

Annual Report 2019/20



30 years
empowering
ordinary people to
meet extra-ordinary
challenges



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Chairperson’s Report

For the year ended 31 March 2020



This year marked the charity’s 30th anniversary and there was much to celebrate. The highlight of the year was our two-day family conference on the 1 and 2 November 2019 at the MacDonald Aviemore Hotel. More than 160 people from all over Scotland came together; the largest conference we have ever had, indicating the strength of our community in Scotland. Our theme was *‘People living with HD making the world better for people with HD’* and speakers included Gillian McNab, who also won this year’s Volunteer of the Year Award.

Hailing from Lanarkshire, Gillian is an inspirational character who epitomises what it means to be resilient in the face of HD. We were also fortunate to have international guests Jeff Carroll and Alice Wexler. Jeff is a scientist living with a positive gene test who has a deep and personal insight into the progress towards treatments for HD while Alice, a historian, shared the story of her sister Nancy, whose team led the work in identifying the HD gene.

The conference was a celebration of how much the HD community in Scotland and across the world has achieved and is continuing to achieve, and a highlight of the event was our Volunteer Awards Ceremony. It was a genuine pleasure to see people living with HD recognised for the extraordinary work they do, and a particular highlight for me was the award to the Moray Support Group who helped to campaign for a new Specialist Nurse post in the area.

This year has seen further steps towards developing a treatment for HD. Roche’s HD Generation 1 study began its phase three clinical trial and I am delighted we have two participating sites in Scotland. We continue to monitor closely other developments and note that the WAVE phase one clinical trial reported promising results and meanwhile several new therapies are in the pipeline. I continue to be optimistic tangible treatments will become available in the next few years, and the charity will use that time to ensure Scottish

families have access to treatments when they become available.

A critical element of our preparation for treatments has been to ensure access to specialist support. I mentioned earlier the success in developing a new Specialist Nurse post in Moray and I am also delighted NHS Dumfries & Galloway has appointed a new Clinical Lead for HD, Dr John Higgon, and is recruiting for a new Specialist Nurse to join him. These developments mean only Scottish Borders is without an HD Specialist and Clinical Lead, however people living there can access the Youth Service and our Financial Wellbeing Service. Our Senior Management Team has already engaged with the local Health and Social Care partnership and is working to find a solution.

Scotland has a formidable network of support services, but we must continue to strive to improve upon what has already been built.

This year ended with the start of lockdown, which has been immensely challenging for HD affected families. We carried out more than 100 interviews with people to ensure we understood the impact and therefore developed a new service – Wellness Matters - to improve the mental health of people with HD, their carers, and families. I hope this is a signal to Scottish HD families that SHA will always step up to whatever challenges the community must face.

This will be a challenging year but, just like the HD community, SHA is a resilient organisation and I am confident we will come through this period having demonstrated the capacity to adapt, having learned how to take advantage of the opportunities to deliver services in new ways and having met the financial challenges of living through lockdown.

Catherine Martin
Chairperson



Welcome from our Chief Executive

Annual reports reflect on the preceding year, however my remarks begin by looking ahead at 2020/21, the events of which will reshape all our lives. The SARS-CoV-2 pandemic has had a colossal impact, the reverberation of which will be felt for the next decade. The ripples of disruption and change have brought new challenges for people with HD and their families.

At the start of lockdown, SHA carried out over 100 telephone interviews with people with HD, carers and young people. This direct contact identified financial stress, isolation, additional strain on carers, and impact on mental health and wellbeing as the areas of greatest concern for our families.

The charity moved swiftly to help families address these concerns. We effected our business continuity plan and supported staff to move to home-based working and provide telephone-based support, reaching out to every individual we have contact with. Our youth team also moved to telephone-based and online support through 'Zoom groups'.

We accessed a short-term Wellbeing Fund, provided by the Scottish Government, to set up a new service called Wellness Matters, recruiting two mental health nurses to provide additional emotional and psychological support. The service was well used, with both workers working at maximum capacity throughout its two-month duration.

SHA's priority is always the wellbeing of families and from the outset we have worked energetically to do as much as possible to support the community. At the same time, we have made huge efforts to tackle the financial challenges arising from the near cessation of our community fundraising activities. We have reviewed our cost base, identified savings, used the Government's Furlough scheme for some of our fundraising team and, crucially, identified new sources of income. This will be a challenging year but the charity will get through it intact and, most importantly, on mission.

SHA celebrated its 30th year in 2019 and its solid foundations have provided resilience in the face of the pandemic. The National Care Framework continues to be an effective approach to improving access to specialist support in areas of Scotland where there is none and this year we confirmed the new Specialist Nurse post in Moray will be funded on an ongoing basis. Shirley Catto joins the team of colleagues at Aberdeen Royal Infirmary, ensuring well-coordinated support across Grampian. In Dumfries & Galloway, the NHS have appointed a Clinical Lead, Dr John Higgon, and although delayed by the pandemic, will shortly recruit a new Specialist Nurse. For the first time, this will give the 30 families living in the region consistent access to specialist support. In February we began our engagement with Scottish Borders, the last area of Scotland without specialist support. This work was paused in March as the NHS diverted resources to

manage SARS-CoV-2, and we will reengage with them as soon as practicable.

It is exciting to be so close to having national coverage provided by a network of specialist services and 2020 will hopefully see the completion of this work.

