

# scottish huntington's association

30 years empowering  
ordinary people to meet  
extra-ordinary challenges

Annual Report  
2018/19



Part of the HDA  
Family Worldwide

# Content

## Scottish Huntington's Association Annual Report 18/19

|   |           |   |
|---|-----------|---|
|    | <b>3</b>  | <b>Report from our Chairperson</b><br>Catherine Martin                          |
|    | <b>4</b>  | <b>Introduction from our Chief Executive</b><br>John Eden                       |
|    | <b>7</b>  | <b>Our impact</b><br>Gordon's story   |
|    | <b>8</b>  | <b>Our impact</b><br>National Care Framework for HD                             |
|    | <b>11</b> | <b>Our impact</b><br>Financial Wellbeing Service                                |
|   | <b>12</b> | <b>Our impact</b><br>Gillian's story  |
|  | <b>13</b> | <b>Our amazing volunteers and donors</b><br>Working together to transform lives |
|  | <b>18</b> | <b>Treasurer's Report:</b><br>2018/19 Statutory Accounts                        |
|  | <b>19</b> | <b>Statement of Financial Activities</b>  |
|  | <b>21</b> | <b>The role of our Board</b><br>What inspires our Trustees                      |
|  | <b>23</b> | <b>Celebrating past, present and future</b><br>A look ahead to 2019/20          |
|  | <b>24</b> | <b>Acknowledgements</b><br>Trusts and Grants 2018/19                            |



## Report from the Chairperson: Catherine Martin

### **The pace at which new drugs that may treat Huntington's disease continues to accelerate.**

This year we have seen WAVE Life Sciences commence their phase one trial and Roche begin their phase three trial for RG6042. I am delighted Scotland continues to play an important role in this work with Dr Ritchie and his team in Glasgow participating in both trials and Professor Miedzybrodzka and her team, in Aberdeen, participating in the Roche trial. It is particularly satisfying SHA played a key role in lobbying NHS Research Scotland and Roche to consider running these trials in Scotland. Our country has an excellent research and development infrastructure, capable clinicians to lead trials, one of the best networks of health and social care in the world, and an engaged and motivated population of people living with HD who have not previously had opportunities to participate in clinical trials.

The next two years we will all wait with bated breath in anticipation of the outcome of the Roche trial, hoping it will fulfil its early promise and become the first treatment that can directly tackle the cause of HD. Equally exciting, newer approaches are just over the Horizon, with UniQure just receiving approval from the Food and Drug Administration in the USA to conduct a phase one trial of their viral vector technology that will use a onetime treatment to deliver a Huntingtin lowering drug. Meanwhile PTC Therapeutics are developing a novel small molecule that can be given by mouth and also aims to reduce levels of the Huntingtins protein. This work is an indication of the progress, effort and ingenuity of patient organisations, the research community, pharmaceutical companies, biotechs, working together in an international collaboration, investing tens of millions of pounds in the search for a treatment. There has never been a time where the HD community has reason for so much hope.

SHA aims to be at the forefront of keeping families informed about all these developments and our new Headline service is an effective way to achieve this. It provides regular social media and email bulletins through a free subscription that will make sure everyone who wants to know the latest research receives it as soon as it becomes available. To back this up, our staff team get regular updates and can answer questions about all aspects of research. We also produce information in our regular SHAre magazine. I talked at this year's family conference about how Scotland is preparing for new treatments (<https://hdscotland.org/headline/questions/cat-martin-how-scotland-is-preparing-for-potential-hd-treatments/>) and there is much work still to be done. We need to understand how the arrival of new treatments might affect people's testing choices. We must help families prepare for difficult decisions about whether treating someone with a Huntingtin lowering therapy might not be in their interests. We must get ready to argue the economic case for giving what are likely to be expensive drugs, by doing health economic studies. We need to work with NHS partners to understand how new drugs can be delivered to those who need them. And while we do all of this, we must ensure that the care of those who may not benefit from treatments is of the highest possible standard.

Scotland remains at the forefront of HD care and as I travel the world, meeting HD families and engaging with clinicians and other patient organisations, I am always proud to represent the charity and I have a clear perspective on the strengths of our organisation as well as things we can continue to improve. What I know for sure is, we have forged an amazing relationship between families and professionals which has been shaped by families and an understanding that they are the experts on living with the condition while also benefiting from a wide range of professional expertise. I don't just mean the staff who deliver services every day, but the Board members who share their knowledge of finance, human resources, communication, and strategy and the back office staff who answer telephones, keep our accounts in such good shape, produce our newsletter and organise conferences. What I know for sure is, together we have created a successful and effective organisation. Our dear friend, Jimmy Pollard, veteran of the HD community said at our 2018 conference, "SHA is the most mission consistent patient organisation in the world." I believe he is right.

*Catherine*



## Introduction from Chief Executive: John Eden



**The vision of Scottish Huntington's Association is to transform the landscape of care for people with Huntington's disease. For thirty years the Scottish HD community has energetically embraced it and no matter whether you speak to branch members, volunteers, staff, trustees, family members, you will hear the same passionate commitment to making that vision a reality.**

The charity has achieved a great deal since it started in 1989 and here are some of our key successes.

The charity has succeeded in creating a governance structure which protects the interests of families and respects their right to determine how the organisation is run, while harnessing the abilities of committed professional staff. It is a potent partnership which has enabled SHA to achieve much.

At the same time, the charity has sought to constantly engage people living with HD in a dialogue about what they need and what SHA can do to support them. This has allowed us to keep a razor sharp focus on what the priorities are. 'Round the Kitchen Table' has been a source of valuable insight and inspiration for the charity in determining how and what services to develop.

The person centred ethos of the organisation flows from our approach to governance and listening to people with HD.

SHA provides high quality services: The HD Specialist Team, The National Youth Service and the Financial Wellbeing Service. Working together, the staff from these teams provide lifeline support. Our HD Specialists are among the most experienced staff in the world, providing specialist care to HD affected families

