

SHArE

Summer 2020

The Magazine of Scottish Huntington's Association - Issue No.90

scottish
huntington's
association



Jordan joins NHS frontline

The 20-year-old nursing student begins work in an A&E department during COVID-19 crisis
See P4



Kathleen's 100th birthday celebrations

Kathleen dedicates her special day to supporting families living with Huntington's disease.
See P12

Expanding our services to support families during crisis

Scottish Huntington's Association has taken urgent steps during the COVID-19 pandemic to ensure that families are able to access lifeline services and receive additional support when needed.

This included securing emergency funding of £27,000 from the Scottish Government's Wellbeing Fund to provide an additional virtual service, Wellness Matters, in direct response to concerns from families about the mental health of loved ones struggling to cope.

Wellness Matters went live at the start of June and ran until the end of July, providing vital support and information for family members, including carers. We recruited two Wellness Matters officers, Alison Tonner and Richard Leckerman for the duration of the project, and they brought an additional layer of mental health and wellbeing expertise to the charity.

Clients referred to the team were each offered five one-hour sessions, and by the conclusion of the project the

Wellness Matters team, led by team leader Patricia Cattrell, had provided a total of 59 1-2-1 support sessions and responded to 20 referrals.

The project drew a conclusion with an online interactive session, open to all, that focused on building resilience, developing coping strategies and using relaxation techniques.

Chief Executive John Eden said: "From the very beginning of the pandemic, we have been listening to what people with HD and their families say about the impact of COVID-19 on their lives.

"Direct feedback from families, our staff, combined with comprehensive survey of the HD community, will continue to shape our understanding about the additional challenges being faced by families, who we know are really worried about their finances, care arrangements, the extra pressure on carers and mental health. "As a community, people with HD are resilient – they have to be – and as a charity we want to show we can step up, quickly and effectively, when the pressure is on."



Alison Tonner



Richard Leckerman

Family survey findings: Full story P10

John Eden, Chief Executive Officer...

Our lives transformed...

SARS-CoV -2, pandemic, COVID-19, and lockdown are all words that just six months ago we had no idea would transform all our lives in 2020. This tiny organism has wrought seismic changes and things may never be the same again.

During April we interviewed 100 people with HD, carers and young people and the impact of the virus was clear. There was widespread concern about becoming more isolated and separated from friends and family, people were worried about the financial impact: loss of jobs, rising debt. Carers told us they were under more pressure because of reductions in services or they had cancelled services over concerns about the risk of infection. Young people were worried about their education and how it might affect their opportunities. Across the board, there was concern about the additional strain on families, mental health, and wellbeing.

There is no doubt, as a community, people living with HD were always likely to be one of the hardest hit groups. Having HD does not confer any additional risk from the virus, though those in the later stages of

the illness may have increased vulnerability from immobility, swallowing difficulties, or weight loss. People with HD and their families do, however, already live with complex and challenging issues arising from the condition: isolation is already common, many families live with financial pressures and uncertainties, being a carer was already demanding and anxiety and depression are common. The pandemic has amplified those pressures.

While all of that is true, none of these issues has drawn my focus as much as the sheer resilience of HD affected families. Some people have drawn strength from their friends and family, some from the local communities in which they live, some from the positives to be found in lockdown (my favourite was the individual who said life was much less demanding in lockdown and so their stress levels were reduced!). Some drew comfort from the knowledge their HD Specialist, Youth Worker or Financial Wellbeing Officer was just a phone call away and expressed trust that if they needed help, it was there. Some used it as an opportunity to reconnect with people in their lives. Above all

though, I repeatedly heard families say that the challenges of living with HD in 'ordinary times' meant they had the fortitude to cope with the new challenges of the pandemic.

When I listen to my friends or family talk about their problems, I sometimes, when it's appropriate and without making them feel judged, reflect what I have witnessed HD affected families cope with and I tell them, if you want to see what resilience really looks like, talk to an HD family member because, by necessity, the HD community has learned the human spirit has an incredible ability to survive and even thrive in the most challenging spaces. I have no doubt the community and the charity have the resilience to get through this difficult time and while we won't emerge unchanged (because good can come of this situation), we will emerge undaunted and ready to face the next challenges that await us.



Sarah shares her experiences in support of families



Earlier this year, our Patron Sarah Winckless MBE was all set to make history as the first woman umpire of the annual Oxford-Cambridge Boat Race.

