

scottish  
huntington's  
association

# 2016/17 Annual Report

*Empowering ordinary people to meet extra-ordinary challenges*



Part of the HDA  
Family Worldwide



# Contents



Personal message from the Chair	3
CEO's report	4
Scottish Huntington's Association Youth Project	5
National Care Framework	6-8
Specialist HD Services	9-10
Financial Wellbeing Service	11-12
Alliance Viewpoint	13
Awareness raising	14-15
Fundraising	16-18
Treasurer's statement	19
Annual accounts	20-21
Acknowledgements	22-23
Staff and Volunteer Contacts	24-25

# Report from the Chairperson: Catherine Martin



Last year, we celebrated the award of new funding from Scottish Government to enable the charity to develop a National Care Framework (NCF) for Huntington's disease. Since then rapid progress has been made and in March 2017, we published the framework. It is a unique achievement for a number of reasons. The framework is the first of its kind in the world and has gained backing from Scottish Government itself and from

the National Advisory Committee for Neurological Conditions, who advise the Government on policy. Of greater importance it has gathered a coalition of support from across statutory health and social care partners, and the third sector, a fact which will become all the more important as the work moves into the next phase where we will create local versions of the framework.

That this national project has been led by a small charity is a credit to SHA and I think exemplifies how the charity punches above its weight. There is no doubt that the passion and commitment of families and staff is the chief reason for this.

The NCF is also unique in addressing the issues faced by individuals and families living with HD along the whole journey and it takes a family centred view. I am particularly pleased to see the inclusion of a section on the support needs of young people.

It is also exciting that the final publication of the framework has been in the form of a web site which has been designed to be accessible from desktop and

mobile devices. The strengths of this approach are to make the information very accessible, ensure it can be easily updated, and link it to NHS systems. It makes the framework fit for purpose in the information age in which we live. What excites me most of all, however, is that within the next two years families throughout Scotland will be able to use this resource to help find their way through the maze of support services and hopefully feel more confident and knowledgeable about the care they should receive.

The NCF, in many ways exemplifies the best qualities of SHA: its ability to build and work in partnership, its capacity for innovation and creativity and its unique understanding of the impact of HD. These qualities are also evident in the core services we provide to the 1100 people supported by the charity every day, in Scotland. Our small committed team of 46 staff who work in the HD Specialist, Youth, and Financial Wellbeing teams and at national office make a huge difference to the quality of life of HD families. We have our eye firmly fixed on the horizon of possible new treatments for HD and it is essential when they come we make sure that we don't lose sight of our focus on our core work. In that regard the NCF plays a crucial role in building a solid foundation of health and social care support. It also means that we are ready to adapt to the opportunities new HD treatments will bring to families when they come.

*Catherine*



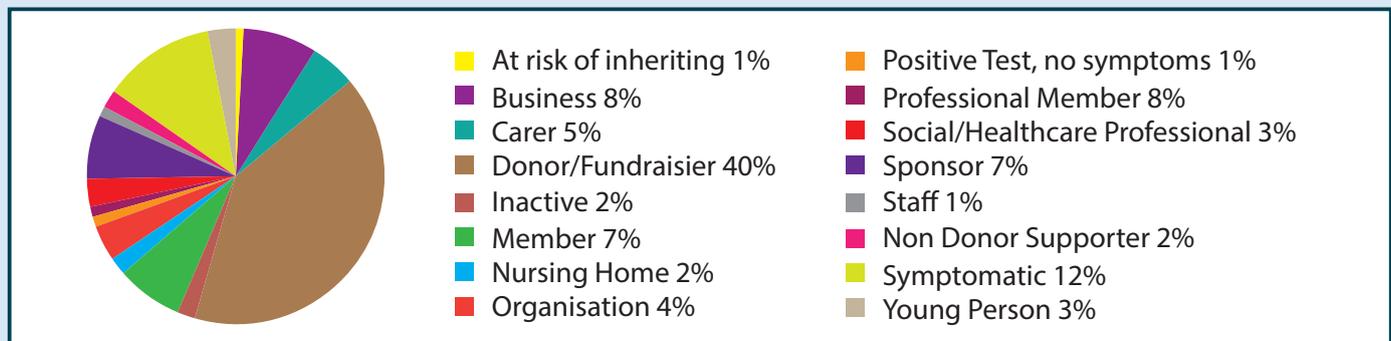
# CEO's Report: John Eden



Charities are successful because of their supporters and charities supporting people with rare conditions face something of an uphill challenge. Huntington's disease affects just 0.001% of the Scottish population and levels of awareness in the general public are around 23%; those are both sobering facts. Factor in the huge competition in the 'charity space' from far more well-known causes and the prospects for Huntington's disease could look gloomy.

My outlook is not, however, gloomy; let me share some other facts that explain why. SHA's turnover is almost identical to the Huntington's Disease Association of England and Wales who serve a population ten times

ours. Last year our supporters raised £230,000. If we were to match the funds raised per supporter in the HDA we would only expect to raise half of that amount. In the last three years we have seen a 300% increase in new donors supporting the charity and a 61% increase in the total number of donors. We are also seeing an increasingly diverse supporter base as is demonstrated by the graph below.



The statistics amply demonstrate SHA is a vibrant and growing charity that is successfully engaging the support of the HD community in Scotland; as in many other areas the charity is performing very well. We owe everyone who has supported Scottish Huntington's Association a huge debt of gratitude. The success of the charity can also be measured in key achievements this year. Catherine Martin, our Chair, talks about the National Care Framework in her report. She's right to highlight it; it might well be one of the defining pieces of work in which this charity has engaged. The achievement however is not the production of the framework, but the changes in care we want it to bring about over the next two years. Our acid test should be, has it made it a difference to the support available to people living with Huntington's disease and their families? I am confident it will. There is huge support from health and social care staff in Scotland and equal support from Scottish Government, we have a great team of staff working on the development and we will work with families throughout Scotland to make the framework relevant to each local area.

Another significant achievement has been the success of our Financial Wellbeing Service which has now operated for two years. The project, funded by the

Big Lottery Fund, has now generated £1.7m pounds of income for families living with HD; that's just over £4,000 per household that has engaged with the service. We have just completed an external evaluation of the service which showed that aside from the financial impact, improvements in wellbeing, reduced stress and more choice over how to live life have also been powerful outcomes. It is clear that our triad of HD Specialist, Youth and Financial Wellbeing Services now form a core and complementary approach which really works well to support the whole family. For that reason we are now pursuing further funding to enable us to continue the Financial Wellbeing Service.

While it's good to celebrate highlights from the year, our greatest achievement remains the day-to-day, lifeline support provided to families by all our Trustees, staff, and volunteers. Along with our myriad of supporters they represent a community committed to advocating the cause of HD and improving the lives of those who live with the condition. Alistair Haw, National Care Framework Lead, who came from a much larger charity, recently said that SHA has far more impact with its relatively modest resources than his former charity which has twenty times the income. I think that's one of the best testament to the hard work of everyone involved in SHA, I've ever heard.

## Focus on Scottish Huntington's Association Youth Project

### David Drain, Specialist Youth Advisor

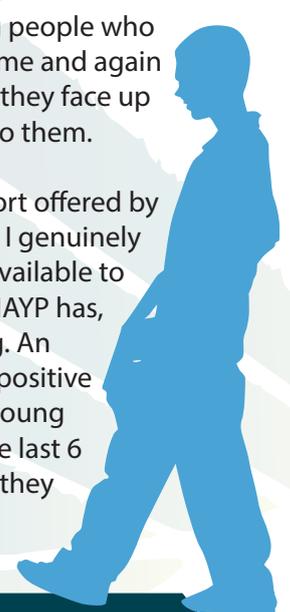


When I started working for Scottish Huntington's Association Youth Project (SHAYP) in 2010 I only had a basic knowledge of what Huntington's disease (HD) was and the impact it had on children and young people. Since then, in my role as Specialist Youth Advisor, I have had the opportunity to work very

closely with these individuals and families and my experiences have made me realise two things very clearly.

The first is how remarkable the young people who live in families impacted by HD are. Time and again I am taken aback at their resilience as they face up to the challenges that are presented to them.

The second is how valuable the support offered by SHAYP is. I may be slightly biased, but I genuinely believe that the world class support available to young people in Scotland through SHAYP has, in many situations, been life changing. An example of how this support made a positive difference occurred recently when a young person whom I have supported for the last 6 years spoke to me during a crisis that they were experiencing.



**Duncan** was referred to SHAYP in 2011 shortly after his mother, who was entering the later stages of HD, was placed into a care home. Duncan's father had an addiction to alcohol and was not able to properly care for him and so eventually he was placed into a long term foster setting. Initially our sessions together focused on providing Duncan (and the various professionals working with him) accurate and age appropriate information related to HD, but naturally over time this shifted towards increasing Duncan's ability to cope with the impact HD was having on his life.