A further focus this year has been the clinical trials run by WAVE and Roche. SHA has invested a great deal of time building a good working relationship with Roche and key pieces of work have been taken forward. We are working with a company called SHIFT and in partnership with the European Huntington's Association, will undertake a 'burden of illness' study which seeks to understand the generational socio-economic impact of Huntington's disease. It will provide further valuable evidence of the need to invest in good quality services and will be vitally important in engaging regulators deciding funding for new treatments.

Simultaneously, we have engaged with the HDA of England, Wales, Northern Ireland, and Ireland to develop a national awareness campaign which we hope collectively will improve public understanding about Huntington's disease. The campaign is scheduled to run during 'awareness month' in May 2021 and we have secured financial support from Roche towards its delivery.

Utilising electronic platforms (Zoom, Teams, Google

Meetings) has been key to working well during the pandemic, and our staff are now using the technology to offer face-to-face appointments with the necessary governance in place to ensure this is done safely. Two of our teams have trialled 'video clinics', providing access to local clinical leads and symptom management support.

There are significant opportunities for delivering services in new ways which SHA will consolidate over the coming year, however it is apparent that 'remote' engagement not a one-size-fits-all solution. From the outset, we were concerned about the challenges it could pose for people with HD and their families. They might have difficulty accessing the online platform and miss the face-to-face contact at their home, making it harder to discuss challenges they are facing or how to get help when a crisis hits. As the months have passed, this has proven to be true and I am pleased therefore that we will be shortly be restarting essential home visits.

While we embrace the benefits of innovation, the personal touch is still the best way to provide help. If SHA is about one thing, it is about lasting relationships, based on trust, mutual understanding and a desire to improve the quality of life of everyone with HD. Whatever the next year brings, that will never change.

John Eden
Chief Executive Officer



Honoured for work to support families

We celebrated with family member Dr Marie Short who was presented with an MBE by the Duke of Cambridge at a ceremony in Buckingham Palace.

The investiture took place on Thursday, 19 December 2019 at the Royal residence, where Marie was joined by her husband Duncan, their two children Arran and Amy, and her mum Rose Heath.

The Queen's Birthday Honours List recognises extraordinary people across the UK for achievements that include making a difference to their community or field of work, improving life for others and long-term voluntary service.

Marie was chosen for her volunteer work that includes supporting people affected by Huntington's disease (HD) as a Trustee and fundraiser with Scottish Huntington's Association.

She said: "It was an amazing experience, and to be able to enjoy it with my family made it all the more special. I am humbled and thrilled to receive such an honour, which I do on behalf of every single family affected by Huntington's disease.

"It was wonderful to have the chance to talk to the Duke of Cambridge about the charity and the work it does in partnership with families and supporters, and I thanked him for the opportunity to help raise awareness about Huntington's disease."

Marie has lost her father and two siblings to the disease, and her older sister requires 24-hour nursing care. After testing positive for the faulty gene in her 20s, Marie knows that she too will go on to develop symptoms at some stage.

These experiences fuel her determination to improve the lives of her loved ones and the wider HD community, and Marie has been a fundraiser for Scottish Huntington's Association for many years. Five years ago she joined the board of Trustees, sharing both her professional expertise as a former Regulatory Affairs clinical trials manager and her personal experience as someone directly affected by the disease.

Her insight is a major driver in helping to steer the direction of Scottish Huntington's Association, which since its founding in 1989 has grown from a small network of family branches to the national organisation with global influence that it is today.

"This award really reflects the combined efforts of many people, including fellow Trustees on the SHA board, fundraisers, supporters and staff at Scottish Huntington's Association, who all share a real determination to improve the lives of people affected by HD."

Dr Marie Short MBE, Trustee and volunteer fundraiser

Setting the standards for care

Three years ago, SHA published the National Care Framework for Huntington's Disease, the first resource of its kind in the world. Since then the charity has been working to develop local versions for each mainland NHS Board area, and stand on the brink of completing this task with Greater Glasgow & Clyde and Highland formally launching their versions this year and Tayside, Forth Valley and Dumfries & Galloway versions also going live.

The frameworks, developed in close collaboration with families and backed by the Scottish Government, signal a step change in efforts to significantly drive up the health and social care aspects of support provided across the country.

This innovative approach, which puts Scotland at the forefront of global efforts to improve the care of the HD community, has been welcomed by families, health and social care professionals and politicians from all parties.

Speaking at the Greater Glasgow & Clyde launch at the Golden Jubilee Hospital in November, George Adam MSP, Scottish Government Chief Whip, member of the Scottish Parliament's Health Committee and Convener of the Cross Party Group on Multiple Sclerosis, said: "The HD Framework is a fantastic tool for local families who have been impacted by this terrible condition. If promoted and used effectively this can make a huge impact on people's lives. It's no surprise that the international HD community is seeking to follow suit."

Two months later saw the launch of the Highland Care Framework, held at the Centre for Health Science at Raigmore Hospital, Inverness. Professor Zosia Miedzybrodzka, University of Aberdeen Professor of Medical Genetics, Consultant in Clinical Genetics and HD Clinical Lead for NHS Highland, said: "The north of Scotland has amongst the highest recorded prevalence of HD in the world, and was one of the first places to have specialised clinics and healthcare for HD. This framework brings together local information with professional guidance to let health and social care staff know what care is required, and when."

During 2019/20, frameworks for Forth Valley, Tayside and Dumfries & Galloway also went live online, with the latter resulting in the appointment of an HD Clinical Lead and funds to appoint an HD Specialist for the first time. Work to develop a framework for Scottish Borders, the last remaining area without its own version, is now under way.