When Covid-19 led to lockdown and the cancellation of all events, including the Thames boat race, Sarah quickly set aside any disappointment and started to pull people together in support of families with Huntington's disease.

From sending an uplifting email message direct to families and sharing her strategies for coping during lockdown, to recording a video promoting SHA's coronavirus crisis appeal, Stay Home and Step Up, Sarah has played a major role in our activities to support families and generate vital income for services. Most recently, Sarah has filmed a

SHAYP Talk about resilience, which has been shared on our social channels. Sarah said: *"My late mum had Huntington's disease, we grew up with it and I know how difficult every day can be during the best of times, never mind in the midst of a global health emergency."*

"Our HD Specialists, youth advisors and Financial Wellbeing officers are working closely with families every day, helping with practical issues like accessing grants and allowances, keeping young people connected with friends in the SHA community, supporting carers and engaging health and social care providers."



Karen Sutherland, Operations Manager, brings you up to date with the work of the Adult Clinical Service teams across Scotland.

Living and working through the COVID-19 pandemic has been an experience like no other, one that has brought many challenges – and a number of unexpected positives.

SHA's staff remain committed to safeguarding the lifeline services relied up on by so many families, and I am so proud of how they are responding to the drastic life and work changes caused by this unprecedented health crisis.

The local teams made literally hundreds and hundreds of calls during lockdown, reaching out to our HD families and other professionals involved in the care management of some of our family members. We have all become very skilled in using Teams, Zoom and Near Me, which has been key in keeping connected to the families we serve.

All our own team meetings and those with our Health and Social care partners have taken place via Teams and this new way of working will most definitely influence the way we work in the future. No more travelling hundreds of miles to attend one meeting! Some of the team are now able to conduct their HD management clinics via teams and Near Me, which has been of huge benefit.

The team has built excellent relationships with local Wellbeing Hubs and referred many families to for essential services such as the delivery of food packages and medications, and assisting with banking issues. Some of the situations our staff have supported people with have been very challenging, and they have all gone above and beyond to help, while many of the routine tasks such as medication changes or getting personal care support have taken three or four times as long to arrange due to support services process changes or difficulties with accessing.

Most staff have found that relationships with H&SCPs have improved and strengthened, with everyone working towards the common goal of ensuring people are well supported and no one is left in crisis.

I am delighted to finally have our two newly-appointed Team leaders on board. Patricia Cattrell who will support the north east team, including new staff Lothian HDS, Julie Wilson. Linda Lucas, SHDS in Lanarkshire, has returned from maternity leave and has been appointed

as Team leader, who will be supporting the south west team. The appointment of the team leaders will be hugely beneficial to all the service staff they will support, as well as to the Operations Manager, strengthening the capacity of the senior management team.

We still have a few vacancies to fill, which were been paused due to lockdown, but we are now in the process of re-advertising the Ayrshire HDS post and Glasgow HDS posts. Kirsten Meikle who was covering Linda's maternity leave left the role at the end of August, Rhona Vernon Smith has been promoted to SHDS in Lanarkshire and Claudia Lang HDS has transferred to Lanarkshire.

Due to the impact of Covid-19, we have unfortunately had to make the decision to cancel this year's Family Conference, however we are looking at ways to bring people together online, so watch this space.

Now that restrictions have eased, in line with Scottish Government guidelines we have put together very robust guidelines for our staff ensuring their safety and that of the families they support. While most will still be working from home, plans were put in place for the HDS may to recommence essential home visits, and this will be reviewed on a regular basis as guidelines and restrictions change.

In the early weeks of lockdown we all were hugely supportive of our frontline NHS staff and showed our support for them by clapping every Thursday at 8pm. I would like to clap every day to show our staff how much we value and support the fantastic work they have done during this very difficult period and raise my hat to everyone of them. Thank you.

Take care and stay safe.



Jordan joins the NHS frontline in COVID-19 battle

Student nurse and SHA youth ambassador Jordan Cullen joined healthcare professionals in a busy A&E ward in response to the Coronavirus outbreak.

The 20-year-old, from Angus, who is in the final year of her degree, was determined to put her training and skills to good use on the frontline.

"I've started work earlier than expected, it's a bit worrying but at least I'm able to do something to help. I prefer to be on the ward and keep busy right now," said Jordan.