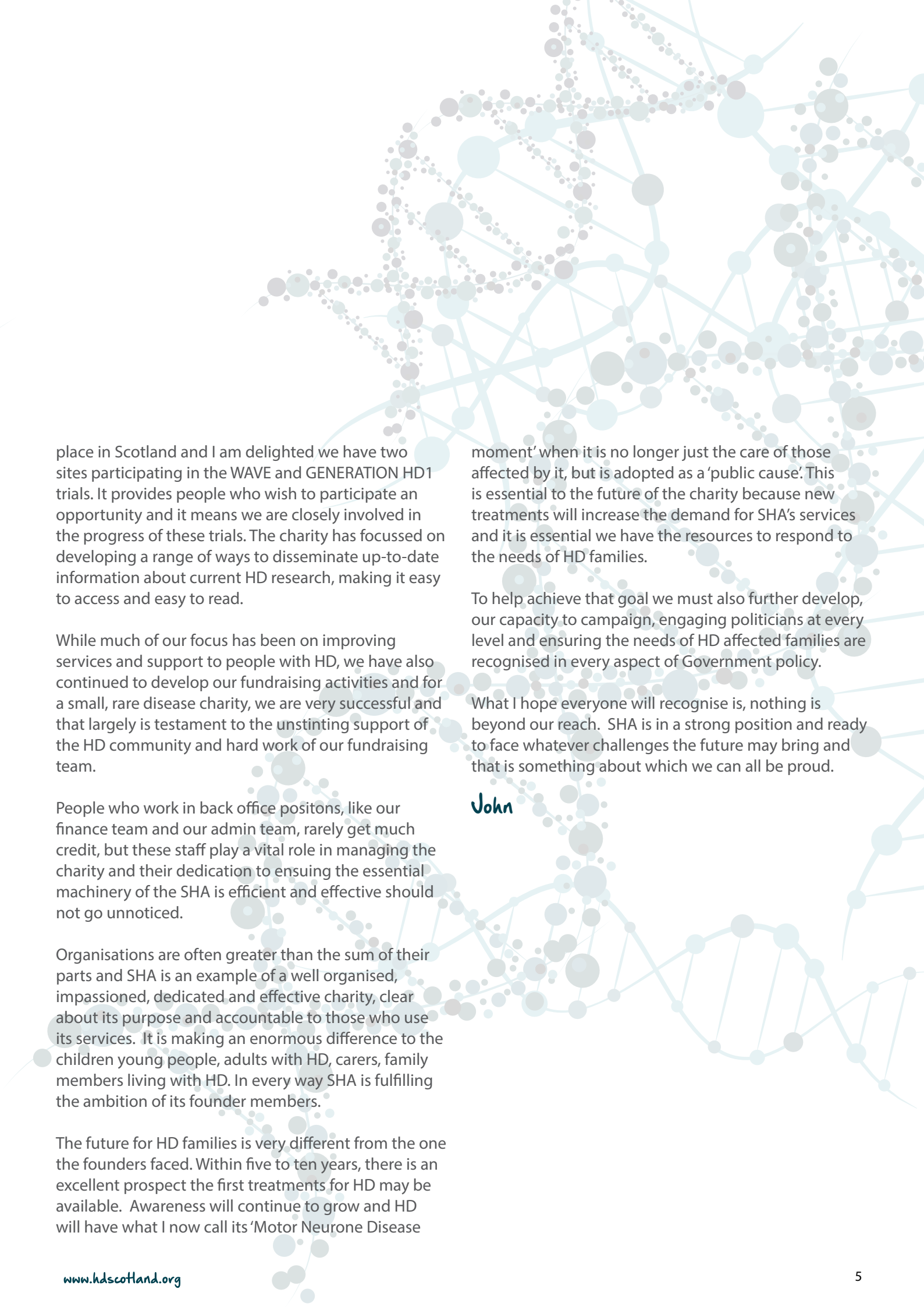
and the same is also true of our National Youth Team. Scotland continues to provide the best resourced and most comprehensive service to young people of any country in the world. We recognise the family impact of HD and our approach also means there is support for every member of a family.

Magnifying the impact these services have is the success SHA has had in integrating with NHS, Health and Social Care Partnership, Local Authority Social Work and other agencies. Our teams are incredibly good at identifying what is available in each area to support each individual family. Nothing exemplifies these close working relationships as much as the joint work that takes place between the charity's staff and the ten HD Clinical Leads in Scotland.

Scotland is the only country to have a National Care Framework funded and backed by Government. This pivotal piece of work is enabling the charity to improve standards of care right across Scotland while also significantly increasing awareness of HD among professionals, civil servants, MSPs and Ministers.

SHA is also tackling the challenge of raising awareness of Huntington's disease and, this year, has employed its first Communications officer, who is already making a significant difference to the volume of engagement about HD with varied audiences. The number of people living with HD who are coming forward to raise awareness is growing year on year and that means SHA can create the platforms they need to get their collective voice heard. I am deeply optimistic about the future of further raising awareness.

In the last five years, the prospect of clinical trials for Huntington's disease has become a reality and the charity has worked hard to lobby for trials to take



place in Scotland and I am delighted we have two sites participating in the WAVE and GENERATION HD1 trials. It provides people who wish to participate an opportunity and it means we are closely involved in the progress of these trials. The charity has focussed on developing a range of ways to disseminate up-to-date information about current HD research, making it easy to access and easy to read.

While much of our focus has been on improving services and support to people with HD, we have also continued to develop our fundraising activities and for a small, rare disease charity, we are very successful and that largely is testament to the unstinting support of the HD community and hard work of our fundraising team.

People who work in back office positions, like our finance team and our admin team, rarely get much credit, but these staff play a vital role in managing the charity and their dedication to ensuring the essential machinery of the SHA is efficient and effective should not go unnoticed.

Organisations are often greater than the sum of their parts and SHA is an example of a well organised, impassioned, dedicated and effective charity, clear about its purpose and accountable to those who use its services. It is making an enormous difference to the children young people, adults with HD, carers, family members living with HD. In every way SHA is fulfilling the ambition of its founder members.

The future for HD families is very different from the one the founders faced. Within five to ten years, there is an excellent prospect the first treatments for HD may be available. Awareness will continue to grow and HD will have what I now call its 'Motor Neurone Disease

moment' when it is no longer just the care of those affected by it, but is adopted as a 'public cause'. This is essential to the future of the charity because new treatments will increase the demand for SHA's services and it is essential we have the resources to respond to the needs of HD families.

To help achieve that goal we must also further develop, our capacity to campaign, engaging politicians at every level and ensuring the needs of HD affected families are recognised in every aspect of Government policy.

What I hope everyone will recognise is, nothing is beyond our reach. SHA is in a strong position and ready to face whatever challenges the future may bring and that is something about which we can all be proud.

John





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# Gordon's Story

**Until February 2015, Gordon was 'living the dream'. He had a successful job, owned his own home, liked to drive fast cars and was in a loving relationship. His four children, from a previous marriage, were doing relatively well.**

While Gordon knew about his family history of HD, and that his father had committed suicide, he had not really thought about genetic testing. He was referred to an HD specialist in January 2015, and five months later Gordon disclosed that he wasn't being totally honest about his situation. Gordon began to describe memory problems and the difficulties he was having in the workplace; he was becoming angry and felt that his personality was changing.

Over the next three years, Gordon's health deteriorated and his life changed dramatically. He didn't feel ready to be tested until 2017 and in January 2018 received a positive result for the HD gene. By then, Gordon had spent time in general hospital and psychiatric wards recovering from three suicide attempts in one year.

He had developed swallowing problems and occasional falling and loss of balance, and although Gordon presented as a very capable man, he was assessed as not having capacity for his wellbeing or finances. His relationship had broken up and his mother had moved into his home as his primary care giver.

Over the past three years, Gordon has continued to meet weekly or monthly with his HD specialist whose role is to assess need, co-ordinate care, train, educate and advocate on behalf of HD families. They are employed through joint funding from NHS Boards, Health & Social Care Partnerships and the Scottish Huntington's Association.