SHA National Care Framework Lead, Alistair Haw, said: "We've come an enormous distance since starting this work way back at the beginning of 2016 and have proved many doubters wrong along the way. Over the year ahead we look forward to ensuring full coverage throughout Scotland and, crucially, ensuring the frameworks are being used effectively to drive up standards for HD families regardless of where they live."

The National Care Framework for HD, and all available local versions, can be viewed at care.hdscotland.org

"When people find out that HD is in their family it can have a devastating impact, especially when they have no idea where to turn. The HD Care Framework stands to change that. Everything you need to know about the disease is all there in one place, helping and guiding families and health and social care staff."

Kathryn Valentine and her son John, who has the disease.





Changing the lives of young people

For Christian, the support of the Scottish Huntington's Association youth service (SHAYP) is vital since discovering that he has the gene that leads to Huntington's disease.

The talented musician was 20 when he received his test result, and it was difficult to come to terms with the reality that he would, at some stage, go on to develop symptoms of the disease.

"Speaking to Pete in the SHA youth service has been crucial, he doesn't talk to me like I'm a symptom. He understands me and I feel there's mutual respect and care between us," said Christian.

"I'm a really private person and this time last year I would not have been able to talk openly about my feelings but meeting Pete and going to the SHA summer camp, where I met other people experiencing what I am, changed my life and my perspective. I didn't realise that by bottling up my feelings, I had been isolating myself."

Christian is one of the many young people who receives 1-2-1 and group support from SHAYP, which helps to ensure that young people living with HD are well informed, more resilient and less isolated, and that they know where to get the help they need when coping with a parent's illness or choosing to have the genetic test.

In 2019/20, the impact of the service was recognised

further with the award of £249,708 from The National Lottery Community Fund. The funding, which was confirmed in March 2019, is enabling SHAYP to continue providing practical and emotional help for young people aged from 8 to 25 years old.

Kirsten Walker, Youth Services Manager, said, "Growing up in a family impacted by Huntington's disease is incredibly challenging. Not only does the young person have to watch their parent dramatically change and deteriorate, but often role reversal occurs with them taking on a caring role while living with the knowledge that they too could develop this devastating condition."

"As HD is not widely known about, many young people we work with tell us they often feel isolated and alone. Enabling them to meet others in the same situation is crucial to helping them cope with daily life and the ongoing changes in their parent's condition."

Now, keen to give back to the service, six young people supported by SHAYP have stepped forward to join SHA's Youth Ambassador Peer Support (YAPS) pilot programme. The project, which has been three years in the making, aims to give 16 to 25 year olds the opportunity to develop new skills while reducing the stigma that can still surround Huntington's disease.

"This phenomenal group of young people are leading the way for increasing awareness of HD in their communities and supporting their peers from HD families," said Kirsten.

"I had feared telling people in case they treated me differently but now I realise talking helps, as does surrounding myself with people who inspire me and have good energy."

Christian, 21

166 young people supported in 2019/20

524 assessments and reviews carried out

Reducing financial hardship

Huntington's disease forces many people to cut short their working lives, including carers who give up their jobs to meet the growing needs of family members. Inevitably, this can lead to serious financial hardship for many households, with research revealing that two-thirds of people affected by Huntington's disease exist on income under the national average, and one in three lives below the poverty line.

It was against this backdrop of critical need that our Financial Wellbeing Service was launched in early 2015. In line with our commitment to deliver practical and personalised interventions to the families we serve, our small team of Financial Wellbeing officers works directly with members of the HD community across Scotland to reduce debt, maximise income and support money management.

In terms of both impact and recognition, we are pleased to report that 2019/20 has been a year of particular significance with the Financial Wellbeing Service being awarded Scottish National Standards for Advice and Information Providers accreditation. This Scottish Government-backed stamp of approval is reserved exclusively for organisations that deliver the highest quality of service and advice.

The endorsement came as the service marked a further milestone – passing the £3 million mark in secured income for families that could otherwise have gone unclaimed, adding to financial hardship being faced.

Having worked with more than 750 people since its inception, the £3.2 million total worked out at an average of an additional £2500 in household income on average for each client each year.

Families tell us they find the benefits system to be confusing and complex, which leads to money problems and adds further to the emotional stress at home. With the support of the Financial Wellbeing Service, they are able to access the appropriate benefits and products, reducing hardship.

Our officers carry out home visits and provide information and advice over the phone to clients and Scottish Huntington's Association HD specialists. In addition to advocating on behalf of clients and intervening in times of financial challenge, the team provides support through periodic financial 'health checks' and claims such as PIP (Personal Independence Payment) and Employment and Support Allowance. Officers also provide advice and information on financial planning matters such as Power of Attorney and Care Costs, as well as helping increase access and understanding of financial products including insurance and pensions, travel concessions, and energy grants such as the Warm Home Discount.

The impact of the Financial Wellbeing Service continues to inspire the confidence of major funding bodies, and we are thankful to charitable trusts, including The Robertson Trust and Henry Smith Charity.

This accreditation is testament to our hard work and commitment to making a positive difference to the lives of people and families living with Huntington's disease."

Jo Baldock, Senior Financial Wellbeing Officer

750 family members supported since service launch

£3.2m in additional income secured for families

William's story

"I was referred to the Financial Wellbeing Service in June 2018 by my HD Specialist for support with claiming Personal Independence Payment (PIP). Working with the HD specialist who provided the required medical evidence, the Financial Wellbeing Service officer helped me to submit a successful claim, increasing my income by £57 per week," said William.