Jordan was 11 when her Gran, who had Huntington's disease, passed away. Three years ago, after moving to Edinburgh to study, Jordan joined Scottish Huntington's Association as a family member and fundraiser, and she is now a volunteer youth ambassador.

*"My status is unknown and when I started university, I felt it was time to find out more about what Huntington's disease could mean for me and my future. I got in touch with **SHAYP - Scottish Huntington's Association Youth Service**, and Kirsten came straight back to me and we had a chat. Then I talked to Pete, who has been my youth advisor ever since."*

"The literature that SHAYP produced really helped me to gain an understanding about the disease and through my studies their research provided the basis of my dissertation, so it has been lovely to have the support from them regarding this too."

"I'm grateful to SHA for the help I've had from SHAYP. It makes life better and it's reassuring to know that Pete will answer any questions and explain what I don't understand. We speak about different things, sometimes we don't talk about HD much at all, but I know he's there if I need him. He'll always pick up the phone."



Jordan and her gran

Financial Welfare Service passes £4m milestone

SHA's Financial Wellbeing Service has now secured more than £4million in benefits, financial products and other allowances for HD families who might otherwise have had difficulties paying household bills and managing their budget.

The small team of three specialist advisors – Jo, Mel and Katrina – work with clients from across Scotland in many ways, from helping to fill in applications for PIP to accessing pensions early, helping to reduce debt and providing financial 'health checks' to help families manage their household budgets.

Passing the £4million milestone came as Scotland prepared to lockdown as a result of coronavirus. Since then the team has been working with families facing new and urgent challenges as a result of the pandemic, including providing advice about issues including benefits and the furlough scheme. They have also helped to resolve a number of domestic practical problems that needed a fast response.

For example, one client was left without heating due to the cancellation of work to swap her prepayment meter to a new Smart meter. The situation was causing a great deal of anxiety before our Financial Wellbeing Services team stepped in. By contacting the power company, the advisor made sure that the family member could access her supply.

Another client was struggling without a washing machine after her local council paused processing of Community Care Grant applications because of COVID-19. Her FWS advisor and HD Specialist worked together to find a solution using SHA's Welfare Fund.

With so much new information coming out about changes to allowances and the introduction of new schemes as a result of the COVID-19 crisis, the FWS team is also keeping families informed through regular updates on its dedicated Coronavirus information page on our website. It covers everything from housing benefit to student finance, support for the self-employed to mortgage holidays. Visit <https://hdscotland.org/covid-19-financial-advice/> to find out more.



Amelia welcomes her baby brothers to the family



Twins joy for the Queen family

Congratulations to the Queen family, who welcomed twins Louis and Harris to their family earlier this summer, baby brothers for five-year-old Amelia.

Juliana (43), who has the HD gene, and her husband Graham (55) made medical history five years ago when Amelia was born. The couple were the first in Scotland to take part in pioneering genetic screening, Pre-implantation Genetic Testing (PGT) that ensured Amelia would be born free of risk from Huntington's disease.

Last year, although they scarcely dared to hope for another child after a number of failed PGT attempts, the couple decided to give the fertility treatment one last try – and were overjoyed when, during a scan at seven-weeks, they were told that Juliana was expecting twins.

Juliana said: *"The sonographers said 'we've got news for you – you're having twins!' I just pulled my jumper over my face and screamed with joy, realising at that moment our lives were going to change massively with two more wee ones about the house. Graham was ecstatic."*

The boys were delivered a month early by Caesarean section at Queen Elizabeth University Hospital in Glasgow. Louis weighed in at a healthy 6lb 13oz and Harris 6lb 10oz – however the delivery was traumatic and Juliana suffered a haemorrhage. Before she was able to see or hold her boys, she was rushed to the high dependency unit for an emergency plasma transfusion.

After two days she was transferred back to the maternity ward and was home with her babies in a week.

"It was a difficult delivery," said Juliana, "but I am home now and Amelia is thrilled to be spending time with her wee brothers. Life is wonderful, and I just want people living with Huntington's disease to know that it is possible to have a family, regardless of whether you've been tested for the gene or not."

Juliana conceived Amelia with NHS fertility care but did not qualify for further treatment because the couple already had a healthy child and she was over 40. For the twins, the private fertility treatment was carried out at the Glasgow Centre for Reproductive Medicine (GCRM), with the embryo selection technique undertaken at a laboratory in Oxford.