Gordon's HD specialist has played a vital role in ensuring the right framework of information and support from SHA and healthcare providers is in place for him and his family. As a result, Gordon has been granted short-term housing support and is now working with the community occupational therapy team to look at opportunities and assess his ability at home. Social services have agreed a support package and neuropsychological testing has begun.

Gordon's youngest child is now engaged with SHAYp, the charity's youth service for young people growing up in HD families, and the SHA Financial Wellbeing team will explore the early release of pensions and maximised benefits on Gordon's behalf. Family members are also turning to the charity for support and information about the impact of Huntington's disease.



# National Care Framework for HD

**Having launched the National Care Framework for HD in 2017/18, we have advanced the roll-out of localised versions while securing enhanced support from the Scottish Government.**

The Scottish Government's National Action Plan for Neurological Conditions now includes a recommendation to consider the HD Care Framework as a model to inform neurological care more widely.

This ringing endorsement has been reinforced further with funding for an additional year to commence this work and finalise the localisation process.

Dr John Harden, National Clinical Lead for Quality and Safety at the Scottish Government, said: "We are fully committed to backing this project until its completion. Not only does it stand to benefit families impacted by Huntington's disease, we are hopeful it could in due course be used as a model to help people affected by other neurological and long term conditions."

By the end of 2017/18 SHA had launched the national and first localised framework in Ayrshire and Arran. During 2018/19 we delivered successful launches in Fife, Grampian, Lanarkshire and Lothian, with Greater Glasgow & Clyde published and on course to be launched in the autumn of 2019.

Frameworks for Dumfries and Galloway, Forth Valley, Highland, Tayside and Borders are on course to be finalised during 2019/20, ensuring that all mainland NHS Board areas will have their own Framework in place.

This work is underpinned by a commitment to influence decision-making and policy development on behalf of the HD community, and further key achievements include the appointment of an HD Clinical Lead by one NHS Board and the safeguarding of an HD Clinical Lead role by another.

Engagement with a Health and Social Care Partnership helped to reverse its decision to cut funding for HD specialist services, while another decided to appoint an HD Specialist and run clinics for the first time.

To build on this local and national impact, the Framework was presented to the 2018 European Huntington's Disease Network Conference in Vienna. An abstract was subsequently published in the Journal of Neurology, Neurosurgery & Psychiatry. On the back of this we have shared our model with HD teams in Norway, New Zealand, USA, Republic of Ireland and Wales.

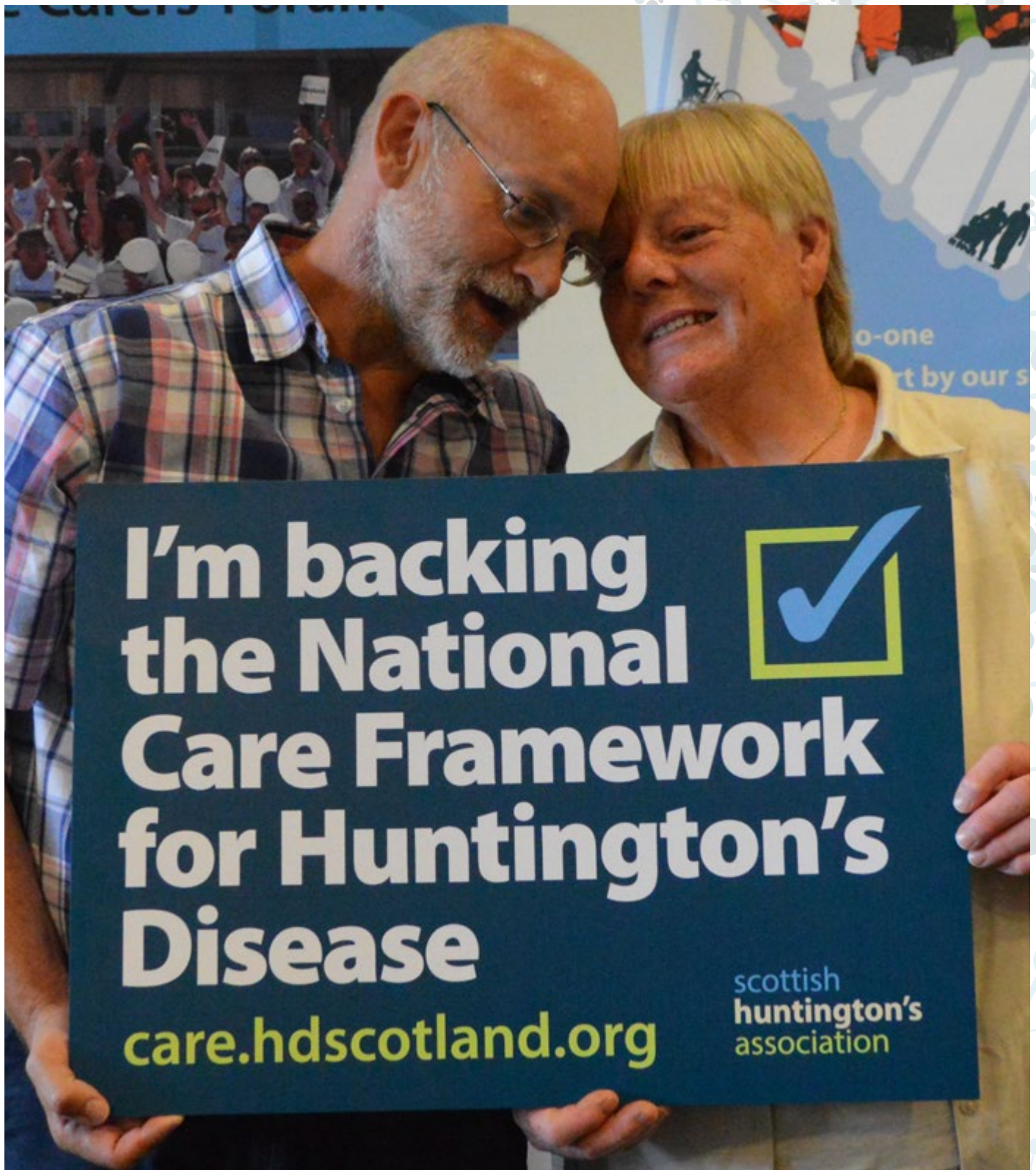
The National and local Frameworks can be viewed at: [care.hdscotland.org](http://care.hdscotland.org)

Lothian Framework, launched at Edinburgh University's Chancellor's Building, Royal Infirmary of Edinburgh.  
*Developing the Framework has been an enormous task, but the result is an extremely comprehensive and easy to use tool that has the ability to transform care and support for families. I would encourage anyone with an interest in the condition to make use of this excellent Framework.*  
Dr Alasdair FitzGerald, Clinical Lead Consultant in Neurorehabilitation, NHS Lothian