Before long Duncan started coming along to the different activities that SHAYP offer such as the annual SHAYP summer camp. For some, events like Summer Camp can appear as light hearted without much substance, but I completely disagree. Alongside 1-2-1 sessions these events provide SHAYP staff with a unique opportunity to build deeper relationships of trust with the young people who attend. For Duncan this meant that when life got difficult he felt comfortable opening up to me about his struggles.

About 6 months ago I picked up Duncan for a scheduled 1-2-1 session. You're never quite sure what issues will come up when you meet a young person, but over the next few miles as we drove in my car towards the café Duncan bravely explained to me how he had been feeling suicidal for some time since a relationship that he was in had ended. We chatted at some length and during our conversation I asked if he had spoken to anyone else about how he was feeling. His answer, that he had not, served to confirm what I already knew - that my

role as Specialist Youth Advisor is not only unique but also hugely significant. Duncan is a popular boy with a lot of friends, he has older siblings, good links with the guidance team at school, a caring foster placement and an engaged Social Worker. And even with all this support in place the person he chose to speak to first in that difficult moment was me... his SHAYP Specialist Youth Advisor.

In the following months the multi-agency team surrounding Duncan put various supportive measures into place. Duncan and I continued to meet 1-2-1 and during our sessions we would routinely discuss his mood and how he was coping. Not surprisingly Duncan initially marked himself very low on the scale that we used, but over the next 6 months this would consistently rise to the point where Duncan would tell me that he felt 10/10. He went on to explain how he felt he could now handle his emotions better and that he now looks at the positives in life without being drawn into negative conflicts with other people. This type of outcome is very encouraging and gives me confidence that, due to the support given by SHAYP and other agencies, Duncan is now safer, healthier, more nurtured, respected and included and experiences significantly increased wellbeing.

Duncan's story, and the many others like it, serve to reinforce the importance that young people impacted by HD are able to access bespoke support focused on their specific needs. SHAYP is making a huge difference in the lives of many young people just like Duncan all across Scotland and for this reason it makes it a hugely enjoyable, worthwhile and satisfying role.

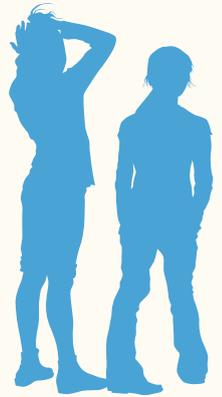


## The year of the National Care Framework for HD!

[care.hdscotland.org](http://care.hdscotland.org)

Over the year SHA led on the development, and publication, of the world's first interactive National Care Framework for Huntington's disease [care.hdscotland.org](http://care.hdscotland.org). The Framework seeks to achieve a number of outcomes, including:

- Establish an integrated health & social care model of support
- Educate and inform health & social care professionals and providers by promoting good HD practice
- Empower HD families by outlining the care and support they should be entitled to receive
- Provide easy access to information about HD services & support
- Minimise regional variations in care
- Act as a national and international model for HD and other long term conditions
- Help to develop a comprehensive national network to assist in HD care & support for the future



We have made significant progress towards achieving these outcomes by publishing the National Care Framework and beginning work to develop localised versions tailored to the needs and expectations of each NHS Board area throughout Scotland.

### The National Care Framework Development Group

We knew we could not deliver and roll out a National Care Framework working in isolation. Instead we set about developing a powerful coalition to help us write the Framework and influence the Scottish Government, NHS Boards and Health & Social Care Partnerships to back it.

As a first step we established a development group representing all parties who have an interest in making the document as comprehensive and successful as possible. The group includes representatives of HD families and carers, psychiatry, psychology, neurology, neuropsychology, genetics, rehabilitation, dentistry, GPs, speech and language therapy, dietetics, physiotherapy, occupational therapy, care homes, palliative care, social work and academic and research institutions. We are hugely grateful to the group whose membership can be viewed below:

- Alison Campbell, Senior Staff Nurse, Murdostoun Neurodisability Unit, Lanarkshire
- Alison Gordon (Dr.), Consultant Psychiatrist & Lead HD Clinician, NHS Lanarkshire
- Alison Hamilton, Lead Speech & Language Therapist, NHS Grampian
- Alistair Haw, National Care Framework Lead, Scottish Huntington's Association
- Bob Bogle, Adult Non-Clinical Services Manager, Scottish Huntington's Association
- Carolyn Craig, HD family member
- Cath Stanley, CEO, Huntington's Disease Association (England & Wales)
- Catherine Martin, HD family member
- David Goudie (Dr.), Consultant Geneticist, NHS Tayside
- David Thomson, Neurology Nurse, NHS Forth Valley
- Debbie Pitcaithly, Clinical Psychologist, NHS Fife
- Esther Sammler (Dr.), Consultant Neurologist, NHS Tayside
- Fiona Smith, Rehabilitation Manager, NHS Greater Glasgow & Clyde
- Gerry Dykes, Self Directed Support Manager, Renfrewshire Health and Social Care Partnership
- Jeni Guthrie, Care Manager, Perth & Kinross Council
- John Eden, CEO, Scottish Huntington's Association (CHAIR)
- Jillian Foster, Senior HD Specialist, NHS Fife
- Karen Sutherland, Operations Manager (Adult Clinical Services), Scottish Huntington's Association
- Katrina Lansdown, Advanced Practitioner Occupational Therapist, NHS Lothian
- Linda Lucas, Senior HD Specialist, NHS Lanarkshire
- Mandy Graham, Team Lead Physio, NHS Lothian
- Marion Ireland, Senior Dietician, NHS Lothian
- Neil Sneddon, Manager, Physical Disabilities Social Work, Dundee Health & Social Care Partnership
- Mary Porteous (Prof.), Consultant Geneticist, NHS Lothian
- Patricia McLaughlin, Senior Specialist Nurse, The Single Gene Complex Needs Service
- Paul Baughan (Dr.), GP & Primary Care Clinical Lead, NHS Forth Valley
- Paula McFadyen, Senior HD Specialist, NHS Tayside
- Sharon Mulhern (Dr.), Consultant Clinical Lead Neuropsychologist, NHS Ayrshire & Arran
- Stuart Ritchie (Dr.), Consultant Psychiatrist & Lead HD Clinician, NHS Greater Glasgow & Clyde
- Tracey Welbury, Senior Dental Officer, NHS Greater Glasgow & Clyde
- Valerie Maxwell, Centre Director, Dee View Court Neurological Centre, Sue Ryder Care, Grampian
- Zosia Miedzybrodzka (Prof.), Consultant Geneticist & Lead HD Clinician, NHS Grampian & NHS Highland

The charity is extremely grateful to all members of the Development Group, which boasts an enormous wealth of knowledge and experience of caring for HD families from a wide range of perspectives. We could not have produced the Framework without their guidance and support.



# The year of the National Care Framework for HD!

[care.hdscotland.org](http://care.hdscotland.org)

## Key milestones in the development of the National Care Framework

January  
2016

- National Care Framework Lead appointed

February -  
April 2016

- Meetings with key stakeholders

May  
2016

- Membership of National Care Framework Development Group finalised

June  
2016

- Development Group convenes and agrees on the purpose and format of the National Care Framework
- Motion tabled in the Scottish Parliament expressing support for the Framework and calling on health and social care providers to get behind it. A majority of cross party MSPs back the Framework

September  
& October  
2016

- Draft Framework text, as agreed by Development Group, goes out to initial consultation (15 September – 7 October)
- Development Group agrees on interactive online format for Framework
- Development Group updates Framework text further to feedback of initial consultation
- Full public consultation on updated text and interactive version of Framework opens (28 October – 9 Dec)
- Meeting with Scottish Government to update and request formal backing

November  
2016

- Minister for Public Health endorses consultation and calls for health & social care providers and staff to participate

December  
2016

- The Herald publishes opinion piece on the Framework, providing contact details to enable readers to participate in the consultation
- Consultation closes on 9 December. 160 responses received in total from the length and breadth of Scotland as well as England, Wales, Northern Ireland, Republic of Ireland, USA & Australia

January  
2017

- Development Group updates Framework on back of consultation responses, and agrees launch version

February  
2017

- Framework presented to Scottish Government, who tentatively agree support pending backing from the National Advisory Committee for Neurological Conditions (NACNC).
- Framework presented to NACNC. Discussions commence on securing endorsement.

March  
2017

- Framework 'soft launched'. Website goes live and is promoted to health & social care professionals, providers & HD families throughout Scotland.
- Framework presented to international HD conference in Oslo.



# What people think of the Care Framework for HD!

[care.hdscotland.org](http://care.hdscotland.org)

Throughout the development phase the charity consulted with a wide range of stakeholders. A selection of feedback provided can be found below...

## HD family members

“ Having seen both my Mother and Brother struggle with Huntington’s Disease, I am hopeful that this will be an invaluable tool to empower family members to get the help their loved ones need at the appropriate time and also enable families to plan for the future more confidently.

