, Lib Dem Leader Alex Cole-Hamilton, Deputy Presiding Officer and SNP MSP Annebelle Ewing and Green Health Spokesperson Gillian Mackay.

SHA CEO Alistair Haw, said: "The Scottish Parliament could barely have backed the call to expand specialist HD services more resoundingly than it has. The time has come for Scotland's health and social care providers to take heed and act.

"Specialist services are not some nice to have optional extra but an absolute necessity. Given the rise in cases over recent years a commensurate rise in specialist services is now required."

Alistair added: "An ENORMOUS thank you to everyone who made this happen. A quite incredible outcome that was only made possible by everyone working together and pulling in the same direction to achieve this success on behalf of the families we support."

SHA intends to use the success of the motion to influence for an increase in HD specialist services throughout the country. Alistair and Deputy CEO and Head of Services, Karen Sutherland, have since met with Minister for Public Health Maree Todd MSP and her team to drive the message home, and we will keep families updated as this work progresses.

SHA takes step forward to widen HD Specialist support

We are now in the process of recruiting SHA's first full-time National HD Specialist so we can reach more families with support when and where it's needed.

The charity's leadership team and SHA's Trustees have been working together to develop the new post, which will be offered initially as part of a 12-month pilot project.

Our National HD Specialist will work alongside SHA's HD Specialist teams throughout the country, stepping in when service gaps materialise due to higher than normal caseloads, staff absence and – where possible - in areas that currently have no service.

Families will be offered virtual and telephone support in addition to essential face to face visits as required.

"We are determined to be here for all family members with the specialist support they need," said Karen Sutherland, Deputy CEO & Head of Services.

"We are continuing to look at ways to expand SHA's HD Specialist services in the longer term.

"Until then it's our hope that this investment in a National HD Specialist post will provide a real boost to our local staff and the families they work so hard to support."

To find an HD Specialist for where you live, or to access other support, visit hdscotland.org.

Mike inspires 'Kirrie Girls' to conquer Three Peaks

"Tackling the UK's three highest mountains over one weekend is nothing compared to the challenges faced every day by people with Huntington's disease. When the going got tough, that spurred us on to reach the top."

The 'Kirrie Girls' from Kirrimuir in Angus – Jennifer Paton, Gill Ferguson, Dianne Scott, and mum and daughter Susan and Claire Dyce conquered Ben Nevis in Scotland, Scafell Pike in England and Snowdon in Wales over three days in support of families with Huntington's disease.

They were inspired to keep going by Jennifer's husband Mike, who was diagnosed eight years ago.

"I had really emotional moments during the climbs but then I would pull myself together and be strong," said Jennifer. "It was tough but I think that's what Mike and I do when we think about his illness. We don't dwell on it, we get on with life."

Mike was 53 when he was tested. Symptoms were emerging that he recognised all too well as both his late mother and his late sister had the same.

It meant giving up his job in the offshore oil industry and adjusting to changes that lay ahead. Since then, Mike's mobility and balance have deteriorated and his speech is becoming more affected.

"Mike is a real inspiration, every day he gets up and he tries his best. He's a fighter," said Jennifer. "We've been married for 31 years and are together through thick and thin. I took early retirement so we could spend our time together, and Mike has wonderful lifelong friends to go out with. He's very sociable; I think he's brilliant."

Mike is delighted with Jennifer and her friends, who have raised over £14,000 for Scottish Huntington's Association.

"Everyone has been so generous," he said. "I'm proud of Jennifer and very happy to have married the prettiest girl in Kirrie!"

Deputy Principal of University of St Andrews joins SHA

We are delighted to welcome Professor Lorna Milne as a Trustee on SHA's Board.

Professor Milne, Master of the United College and Deputy Principal at the University of St Andrews, brings extensive professional and personal insights to the charity.

Professor Milne is line manager to the Heads of Schools and Faculty Deans, and oversees forward planning in relation to the University's intellectual portfolio, academic appointments, space management and resource allocation.

She sits on the University Senate - the supreme body at St Andrews concerned with academic governance, learning and teaching, research and student experience - and on the Court, the University's governing body.