Work continues to develop final local care framework

Work is continuing on the development of local versions of the National Care Framework for HD, with the Dumfries and Galloway Framework now online.

This means that Scottish Borders is now the only area not to have a Framework in place, however SHA's National Care Framework Lead, Alistair Haw, has met with the Chief Officer of Scottish Borders Health and Social Care Partnership (HSCP), who has committed to supporting the work when the situation allows.

"With the onset of the pandemic work to move forward in Scottish Borders was, like so many other things, temporarily paused. However as we continue to move beyond the lockdown

phase it is now a top priority to get things moving again," said Alistair. "The good news is that I have received a personal assurance from the Chief Officer of Scottish Borders HSCP that he will be assisting us with this work as soon as is possible."

The lifting of lockdown measures will also enable SHA to turn its attention to arranging formal launch events for the Dumfries & Galloway, Tayside and Forth Valley Frameworks, which are all online and can be used by families and staff in the meantime.

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

100 dances in ONE day dedicated to families with HD

Neighbours who danced in the street every morning for 100 days during lockdown have topped their amazing feat– by performing 100 DANCES IN ONE DAY in support of families living with Huntington's disease (HD).

The daily dancers from the Poplars estate in Lanark sent the special message of solidarity to the HD community to celebrate the 51st birthday of mum-of-three Gillian McNab, who has the gene that leads to the incurable disease.

And their six hours and five minutes of non-stop dancing has so far raised more than £4500 for SHA.

Gillian, a staff nurse in a hospice, said: *"I'd like to give a huge thanks to all those who supported us in any way, whether you dropped in and joined us for a dance or two, put money in the collection buckets, donated money or raffle prizes, bought raffle tickets, baked or provided food and drinks. A special shout out to the very generous local businesses who donated such amazing raffle prizes*

"I couldn't be prouder of our wee street. I am so grateful to my wonderful neighbours. When Julie Main came up with the idea, everyone else immediately got behind it and put so much work into making the day a big success.

"They not only helped to raise awareness about Huntington's disease, we also raised a great deal of money for the SHA. It really was a birthday to remember. I feel very lucky and blessed to have turned 51, with no symptoms and still able to dance at all, never mind for over six hours solid."

Julie said: *"We've made dear new friends and we've looked after each other and supported each other through difficult times. I couldn't be prouder of the community spirit we have built and the way we have pulled together to raise such an amazing amount to support people with Huntington's disease."*

Neighbour Karen MacDonald added: *"I feel proud, privileged and grateful to be able to dance, which is just one of the joys that are lost to so many people living with Huntington's disease. As we danced and fundraised, we were thinking about every person, young and old, who lives with this disease in their family."*



Carolyn's virtual fundraising journey takes

How do you complete a 117-mile fundraising challenge during lockdown? For Carolyn Craig, it was time to let her imagination and creativity run free...

Carolyn grew up in a family affected by Huntington's disease. Her mum Christine was diagnosed in 1979 and Carolyn lost her brother Hugh to the disease in 2015. Carolyn, who has tested negative, has been a keen supporter of SHA for many years, attending Family Conferences and taking part in local activities before joining the charity as a trustee in 2009.



Student Bruce praises SHA for family support

Because of the uncertainty that's always there for a family living with Huntington's disease, I'm kind of used to not knowing what's coming next. Living through the pandemic is just more to add to the pile."

Bruce Wilson, a 20-year-old Computing student from Edinburgh, stayed at home with mum Lesley (53) and dad Graham (53), who has Huntington's disease. He shares their experiences of life in lockdown and how he and his family found ways to cope with the 'new normal' while staying connected with loved ones in the outside world.

"Like many people who have HD symptoms, any change in routine was especially hard for Dad but we tried to have a laugh and not take things too seriously. Mum is the most amazing and strongest person I know. She works full time and while lockdown did mean that we both had more time to spend with Dad, it also meant also had no escape from home life, whether that be work, university, or just something like eating out.

"But Mum stayed positive by keeping busy, especially in the garden, and we took part in online quizzes every week or so. They usually had some sort of dress-up theme, something that I could throw together from what was in the house. One week we were all wearing funny hats and another time we made a giant rainbow out of wood for the 'Rainbows for NHS' themed week. Those little creative moments definitely help to keep me sane.

"SHA has been a great support. My youth advisor Pete is in touch all the time and he organised Zoom sessions so I could catch up with friends I've made through SHA. Mum and Dad speak regularly to Trevor, our HD Specialist, and that helps a lot too. As a family, we couldn't ask anything more of them."