**Carolyn Craig, HD Family Member** ”

## Professional bodies

“ The College welcomes this approach and suggests it may be a good template for other conditions.

**Royal College of Physicians & Surgeons, Edinburgh** ”

## Third sector partners

“ What can I say? A masterpiece! It seems to have covered everything I can think of and a lot more. Brilliant! Well done!

**Errol Walsh, Huntington’s Disease Association of Northern Ireland** ”

## Health & Social Care Providers

“ Well done on producing such a detailed and comprehensive document. I’m hugely impressed with the interactive version, not only will it prove useful in the HD field but I’m sure that the model will be able to be developed in other specialities.

**Martin Bird, Mental Health Planning Officer, Health & Social Care, Midlothian Council** ”

## Health & Social Care Staff

“ I must commend the Framework Development Group for producing such a concise document with very clear purpose and outcomes. I think this is an excellent piece of work.

**Dr. Jenny Preston, Chair of College of Occupational Therapists Specialist Section Neurological Practice, Consultant Occupational Therapist & Clinical Lead Neurological Rehabilitation** ”

“ The document is excellent and includes pretty much anything I can think of that should be on offer to our patients with HD.

**Dr. Alison Livingston Consultant Neuropsychologist, NHS Tayside** ”

In addition to support from the Scottish Government the Framework has attracted the support of a majority of MSPs, including the leaders of all opposition parties (Ruth Davidson, Kezia Dugdale, Patrick Harvie & Willie Rennie):

## Next steps for 17/18

Further to the ‘soft launch’ of the Framework in March a formal launch event is to take place in the Scottish Parliament in May.

Work begins on producing localised versions of the Framework for each NHS Board area, commencing with NHS Ayrshire & Arran, NHS Fife and NHS Grampian (Phase 1, commencing April) followed by NHS Greater Glasgow & Clyde, NHS Lanarkshire & NHS Lothian (Phase 2, commencing autumn 2017).



# Specialist HD service case study

**Huntington's Disease Specialist**    **Date** 08/08/17

**Referral Date:** 27/01/2015    **Status:** Symptomatic

**Frequency:** Two monthly    **Identified need:** Support, signposting and collaborative multi-disciplinary approach for ongoing management of HD symptoms and social issues and concerns.

## Background

Mary was diagnosed with HD in 1988, physical symptoms developed in 2013; she owns a first floor flat with stairs to access with her husband James. The flat is in poor state of repair, signs of neglect and significant clutter. Both Mary and James declined initial offers to address the home issues.

Comments initially raised by their daughter Rosie around her dad's alcohol excess and his ability to care for Mary became an increasing concern, she disclosed this to her specialist youth adviser (SHAYP) At this time the case was reallocated to a new Huntington's Disease Specialist and a new assessment was initiated.

It was highlighted that Mary's balance and mobility had deteriorated; she has experienced a number of falls and now has difficulty with showering independently. Her involuntary movements have worsened and Mary has regular reviews to assess swallowing difficulties which have caused her to choke.

Mary denies that her husband drinks excessively, however, she reluctantly shared the increasing difficulty he has coping with their current situation.

## Action

### March 2017

- Referred to Occupational Therapy for functional and environmental assessment and intervention, including any equipment/aids.
- Referred to Physiotherapy for a mobility, balance and falls assessment and intervention.
- Referred to social work to provide personal care with hygiene.
- Referred for a Lifeline falls alarm.
- Social work declined referral stating that the situation is not an Adult Support and Protection issue and thus not a social work need however carer support was suggested by social work around James's ability to cope.

### April 2017

- James and Mary declined a social work assessment and carer support.
- Mary retracted her decision a week later for social work input and help with personal care.
- A follow up HDS visit highlighted the care package was not in place and still awaiting Physiotherapy and Occupational Therapy input.
- The Care Manager stated it was James and Mary's cultural choice to live in a property in that state and that not enough risks to require a social work assessment. The care manager advised she saw no evidence James was under the influence of alcohol during her visit, advised Rosie will need to report concerns directly to social work for them to act. She explained James and Mary can contact them to request a social work assessment if they feel it is needed.
- SHAYP reported Rosie's concern of a hole in the roof; She also advised that James was a functional alcoholic so professionals would not notice. Rosie advised she does not want to report her concerns to social services as it may cause a family rift.



## May 2017

- Liaised with care manager, care package still outstanding.
- Liaised with the community rehabilitation team as Mary had not received Physio or Occupational Therapy input.
- Liaised with Speech and Language Therapist who expressed concerns regarding hygiene of the property and advised that if Mary requires a modified diet or PEG in the future there would be significant infection control risks.
- Home visit, exposed severe damp and water damage due to damaged roof.
- Financial constraints for repairs identified; home insurance does not cover water damage. James and Mary expressed they would like to be re-housed via the council. Re application forms requested.

## June 2017

Mary and James state they do not want to move at this stage in their lives so do not want to proceed with the re-housing process.

## July 2017

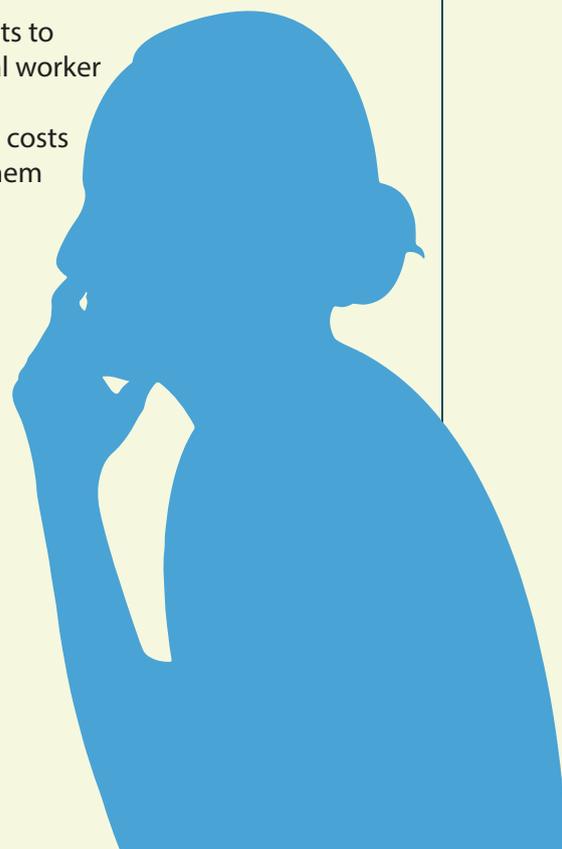
- Occupational Therapist (OT) reported concerns regarding the property around the hygiene and disrepair. Also concerns of Mary's presentation and personal hygiene. OT advised the carers have stopped personal care assistance due to home conditions. OT in the process of completing a comprehensive assessment, agreed to continued liaison.
- Social worker visited Mary, James was not present. Recognised concerns regarding capacity and lack of factual detail. Requested joint visit with HDS.

## August 2017

- Joint home visit with social worker with James and Mary present. A productive meeting where Mary and James were able to be open and honest regarding their vulnerabilities and concerns.

## Outcome

- Consistent contact and support has overcome the couple's initial reluctance to engage with services and established a much greater degree of trust and openness. The couple are now more able to accept help, but at a pace that feels right to them.
- James was offered support to arrange repairs; he declined because he wants to manage this himself. A timescale was agreed between James and the social worker so that it can be re-visited if he feels too overwhelmed.
- The couple are aware there are alternative housing options and should the costs of repairing their home be unmanageable the social worker will support them with finding alternative housing.
- With greater openness about James drinking, the Social Worker is gently exploring the impact this is having on him and his wife and whether this is something with which he wants support.
- There is now recognition that James needs a break from his caring responsibilities and Mary has agreed to go into respite care for one week.
- There is also greater recognition that James and Mary need support with Mary's personal care and her personal care is being reinstated.
- Working together the Social Worker, Occupational Therapist and Huntington's Disease Specialist will spend time with James and Mary to complete a comprehensive assessment of their needs and develop a care plan.
- Although there is a need for Physiotherapy to assess Mary's falls and balance, she remains on a waiting list.
- Mary is seen regularly at the Huntington's Disease Management Clinic and her HD symptoms are being well managed.
- The support Mary and James receive is now much better coordinated.



## Key messages about funding of the Financial Wellbeing Service



Following consultation with families, four years ago, we set up the Financial Wellbeing Service to improve support with benefits, debt management, financial planning for the future and accessing financial products.

The project was initially funded by the Big Lottery Fund and this funding comes to an end in March 2018. The project was independently evaluated and there is clear evidence it has made a dramatic difference to the lives of people with HD and their families.

In two and a half years it has generated £1.75m additional income for families with the average household £4,000 per year better off.

**91%** of benefit applications made by the team were successful at the first stage.

Just as importantly it has greatly reduced the financial stress on families, improved wellbeing, increased life choices and quality of life.

The project has become an integral part of the way SHA supports the whole family and has greatly enhanced the overall support we provide.