Professor Milne said: "Since its foundation, SHA has made a real and increasing improvement to the lives of Huntington's patients and their families - but we know there's still more we can do. It's a privilege to join such a committed group of people in this important work and I look forward to contributing in whatever way I can."

Gillian rounds off incredible year

Joining Professor Milne as a newly-appointed Trustee rounds off a whirlwind 2021 for family member Gillian McNab who has taken her Huntington's disease awareness raising mission to new heights.

Musician Kyle Falconer presented award

From raising more than £7000 for SHA by doing a quadruple loop-the-loop wing-walk to appearing as an extra in an episode of BBC's Casualty, palliative care nurse Gillian has continued to do all she can in support of HD families.

"Scottish Huntington's Association is a lifeline for families and joining the Board seems like the natural next step for me. I really want to make a difference if I can and create change for HD families, and for as long as my health allows I will continue to support SHA and the HD community in whatever way possible," said Gillian.

To help drive the UK and Ireland wide Family Matters campaign during Huntington's Disease Awareness Month in May this year, Gillian took part in family webinars and gave media interviews about testing positive for the gene and what that means for her and her family.

All the while, she was juggling life as a busy mum and working full time as a palliative care nurse at Strathcarron Hospice with volunteering to give talks about HD to community groups and healthcare professionals to help increase their understanding about the disease.

Gillian meets Midge Ure

When HD Awareness Month was over, Gillian signed up for the thrill of a lifetime fundraising wing-walk in Yorkshire and visited the set of BBC Casualty – her favourite TV drama – to take part in filming at the invitation of actor and HDA England and Wales Patron George Rainsford.
Every opportunity that came Gillian's way was taken to reach more people on behalf of the HD community.

With SHA CEO Alistair Haw and Sir Tom Hunter

In September, Gillian's dedication was recognised when she was named Scotland's Champions Caring Champion by the Daily Record and Sunday Mail news titles. At the awards ceremony, Gillian took the opportunity once again to raise awareness amongst attendees, which included Sir Tom Hunter, The View singer Kyle Falconer, musician Midge Ure and the cast of River City. She was joined on stage by SHA's CEO Alistair Haw who urged guests to support the charity's call for the improved care of HD families.

My son noticed changes in my moods, he said I could be like Jekyll and Hyde

For 57-year-old Lesley, the support of Scottish Huntington's Association has been vital as she struggles to cope with symptoms of Huntington's disease and fears about her family's future.

Lesley, from Fife, is mum to two sons Gavin and George, and grandmother of Ryan. In the three years since being diagnosed, Lesley's physical and mental health has worsened. Having watched the disease overwhelm her late mother and her late aunt, she is scared of what lies ahead for herself and for the people who love her.


Lesley and her son Gavin

"Both my mum and auntie had really bad symptoms, including a lot of movements. People used to think my auntie was drunk because of it and she ended up being looked after in the Sue Ryder Home in Edinburgh before she died," said Lesley.

"Mum's speech and swallowing were badly affected and she was choking all the time. She died when I was 39 and I've never gotten over it.

"I wasn't going to be tested. I'd look in the mirror and say, 'I look alright and I feel alright'. Then my son Gavin noticed changes in me, especially the mood swings. He said I was like Jekyll and Hyde. I didn't want to think it could be Huntington's but Gavin suggested that I should make sure. When the result came back positive I could have fallen through the floor.


Lesley's mum, dad and auntie

"Since then the symptoms have become more obvious. I drop cups of tea and my balance is affected, I've fallen down the stairs a few times. But the biggest change is to my mental health. I've been hospitalised three times this year because I've felt like I can't take it any longer. I don't want my boys to see me going through what my mum and auntie went through. Sometimes it feels really overwhelming.

"Having Nicola, my SHA HD Specialist, really helps. She's in touch all the time with us to make sure we have what we need and to see how we're feeling. I chat to her about anything and everything, sometimes we don't talk about Huntington's disease at all. Then there are the days when I talk about wanting it all to end. Nicola understands and knows what I need, which has at times included going into hospital. Quite honestly, without her I don't think I'd still be here.