Grampian Framework, launched at Aberdeen University's Suttie Centre, Aberdeen Royal Infirmary  
*The National Framework has secured widespread support throughout Scotland and it's great to see Grampian being one of the first to develop its own localised version. I look forward to working with SHA and local HD staff to raise awareness of this terrible condition and improve support for those impacted by it through the use of this groundbreaking Framework.*  
Lewis Macdonald MSP, Convener of the Scottish Parliament's Health & Sport Committee

Lanarkshire Framework, launched at NHS Lanarkshire's HQ, Kirklands Hospital  
*This is a great day for the whole of Lanarkshire. I pay tribute to all involved in the development of the Framework and look forward to promoting it to elected members and hearing of its positive impact for Huntington's disease families in the area.*  
Provost Jean Jones, North Lanarkshire





Fife Framework, launched at Victoria Hospital, Kirkcaldy

*We are very fortunate to have a Lead Clinician for HD, dedicated HD Specialists, youth workers and specialist financial advisers plus a whole team working round about them to deliver the care and support that families with Huntington's disease require. In launching the Framework we hope to kick start further improvements and lead the way for providers throughout Scotland to follow.*

Nicky Connor, Associate Director of Nursing for Fife Health & Social Care Partnership





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# The Financial Wellbeing Service

**The Financial Wellbeing Service has extended its reach and influence as it continues to support families in Scotland who are facing hardship as a result of Huntington's disease.**

There has been much to report from the past 12 months including, as we went to press, recording that since 2015 more than £3million in extra income has been secured for around 750 people affected by HD in Scotland.

Two-thirds of families affected by HD live on income below the national average and one in three families lives below the poverty line. The debilitating nature of the disease often means that people's working lives are cut short, and carers may also need to give up work to meet the growing needs of family members.

It was against this background that the Financial Wellbeing Service was established four years ago to advise on benefits and the complex world of personal and family financial planning. In that relatively short period of time, the service has come to be regarded by the HD community as a lifeline resource and its impact has been recognised further with endorsements from major funders.

Having come to end of its initial three-year funding partnership with Big Lottery Fund in 2017/18, SHA moved forward in 2018/19 to secure a further £340,000 to operate the Financial Wellbeing Service for another

three years. We are thankful to the Henry Smith Charity (£178,500); Robertson Trust (£106,500); R S MacDonald Charitable Trust (£36,000); Zurich Insurance (£15,000); and the Yorkshire & Clydesdale Bank Foundation (£5,000).

Committed to providing the best guidance for clients, the Financial Wellbeing Service has progressed its submission for Scottish National Standards for Advice and Information Providers accreditation, the Scottish Government-backed endorsement that can only be achieved by organisations that demonstrate a high quality of advice.

The service has completed the first stage – peer review – of the comprehensive accreditation process with all case studies deemed to be 100% compliant with a view to progressing to the audit and full accreditation in 2019/20.

It is also noted that while the number of new clients has reduced in 2018/19 compared with previous years, there has been a significant increase in the number of returning clients seeking further support and advice. This is testament to the strong and trusting relationships that have been established and the expertise of the FWS team. It is also an indicator of the impact of HD on individuals and families, the changes of circumstance over time and the complex support needs that can develop.

## What our clients say:

*If we hadn't had the help, we would have had to sell our home. We are struggling now, but it would have been more difficult if we hadn't got the benefit that we are getting, and we wouldn't have known about them. I felt like throwing the towel in a couple of weeks ago, the PIP folk were hassling me to fill in forms to deal with the points not made at the assessment about my fractured pelvis. One phone call from Katrina [Financial Wellbeing Officer] and it stopped.*  
(Lorraine, 55-64, Carer)

*Before, I had a big black cloud, now Jo [Senior Financial Wellbeing Officer] is there sorting it out. I am definitely less anxious because she is there. Before I would just put stuff away and not deal with it. I knew I would have to deal with it, I'd just put it off because I couldn't face it.*

*It's definitely helped with the kids as well. My relationship with my son is very problematic, he's taken his dad's illness very badly. We aren't communicating very well, Jo's dealing with him and our relationship has got better. She's sorting him out with money for college.*  
(Sarah, 45-54, Carer)



# Gillian's Story



**I knew nothing about Huntington's disease (HD) before my Mum was diagnosed in 1999. I was 30 then and it was a massive blow to me and my family. Mum already had very complex symptoms, so discovering that it was relentlessly progressive, fatal and that there was a 50 per cent chance of my brother, sister and I developing it too, was terrifying.**

Caring for my Mum and watching her deteriorate and struggle, knowing I may develop HD too, was a lot to deal with. SHA helped us to find the support that my Mum needed and I had counselling and began to consider getting tested – however the counselling helped me decide that I wasn't quite ready to know at that point.

After my Mum died in 2001, I found myself taking a step back and just quietly getting on with life. Knowing that SHA were still there to support me any time I needed it was reassuring.

But I did struggle with the uncertainty of not knowing, and in 2011 I had the test and discovered that I have the faulty gene that means I will go on to develop HD.

I was as prepared as I could be by then, and decided to not to waste precious time worrying about the disease. Instead I compiled a bucket list, stepped out of my comfort zone and started really living. I try to make the most of every moment and have taken part in two Firewalks to raise money for SHA. I've been on my first motorbike ride and visited Australia. Later this year I am planning to take on my biggest challenge yet – a fundraising skydive.

In 2016 I became involved in research. It helps me to know that I am doing something positive to help others and to potentially help scientists find better treatments or even a cure.

For me, despite the bad test result, knowing what's ahead for me is better than living with the uncertainty. I am so grateful for the support of my friends and family and the support of SHA. It really is a lifeline for people and families affected by HD.



## Thank you to our amazing volunteers and donors

The creativity and energy of our supporters continues to amaze and inspire us, and this year we are happy to report a record number of fundraising events, an increase in the number of supporters, and strengthened relationships with funders such as corporates, trusts and foundations.

From our earliest days as an Association, we have grown to deliver impact on a national scale thanks to the grassroots support that remains at the very heart of all that we do. We rely on the commitment of our volunteers and fundraisers in Scotland who make possible the delivery of SHA's vital services, and we are thankful to all those who contribute so generously to support our work.

As you read through the next few pages, you will find out more about how an army of volunteers and donors has worked in partnership with our small team of professional fundraisers to ensure that SHA is able to progress its work to transform the landscape of care for people impacted by HD.

Giving to SHA helps to make sure that families receive the right support at the right time in the right way. Donations

are used to support individuals and families through a network of specialist services, including our world-leading youth project for young people growing up in HD families.

Fundraising this past year has supported the provision of HD specialists, the development of the world's first care framework and delivery of bespoke training opportunities for SHA staff, carers, and health and social care professionals. It has also sustained the Financial Wellbeing Service, a lifeline resource for families facing financial hardship as a result of HD.

We are committed to good stewardship, ensuring that we maximise the impact of every donation entrusted to us. On behalf of SHA, we offer our sincere thanks to everyone who has supported us by organising or attending an event, dropping a few coins into a collection bucket or picking up a leaflet to find out more about our work.