We have a unique way of working with families because we understand HD, work closely together as a team, and make support accessible by providing an outreach service.

Without this service families will experience much greater financial hardship and stress.

SHA has been working hard to secure ongoing funding, but we haven't yet identified support for the service. We need your help to make sure we can continue to deliver this service.

### Why it's needed - "Quotes from Family Members"

As soon as you get Huntington's you are almost unemployable. I thought about starting up my business again, but you can't even get public liability insurance with that. I knew I couldn't go back to the machines so that was it.

The mental health side of things has been difficult. I've got anxiety issues, it's had a huge impact, the mental health side of things is just bad.

At some point [my wife] will need more care than I can provide at home. We've already got someone coming in three days per week. It's hard to say when that [his wife going into care] will be, it's difficult to predict. At that point I will need to think about work, but I've had a patchy career and haven't got great qualifications.

We're just not bringing in enough money. We've got rent arrears and all sorts of arrears, we're behind on gas and electricity. We don't have any borrowing, it's all everyday bills that we rely on.

My husband gets ESA, he's struggled to attend interviews and assessments. It's difficult to get them to understand what a serious illness Huntington's is.....I'm also ill. My husband can't get Carers Allowance though he is entitled to it, because he is getting ESA. But the council tax people treat me as if I'm entitled because it's there in black and white.

You can understand why I am depressed. It's only natural. I'm fed up with filling in forms, I'm sick of dealing with it and I just can't manage.



## The difference it has made - "Quotes from Family Members"

Jo told me about PIP changing to DLA and advised me that I might as well go through the process straight away. She filled out all the forms. I wanted [the PIP assessor] to come out and see me, but they gave me a date two days ahead and I couldn't cope. They managed to get in touch with ATOS to explain that this made me really stressed and get it stopped. In the end I didn't have a face to face.

The Financial Wellbeing Officer sorted out my council tax so I don't have to pay anything because I am getting severe disablement premium.

Jo (FWO) helped get us enhanced rates for both mobility and daily living. She managed to get us both the taxi card and the bus card, and you usually get one or the other.

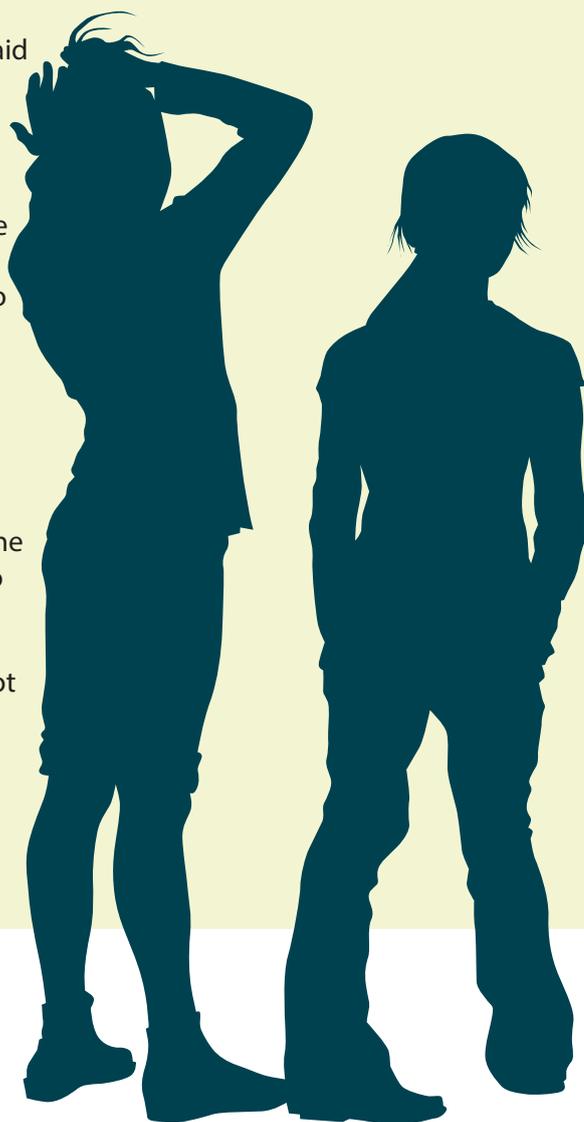
Katrina (FWO) got lots of debts written off. Council tax was an absolute nightmare, there was nothing sensible with the letters. I don't know how many companies she contacted, so many different companies, I wouldn't have known what I was talking about.

Jo helped us reduce some of our outgoings. She has talked with different people, she has got us a deal on gas and electricity and she managed to arrange lower payments. She's sorted our gas and electricity arrears being paid off, she applied for a grant at the start of the year and that will be coming off in February, March or April. We'll be where we were before I had arrears.

The money I've been getting has almost doubled. It's made life bearable. I got an extra £60 because no one was claiming Carers Allowance for me. It's made life more bearable, I used to have to watch things very carefully like the heating and I did suffer with it. I can spend more on food, and am OK with my bills, and I can cope even though my step granddaughter is staying with me because she's having issues with her mum. I haven't had to turn the heating down, things like that.

We've been able to repay some money to the family. A lot of the family don't want that immediately, but eventually we'd like to pay it all back.

The Financial Wellbeing Officer just made it not so stressful, not so worrying. I was really worrying about money, I'd worked all my life, and I found it really difficult to accept that I wasn't working.



The Salem witch trials of the late seventeenth century are notorious, but their connection with a devastating neurological condition is less well known. There is good evidence that some of the unfortunate victims of the trials may have suffered from Huntington's disease. The condition has always been blighted by secrecy, misunderstanding and stigma; it was a full two centuries later that it was properly described and understood by Long Island GP, Dr George Huntington.

The condition causes severe motor changes (loss of speech and swallow), impaired cognition caused by a type of early onset dementia and mental illness; difficult enough, but the family impact is deepened because it is a genetic condition. Each child with a parent has a fifty-fifty chance of inheriting the gene.

The legacy of Huntington's disease has created a vacuum of silence in which families have struggled with isolation, lack of access to support and frequently huge personal tragedy. Like many rare diseases, little is known about it and health and social care services are frequently confounded by its complex and sometimes challenging presentation. Conversely it is difficult to imagine a group of people more in need of a well-coordinated approach to support.

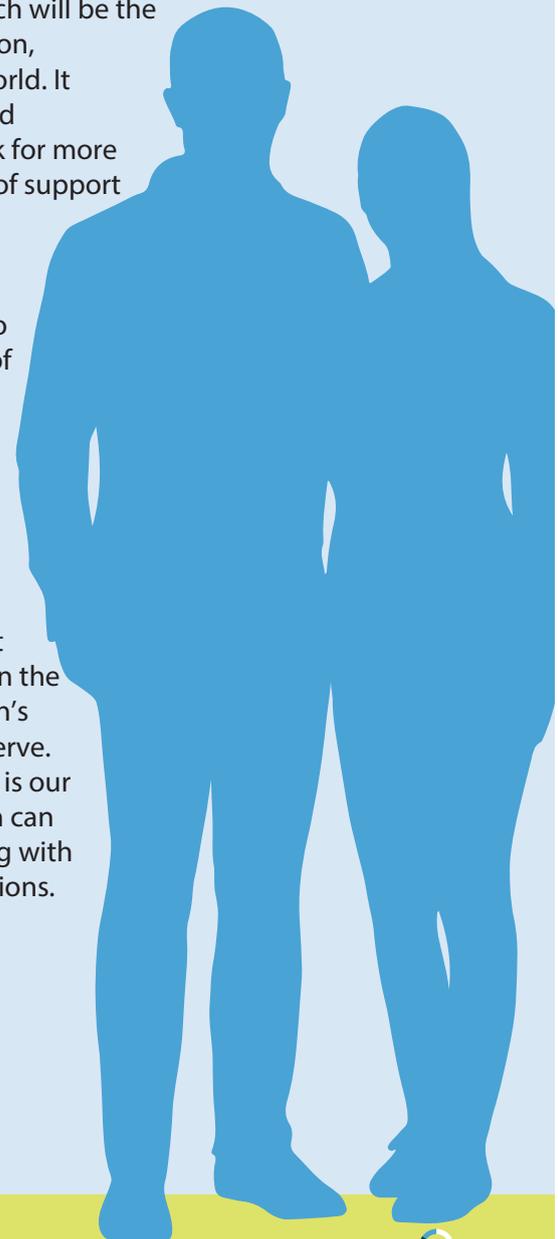
What if it was possible to describe a national framework of care that had at its core the principles, of person-centeredness, an integrated health and social care approach and a well thought out set of multi-agency arrangements? What if it was headlined by a lead professional approach, which focussed on specialist support and assisting people to navigate the health and social care maze. What if it spanned the spectrum of issues that really matter to the families who live with the condition, whether genetic testing, telling children about the condition or getting good symptom management?

For families living with HD, that would be a godsend, but perhaps, if it is possible to construct a framework like this for a condition as complex as HD, it might create a model for others.