"Now, in return, I do what I can for Scottish Huntington's Association. I volunteered at the fundraising pop-up shop organised by the SHA Fife Family Branch. I really enjoyed being back in a shop - I recently lost my job in a local jewellers when it closed because of the pandemic. I've worked all my days and I miss it, especially meeting customers."

We thank Lesley for sharing her experiences with SHAre readers and also with potential funders. By doing so, she is helping to lift the voices of HD families and generate funding for the services we provide. If you would like to help SHA in this way, please contact Roisin, our Communications Lead, at** Roisin.Eadie@hdscotland.org**

New Trustees bring shared commitment to our work

Welcoming Lorna and Gillian as Trustees, Chair of SHA's Board Cat Martin said:

"Lorna and Gillian bring additional professional skills to the Board from the fields of academia and palliative care, a shared understanding of our work and, crucially, a deep respect for the families who lie at the heart of all that we do.

"With the collective expertise of our Trustees and staff, input from the HD community, growth in strategic partnerships, and a strengthened leadership team, SHA is now in a stronger position than ever before to increase its influence and advocacy for the improved care and support of anyone and everyone whose life is impacted by this devastating and incurable disease."

Scottish Huntington's Association is managed by its Board of Trustees who ensure the charity's goals, vision and values, upon which SHA was founded, continue to underpin all our work and meet the high standards expected by families, donors, volunteers and partner organisations.

Get in touch to see if we can cut your energy costs

SHA's Financial Wellbeing Team's Energy Advice Service is inviting families to contact their area adviser to see what can be offered depending on individual circumstances.

Our advisers can help with energy Issues such as:
- Managing bills and arrears
- Energy efficiency, use of energy and efficiency measures you can take
- Applying for grants, loans and social support to help with energy arrears or household improvements such as insulation or new heating systems.

The team can also help with any questions about the current energy crisis and what steps families should take.

"We appreciate that the closure of nearly 24 energy suppliers, at the time of writing, and rising prices this close to Christmas is likely to have given everyone a bit of a shock," said Ben Peter, Financial Wellbeing Officer for Tayside, Fife and Forth Valley

"If you have received a letter from your supplier or the regulator, Ofgem, that your supplier is about to change; we suggest that you take a photo of your meters at the time of the notice but otherwise take no action for a period of between 4 to 6 weeks while the movement process completes itself.

"You should be contacted within that time by your new supplier with information about your new energy charges going forward.

You can find the contact details for the adviser in your area alongside the full range of advice services that we can offer you at https://hdscotland.org/services/getting-specialist-financial-advice/

Rachael and Graham share their love with HD families

We were especially touched when a bride and groom chose to raise awareness about Huntington's disease and support Scottish Huntington's Association as part of their celebrations.

While making plans for their wedding, Rachael and Graham were determined to make it extra special for mother of the bride June, who was diagnosed with Huntington's disease over 15 years ago.

So they decided to make a donation to SHA and swap traditional favours for a beautiful pin badge, which features the amaryllis flower of the international HD community.

Mum June, who had no idea until she walked into the reception, shed a wee tear on seeing the pin badges for each guest as part of the table setting.

"What a lovely surprise it was, and now more people have heard of Huntington's disease," said June.

Graham added: "It was a pleasure to include Scottish Huntington's Association in our big day."

What a lovely gesture from a wonderful couple – we send them our warmest congratulations and best wishes for their lives together.

*There are lots of ways you can include SHA in your special days – find out more by emailing fundraising@hdscotland.org

in lieu of favors

THANK YOU FOR SHARING OUR DAY WITH US. INSTEAD OF FAVOURS, WE HAVE GIVEN A DONATION TO THE SCOTTISH HUNTINGTON'S ASSOCIATION

with love
RACHAEL & GRAHAM

Join Cup O' Kindness, our annual fundraising appeal led by the family members we serve.