"While this was going on, there were also a number of issues with my Employment and Support Allowance and claiming Council Tax Reduction. Both had been stopped after my partner moved in with me. Despite working significant hours in self-employment, her income was low and due to her own ill health, she was not able to work for significant periods of time. She was also caring for me.

"The drop in household income left us struggling to pay essential bills such as gas and electric, which worsened problems with Council Tax, and other debts.

Jo Baldock, Senior Financial Wellbeing Officer, said: "The case law and legal issues affecting William's situation were complex and the FWS team put together a case to dispute the Benefits Agency decision not to award Employment Support Allowance. Following two appeals, and substantial casework, the team secured a successful outcome and the benefit was awarded and backdated, significantly improving William's financial situation."

William added: "There were problems with the Department of Work and Pensions processing the decision, which were resolved following further support by the SHA's Financial Wellbeing Service, and in December 2019 we received a backdated lump sum of more than £9000 and ongoing payments worth £126 per week. I was overjoyed.

"Our FWS officer helped us to manage our budget and debt throughout the process, and the lump sum has reduced the pressure and helped to pay off some arrears. A Council Tax reduction award followed the appeal, lowering that debt, and we've been supported to negotiate payment arrangements for the remainder of money owed."

30 years of working together

During our 30th anniversary, a landmark year of advance in the care and support of the HD community, we celebrated the families who inform and drive forward this vital work.



We welcomed friends old and new to SHA, including fantastic fundraiser Edna McIvor (centre left) who celebrated her 80th birthday by taking part in a skydive to help fund vital services and raise awareness about Huntington's disease and our work.



It was fitting that families, who are at the heart of all that we do, should lead the anniversary celebrations. Commemorative 30th Anniversary benches were installed in care home grounds, gifted by Family Branches in Fife, Tayside, and Edinburgh and Lothian. Speaking at the bench unveiling in Lasswade, Lothian, Dina De Sousa, Chair of SHA Edinburgh Lothian Family Branch and trustee of SHA, said: "We hope this bench will welcome many individuals to have a seat and contemplate the good things in life and bring positivity. It will also serve as a conversation starter about HD and raise much-needed awareness about this silent disease."



We came together for a two-day 30th Anniversary Family Conference, hosted by our Patron Sarah Winckless MBE. The theme was 'How people affected by HD are taking control of their lives and creating change that will benefit everyone living with the disease' and key speakers included historian Alice Wexler, who has documented the story of how her sister worked with others to identify the HD gene, and HD Buzz founder Jeff Carroll who has dedicated his life to science that may lead to treatment. Further speakers included family member Gillian McNab and author Paula Merit, and Dr Oliver Quarrell who focused on Juvenile HD.



Our 30th Anniversary Volunteer Awards celebrated the incredible contribution of volunteer fundraisers and supporters to the work of SHA. Volunteer of the Year was presented to Gillian McNab, who had dedicated herself to raising awareness and funds for the charity, and Young Volunteer of the Year was presented to Bruce Wilson, an SHA youth ambassador and keen fundraiser. Further awards were presented by our Patron Sarah Winckless MBE to Marie Short MBE, Most Inspiring Volunteer of the Year; Moray Support Group, Volunteer Group of the Year; and Lauren Boag, Fundraising Champion of the Year.



Renfrewshire Council hosted a civic reception, which was attended by families, volunteers, staff and dignitaries, including Provost Lorraine Cameron. She praised the charity for its work to improve the lives of people and families impacted by HD, adding: "Scottish Huntington's Association, which has its national headquarters here in Renfrewshire, supports many families and it is important that we recognise that important contribution." Speaking after the event, John Eden, Chief Executive of SHA, said: "There was a real sense of joy and friendship in the room as we looked at the ways we have improved the care and support for HD families."

Empowering families to speak out

In March 2019, as part of our 30th Anniversary year celebrations, Scottish Huntington's Association launched You, Me and HD, a landmark campaign funded by the James Tudor Foundation to build on SHA's strong record of advocacy.

It was led by HD families, the most powerful voices for change in the care and support of the HD community, with the support of a specially-assigned You, Me and HD project team at Scottish Huntington's Association. Family members stepped forward as You, Me and HD Volunteer Ambassadors to deliver a series of talks, events, conversations and presentations across Scotland. Darren Clark, from Ayrshire, was one of the first to sign up.

"My family is affected by Huntington's disease. I lost my mum Dorothy to HD in July 2018, she was only 58 when she died. My grandpa and my uncle had

the disease as well, and because the faulty gene is hereditary, there's a chance that I will develop it too.

"For now, I'm living life to the full. I married my long-term girlfriend Robyn earlier this year. Robyn helped to care for my mum so she's seen how the disease progresses. She is very supportive and has joined me as a volunteer speaker for Scottish Huntington's Association to raise awareness."

Thanks to the efforts of Darren and his fellow You, Me and HD Ambassadors, we have raised awareness about the disease at local levels and built wider support for the work of Scottish Huntington's Association.

In addition, the campaign extended to a wider audience at community and national level when Ambassadors chose to share their stories with local newspapers, on the website, in our regular newsletter, and on social media.



"We want people to know just how awful this disease is, not just for the person who has Huntington's disease but also for their family and the people who love them."