With funding and partnership support from Scottish Government, that is what Scottish Huntington's

Association set out to do in 2016. Developed by an expert group and drawing extensively on the lived experience of families, the Framework was launched on the 18th May 2017 <http://care.hdscotland.org/>.

The framework is a waypoint in the journey towards improving care for people living with Huntington's disease. It has been designed to avoid being a prescriptive document that sets out unrealistic expectations and in 2017, the goal is to have local versions of for each of the fourteen regional health boards. This will mean families and professionals will have a readily available, web-based resource, that will guide them to the specific support they need and it will accurately reflect local arrangements. That work is already underway in Ayrshire, Fife and Grampian. The framework will set a standard of care throughout Scotland and as such will be the first for this condition, anywhere in the world. It enables families and professionals to ask for more appropriate levels of support and in some areas to challenge deficits in support. By 2018 we hope to be in the position of having mapped significant change; perhaps we will also be able to celebrate a greater degree of awareness and understanding that people caught up in the wake of Huntington's disease rightly deserve. And if successful, it is our hope this approach can benefit others living with neurological conditions.



# Awareness raising

## Raising public awareness of HD

**The FALKIRK HERALD**

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### Kelpies illumination has a message for the world

Falkirk's Kelpies were this week transformed into an iridescent beacon of support for families struggling to cope with a terrible disease.

The town's landmark public art masterpiece was one of an elite band of iconic sites chosen for a special international Huntingdon's Day Awareness Week stunt.

0 comments

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**Daily Record**

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17°C MOSTLY CLOUDY

### Perth punk band The Trendies reunite to issue their long-awaited album to support the Scottish Huntington's Association

Four-decade wait for fans is over in an effort to boost charity helping former band member Colin 'Peecie' Thomson.

BY IAIN HOWIE

Forty years after splitting up, Perth's punk prodigies The Trendies, have released their first album, all to help the band's former singer now living with the degenerative brain condition Huntington's disease (HD).

The band were a regular feature on the Scottish punk scene in the late seventies before moving to London in search of a record deal that never came - until now.

The 14 track CD 'The Trendies' is based on sessions the band played with Capitol Radio and Radio Forth and some unreleased material previously recorded at REL Studios in Edinburgh in 1978.

All proceeds from the CD will go to help the work of the Scottish Huntington's Association (SHA) the only charity in the country supporting people like former Trendy, Colin 'Peecie' Thomson, now living with the condition.

RECOMMENDED

Award-winning Scots dentist to the stars dead at just 39 years old

"I hope you died in agony" Disgusting messages left by tree where tragic biker died in

Drunken sailors on rampage as frightened Faslane locals claim Navy bosses have lost control of staff

Travellers shop for BLING from giant velvet shelves to diamond armchairs at gaudy Kilmoroch Horse Fair

Thug battered gran black and blue over cigarettes and dragged her

**Daily Record**

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17°C MOSTLY CLOUDY

### Showaddywaddy plan little walk down memory lane with Dumfries fundraising gig

Legendary hitmakers will play Easterbrook Hall in Dumfries on Friday, September 25 in aid of the Scottish Huntington's Association.

Vintage chart-toppers Showaddywaddy will take to the stage in Dumfries tomorrow night for a special fundraising concert.

They are set to perform their first gig in the region for more than 20 years in aid of Scottish Huntington's Association.

Lecturer - Robert Gordon University

Lecturer (Maternity Cover) - Robert Gordon University

Muirhouse Housing Association - Board Member

Solicitor - South Lanarkshire Council

Solicitor (Litigation/Employment) - West Lothian Council

Property/Planning Solicitor - West Lothian Council

RECOMMENDED

Award-winning Scots dentist to the stars dead at just 39 years old

"I hope you died in agony" Disgusting messages left by tree where tragic biker died in

**SCOTTISH LEGAL NEWS**

NEWS • JOBS • EVENTS • FT

### Edinburgh legal team conquers three peaks charity challenge

A seven-strong expedition led by Edinburgh solicitor Lucy Frazer laced up their boots and took on the Three Peaks Challenge to raise money for the fight against Huntington's disease (HD).

Ms Frazer and her team raised more than £4,600 for the Scottish Huntington's Association (SHA), the only charity in the country supporting families living with the degenerative neurological condition.

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**Evening Times**

26th November 2016

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## Anniesland writer Claire Hamilton Russell wins Huntington's Disease short story competition

Ann Fotheringham @annforthamrn  
Senior features writer



Glasgow writer Claire Hamilton Russell picks up her prize from authors Michael Malone (left) and Alan Bissett.

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A Glasgow writer has become the first winner of a short story competition designed to raise awareness of the degenerative neurological condition Huntington's Disease (HD).

Claire Hamilton Russell from Anniesland won £500 for her entry to the flash fiction competition Writing out of the HD Shadow, organised by the Scottish Huntington's Association (SHA).

THE SCOTSMAN  
SCOTLAND'S NATIONAL NEWSPAPER

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## Scottish Huntington's disease patients missing out on care

# scottish huntington's association

Age Partnership  
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Published: 08:09  
Sunday 23 October 2018

Scottish patients with an incurable neurological condition are facing patchy access to specialist care, campaigners have warned.

Large areas of Scotland are missing out on adequate services for Huntington's disease, a degenerative brain disorder which can cause a form of early onset dementia as well as loss of muscle control and involuntary movements.

The Scottish Huntington's Association (SHA) said only 58 per cent of people living with the disease were properly supported, as areas such as Forth Valley, the Borders and Dumfries and Galloway lacked access to specialist care.

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### Live Coverage - Part 2

2017

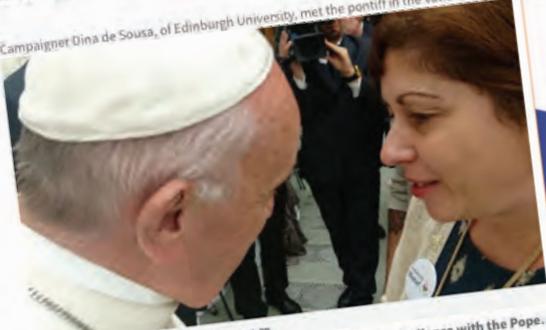
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PREVIOUS Live Coverage - Part 1 2017

STV Player News Win Scotland UK International Politics Sport Features Entertainment Weather

## Huntington's disease sufferer has audience with the Pope

Campaigner Dina de Sousa, of Edinburgh University, met the pontiff in the Vatican.

Chris Foote 23 May 2017



Vatican: Dina de Sousa meets Pope Francis, Cambrough PR

A Huntington's disease sufferer from Edinburgh has had an audience with the Pope. The pontiff met campaigner Dina de Sousa and others at the Vatican last week. Huntington's is a degenerative neurological condition which leaves sufferers needing 24 hour care.

Fischer Future Heat  
The future is electric



## Fundraising



### Another Bumper Year for the Fundraising Department!

#### Overview

A HUGE thank you to all our community fundraisers for all the volunteer led fundraising activities that took place over the past financial year, helping us to raise much needed funds for the Association. The range of events was spectacular from people organising Pop Up Shops, Barn Dances, Charity Nights and someone who even completed the Great Wilderness Challenge and raised £3,000 for SHA. Well done to you all. All this activity has pushed us on to create an even more exciting fundraising calendar next year and beyond. Our own SHA organised events such as the Falkirk Wheel Abseil, the Skydives at Glenrothes Airport and the Virgin London Marathon raised £35,000.

As we say in the Fundraising Department every penny counts and every pound is a prisoner! So it didn't

matter whether you raised £5 or £5,000 as 87% of every £1 donated to SHA goes towards providing much needed lifeline services to individuals and families impacted by Huntington's disease across Scotland. We couldn't have done it without you and our hope is you will continue this sterling effort this year and beyond.

The total income raised by the Fundraising Department last year was £422,668 which included all the areas mentioned above and below. This is a really valuable contribution to the work of the Association and accounts for nearly one third of the budgeted income. Let's hope we can meet that magic half a million pounds mark this financial year!

#### eBay Online Store

Unfortunately our eBay Online Store didn't quite make the financial target needed to continue David's post as Project Co-ordinator, however, the good news is that Jock, one of our stalwart volunteers, has continued to keep the store open for business. With regular car boot sales topping up the income from the SHA eBay site, enough income is being generated to keep the project running. Thanks to all the donors who kindly gifted a wide selection of items such as sewing machines, electronic keyboards and old mobile phones, all which were very saleable on eBay or at one of our monthly car boot sales. We can always accept more donations of unwanted items and turn these into pounds, shillings and pence for the Association, so if you are having a clear out just get in touch and someone will pop round and collect your gifts.