Darren and Robyn bring friends together to change lives

A young couple from Ayrshire inspired their community to reach HD families with vital support during these difficult times.

When the lockdown was announced, Darren and Robyn Clark, from Irvine, were in the final stages of organising their annual fundraising day. They immediately set aside the disappointment that it couldn't go ahead and got busy coming up with an alternative.

Darren, who lost his mum Dorothy to HD two years ago, said:

"Our friends always made the fundraising day a massive success. We hold it in a local venue and people bring their children during the day then it goes on into the evening. There are raffles, competitions, face painting and fantastic prizes, and we all come together to help families who are living with the disease.

"We needed to think differently this year, knowing that our friends want to give their support, especially at a time when families needed SHA's services more than ever."

Darren and Robyn hit upon Facebook and football, bringing pals together online to buy spaces on a mystery football team scratch card. In just a couple of hours all 100 squad names had been snapped up, raising £500 for SHA. It was so popular that they did it again a couple of days later – boosting their charity total by a further £500.

"We announced the winners live on Facebook and everyone watched Robyn scratching the cards to reveal the winning teams," said Darren.

"We knew our friends wanted to do more, so we organised two more football cards and ended up raising more than £2000. With such amazing friends, nothing was stopping us!"

es in Fife's top beauty spots

Shortly after lockdown was announced, and in response to SHA's Stay Home and Step Up coronavirus crisis appeal, Carolyn decided to stride out in support of the HD community by clocking up 7,800 fundraising footsteps each day.

Knowing that she couldn't stray far from home, she decided to add interest by plotting out a virtual route along the 117-mile Fife Coastal Path and blogging on her Justgiving page about the picturesque villages, places of historical interest, amazing scenery and beauty spots along the way.

Carolyn's virtual walk from Kincardine took in Longannet, home of the last coal-fired power station in Scotland; over the Queensferry Crossing to Inverkeithing and Burntisland. Onto Kinghorn with its monument to Alexander III, beaches and a lifeboat station towards West Wemyss and East Wemyss, from Buckhaven to Elie and the East Neuk fishing villages of St Monans, Pittenweem and Anstruther. Then St Andrews, through the pretty village of Wormit and on to her final destination, Newburgh Bay.



Remember a charity in your will Help SHA's work live on

Mark's kindness is already changing the lives of HD families

For Mark*, who cared for his dear wife Morven until her death from Huntington's disease, there was always a determination to do more to help people in the HD community.

He became a donor to Scottish Huntington's Association, quietly giving what he could when he could to the charity that had been such a support to him over the years. Earlier this year, we received a letter from his solicitor, informing us that Mark had recently passed away.

Before his death, Mark had decided to make one final gift in support of other HD families by leaving a portion of his estate to Scottish Huntington's Association in his will. He had never told us about his plans and this wonderful kindness will be long remembered; it is already making a difference to the lives of families, a fitting legacy for a man who cared so deeply about others.

September is Remember A Charity In Your Will month, the perfect time to consider leaving a gift that will help the vital work of Scottish Huntington's Association to continue. Through our partnership with McClure Solicitors, you have an opportunity to make a will free of

charge, or review an existing will, all year-round. While there is no fee for this service, you are invited to make a donation to the charity of your choice.

Our Chief Executive John Eden has already taken steps to include SHA in his will.

"Working with HD affected families has been the most rewarding experience of my life and I know it is vital Scottish Huntington's Association continues to provide lifeline services and support until there are effective treatments for the condition and hopefully, one day, a cure," said John.

"I feel part of the HD community in Scotland and have been inspired by and cared about many of those who live with the condition, which is why I want to leave a gift in my will to help the charity to continue its mission."

To find out more about how you can leave a gift to SHA in your will, please contact Gemma Powell at gemma.powell@hdscotland.org or **0141 848 0308**

***names have been changed**

Zurich Community Trust shows its support

Following a successful application for funding, the Trust has donated £10,000 in support of SHA's work with families in Glasgow and Lanarkshire.

The organisation is also sharing its wellbeing, fundraising and communications expertise with partner charities, including SHA, through a series of online workshops and webinars to help build resilience and generate impact despite the restrictions resulting from the pandemic.

Zurich Community Trust has a wide range of community partners and is supported by the funds, time and talent donated by Zurich Insurance UK and its employees. It aims to help address a raft of social issues to bring about positive change to those facing tough times.