It is our privilege to be part of this amazing community of people, as we work together to transform the lives of families impacted by HD.



## Highlights of our fundraising year – at a glance

In 2018/19, £160,411 was raised through community fundraising, thanks to the amazing efforts of donors, volunteer fundraisers, their families and friends.

### Fundraising events and challenges



Our growing network of volunteer fundraisers have organised events up and down the country. Between them, they collected a remarkable **£79,469**, while SHA-organised challenges raised a further **£72,281**. The **£151,750** combined total is a wonderful testament to the expertise, passion and partnership working of volunteers and our small team of professional fundraisers.

### In-Memoriam and Legacy gifts

It is especially humbling to hear from families who chose to support SHA during the most difficult of times.

Legacy and In-Memoriam Gifts are given on behalf of a loved one, and as we went to print, news had just been received that a **£50,000** legacy will help fund the Association's work in 2019/20.

We promise to honour the legacy of loved ones and use all donations to make life better for HD families.

### Bag packing, bucket collections and collection cans

Thank you to the volunteers and organisations who hosted collections on our behalf. In total last year, we received an amazing £5,419.83 from bag packing, bucket collections and collection cans.

**St Mirren Football Club, Asda Bearsden, Asda Linwood, Glasgow Airport, Edinburgh Airport, Tesco Elgin**



### Corporate supporters

Our corporate supporters gave a fantastic **£16,000** raised through charity partnerships, workplace fundraising, employee charity nominations, fantastic events and a Tesco Bags for Help Grant. We are grateful to the business community and workforces across Scotland for joining with us to fund services and raise awareness by hosting talks and events.

**Technip FMC**  
**Barclays Bank**  
**Order of the Easter Star, Strathmore Chapter**  
**Zurich Community Trust**  
**Tesco Bags of Help Grant**  
**Moray Council**  
**Duthie and Summers**  
**Jobcentre PLUS Leith**

**Aberdeen Referees Association**  
**Inverallochy Golf Club**  
**Asda Bearsden**  
**Golden Charter**  
**Waitrose - Glasgow Byres Road**  
**OOTES Chap No134**  
**Lycetts**  
**Decora DIY store**  
**COOP community champion grant**





## Individual Giving

We received more than **£58,000** last year from single donations, regular gifts and players of our Lucky Lotto.

There was great enthusiasm for our Jam Jar Pledge, with donors filling up glass jars with coins. Supporters loved this campaign as it showed how small change can create a big difference in the lives of HD families.

Lucky Lotto players snapped up our 'buy a friend a ticket' gift offer in the lead up to Christmas, helping to attract supporters who were new to SHA and Lucky Lotto.

Christmas 2018 was certainly a time of goodwill – during December there was a significant increase in the number and value of donations and we are grateful to all those who remembered SHA during this special season of giving.

The commitment of our Lucky Lotto players and regular givers, whose donations come in every month, helps us to look to the future with confidence when planning and allocating resources to vital services.

## SHA-led events and experiences

This year's calendar of SHA-led fundraising events has been more exciting than ever before.

People took to the skies at our annual Skydive then again at our new Wing Walk event.

The annual Zipwire moved to Aviemore with a challenge to brave 14 ziplines in a row in the aptly renamed 'Ultimate Zipwire Challenge'.

Teams of white water rafters braved the river rapids and cyclists pedalled their way to fundraising glory by taking part in our Arran Hike and Bike and annual Ride the Clyde events.

A particular highlight was The Great Wall Discovery challenge, during which Bruce, Rocio, Sharon and Stacey walked the Great Wall of China. Incredible effort was put in to the training, fundraising and, of course, the six-day hike.

We loved meeting supporters at SHA-organised events, including Dancing Through The Decades, The BIG Sing, a Wacky Race Night, the Edinburgh Fringe comedy evening and our ever-popular Ceilidh. Thanks to everyone who came along to lend their support and please keep reaching out to us to share your ideas and invite us along.



## Trusts and Grants



It has been a very successful year with more than £220,000 raised from charitable trusts and foundations, a 36 per cent increase on the previous year.

A highlight was receiving funding to continue our Financial Wellbeing Service for a further three years. We are extremely grateful to the following trusts who committed their support to this vital service:

- The Henry Smith Charity
- The Robertson Trust,
- The R S MacDonald Charitable Trust
- The Yorkshire & Clydesdale Bank Foundation.

SHA's youth service delivered another fantastic five-day Summer Camp thanks to the generous support of Shared Care Scotland Creative Breaks, the D'Oyle Carte Charitable Trust and the Happy Days Charity.

The annual camp gives young people the chance to grow in confidence and develop, while receiving support on issues relating to HD and being a young carer. This year it was at full capacity, with 51 young people attending, a mark of the camp's popularity and importance amongst the HD community in Scotland.

At the beginning of 2019 we launched our You, Me and HD Campaign following a generous donation of £5,000 from the James Tudor Foundation.

The campaign aims to recruit thirty volunteers who will reach out to community groups in their local area to raise awareness of HD by sharing their personal stories of living with the condition.

*A full list of the charitable trusts and foundations which supported Scottish Huntington's Association in 2018/19 can be found on page 24.*







## Treasurer's Report: 2018/19 Statutory Accounts

**The financial performance of the charity in 2018/19 remains solid. The Statement of Financial Activities shows income received in the year of £1,567,142 with expenditure of £1,523,070. There was some improvement in the charity's pension liabilities which released £59,000 from the restricted pension liability to unrestricted reserves. The net effect is the charity closed the financial year with a surplus of £82,744.**

The Board is committed to an investment strategy to make best use of reserves. Investment portfolio through Aviva increased by £2928 for this year and continues to be monitored six monthly and other investments contributed to £3678 in this year.

The charity's total reserves now stand at £660,367 with unrestricted reserves of £453,367. This year the Board of Trustees elected to review the reserves policy. Until this year, the Board had set the policy at six months of annual income, but after reviewing the risks, decided four months of reserves was more appropriate. This decision takes account of the level of reserves required to protect services, while ensuring reserve levels are not so high, potential funders are deterred from supporting the charity. The current unrestricted reserve is 83% of our annual income.

The charity secures income from a wide range of sources: Fundraising (30%), Local Authorities (26%), Large Grants (13%), NHS (17%), Scottish Government (12%), EHDN (2%). There are forty main funders of the charity's activities which, because SHA is not overly dependent on one funder, creates a significant degree of financial resilience.

Huntington's Disease Specialist services in eight locations across Scotland account for the greatest proportion of expenditure (47%), next, the national youth service (16%) and the Financial Wellbeing Service (6%), and another 18% is spent on a wide range of activities that include the annual carers conference, family conference, welfare grants, short break fund grants and information services like the web site. 13% of income is spend on Fundraising and 'back office services' e.g. HR and Financial control. This profile continues to demonstrate SHA is spending the greatest proportion of its resources on services that directly benefit families while operating a lean, but effective infrastructure which ensures the prudent management of the charity.