#### Legacy Giving and In Memoriam Giving

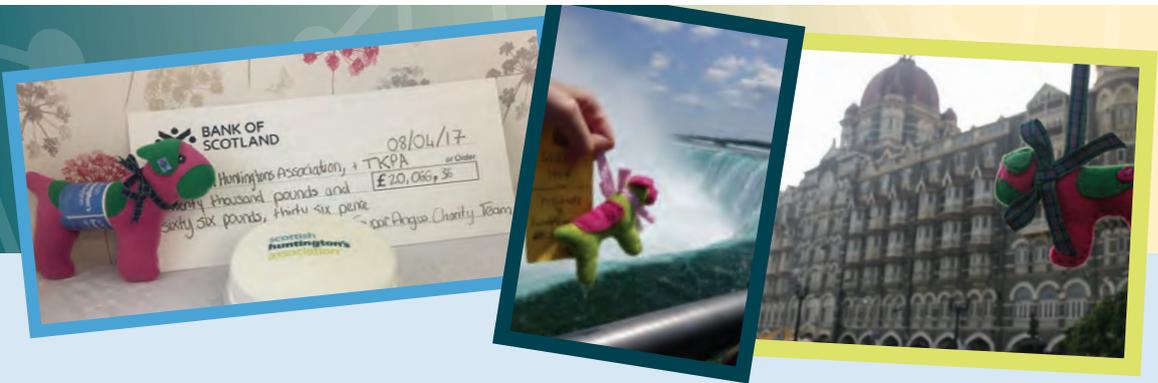
Legacy giving has remained strong throughout 2016-2017, with nearly £20,000 raised from both the deep generosity of the two SHA supporters who remembered us in their Wills, and also from regular In Memoriam gifts. SHA supporters have remembered us, repeatedly, in some very sad times and we remain truly grateful. We hope that the money raised will act as a celebration of the lives and values of those departed and believe that every penny will be spent as they would have wanted.

#### Individual and Regular Giving

In Individual Giving, 2016-2017 was the Year of Communication. Communication became a theme in every area of Individual Giving, from the growth of the Talks Programme and then our eBulletin, which now has 992 unique subscribers, to the huge success of our fiction competition – Writing Out Of the HD Shadow. Supported by Scottish writers Alan Bissett and Michael Malone, and the Scottish Association of Writers, the competition attracted 138 entries from as far afield as Australia, Macau and Thailand.

Beyond all the conversation, Individual Giving also grew massively in 2015-2017, with almost twice as many individual donors, raising over £85,000 between them. We were amazed by the generosity of our individual single donors, who donated nearly £40,000 by themselves, and very touched by the nine individuals who between them donated over £20,000. We also saw growth in both the Lucky Lotto and in Regular Giving.

# Fundraising



## Sybil on Tour #sybilontour

Jackie Harrison from York created Sybil on Tour, a felt dog replicating her own pet border terrier to help raise awareness of Huntington's disease across the globe. Sybil has been travelling to many countries across the

world from Scotland, Nepal, India, Canada, Australia and Europe, offering an opportunity to people to ask about the story of Sybil and her plight to raise awareness of Huntington's disease.

## Corporate Support

From our corporate supporters we have some fantastic examples of staff coming together to fundraise for SHA this year. Bibby Offshore amongst various activities took part in Glack Attack and raised over £6,000! Tepnel Pharma Services organised a sponsored cyclethon raising £2,210! Royal Bar Golf Club organised a golf tournament raising a fantastic £1,700!

The Kitchin Restaurant Limited fundraised a very generous donation of £1,187. Hamilton Rugby Club raised over £1,300 and represented SHA on their kits to raise some much needed awareness. Marks and Spencer Newton

Mearns staff organised various activities and donated money from the sale of plastic bags in store donating £2,623!

Most corporates that have supported us have done so because of a staff member or someone known to the company having a connection to the charity. This has resulted in a huge increase in support for the charity so we can't thank everyone involved enough! All those wonderful people who nominated us for staff fundraising efforts or those who undertook fundraising themselves and got match funding -really made a difference to SHA!

## Trusts and Grants

In 2016/17 charitable trusts contributed over £149,000 towards the work of Scottish Huntington's Association, We are extremely grateful to all the charitable trusts and foundations that have supported our work this year, helping us to develop and maintain our vital services.



We would like to say a huge thank you to the ScottishPower Foundation for their continued support this year. We were

delighted to receive a donation of £25,000 towards the development of our online carers' support forum. We also received an additional £5,000 from the Foundation as our Patron, Sarah Winckless, was crowned UK charity champion at the ScottishPower Foundation Charity Awards.

Our SHAYP Summer Camp was made possible again this year through the very generous support of the Shared Care Scotland Creative Breaks Programme, which allowed 35 young people living in a family impacted by HD to have respite from their responsibilities at home to enjoy a fun filled 5-day break at Lagganlia Centre for Outdoor Learning in the Highlands.

We were delighted to receive a donation of £10,000 from the Garfield Weston Foundation towards our core services. The Ardoch Foundation continued to support our SHAYP Residential Weekend by gifting the use of their centre at Gartocharn, near Balloch, which is a gift in-kind valued at £1,500 per annum.

*A full list of the charitable trusts and foundations which supported the Association in 2016/17 is printed on page 23.*



Donating through Gift Aid means we can claim an extra 25p for every £1 you give. It won't cost you any extra.

# Fundraising



## Community Fundraising Highlights

Our fundraising activities wouldn't have been possible without the hard work, passion and determination of our volunteers, community fundraisers and supporters. Here are some of the highlights from 2016/17.

In 2016 the Cupar Angus Pop up Shop really outdone themselves with a grand total of £20,966 being donated. The shop has been running for several years now going from strength to strength gaining in donations, volunteers and money raised! And it's all down to the fantastic ladies at the helm and their team!

We had a lot of fun last year working with the amazing 'SHAvengers' team of superheroes who took part in various events throughout the year including a Skydive, Zipwire and Assault Course Challenge! The team raised close to £9,000!

'Support from volunteer fundraisers is integral to the charity. Through their generosity, passion and commitment SHA is able to help more people impacted by an inherited neurological condition.'

## Exotic Overseas Treks

For the first time we had not one, but three overseas treks all raising funds for people impacted by Huntington's disease.

Marie Short, Family Member and SHA Trustee took off on an overseas eight day trek of the Himalayas in Nepal joined with a friend and SHA community fundraiser. The team were raising funds for three great causes finishing with a team total of over £7,000 for SHA.

We also had two other amazing supporters, Moira Stevenson & Hayley Mills, who organised two terrific overseas treks taking the name of Scottish Huntington's Association to faraway places, Kilimanjaro and Machu Picchu. Both treks raised a total of nearly £5,000 taking our total to £12,000 for overseas trekking.

## Virgin London Marathon

We had another successful year for the marathon raising over £11,000. This event goes from strength to strength each year and adds a substantial amount of income to the SHA funds.

## Annual Skydive

The Skydive at Glenrothes Airport raised over £8,000 helping us to provide the specialist services to people who need our support the most.

## Falkirk Wheel Abseil

Our biggest community event to date raised over £12,000. Everyone had an amazing time.

## Thank you

There are so many superb events that our volunteer fundraisers have organised from overseas treks, walks, runs, tea parties, themed nights, hair & beard shaving, collection cans, bag packing and much, much more, which, are not only about raising vital funds but more importantly about raising awareness in communities on the impact of living with Huntington's disease for families.

We continue to be astounded by the countless achievements of our amazing supporters; you have done us all proud. There are too many to name individually but please be assured you have been recognised for your hard work, commitment and successes, we couldn't have done it without you.

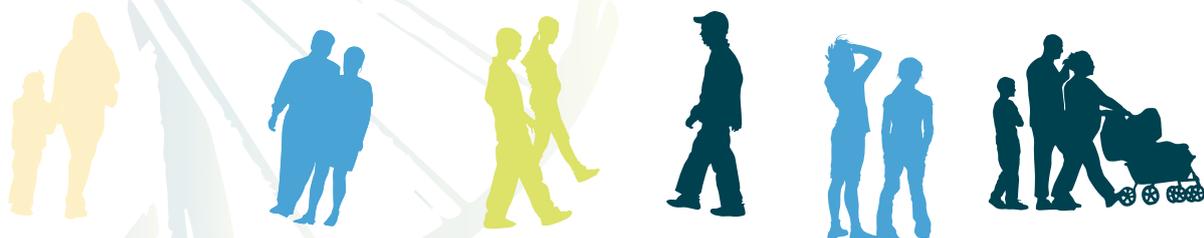
The events our supporters organise offer a social network of activities helping to reduce isolation for families and their network of friends. We have also enjoyed attending various community events and been honoured to be part of it. We look forward to joining in the fun by attending more events and cheque presentations next year.

The community fundraisers will continue to offer support and advice to anyone looking to get involved, so whether you have experience or not, we will work together. We look forward to an exciting year ahead welcoming, yet again, more supporters on board.

We send sincerest thanks and warmest wishes to SHA supporters, volunteers and everyone who got involved.