SHA was first introduced by family member and Zurich employee Karen Black, from Glasgow, whose approach led

to a grant of £15,000 from ZCT over three years from 2017 to support the work of our Financial Wellbeing Services team. Since then, the relationship has gone from strength to strength, with Zurich staff members volunteering at SHA events and holding office raffles to raise additional funds for the charity, organised by a second family member and Zurich employee Stephanie Clark.

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

Steven completes marathon alternative

He's more used to pounding the streets of London lined with 700,000 cheering spectators – but for Steven Henderson completing his solo alternative to the world-famous marathon was every bit as challenging and rewarding.

The 36-year-old dad, who works in the oil and gas industry in Aberdeen, spent months training for the 2020 London Marathon in support of Scottish Huntington's Association.

When COVID-19 forced organisers to postpone the event, Steven decided to hang up his running shoes and take it easy for a few months – until he woke up on the Sunday morning that should have been London Marathon day.

"I just decided then and there that I would go ahead with it anyway, but instead of running 26.2 miles, I would try to do 26 circuits of the housing estate where we live," said Steven.

"The development is on a hill so it was pretty hard going towards the end. I was very tired but my wife, children and our neighbours came out into their gardens to cheer me on to the finish."

Steven took a little over three hours to complete the 20-mile run, and his efforts boosted his fundraising total by donations of nearly £200 from friends, family and colleagues. He is adding that to the £475 raised at a poker night event earlier this year, and is looking forward to hitting the road again when the rescheduled London Marathon comes round in October.

"It will be my fourth time and I always do it to raise money for Scottish Huntington's Association. Huntington's disease is in my family and we know how well the charity supports the HD community all over Scotland."



Thank you to Moray families

We received a wonderful gift of £760.65 from our friends in Moray to the Stay Home and Step Up Coronavirus crisis appeal. Jock Anderson, a founder member of the Moray Support Group said:

"The money was for local group activities but now it feels right to donate to Stay Home and Step Up instead. These are difficult times for everyone and by supporting SHA, we're able to help more families. It's also a chance to give back because, over the years, SHA has always been there for our HD community."

Jock's relationship with the charity goes back to when he cared for his late wife Maureen, who died of Huntington's disease in 1997. Two of their three daughters – Lynn and Judith – are symptomatic, while Jackie has tested negative.

As a family, including Jock's second wife Alison, the Andersons seize every opportunity to do what they can to raise awareness and funds. At Jock's 70th birthday party, which took place before the Coronavirus lockdown, a collection bucket was filled to the brim by generous guests. Jock also completed last year's Kiltwalk, and the total was topped up by his sister Diane, who collects donations in return for giving quilting and craft demonstrations at local clubs.

Building a picture of life at home during COVID-19 lockdown

More than 170 people took part in our online and telephone survey, which was carried soon after lockdown began.

It found that 64% of respondents were worried about the mental health of a loved one with HD and the impact on other family members. Over 60% believed they would become more isolated during the pandemic, and one in three was unsure about how easy it would be to access appropriate mental wellbeing support.

Nearly 50% of family members said that the person with HD in their household was at risk of police action because they don't understand social distancing rules.

Changes in household circumstances added to the stress – 64% of families were worried about the financial impact of COVID-19 and one in three feared not being able to meet essential costs like food and fuel. A reduction in agency support meant that 40% of families were also taking on additional caring responsibilities.

During the first month of lockdown, our frontline HD Specialist team took part in more than 1000 support calls with families across Scotland, carried out more than 2500 contacts with health and social care bodies, and completed more than 200 review assessments.

SHAYP provided 1-2-1 and group support for young people, including those who looked after loved ones or were unable to visit parents in care homes. Specialist youth advisors also spoke to a sample group of under-25s to find out more about how lockdown was affecting them.

Kirsten Walker, Youth Services Manager, said: *"Our young people were very open and honest with us about what they were going through."*

"At a time when we'd usually be getting ready for our annual residential trip, we were holding online group sessions to reduce isolation, improve mental wellbeing and bring friends together. The conversations we were having every day, combined with the findings of the survey,

told us this support was more needed than ever."

There were widespread concerns about the additional pressure on family life (81% of respondents) and increased isolation (72%). Separation from loved ones was also having a major impact, as was missing friends, activities and milestone moments such as taking exams and attending a school prom.