Darren Clark, You, Me and HD Ambassador

Celebrating our community



This year, we recognised the invaluable contribution of our supporters, and presented the award of Fundraising Champion of The Year to family member, Lauren Boag.

The 33-year-old tested positive for the disease in 2015, and since then she has thrown herself into organising events and taking part in SHA-led organised challenges in support of the charity.

Lauren said: "I always knew I could have HD as it runs in my family. When I decided to start the process of finding out it was months of counselling and tests, and I was told I had the gene around the same time I was pregnant.

"I took the news pretty hard and it took some time to get my head around the diagnosis. But once I was over the initial shock, I wanted to do something positive

with my time and I started fundraising. I want to set a positive example to my two daughters and make them proud."

"I've kind of started to lose count of the fundraising I've done. I don't really use SHA's services myself but I support the charity because it's helped my family in the past."

Presenting the award, SHA Patron Sarah Winckless said: "Lauren has raised an amazing £16,000 – and is increasing awareness amongst people who have never heard of HD.

"She has a busy life with two young daughters, yet still manages to organise amazing events including a ladies' night, a dinner dance, afternoon tea and an evening with a medium. Lauren is a real inspiration to her family and SHA."

"SHA does a lot for everyone affected by HD and for the first time, I think a people are more hopeful and have more courage."

Lauren Boag, Fundraising Champion of the Year

Growing our income

This year, we raised a record £557,257 in fundraising income from charitable trusts and foundations, community fundraising, corporate supporters, legacies and gifts in memoriam, and individual giving.

A further £199,736 was received through grants from our long-standing partnerships with BBC Children in Need, the Lottery Community Fund and the Corra Foundation.

By directly raising funds, participating in challenge

events and encouraging employers and business networks to partner with us, the grassroots support from individual donors is vital to our continued growth.

With investment in the professional fundraising team, including the appointment of a Head of Fundraising in February, we are in a strong position to grow our profile and income in the years ahead.

We look forward to continuing to work alongside the HD community, and thank all those who support the vital work of Scottish Huntington's association.

▲ £80,527 received from individual donors	Five donors gave in excess of £2000, gifting a combined total of £20,000 including Gift Aid. This year also saw the launch of SHA's first seasonal giving campaign, Cup O' Kindness, which raised £17,500, a 500% increase in donations when compared to the same period the previous year.
▲ £213,955 given by 55 charitable trusts and foundations	Two thirds of the total income secured was for our Financial Wellbeing Service. The two largest funders of this service are The Robertson Trust and The Henry Smith Charity. New financial support was received from several other trusts and foundations for our youth service and core work.
▲ £75,887 from legacies and and gifts in memoriam	This marked a significant increase of £5500 on 18/19, with our largest donation of £50,000 left to SHA in the will of one of our supporters. A further £4700 was donated in memory of Val Hart, the late mother of our Patron Sarah Winckless.
▲ £154,052 from volunteer and SHA-led community fundraising	Supporters braved skydives, shark experiences and zipwire challenges; they joined SHA's My Zen Run, took part in the The Kiltwalk and completed marathons in Edinburgh and London. They also attended events included Dancing Through The Decades and the Big Sing, as well as inspiring donations from community groups and schools across Scotland.
▲ £32,836 donated by the business community	Roche donated £10,000 towards our Family Conference, while Zurich Community Trust donated £5000 in support of the Financial Wellbeing Service. Zurich's employees also volunteered at events and held a fundraising raffle at the Zurich Glasgow office which raised £4518.

Inspiring new supporters



When Karen and Craig moved into their first home together, they had no idea that weeks later their hopes and dreams would be changed forever with a shock diagnosis. Since then, they've been determined to make the most of every moment, while reaching out to other HD families, raising awareness and supporting the work of SHA.

Karen said: "Three years after we met, in May 2017, we got the keys to our first home. It was very exciting and we were very happy planning our life and our future together. It was around that time that Craig's uncle started to notice changes in Craig's movement and behaviours at work.

"The very first doctor we saw started talking about HD. We were shocked because no one knew Craig was at risk. When the test came back positive there was a lot of disbelief and denial at the beginning.

"The diagnosis changed our priorities, Craig is

symptomatic and some days are better than others but we're doing the best we can. He keeps active and is able to work and drive.

"Craig was lucky to be selected to take part in a HD trial, this meant lumbar punctures every month at the hospital. A year after his diagnosis, on my birthday in July 2018, he proposed and we were married the following year, it was the best day ever with our family and friends.

"There's nothing we can do to change Craig's diagnosis but there is a lot we can do to help SHA to support HD families. My sister and I have taken part in two Big Runs at Bellahouston Park and we brought a big crowd to the SHA Ceilidh Dancing Through The Decades events."

"I approached the charity committee at Zurich, where I work, and they agreed to award a grant of £15,000 to SHA over three years."

"As a family, regardless of everything going on, we stay positive and support one another while raising awareness about HD."

Karen and Craig, family members and SHA supporters



Leading the campaign for improved local services

Scottish Huntington's Association supports families – and families support Scottish Huntington's Association. The charity was founded upon this distinct understanding, which remains at the heart of all that we do.

This partnership in action was never more evident than when families from the newly-formed Moray Support Group decided to fight for better local services. Formed in 2017 to provide a supportive social network for families, friends and carers, the group quickly became one of the most active of its kind in Scotland, holding regular meetings, reaching out to HD families and reducing isolation, fundraising and working to increase understanding about Huntington's disease in the community.