## For the year ended 31 March 2017

- ① 2015/16 was a hard act to follow. The much welcomed anonymous donation of £200k plus an operating surplus of £56K, less a year end provision of £72k for the charity's defined benefit pension scheme (now closed), meant that £184k was added to the adjusted (depleted) reserves of £180k.
- ② In order to compare 2016/17 results with 2015/16 on a like for like basis, it is best to put the £200k donation temporarily to one side. The Statement of Financial Activities (SoFA) for 2016/17 shows an overall deficit of £30k, being the operating deficit for the year of £16k plus a £14k deficit on the charity's defined benefit pension scheme. This £30k deficit reduces the charity's reserves to £334k.
- ③ It also means a £72k negative turn round from 2015/16's operating surplus because, while total income to the charity was marginally up on the previous year by £44k (excluding the £200k anonymous donation), the charity's costs rose by £116k in the year.
- ④ The small net increase in income hides the following movements; contract income for HD Specialist services remained relatively static in the year, income for non clinical services rose by £92k in line with increased activity, income from fundraising activities, donations and sundry income also rose marginally but income from charitable trusts fell by £44K despite the increased efforts of our fundraising team.
- ⑤ The £116k rise in running costs comes entirely from charitable activities: HD specialist costs rose by £48k without a corresponding increase in contracted income, while the £80K rise in non clinical cost was offset, in this year, by a greater rise in non clinical income of £92K.
- ⑥ Because of the fall in funding, it was necessary to take the difficult step to discontinue the Volunteer Co-ordinator post, for which a secure source of funding could not be reasonably foreseen in the near future.
- ⑦ The adjustment the charity was required to make in the year for the defined benefit pension scheme fell from £72k last year to £14k this year. The charity is informed by The Pension Trust at the year end what the value of the adjustment is to be.
- ⑧ At first glance, the charity's balance sheet shows that it is in a very healthy position, being in possession of bank and other assets of £861k. However, when adjustments are made for known liabilities (creditors and pension liability) of £528k, the charity only has free access to funds £333k, or less than the ideal three months running costs.
- ⑨ We are extremely grateful to all our supporters without whom, we could not continue to deliver the support and services we provide.



## Statement of Financial Activities (incorporating Income and Expenditure Account) For the Year ended 31 March 2017

	Notes	Un-restricted funds £	Restricted funds £	2017 Total Funds £	2016 Total Funds £
<b>Income and endowments from</b>					
Donations and legacies	3	170,775	23,191	193,966	403,882
Charitable activities:	4	11,594	1,274,401	1,285,995	1,248,803
Other trading activities	5	69,797	1,450	71,247	58,171
Investment income	6	7,464	-	7,464	342
Branch income		10,574	200	10,774	13,444
<b>Total income</b>		<b>270,204</b>	<b>1,299,242</b>	<b>1,569,446</b>	<b>1,724,642</b>
<b>Expenditure on</b>					
Raising funds	7	191,820	-	191,820	197,231
Charitable activities	8	-	1,375,555	1,375,555	1,248,231
Other (including Branches)		17,921	-	17,921	23,588
<b>Total expenditure</b>		<b>209,741</b>	<b>1,375,555</b>	<b>1,585,296</b>	<b>1,469,050</b>
<b>Net income/(expenditure) before gains losses on fixed asset investments</b>		<b>60,463</b>	<b>(76,313)</b>	<b>(15,850)</b>	<b>255,592</b>
<b>Gains/(loss) on fixed asset investments</b>	17	<b>(425)</b>	-	<b>(425)</b>	<b>390</b>
Net income/(expenditure) before transfers		60,038	(76,313)	(16,275)	255,982
Transfers	23	(77,168)	77,168	-	-
<b>Net income / (expenditure)</b>		<b>(17,130)</b>	<b>855</b>	<b>(16,275)</b>	<b>255,982</b>
<b>Other recognised gains and losses:</b>					
Actuarial loss on defined benefit pension scheme		(14,000)	-	(14,000)	(72,000)
<b>Net movement in funds</b>		<b>(31,130)</b>	<b>855</b>	<b>(30,275)</b>	<b>183,982</b>
<b>Reconciliation of funds</b>					
<b>Total funds brought forward</b>	23	<b>345,050</b>	<b>18,710</b>	<b>363,760</b>	<b>179,778</b>
<b>Total funds carried forward</b>		<b>313,920</b>	<b>19,565</b>	<b>333,485</b>	<b>363,760</b>

The notes form part of these financial statements.

All activities are continuing. All gains and losses in 2017 and 2016 are shown above.

## Balance Sheet As at 31 March 2017

	Notes	2017 £	2016 £
<b>Fixed assets</b>			
Tangible assets	16	-	-
Investments	17	16,910	17,335
		16,910	17,335
<b>Current assets</b>			
Debtors	18	36,219	50,429
Investment portfolio (Aviva)		116,227	110,000
Cash at bank and in hand		691,731	702,235
		844,177	862,664
<b>Creditors:</b>			
<b>Amounts falling due within one year</b>	19	<b>(240,602)</b>	<b>(229,239)</b>
<b>Net current assets</b>		<b>603,575</b>	<b>633,425</b>
<b>Net assets excluding pension liability</b>		<b>620,485</b>	<b>650,760</b>
<b>Defined benefit pension scheme liability</b>	21	<b>(287,000)</b>	<b>(287,000)</b>
<b>Total net assets</b>		<b>333,485</b>	<b>363,760</b>
<b>The funds of the charity:</b>			
Unrestricted funds:			
General		574,640	595,250
Designated		26,280	36,800
Pension reserve		(287,000)	(287,000)
		313,920	345,050
Restricted funds		19,565	18,710
<b>Total charity funds</b>	23	<b>333,485</b>	<b>363,760</b>

The financial statements were approved by the Board of Trustees on 16 September 2017



# Acknowledgements

## Statutory Funders

- The Scottish Government
- Aberdeen City Council
- Aberdeenshire Council
- Angus Council
- Ayrshire & Arran NHS Board
- City of Edinburgh Council
- Dundee City Council
- East Ayrshire Council
- East Lothian Council
- East Renfrewshire HSCP
- Fife Council
- Fife NHS Board
- Glasgow City Council
- Grampian NHS Board
- Highland Council
- Highland NHS Board
- Inverclyde HSCP
- Midlothian Council
- NHS Greater Glasgow & Clyde NHS Board
- NHS Lanarkshire
- NHS Lothian
- North Ayrshire Council
- North Lanarkshire Council
- Perth & Kinross Council
- Renfrewshire Council
- South Ayrshire Council
- South Lanarkshire Council
- Tayside NHS Board
- West Dunbarton HSCP
- West Lothian Council

## Corporate Supporters

- Arisaig Marine Ltd
- Attack Plumbing & Heating
- Bank of Scotland Foundation
- Claire Clifford Office Products
- Co-operative Maybole
- Di Maggio's
- Dundee Heritage Trust
- East Dunbartonshire Council
- East Dunbartonshire Voluntary Action
- Jaw Brew
- Landmark Forrest Adventure Park
- Lloyds Banking Group
- Loch Insh Watersports
- Loch Katrine Experience
- Lomond Platform Charity Committee
- M & D Leisure Ltd
- Queen Victoria School
- Renfrewshire Council
- Renfrewshire Seniors' Forum
- Rolls Royce Staff Charity Committee
- Rotary Club of Kirkintilloch
- Sainsbury's Supermarkets Ltd
- Scottish Council for Voluntary Organisations
- Scottish Enterprise
- Speedbird Developments Ltd
- Starbucks UK
- The Cairngorm Reindeer Company
- The Grand Lodge of Antient Free and Accepted Masons of Scotland
- The Shine Agency
- The State Hospital
- The Weather Lottery
- Troon Cabin Club
- Whyte & MacKay
- Yorkshire Building Society

# Acknowledgements

## Trust and Grants Acknowledgements 2016 - 2017

- Alexander Moncur Trust
- Bellahouston Bequest Fund
- Broughton Charitable Trust
- Crerar Hotels Trust
- Dalziel Charitable Trust
- D'Oyly Carte Charitable Trust
- Gannochy Trust
- Gaul Trust
- Gordon Fraser Charitable Trust
- Hospital Saturday Fund Charitable Trust
- J T H Charitable Trust
- M E B Charitable Trust
- Margaret Douglas Trust
- Mary D M Andrew Charitable Trust
- Miss Agnes H Hunter's Trust
- Miss E C Hendry Charitable Trust
- Miss Isobel Ferguson Harvey's Charitable Trust
- Nancy Roberts Charitable Trust
- Netherdale Trust
- Northwood Charitable Trust
- Schuh Trust
- ScottishPower Foundation
- Shared Care Scotland Creative Breaks Fund
- St. Katharine's Fund
- Sylvia Aitken Charitable Trust
- Talteg Limited
- Tay Charitable Trust
- The ACT Foundation
- The Albert Hunt Trust
- The Appletree Trust
- The Ardoch Foundation
- The Garfield Weston Foundation
- The John K Young Endowment Fund
- The Leng Charitable Trust
- The Lynn Foundation
- The Mickel Fund
- The New Maclay Murray & Spens Charitable Trust
- The Pixel Fund
- The R J Larg Family Charitable Trust
- The Row Fogo Charitable Trust
- The Rozelle Trust
- The Russell Trust
- The Ryvoan Trust
- The Sir Jules Thorn Charitable Trust
- The Templeton Goodwill Trust
- The Tillyloss Trust
- The W A Cargill Fund
- William Sword Charitable Trust