The impact on education was flagged by 72% of young people, many of whom juggled studying at home with increased caring responsibilities – 65% of the young people were providing support to someone with HD in their family, while 40% were worried about the risk of COVID-19 infections at care homes where loved ones were being looked after.

The findings of the surveys have helped SHA to ensure the right services are in place for families during the lockdown and will continue to inform our work as we move past the pandemic.

Research news

Our CEO John Eden looks at the impact of COVID-19 on HD clinical trials:

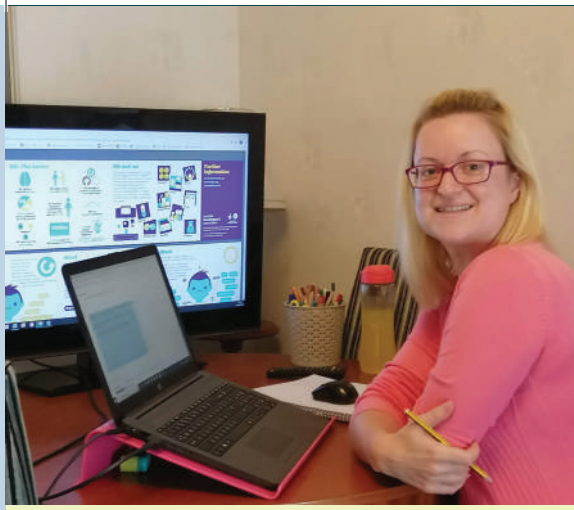
With many countries' entire healthcare systems turned over to providing care for people with COVID illness, and many doctors and nurses diverted from research into frontline care, an impact on Huntington's disease was clinical trials is inevitable. However, all those involved were doing everything they could to minimise the impact and carry on with whatever trial activity they can.

In practice, the impact will vary quite a bit from one site to another, and from one trial to another. Some sites may still be enrolling new patients, while many will be forced to pause recruitment of new participants and focus on continued care and dosing of patients already involved. In Scotland, our two trial sites in Aberdeen and Glasgow temporarily suspended visits.

Decisions about what activity can carry on are largely determined locally, by the hospitals and local and national governing bodies that direct healthcare resources. Trial

sponsors (companies like Wave, Roche and UniQure) fund, support and organize the trials. So far, all the trial sponsors we've heard from have indicated that they continue to be committed to running and completing the trials despite the interruption the viral pandemic may cause.

It may be that some modifications need to be made later, to compensate for trials that were unexpectedly interrupted. For instance, they might need to treat existing patients for longer, or recruit additional patients to make up for lost time. And later, the regulatory agencies like the FDA might need to be more flexible when considering data from trials with higher than normal levels of missing data. With so much unknown about how long COVID will impact things, it's difficult to be more specific, but the smart people who invented this cool generation of HD drugs and brought them to trials, are now working full time to keep those trials running as well as humanly possible.



SHAYP Update

from Kirsten Walker,
Youth Services Manager

Hello everyone, I hope this edition of SHAre finds you well? It's been a challenging time for SHAYP as we navigate complex circumstances while continuing to provide support to our young people and families. I'm immensely proud of my team, Pete, Grant and David, for all their hard work and creativity in keeping the service running during these difficult times.

"As with the HD Specialist and Financial Wellbeing Service, SHAYP has provided telephone and online video support to their young people. For those who have chosen to take up this offer, it has been well used and a lot of good work has been undertaken.

"SHAYP also offered a weekly plan of online interactive activities. We had an 8-12 zoom group, 13-17 Zoom Group and 18+ Zoom group who took part in activities including a quiz, scavenger hunt, games and competitions. These became the highlight of the week for SHAYP staff and it was heart-warming to have so many young people joining in.

"Moving forward, as restrictions ease, SHAYP is reviewing how it provides its service. Zoom groups reduced to once a week during the summer holidays and further details will be provide on social media channels when our plans are finalised. Hopefully we can soon start going out on essential visits, and SHAYP staff will be in touch when this is possible.

"As some of you may know, David Drain has left to follow his calling as Pastor of his Church. On behalf of Scottish Huntington's Association, I thank David for 10 years of

dedicated service. SHAYP, our staff and young people, and the service as whole, have benefited greatly from David's input and insight, and he will certainly leave a positive lasting legacy. David has positively impacted many of his young people over the years as their 'one trusted adult' and the one person they could turn to in times of difficulty to help guide and support them on their journey, and he will be greatly missed by all at SHA.