I hope this will help more people to understand what families like mine go through every day

Zoe, from Clackmannanshire, is supporting Cup O' Kindness in tribute to her dad George, who passed away in August 2020. The oldest of four siblings, Zoe cherishes memories from when he was well, all the while knowing that her younger sisters don't have that same comfort because they were younger when George's health started to deteriorate.

"I feel like I've lived with Huntington's disease every day since I was a teenager," said Zoe, who works in a jewellers shop. "But at least I know there were happier times before Dad was ill. When he passed away, I was really aware that my sisters didn't have many stories to tell about him. It's not their fault, I think it's a shame they didn't get to grow up with Dad the way he was for me when I was their age.

"I remember him falling over and tripping a lot, and there was a problem with his knee. He was sent for an MRI and through various investigations they realised it was Huntington's disease causing Dad's imbalance. Then after Dad was diagnosed, the disease progressed quite quickly."

As Zoe grieves for her father and what might have been, she lives with the reality that her own health could also be at risk. Zoe and her siblings each have a 50% chance of having inherited the same gene fault that was passed down to their dad.

She talks about her worries with Grant, her dedicated SHA Specialist Youth Advisor. Grant has known the family for years; he supported Zoe and her siblings when George was ill. He was there to answer questions when George went to live in a care home. Now he is helping the family to come to terms with losing their much-loved father.

"It's good to have Grant to talk to. Just knowing we can have a chat over a cup of tea makes a difference because it gives me the chance to open up and have conversations that I wouldn't have with anyone else. I can get things off my mind rather than leaving it to fester and causing me to worry," said Zoe.

"Sometimes we talk about things that are nothing to do with HD, which I like because it's a bit of a break from real life. And it's nice to have a friendly face to talk to."

Zoe and her Dad George

Someone who thinks you're great, sent you this Cup O' Kindness and wishes you a Merry Christmas!

How you can support Cup O' Kindness

Donate Visit Cup O' Kindness at hdscotland.org/cupokindness

Spread the word Like, share, retweet our Cup O' Kindness posts on social media.

Send a card When you make a donation, we'll send you a Cup O' Kindness Christmas card! You can send this card to anyone you choose and spread some extra goodwill this festive season!

Have a chat over a cuppa Take some time to sit down with someone and talk about what HD is and how it impacts you and the people you love.

Donate at hdscotland.org/cupokindness

Big Walkers make every step matter

As 2021 draws to a close, SHA's team of Big Walkers is nearing the finishing line of this incredible year-long fundraising challenge.

Twenty three people from all over Scotland stepped up to walk 2021km during 2021 – and what an amazing success this first event of its kind has been. Together our Big Walkers have raised a combined total of more than £18,000 – incredible! And the feedback from them has been just as positive, with participants telling us that taking part has given them a real mental and physical wellbeing boost.

For Hugh Heath from Fife it was also about exploring the great outdoors.

"I loved finding new places on my doorstep that I never knew existed before the Big Walk," said Hugh.

We thank Hugh and his fellow Big Walkers for making this year's event such a success. Now we're looking forward to making it even bigger and better in 2022.

If this sounds like the challenge for you – and you fancy being part of something BIG! - please visit https://bit.ly/SHABigWalk to find out more and to register.

We're all set for a return to Summer Camp in 2022

Funding is now in place for the Scottish Huntington's Association Summer Camp 2022 thanks to a grant of £19,603 from the Short Breaks Fund, which is operated by Shared Care Scotland on behalf of the Scottish Government.

This is combined with additional funding, including a £5000 donation received in October from Scotmid Co-Operative's Community Fund towards helping young people in Fife, Edinburgh and the Lothians.

We are all set to accommodate 50 young people from across Scotland for a five-day stay at Lagganlia Outdoor Learning Centre, near Aviemore, hosted by our Specialist Youth Advisors next July.

The Coronavirus pandemic forced the cancellation of the 2020 and 2021 camps. Instead, young people were supported through a series of tailored virtual events and workshops.

SHA's annual Summer Camp gives young people aged 8 to 25 from across Scotland a break away from home and their caring responsibilities, the chance to meet up with friends and make new ones, and an opportunity to try new activities.