The full accounts of the charity show that this year SHA invested £50,000 in the Financial Wellbeing Service to enable it to continue to operate for a short period while transitioning from the Big Lottery Fund funding to the current funding arrangements with The Henry Smith Charity, Robertson's Trust, and RS MacDonald Charitable Trust. This represents both a belief in the excellent performance of this team, who have generated £3.2m income for Scottish families and an understanding that financial pressures often loom large and can make life with HD much more difficult.

Throughout the year we have met with statutory funders to discuss levels of funding for each of our HD Specialist services. The trustees are pleased to note significant progress in the funding of the HD Specialist services and in particular that the management team secured a tender for the Glasgow service, increasing total funding from £143,807 to £179,500 of operational costs (a net gain of £35,695). In addition, funding from Edinburgh City Council for 2019/20 has been increased from £26,258 to £32,452 (a net gain of £6,194). Together both increases represent a significant improvement in funding for the HD Specialist service of £41,887. In the next financial year, this will reduce the need for the charity to transfer unrestricted income to these services.

In conclusion, SHA continues to operate on a robust financial basis in what remains a challenging financial environment and indeed there is a real sense in which the charity is delivering excellent value for money, efficient and effective services.

## Finance

### Statement of Financial Activities (incorporating Income and Expenditure Account) For the Year ended 31 March 2019

|   | Notes | Unrestricted funds<br>£ | Restricted funds<br>£ | 2019<br>Total Funds<br>£ | 2018<br>Total Funds<br>£ |
|---|-------|-------------------------|-----------------------|--------------------------|--------------------------|
| <b>Income and endowments from</b>                                       |       |                         |                       |                          |                          |
| Donations and legacies  | 3     | 176,147                 | 13,963                | 190,110                  | 197,701                  |
| Charitable activities:  | 4     | 58,344                  | 1,215,341             | 1,273,685                | 1,288,600                |
| Other trading activities  | 5     | 77,948                  | 525                   | 78,473                   | 57,051                   |
| Investment income   | 6     | 3,678                   | -                     | 3,678                    | 2,113                    |
| Branch income   |       | 20,868                  | 328                   | 21,196                   | 18,063                   |
| <b>Total income</b>   |       | <b>336,985</b>          | <b>1,230,157</b>      | <b>1,567,142</b>         | <b>1,563,528</b>         |
| <b>Expenditure on</b>   |       |                         |                       |                          |                          |
| Raising funds   | 7     | 205,778                 | -                     | 205,778                  | 215,856                  |
| Charitable activities   | 8     | -                       | 1,296,643             | 1,296,643                | 1,302,262                |
| Other (including Branches)  |       | 20,649                  | -                     | 20,649                   | 12,960                   |
| <b>Total expenditure</b>  |       | <b>226,427</b>          | <b>1,296,643</b>      | <b>1,523,070</b>         | <b>1,531,078</b>         |
| <b>Net income/(expenditure) before gains on fixed asset investments</b> |       | <b>110,558</b>          | <b>(66,486)</b>       | <b>44,072</b>            | <b>32,450</b>            |
| <b>Gains/(loss) on fixed asset investments</b>                          | 17    | <b>(3,328)</b>          | <b>-</b>              | <b>(3,328)</b>           | <b>688</b>               |
| Net income before transfers   |       | 107,230                 | (66,486)              | 40,744                   | 33,138                   |
| Transfers   | 23    | (66,986)                | 66,986                | -                        | -                        |
| <b>Net income / (expenditure)</b>                                       |       | <b>40,244</b>           | <b>500</b>            | <b>40,744</b>            | <b>33,138</b>            |
| <b>Other recognised gains and losses:</b>                               |       |                         |                       |                          |                          |
| Actuarial gain on defined benefit pension scheme                        | 21    | 42,000                  | -                     | 42,000                   | 4,000                    |
| <b>Net movement in funds</b>  |       | <b>82,244</b>           | <b>500</b>            | <b>82,744</b>            | <b>37,138</b>            |
| <b>Reconciliation of funds</b>  |       |                         |                       |                          |                          |
| <b>Total funds brought forward</b>                                      | 23    | <b>350,958</b>          | <b>19,665</b>         | <b>370,623</b>           | <b>333,485</b>           |
| <b>Total funds carried forward</b>                                      |       | <b>433,202</b>          | <b>20,165</b>         | <b>453,367</b>           | <b>370,623</b>           |

The notes form part of these financial statements.

All activities are continuing. All gains and losses in 2019 and 2018 are shown above.

## Finance

### Statement of Financial Activities (incorporating Income and Expenditure Account) For the Year ended 31 March 2019

|   | Notes | 2019<br>£        | 2018<br>£        |
|---|-------|------------------|------------------|
| <b>Fixed assets</b>                             |       |                  |                  |
| Tangible assets                                 | 16    | -                | -                |
| Investments                                     | 17    | 14,270           | 17,598           |
|   |       | <b>14,270</b>    | <b>17,598</b>    |
| <b>Current assets</b>                           |       |                  |                  |
| Debtors   | 18    | 15,600           | 82,110           |
| Investment portfolio (Aviva)                    |       | 120,584          | 117,656          |
| Cash at bank and in hand                        |       | 679,960          | 597,211          |
|   |       | <b>816,144</b>   | <b>796,977</b>   |
| <b>Creditors:</b>                               |       |                  |                  |
| <b>Amounts falling due within one year</b>      | 19    | <b>(170,047)</b> | <b>(177,952)</b> |
| <b>Net current assets</b>                       |       | <b>646,097</b>   | <b>619,025</b>   |
| <b>Net assets excluding pension liability</b>   |       | <b>660,367</b>   | <b>636,623</b>   |
| <b>Defined benefit pension scheme liability</b> | 21    | <b>(207,000)</b> | <b>(266,000)</b> |
| <b>Total net assets</b>                         |       | <b>453,367</b>   | <b>370,623</b>   |
| <b>The funds of the charity:</b>                |       |                  |                  |
| Unrestricted funds:                             |       |                  |                  |
| General   |       | 605,402          | 590,678          |
| Designated                                      |       | 34,800           | 26,280           |
| Pension reserve                                 |       | (207,000)        | (266,000)        |
|   |       | 433,202          | 350,958          |
| Restricted funds                                |       | 20,165           | 19,665           |
| <b>Total charity funds</b>                      | 23    | <b>453,367</b>   | <b>370,623</b>   |

The financial statements were approved by the Board of Trustees on 28 September 2019



# Trustees

SHA is supported by a Board of voluntary trustees, who share our determination to transform the landscape of care for HD families. Their governance ensures that SHA's goals, vision and values – the principles upon which the charity was founded by Scottish families – underpin all our work and meet the high standards expected by donors, volunteers and the HD community we serve.

It is with sincere gratitude that we send best wishes to Philip Fox and Josephine Saunders, who have stepped down as trustees, while welcoming Lisa Morton, a communications specialist with the NHS. Lisa adds to the diverse range of expertise, knowledge and skills of the Board, which also includes, importantly, members from HD families who bring invaluable insight.