It wasn't long before members began leading calls for improved specialist services for the area. At this point, families in Moray had to do a 100-mile round trip to Aberdeen to access the care they needed.

In addition to lobbying councillors, MSPs, MPs and First Minister Nicola Sturgeon, members took an active role in the cross-party working group which included NHS Grampian, Moray Council, SHA Chief Executive John Eden and Douglas Ross MP.

In 2019, their shared efforts paid off with the appointment of Moray's first HD specialist nurse by the local Health and Social Care partnership. On hearing the announcement, Moray Support Group founder Brian Watt described it as 'the best news in Moray for 30 years!'

He added: "My father had Huntington's disease, when he died 31 years ago there was no specialist HD care in Moray and little had changed since. Our first specialist HD nurse for Moray started in post in July, and it has made such a difference for families here."

The commitment of the Moray families was praised by John Eden, Chief Executive of SHA, who said: "I'm very proud of the local families who have been wonderful advocates and worked very hard to engage with the health and social care partnership in Moray to achieve this outcome. I'm also encouraged by the constructive working relationship we have developed with the senior officers of the partnership with whom we continue to work."

Their achievements were recognised further by the charity when Moray Support Group was named SHA's Volunteer Group of the Year at the 30th Anniversary Family Conference.

Presenting the award, SHA Patron and Olympic bronze medal winner Sarah Winckless MBE said: "They are determined to make sure that no one in Moray is left to face Huntington's disease alone."

"As if that wasn't enough, the Moray members are fierce! They don't take no for an answer and after campaigning with the support of SHA, they have secured the appointment of the first Huntington's specialist nurse for Moray. It's a fantastic achievement – and we have the feeling there is more to come from them."

"There's more to do and we're will continue to fight for equal care for the HD community."

Brian Watt, Chair of Moray Support Group

Treasurer's Report

SHA closed the year with an operating surplus of £42,130 which adds to our existing reserves and brings us to 90% of our four-month reserves policy. This out turn continues the positive trend of the charity managing its resources well. Behind the headline figure, there was an increase in expenditure on last year, but this was matched by an increase in fundraising income. The fundraising team brought in the highest ever annual income at £557,258 with trust income, community fundraising and legacies accounting for the greatest proportion.

Legacies have become an important component of the charity's annual income and the gifts left by families to SHA are humbling and deeply appreciated. I would like to take this opportunity to highlight that including the charity in your will is a straightforward exercise and the fundraising team can provide advice if you are considering doing this.

Congratulations are due to the fundraising team and it seems a fitting celebration of Dougie Peddie's final year as Fundraising Manager at SHA. Dougie retired in February 2020 to travel Europe in his beloved VW camper van, Bessie (though those plans have changed in the light of COVID-19) and I would like to express my thanks for his hard work over the six years he led the fundraising team and wish him well on his journeys. As we say farewell to Dougie, we also welcome Lee Johnstone, our new Head of Fundraising, who joins us from Barnardo's. He joins the charity at a challenging time when our community fundraising activities have had to be paused because of social distancing regulations. We have calculated we will lose £150,000 of income in 2020/21. The Senior Management Team have been working hard to identify savings and find new income and our forecast is a £30,000 deficit. Considering our current reserves, and the difficult circumstances facing every charity, this is a sustainable loss.

SHA has a diverse income base with more than 30 major funders and about £1.1m of the charity's income comes from contracts with the NHS, Health and Social Care Partnerships, and large grantors such as the Big Lottery Fund. In addition, 50% of our fundraising income comes from trusts and grants, legacies and in memoriam gifts. The fundraising team is diverting more time and energy to trust income and, if successful, this will help to reduce the 'fundraising gap'. All these

factors give us a great deal of financial resilience, however without doubt the next financial year will be challenging. Lee has also formulated a new fundraising strategy, which is being energetically implemented by his team. I particularly note the greater emphasis on building the charity's supporter base and identifying where members of the HD community have strong links to companies, wealthy individuals, or philanthropists. This is something we can all help with and if you do have a good contact who might help support the charity, please get in touch with Lee or another member of the fundraising team.

So, we can tuck 2019/20 away knowing the financial foundations of the charity are sound. Income remains strong and diverse, reserves are healthy, the fundraising team is performing well and the charity is adapting to the new challenges of the pandemic.

However, we have a great deal of hard work to do this year to ensure SHA continues to perform well financially, and there has never been a more significant time when we need our supporters to rally around the charity.

Statement of Accounts

Statement of Financial Activities
(incorporating Income and Expenditure Account)
For the Year ended 31 March 2020

	Notes	Unrestricted funds £	Restricted funds £	2020 Total Funds £	2019 Total Funds £
Income and endowments from					
Donations and legacies	3	248,980	54,225	303,205	190,110
Charitable activities:	4	39,091	1,190,581	1,229,672	1,273,685
Other trading activities	5	81,820	-	81,820	78,473
Investment income	6	736	-	736	3,678
Branch income		23,258	-	23,258	21,196
Total income		393,885	1,244,806	1,638,691	1,567,142
Expenditure on					
Raising funds	7	232,626	-	232,626	205,778
Charitable activities	8	-	1,352,847	1,352,847	1,296,643
Other (including Branches)		20,272	-	20,272	20,649
Total expenditure		252,898	1,352,847	1,605,745	1,523,070
Net income/(expenditure) before gains on fixed asset investments		140,987	(108,041)	32,946	44,072
Gains/(loss) on fixed asset investments	17	3,184	-	3,184	(3,328)
Net income before transfers		144,171	(108,041)	36,130	40,744
Transfers	23	(124,717)	124,717	-	-
Net income / (expenditure)		19,454	16,676	36,130	40,744
Other recognised gains and losses:					
Actuarial gain on defined benefit pension scheme	21	6,000	-	6,000	42,000
Net movement in funds		25,454	16,676	42,130	82,744
Reconciliation of funds					
Total funds brought forward	23	433,202	20,165	453,367	370,623
Total funds carried forward		458,656	36,841	495,497	453,367

The notes form part of these financial statements.