Crucially, it also provides age appropriate support, workshops and information about Huntington's disease and its impact, delivered by SHA's Specialist Youth Advisors to help young people to build their resilience and prepare for what lies ahead.

Youth Service Lead Kirsten Walker said: "For the young people we support this is one of the few opportunities they have to get together with others who understand their situation and receive specialist support tailored to their needs. There are no other similar opportunities available to young people living with Huntington's disease in Scotland."

Living in a family impacted by Huntington's disease is extremely challenging for young people who will see their parent change dramatically and deteriorate, whilst also living with the reality that they too could develop the disease. Most of the young people supported by SHA's Youth Service are young carers, which impacts their school life, peer relationships, leisure activities and, later in life, employment.

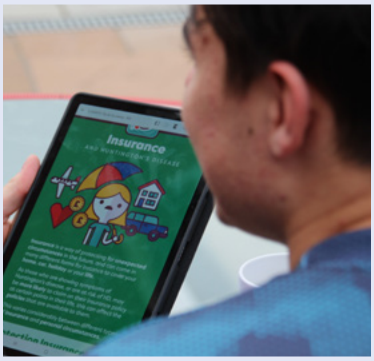
SHA's Youth Service has found that three in every four of the young people it supports have reported self-harm behaviours, low self esteem, low confidence, low mood, anxiety and depressive traits. And because of the stigma that surrounds Huntington's disease, the young people are often isolated within their peer groups and can experience bullying.

Kirsten added: "Throughout the camp there will be a range of evening activities to keep our young people entertained and active. These will include games night, circus skills, swimming and a party night. We hope that the young people can then consider taking part in similar activities when they return home and perhaps use them as a coping mechanism should things become difficult there.

"We also hold a festival for all young people aged 13 and above, during which we look in depth at HD topics including genetic testing, living with HD, and rights and responsibilities. Many young people have no other opportunity to have these in-depth discussions which are essential to increase their resilience and understanding."

Feedback from the most recent Summer Camp (2019) revealed that 90% of participants stated that their coping skills had increased and 98% concluded that their wellbeing had improved. Furthermore, through attending camp 100% of those who identify as young carers said that they had enjoyed their break away and it had given them a renewed energy for returning home to their caring responsibilities.

Tip Jar is a real hit



Have you seen our new digital financial wellbeing and information resources for young people?

The animations and downloadable factsheets, developed by our Youth Service in collaboration with our young people and SHA's Financial Wellbeing Service, aim to help young people growing up in HD families to manage their money and take the right steps when faced with important financial decisions.

They include a beginner's guide to managing money and information about student loans, fees and bursaries for those considering college or university; how to choose an insurance policy; managing debt; mortgages; end of life planning and, importantly, how money problems at home can impact mental wellbeing.

Bruce Wilson, 21, from Edinburgh, said: "It can be difficult as a student to focus on studies while also having the worry of making sure you have enough money for everything you want to buy. Being able to access information to help me manage my budget and think about debt has been really helpful."

The Tip Jar project was made possible thanks to funding from Advice UK, which distributes Scottish Government Debt Advice Levy Funding.

Visit Tip Jar at https://bit.ly/TipJarSHA

Louise smashes Marvel superhero challenge

Louise from Lanarkshire has become a real life superhero by raising funds to help other people who also have Huntington's disease.

The 41-year-old was chosen to join the Marvel-sponsored At Home Superhero Challenge Series in partnership with Zurich Community Trust.

And she smashed her challenge target of naming as many songs as possible by her favourite 80s pop star – Adam Ant – in her first go, raising more than £200 in sponsorship and donations from friends. For super-fan Louise, a former DJ, it was a chance to showcase her knowledge about the singer she has followed since her teenage days.

And it was a great personal triumph too because as the disease progresses Louise is finding it more and more difficult to speak. She has just started using a special 'talking' tablet and also relies on the help of carer Joan – who Louise jokes "does enough talking for both of us!"

"I've always loved Adam Ant," Louise told us, adding that she has met the singer on a number of occasions and seen him in concert 15 times. Another favourite is Boy George – "I'd love to meet him – or Johnny Depp!" she said, with a cheeky smile.