## Our Trustees

### **Catherine Martin, Chair of SHA/Family Member/Youth Work**

*"I'm determined to try to remove the stigma and improve understanding, including the affect HD has on the person and their whole family. I would like to see greater equality of services for HD families across the country. It's a complex condition and we need to be thinking about how we use existing resources more creatively."*

### **Carolyn Craig, Family Member/Estate Agency Business Owner, Educator and Trainer**

*"I'm most proud of our support and communication with families. We're the only charity to help the whole family. We support young people who are coping within a family, often caring for an affected family member while being at risk of HD themselves, and we're at the forefront of innovative services, including the national care framework and welfare support. For a small country, Scotland and the work of SHA seem to be well known in the HD world."*

### **Dina De Sousa, Family Member/ Research Assistant (Retired) /Board Member European Huntington's Association**

*"SHA is celebrating its 30th anniversary and worldwide it is one of the strongest associations. It's a big accomplishment, and I'm sure there's more great work in helping families to come. The care framework is such an important document, the first of its kind in the world with the backing of the Scottish government and a crucial first step in the long road to providing equal access to care for Scottish HD affected individuals and families no matter where they live."*

### **Chris Mosedale, Application Specialist in Cell and Gene Therapies**

*"SHA delivers highly-specialised support to everybody affected by HD, including families and caregivers. Acting as a stronger voice with the NHS is particularly vital, especially where services differ across regions. Finally, being part of the CareHD Framework, a European-wide collaboration to deliver tele-healthcare to patients with HD and other diseases, is a point of pride in the wider, global role of SHA."*

### **Melanie Hill, Human Resources**

*"It's a privilege to give my time to a really inspiring charity. Looking ahead, gene trials make the future scary and exciting in equal measure. SHA is innovative in the services it*

*provides, for example financial wellbeing support, and I see more innovations in the future as we listen to the needs of the families we serve."*

### **Lisa Morton, Communications and Stakeholder Engagement**

*"With my four children needing less of my time, I began looking for a volunteering opportunity where I could share my skills as a professional communicator with a charity that might in some small way benefit from what I could give. I've been extremely impressed by the dedication not only of the Board members, but also by the team of staff who go above and beyond their daily duties in order to provide support."*

### **Stan Pearson, Family Member/Finance**

*"Our engagement through SHA allows us to share best practice and keep abreast of developments. It also provides a formal and informal network for research and resource at many levels that would be difficult to achieve at a national level."*

### **Dr Marie Short MBE, Family Member/Regulatory Affairs Associate Director (Retired)**

*"SHA has the expertise of families who are actively experiencing what it's like to live with HD. I see lots of changes as we navigate through the development of treatments. And, I hope excitement, as it becomes reality for families. What am I most proud of? The international reputation SHA has earned."*

### **Denise Lavelle, SHA Treasurer/Accounts and Audit**

*"Having gained a deeper understanding about the impact of HD, I hope that in some small way I'm helping families to access the help and support they need. SHA is in a strong position to provide outstanding care in Scotland, leading the way in the UK and around the world. Its staff and volunteers are so committed and are key to the success of the organisation."*

### **Alison Gordon, Clinical Lead for HD, NHS Lanarkshire**

*Alison is the Clinical Lead for Huntington's disease in NHS Lanarkshire and is a practising Psychiatrist. Alison brings clinical expertise in the management of HD to the Trustee group.*







# **30<sup>th</sup>** **scottish** **huntington's** **association**

**It is with real optimism that we enter 2019/20, during which we will mark our 30th Anniversary with a series of activities that reflects on the past, celebrates the present and looks forward to the future.**

Scottish Huntington's Association (SHA) was founded in 1989 after members of the HD community in Scotland joined forces to campaign for improved services and support for individuals and families. Now a national charity with global influence, SHA delivers a network of HD-specific services for individuals and families across the country, including nine HD specialists and a nationwide Financial Wellbeing Service.

We are recognised for our groundbreaking approach to young people growing up in HD families, while our determination to ensure that every person impacted by HD receives the best possible care led to the development of the world's first National Care Framework for Huntington's disease.

However, we remain mindful that HD families continue to face extraordinary challenges each day, and there is so much more to do as we work with those affected by this devastating condition.

SHA's fundraising team and an army of volunteers are ready to take our 30th Anniversary message into cities, towns and villages across Scotland, generating awareness and income that will safeguard and enhance vital services.

They will be supported in 2019/20 by the recruitment of up to 30 You, Me and HD Ambassadors, specially trained volunteers who will reach out to clubs, organisations and businesses to share their own experiences and build support for our work.

We will continue to lobby health providers and influencers for local, tailored healthcare and service provision, and are on schedule to publish local HD Care Frameworks for every mainland area in Scotland by the beginning of 2020. Greater Glasgow and Clyde, Forth Valley, Highland and Dumfries & Galloway are advancing with a view to being rolled out from the summer of 2019, building on the success of the regional versions already in place in Fife, Lanarkshire, Ayrshire and Arran, Grampian and Lothian.

Families will always be the guide for all that we do, and never more so during this special year. We will continue to work in partnership, supporting with celebration events, including the installation of commemorative benches at sites in Lothian, Tayside and Fife, and look forward to coming together at our special two-day 30th Anniversary Family Conference towards the end in November 2019.

## Acknowledgements

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### **We are grateful to the following Trusts and Foundations for their support in 2018/19:**

- Allander Youth Activities Charitable Trust
- Anton Jurgens Charitable Trust
- Big Lottery Fund Awards For All Scotland
- Carers Trust
- Chance to Flourish
- Colin Grant Charitable Trust
- Crerar Hotels Trust
- Dalziel Charitable Trust
- Happy Days Charity
- I B B Trust
- J T H Charitable Trust
- Jeans for Genes
- John Watson's Trust
- Louis and Marion Ferrar Charitable Trust
- Margaret Douglas Charitable Trust
- MEB Charitable Trust
- Miss E C Hendry Charitable Trust
- Miss I F Harvey's Charitable Trust
- Netherdale Charitable Trust
- Northwood Charitable Trust
- Ponton House Trust
- R K T Harris Charitable Trust
- The Alexander Moncur Trust
- R S MacDonald Charitable Trust
- The D'Oyly Carte Charitable Trust
- The Gannochy Trust
- The Gunter Charitable Trust
- The Hedley Foundation
- The Hugh Fraser Foundation
- The John K Young Endowment Fund
- The Margaret Murdoch Charitable Trust
- The Mugdock Children's Trust
- The Nancie Massey Charitable Trust
- Robert O Curle Charitable Trust
- Row Fogo Charitable Trust
- Rozelle Charitable Trust
- Shared Care Scotland Creative Breaks
- Silverhill Trust
- Sir Iain Stewart Foundation
- Souter Charitable Trust
- St. Katharine's Fund
- Sylvia Aitken Charitable Trust
- Tay Charitable Trust
- The Appletree Trust
- The Broughton Charitable Trust
- The Cruden Foundation
- The Gamma Trust
- The Gannochy Trust
- The Gaul Trust
- The Graham Trust
- The Grand Lodge of Ancient Free and Accepted Masons of Scotland
- The Hoover Foundation
- The J & J R Wilson Trust
- The James Wood Bequest Fund
- The Leng Charitable Trust
- The Martin Connell Charitable Trust
- The Merchants' House of Glasgow
- The Mickel Fund
- The New Maclay Murray & Spens Charitable Trust
- The Russell Trust
- The Ryvoan Trust
- The Sir Jules Thorn Charitable Trust
- The Stuart Gordon Fund
- The Templeton Goodwill Trust
- The W A Cargill Fund
- Yorkshire & Clydesdale Bank Foundation