All activities are continuing. All gains and losses in 2020 and 2019 are shown above.

Statement of Accounts

Statement of Financial Activities
(incorporating Income and Expenditure Account)
For the Year ended 31 March 2020

	Notes	2020	2019
Fixed assets			
Tangible assets	16	-	-
Investments	17	17,454	14,270
		17,454	14,270
Current assets			
Debtors	18	29,740	15,600
Investment portfolio (Aviva)		111,872	120,584
Cash at bank and in hand		666,181	679,960
		807,793	816,144
Creditors:			
Amounts falling due within one year	19	(152,750)	(170,047)
Net current assets		655,043	646,097
Net assets excluding pension liability		672,497	660,367
Defined benefit pension scheme liability	21	(177,000)	(207,000)
Total net assets		495,497	453,367
The funds of the charity:			
Unrestricted funds:			
General		560,856	605,402
Designated		74,800	34,800
Pension reserve		(177,000)	(207,000)
		458,656	433,202
Restricted funds		36,841	20,165
Total charity funds	23	495,497	453,367

The financial statements were approved by the Board of Trustees on 22 October 2020

Scott's story

"I was eight or nine when I found out Dad was ill and he passed away when I was 12. I was keen to get tested as soon as I could and I was 18 when I found out that I have the HD gene. I did sort of give up on things a bit after that. I withdrew from the world and just didn't have the motivation to get through college, or for anything else really.

"Then, when I was 26, Pete from the SHA youth service asked me to volunteer at their youth summer camp. It wasn't typical of me to do something like that, I feel pretty awkward and anxious in social situations, but I've been back every year since. It's a great environment for meeting young people from HD families and finding out more about SHA and the research that's going on.

"It really inspired me, honestly. I realised I could be doing a lot more and it made me want to try and give something back to an organisation that's been such

a support for me and countless other HD families. I regained a bit of the confidence I'd lost during those darker years.

"I hadn't told my friends about my diagnosis before that first summer camp – I spoke to them about it for the first time after I got back. They were really positive and it made me wonder why I tried so hard to keep it a secret all those years. Although we don't talk about it much it's not an awkward subject, I know they're there for me if I need them.

"Now I do a bit of fundraising to raise money for SHA. I ran a 12K obstacle race and was really touched by everyone's support and generosity. I'm still entering events and pushing myself to do tougher races, so I've found myself a new hobby in the process."

Scott, 30, SHA Youth Ambassador.



Acknowledgements

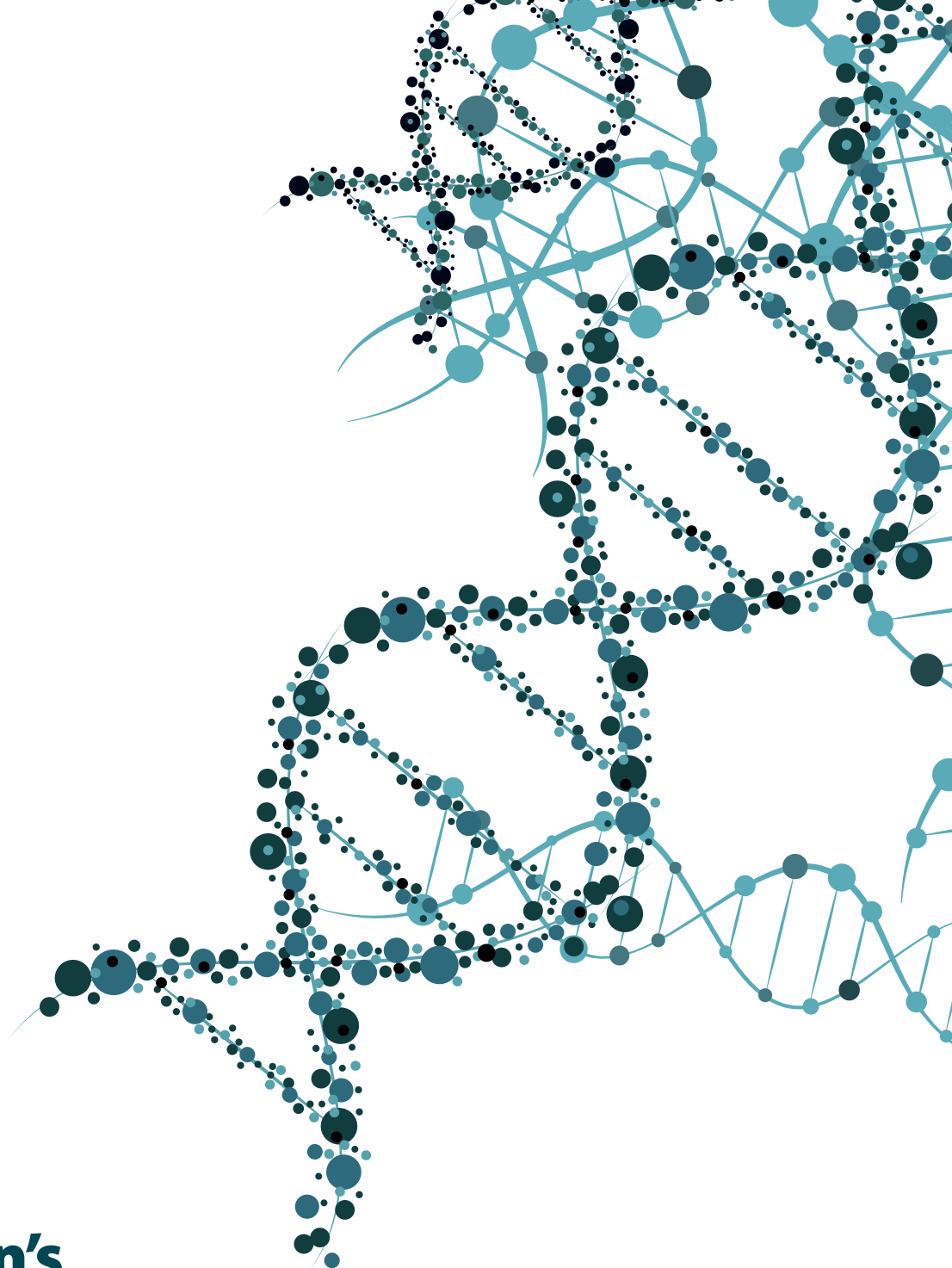
Thank you to the following grant funders, trusts/foundations and corporate supporters who have helped make our work possible, including those who wish to remain anonymous.