Now that Louise is no longer able to get out and about the way she once did, she misses going to live gigs, walking dogs and having adventures – especially skydiving.

"I've done three skydives and I loved them all. My last one was in 2018. I'm an adrenalin junkie; I felt free up there, my Huntington's disease and its symptoms didn't matter when I was flying through the air," she told us.

Both of Louise's parents had Huntington's disease and she tested positive in her 20s. In addition to affecting her speech, Louise is also losing her mobility and balance.

As we're chatting, Joan is busy looking for Louise's skydiving certificates and photos taken with Adam Ant, chipping in to the conversation to help Louise share her story.

"Louise is an amazing person, I don't know how she manages to be such fun to be around when she has the serious health issues that Huntington's disease causes," said Joan. "She's an inspiration, I've learned a lot from Louise and SHA's HD Specialists who give us lots of information, support and advice so Louise has what she needs."

Thank you Louise for being an At Home Superhero in support of the Huntington's community – and for completing your fabulous fundraising challenge by listing more than 20 Adam Ant tracks.

We think you're f-ANT-astic!

Marvellous Margaret is praised in Parliament

This year marked the 10th Walk of Hope by volunteer Margaret Moncrieff in support of families, including her own, who are impacted by Huntington's disease.

Since 2012, the 76-year-old has been bringing people together to make their way along the banks of the Clyde at Erskine. This year's event pushed the total amount raised by Margaret over the past decade to more than £10,000 for Scottish Huntington's Association. And it prompted MSPs to acknowledge Margaret's amazing efforts, adding their signatures to a Scottish Parliamentary Motion tabled by Natalie Don MSP to congratulate Margaret.

"I tested negative for the HD gene but I'm walking through life feeling like I got away with something when my brother and sister weren't able to," said Margaret. "So I do everything I can to raise awareness and funds because Huntington's disease is still widely misunderstood or not known about at all by too many people."

SHA marks step change with corporate partner

Scottish Huntington's Association has secured its largest ever corporate partnership.

The William Grant Foundation, the charitable arm of William Grant & Sons, has committed to providing us with £154,272 over two years.

This investment will be used to help fund our HD Specialist services across Scotland. Having it in place also offers an opportunity to negotiate with our NHS and Local Authority partners to resolve existing shortfalls in funding that impact on the level of support available for families across Scotland.

William Grant & Sons is an independent family-owned distiller headquartered in Scotland and founded by William Grant in 1887. The company has committed to set aside 1% of pre-tax profits generated each year for donations to charitable causes.

WILLIAM GRANT
FOUNDATION

The William Grant families established the William Grant Foundation in 2014 as a non-profit association to manage and direct these donations.

Since then it has donated over £15 million to various charities.

Work to secure this partnership was spearheaded by Head of Income Generation & Administration Lee Johnstone, who carried out research into the foundation, including the charities and causes it chooses to support.

Family member and SHA supporter Robert Hannah then reached out through his professional connections to help secure key meetings for SHA with William Grant Foundation.

Lee, alongside CEO Alistair Haw, met with the Trustees of the Foundation, after which the successful application was submitted.

Lee said "This major investment will help us sustain our vital HD Specialist Services and give us the platform, over time, to work with our NHS and Local Authority Partners to resolve shortfalls in our funding.

"We thank Robert for providing the initial introduction to William Grant & Sons.

"And we thank the William Grant Foundation for its commitment to the HD community through this significant funding award."

***To find out more about how employers and business contacts can support our work, please contact** gemma.powell@hdscotland.org*

Eve welcomed to Youth Service team

Eve Graham has joined SHA as Specialist Youth Advisor for Highland, Grampian and Tayside.

Following her graduation from University of Strathclyde with a BA (Hons) in Community Education, Eve chose to work with children and families experiencing domestic abuse, and adult survivors of childhood sexual abuse. She then joined Dundee City Council's Youth Work team to support LGBT young people, refugees and children and teenagers at risk of not engaging at school.