"Two further SHAYP Talks have been completed and are available for your viewing pleasure – Better Sleep and Self Care. The short films provide practical hints and tips about how to improve your sleep and take better care of yourself. Follow SHAYP on YouTube to view these.



"In the meantime, looking ahead to whatever the next few months brings, we keep our fingers crossed that we'll soon see some of you face to face again."

Scottish Huntington's Association awarded £120,000 by BBC Children in Need



**BBC
Children
in Need**

The charity has received a grant of £120,000 over three years by BBC Children in Need. This grant will fund vital work by SHAYP, the charity's youth service, and help make a difference to the lives of children and young people in Fife, Edinburgh and Lothian.

Through 1-2-1 support and group activities, young people will be helped to build resilience, make friends, access services to reduce caring responsibilities, and improve family relationships.

Kirsten Walker, Youth Services Manager at Scottish Huntington's Association, said: "We could not reach out to the young people in Fife, Edinburgh and the Lothians without the support of BBC Children in Need. This grant will go on to change the lives of so many young people and give them the support they need.

"The funding secures Pete's post for an additional three years, and we are overjoyed, as is Pete who has done a tremendous job in Fife and Lothian

developing and running the service. Simon Antrobus, Chief Executive of BBC Children in Need, said: "At a time when children and young people need our support more than ever, I am incredibly proud to be awarding funding which will go on to positively impact their lives. These grants were only made possible thanks to our remarkable supporters, so a big thank you to everyone who supported us in 2019." Across Scotland, BBC Children in Need currently funds 309 projects to the value of more than £19.4million.



Kathleen celebrates 100th birthday by helping families with Huntington's disease

Kathleen Simpson, from Dundee, spent her special day with her family who threw a socially-distanced garden party in her honour. Neighbours and friends gathered in the street to wish Kathleen well with a round of applause as a Highland dancer launched the celebrations.

Instead of gifts, the great-grandmother requested donations to Scottish Huntington's Association, a charity close to her heart because of the support it has given her family over the years. Her loved ones rallied round and Kathleen is delighted to have smashed the £500 target. Family members surprised her with the news that she has raised more than £800 so far.

Reaching the age of 100 years brings mixed emotions for Kathleen, who lost her beloved husband and both of their children to Huntington's disease. Two of her grand-daughters have since tested positive for the disease and she has great-grandchildren who are at risk of developing it too.

There are around 1100 people with HD in Scotland and up to 6000 people at risk, with each child of those diagnosed at 50% risk of developing the hereditary disease. There are three main groups of symptoms: changes to thinking processes (a type of early onset dementia); loss of muscle control which impacts mobility, speech and the ability to swallow; and mental illness. People with Huntington's disease may eventually lose the ability to walk, talk, eat, drink, or make decisions, and go on to need for 24-hour care outside the family home.

Little was known about the disease when Kathleen and RAF serviceman David met at a dance and fell in love during World War 2. They were married on 22 December 1945, and had their two children, Ronald and Morag.

David, who built his career as a senior buyer for a Dundee hardware company and was known for his fantastic dancing, started to show symptoms as he grew older, and Kathleen cared for him until his death in 1995. Their son Ronald began to develop symptoms in his early 40s and died aged 61 in 2012. After living with symptoms for more than 20 years, Morag passed away aged 66 in 2013, a year to the day after her brother.



Speaking on behalf of the close-knit family, Kathleen's great grand-daughter Megan Stewart (21) said: "At first, we weren't sure what to do for my great-gran's birthday. She has mixed feelings about reaching 100 and feeling fit and well when so many of those closest to her continue to be affected by Huntington's disease.

"But she means everything to us and we wanted to celebrate her and the loving family she has created. It's typical of her to want to help other people, and the money donated in her honour is a thank you to Scottish Huntington's Association for always being here for our family and the wider HD community across Scotland. "We're supported by our Scottish Huntington's Association HD Specialist, while my younger sister Ellie has a dedicated youth advisor and she attends camps and events organised by the youth service. We can pick up the phone and talk to somebody whenever we need to.

"My great-gran was thrilled at how much has been raised, we surprised her at her party with the news. It was a wonderful way to celebrate Kathleen, a wonderful mother, grandmother and great-grandmother who inspires us every day with her strength and love for her family."