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## Local Offices

| LOCALE     | ADDRESS   | LOCALE     | ADDRESS   |
|------------|---|------------|---|
| <b>AYR</b> | Scottish Huntington's Association (Ayrshire)<br>Douglas Grant Rehabilitation Centre<br>Ayrshire Central Hospital<br>Kilwinning Road<br>IRVINE<br>KA12 8SS | <b>HIG</b> | Scottish Huntington's Association (Highland)<br>Recreation Hall Building<br>Raigmore Hospital<br>INVERNESS<br>IV2 3UJ                               |
| <b>EDI</b> | Scottish Huntington's Association<br>Financial Wellbeing Service<br>Citizen's Advice Bureau<br>23 Dalmeny Street<br>EDINBURGH<br>EH6 8PG                  | <b>LAN</b> | Scottish Huntington's Association (Lanarkshire)<br>Hunter Community Health Centre (4th Floor)<br>Andrew Street<br>EAST KILBRIDE<br>G74 1AD          |
| <b>FIF</b> | Scottish Huntington's Association (Fife)<br>Whyteman's Brae Hospital<br>Whyteman's Brae<br>KIRKCALDY<br>KY1 2ND   | <b>LOT</b> | Scottish Huntington's Association (Lothian)<br>Clinical Genetics Department<br>Western General Hospital<br>Crewe Road South<br>EDINBURGH<br>EH4 2XU |
| <b>GLA</b> | Scottish Huntington's Association (Glasgow / SHAYP)<br>Unit 2A<br>David Dale Business Centre<br>159 Broad Street<br>GLASGOW<br>G40 2QR                    | <b>NAT</b> | Scottish Huntington's Association National Office<br>Business First<br>Burnbrae Road, Linwood Industrial Estate<br>PAISLEY<br>PA3 3FP               |
| <b>GRA</b> | Scottish Huntington's Association (Grampian)<br>Clinical Genetics Centre<br>Ashgrove House (Ground Floor)<br>Foresterhill<br>ABERDEEN<br>AB25 2ZA         | <b>TAY</b> | Scottish Huntington's Association (Tayside & Angus)<br>East Day Home (Room 3010)<br>Kings Cross Hospital<br>Clelington Road<br>DUNDEE<br>DD3 8EA    |

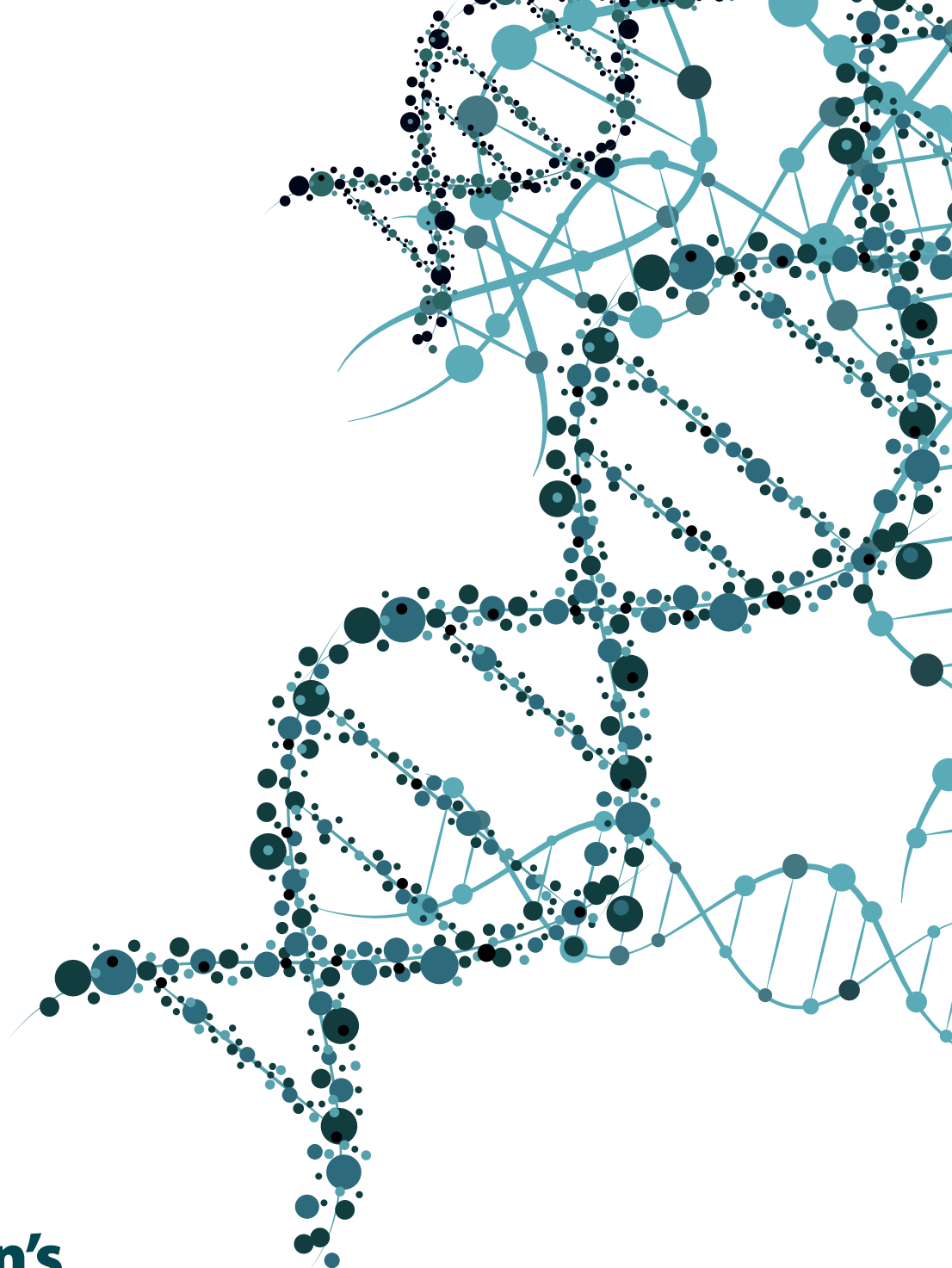


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