After taking part in a Youth Service activity day and the first post-lockdown residential trip, Eve said: "I'm enjoying meeting our young people - from their feedback it's clear how important it is to have support from the Youth Service. I feel privileged to have an opportunity to make meaningful impact on their lives and to improve my own knowledge through what they share with me."

Student placement in an HD unit led Lindsay to a career-defining decision

HD Specialist Lindsay Wilson works in the Tayside service, with part of her working week contracted to supporting clients in Rumbling Bridge care home in Kinross. A registered Adult Nurse and mum of two, Lindsay decided early on to work alongside the Huntington's disease community.

"I wanted a career that would make my sons proud of me and I started studying for a nursing degree at University of Dundee in 2008 when the boys were three and five years old. It was the best decision I ever made, I loved the course and when I graduated in 2012 I already knew where I wanted to work," said Lindsay.

"In my second year at university, I spent 12 weeks in a specialist Huntington's disease unit. It opened my eyes to how the disease impacts individuals and their families. I wanted to find out more about the specialist care that is needed, especially because it's a rare disease that even today is not well known or understood by the wider public. And, in some cases, by health and social care professionals.

"I was offered a job as a carer in the unit at the end of my placement and this helped me develop my skills and knowledge about Huntington's disease during my studies.

"When I qualified, I joined the unit as a Staff Nurse and after two years was promoted to Senior Staff Nurse. Then I moved to Scottish Huntington's Association and I've been here ever since. As an HD Specialist I can take a more holistic approach to supporting families while gaining new skills in nursing and other disciplines such as advocacy and training.

"Every person is having a different experience. The symptoms are incredibly severe, people change so much and the hereditary nature of Huntington's disease adds to what is already considerable emotional strain on loved ones. The lack of public awareness makes life even more difficult.

"The families I meet inspire me every day to make sure they have the right support when they need it. That's important to me. I see people at home, in care homes and in hospitals, and we build strong relationships that can last for many years. I advocate on behalf of families, helping them to access the services they need and I liaise with colleagues across the charity, for example in the Financial Wellbeing Service and the Youth Service teams, to make sure the right support package is there from Scottish Huntington's Association too.

"I like being part of a global network of professionals dedicated to the HD community, including researchers on the Enrol programme which is taking place here in Tayside.

"Having travelled to different countries, and seeing the level of services available there, I know families in Scotland have some of the best support in the world.

"Locally, we also have the Tayside Family Branch, which does an incredible amount of fundraising to support Scottish Huntington's Association – it recently donated £20,000 to the charity. The branch has also paid for new equipment, including items for the sensory room at Rumbling Bridge.

"During the Covid pandemic lockdown, branch volunteers went a step further by providing funding for care packages for local families and they also make sure family members, including carers, have the social support they need."

scottish
huntington's
association

To sign up for any of these events or view our full Events Calendar, please visit www.hdscotland.org/events. Alternatively, you can contact us on 0141 848 0308 or email fundraising@hdscotland.org

SHA's Fundraising Calendar of Events 2022

Running Events

Edinburgh Marathon Festival
Sunday, 29 May 2022

Stirling Marathon
Sunday, 15 May 2022

My Zen Run
1 - 30 September 2022

Great Scottish Run
Sunday, 2 October 2022

London Virgin Marathon
Sunday, 2 October 2022

Something different

Tough Mudder
Saturday, 2 July to Sunday, 3 July 2022

Glasgow Zipslide across the Clyde
Date TBC

Skydive, Wingwalk or Sharkdive Challenge
Choose your own date!

Great Wilderness Challenge
Saturday, 13 August 2022

Walking events

SHA's Big Walk
1 January to 31 December 2022

Glasgow Kiltwalk
Sunday, 24 April 2022

Aberdeen Kiltwalk
Sunday, 29 May 2022

Dundee Kiltwalk
Sunday, 21 August 2022

Edinburgh Kiltwalk
Sunday, 18 September 2022

Scotland's Virtual Kiltwalk
Saturday, 7 October to
Sunday, 9 October 2022

Go your own way!

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

Your preferences

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

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