- Aberbrothock Skea Charitable Trust
 - Alexander Moncur Trust
 - Annie Ramsay McLean Trust
 - BBC Children in Need
 - Broughton Charitable Trust
 - Corra Foundation
 - Cruden Foundation Limited
 - DWF Foundation
 - George and Grace Thomson Trust
 - Gisela Graham Foundation
 - Intrepid Charitable Trust
 - Louis and Marion Ferrar Charitable Will Trust
 - M E B Charitable Trust
 - Mary Andrew Charitable Trust
 - Miss A M Pilkington Charitable Trust
 - Miss Caroline Jane Spence’s Fund
 - Miss Isobel Ferguson Harvey’s Charitable Trust
 - Miss M E S Paterson’s Charitable Trust
 - Mrs Ina B Briggs Memorial Trust
 - Murray Foundation
 - Nancy Roberts Charitable Trust
 - Northwood Charitable Trust
 - Ponton House Trust
 - Pump House Trust
 - Roche Products Limited
- Susan H Guy Charitable Trust
 - Tesco
 - The Appletree Trust
 - The Company of Actuaries Charitable Trust Fund
 - The Edward Gostling Foundation
 - The Graham Trust
 - The Henry Smith Charity
 - The Hugh Fraser Foundation
 - The J & J R Wilson Trust
 - The James Wood Bequest Fund
 - The John K Young Endowment Fund
 - The Leng Charitable Trust
 - The Martin Connell Charitable Trust
 - The National Lottery Community Fund (Scotland)
 - The R J Larg Family Charitable Trust
 - The Robertson Trust
 - The Row Fogo Charitable Trust
 - The Sir Jules Thorn Charitable Trust
 - The Templeton Goodwill Trust
 - The W A Cargill Fund
 - Thistledown Trust
 - W M Mann Foundation
 - Ward Family Charitable Trust
 - William Sword Charitable Trust
 - Zurich Community Trust

Local offices

LOCALE	ADDRESS	LOCALE	ADDRESS
AYRSHIRE	Scottish Huntington's Association (Ayrshire) Douglas Grant Rehabilitation Centre Ayrshire Central Hospital Kilwinning Road IRVINE KA12 8SS	HIGHLAND	Scottish Huntington's Association (Highland) Recreation Hall Building Raigmore Hospital INVERNESS IV2 3UJ
EDINBURGH	Scottish Huntington's Association Financial Wellbeing Service Citizen's Advice Bureau 23 Dalmeny Street EDINBURGH EH6 8PG	LANARKSHIRE	Scottish Huntington's Association (Lanarkshire) Hunter Community Health Centre (4th Floor) Andrew Street EAST KILBRIDE G74 1AD
FIFE	Scottish Huntington's Association (Fife) Whyteman's Brae Hospital Whyteman's Brae KIRKCALDY KY1 2ND	LOTHIAN	Scottish Huntington's Association (Lothian) Clinical Genetics Department Western General Hospital Crewe Road South EDINBURGH EH4 2XU
GLASGOW	Scottish Huntington's Association (Glasgow / SHAYP) Scottish Huntington's Association National Office Business First Burnbrae Road, Linwood Industrial Estate PAISLEY PA3 3FP	NATIONAL	Scottish Huntington's Association National Office Business First Burnbrae Road, Linwood Industrial Estate PAISLEY PA3 3FP
GRAMPIAN	Scottish Huntington's Association (Grampian) Clinical Genetics Centre Ashgrove House (Ground Floor) Foresterhill ABERDEEN AB25 2ZA	TAYSIDE	Scottish Huntington's Association (Tayside & Angus) East Day Home (Room 3010) Kings Cross Hospital Cleington Road DUNDEE DD3 8EA





scottish huntington's association



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