## Staff and Volunteer Contacts

NAME	TITLE	LOCALE	CONTACT NO.	HOURS	EMAIL	
Alan	Cossar	Volunteer	NAT	0141 848 0308	Wed (typically)	<a href="mailto:alan.cossar@hdscotland.org">alan.cossar@hdscotland.org</a>
Alan	McGill	Senior HD Specialist	AYR	01294 322305 07956 011231	Mon-Wed 9.30-5	<a href="mailto:alan.mcgill@hdscotland.org">alan.mcgill@hdscotland.org</a>
Ali	Shearer	Admin/Resource Worker	AYR	01294 322305	Mon-Fri 9-1	<a href="mailto:alison.shearer@hdscotland.org">alison.shearer@hdscotland.org</a>
Alistair	Haw	National Care Framework Lead	NAT	0141 848 0308 07736 457247	Mon-Thu 9-5, Fri 9-4	<a href="mailto:alistair.haw@hdscotland.org">alistair.haw@hdscotland.org</a>
Anita	Dasgupta	Admin/Resource Worker	GLA	0141 556 4100	Mon, Thu, Fri 8.30-12.30, Tue, Wed 8.45- 4.45	<a href="mailto:shaglasgow@hdscotland.org">shaglasgow@hdscotland.org</a>
Annette	Brown	Senior HD Specialist	LOT	0131 537 1058 07944 274521	Mon-Thu 8-4.30, Fri 8-12	<a href="mailto:annette.e.brown@nhslothian.scot.nhs.uk">annette.e.brown@nhslothian.scot.nhs.uk</a>
Christine	Malhan	Admin/Resource Worker	HIG	01463 729958	Mon-Fri 9.30-1.30	<a href="mailto:shahighland@hdscotland.org">shahighland@hdscotland.org</a>
Colin	Wilson	Admin Officer	NAT	0141 848 0308	Mon-Thu 8-5, Fri 8-12	<a href="mailto:colin.wilson@hdscotland.org">colin.wilson@hdscotland.org</a> <a href="mailto:sha-admin@hdscotland.org">sha-admin@hdscotland.org</a>
Corinne	Payne	HD Specialist	LAN	01355 597455 07714 245740	Mon-Thu 9-4, Fri 9-12	<a href="mailto:corinne.payne@lanarkshire.scot.nhs.uk">corinne.payne@lanarkshire.scot.nhs.uk</a>
Craig	Kennedy	Volunteer	NAT	0141 848 0308	-	<a href="mailto:craig.kennedy@hdscotland.org">craig.kennedy@hdscotland.org</a>
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## Staff and Volunteer Contacts

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Trevor Law	HD Specialist	LOT	0131 537 1058 07957 374417	Mon 8.30-12, Tue 9-4.50, Wed 10-7.40, Thu 9-7, Fri 9-4	<a href="mailto:trevor.law@nhslothian.scot.nhs.uk">trevor.law@nhslothian.scot.nhs.uk</a>

## Local Offices

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<b>EDI</b>	Scottish Huntington's Association Citizen's Advice Bureau 12 Bernard Street Leith EDINBURGH EH6 6PY Tel: 0131 554 8144	<b>LAN</b>	Scottish Huntington's Association (Lanarkshire) Hunter Community Health Centre (4th Floor) Andrew Street EAST KILBRIDE G74 1AD Tel: 01355 597 457
<b>FIF</b>	Scottish Huntington's Association (Fife) Whyteman's Brae Hospital Whyteman's Brae KIRKCALDY KY1 2ND Tel: 01592 643 355	<b>LOT</b>	Scottish Huntington's Association (Lothian) Clinical Genetics Department Western General Hospital EDINBURGH EH4 2XU Tel: 0131 537 1116
<b>GLA</b>	Scottish Huntington's Association (Glasgow) Unit 2A David Dale Business Centre 159 Broad Street GLASGOW G40 2QR Tel: 0141 556 4100 SHAYp Tel: 0141 556 2136	<b>NAT</b>	Scottish Huntington's Association Business First Linwood Point PAISLEY PA1 2FB Tel: 0141 848 0308
<b>GRA</b>	Scottish Huntington's Association (Grampian) Clinical Genetics Centre Ashgrove House (Ground Floor) Foresterhill ABERDEEN AB25 2ZA Tel: 01224 550 062	<b>TAY</b>	Scottish Huntington's Association (Tayside & Angus) East Day Home (Room 3010) Kings Cross Hospital Cleington Road DUNDEE DD3 8EA Tel: 01382 424 172



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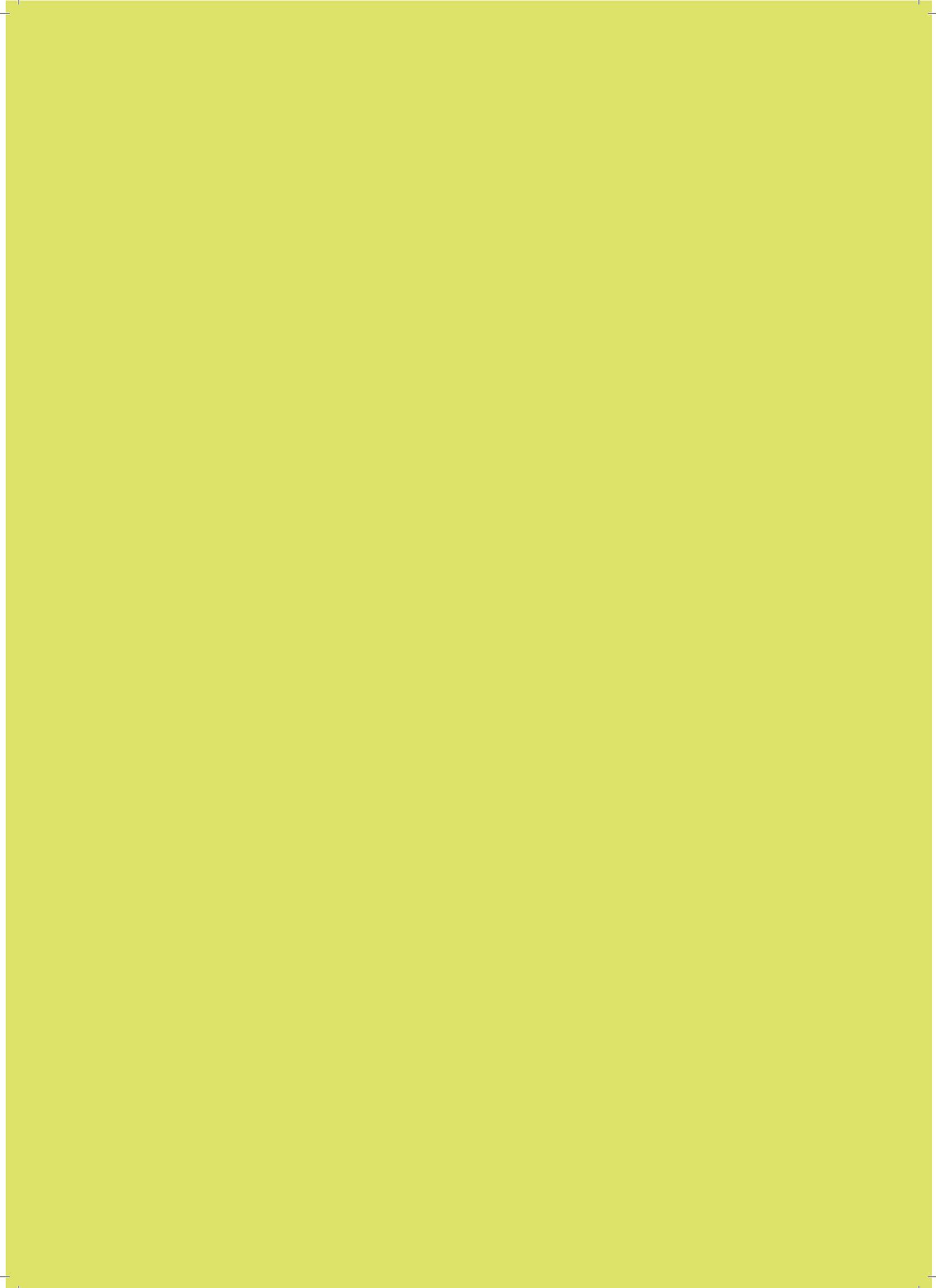


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