

# SHAre

Summer 2017

scottish  
huntington's  
association

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## National Care Framework formally launched at Holyrood reception

Model receives £60,000 funding boost and is shortlisted for prestigious Award

The National Care Framework for Huntington's disease has been formally launched at an event in the Scottish Parliament.

Amongst the speakers was Cabinet Secretary for Health & Sport, Shona Robison MSP, who heaped praise upon the Framework and announced an additional £60,000 funding to allow development work to continue until 2019.

Ms Robison said:

**"In 2015 the Scottish Government provided Scottish Huntington's Association with funding and support to develop a National Care Framework for HD and begin the process of rolling it out across the country. The national and international feedback on the work undertaken so far has been extremely positive, and I am therefore delighted to announce an additional £60,000 allowing the work to move forward.**

**"From the outset we were hopeful that the HD Framework could have the potential to be used as a template for other neurological and long terms conditions. Widespread feedback from stakeholders representing such conditions appears to have borne this out. We look forward to seeing how this exciting prospect develops, and are pleased to continue working with Scottish Huntington's Association and others to make this a reality."**

The event - hosted by Olympic athlete turned MSP Brian Whittle - received appearances from 70 MSPs who came to express their support. Conservative Leader Ruth Davidson, Labour Leader Kezia Dugdale and Green Leader Patrick Harvie were amongst those popping by to endorse the Framework.

The launch and funding boost was shortly followed by encouraging news that the Framework had been shortlisted for Public Affairs Campaign of the Year at the prestigious Chartered Institute of Public Relations (CIPR) PRide Awards 2017.

Alistair Haw, National Care Framework Lead for Scottish Huntington's Association, said:

**"Scottish Huntington's Association owes an enormous debt of gratitude to everyone who participated in the development of the Framework. The funding boost and award shortlisting is a huge vote of confidence in their work. Together we have created a momentum that will carry this project into its most important phase: improving the way services are delivered to families affected by this appalling condition. We are determined to do exactly that."**

The Framework seeks to help ensure families impacted by the condition are given the best possible care, information and support, regardless of where they live in Scotland. It has been supported by the Scottish Government, all opposition parties, the National Advisory Committee for Neurological Conditions, NHS Boards, HSCPs, health & social care staff, professional bodies, HD family members, academics and national and international third sector partners. It can be viewed at: [care.hdscotland.org](http://care.hdscotland.org)

Work is currently underway to develop localised versions of the Framework for each NHS Board area by 2019, commencing with NHS Ayrshire & Arran, NHS Fife and NHS Grampian in the first instance.



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## John Eden, Chief Executive Officer...



**Many readers will be aware that the European Huntington's Disease Association runs a long-term study called ENROLL which collects data about how HD affects people. The study has recruited an amazing 13,147 people from 135 different research sites in 14 different countries. I think that's an amazing achievement!**

You may also have heard of the HD CLARITY study. This study was set up to establish whether it was possible to detect the faulty protein that causes HD in spinal fluid by means of a lumbar puncture. It's an incredibly important study because, if successful, it will provide a biomarker for

HD. That means, when treatment becomes available (notice I said when and not if!) people who have the gene will be able to get a regular test to find out if their HD is active. This will then trigger treatment for HD.

Spinal fluid may not be the only bio marker. The TRACK-HD study recently reported that a protein called a neurofilament light chain may also be used to detect the onset of HD. This is great news because it means there will be more than one way of detecting when treatment is needed.

I recently joined the ENROLL and HD CLARITY studies as a 'control'. Both studies need people who don't have HD in order to compare the results they get and be sure that what they are seeing is caused by HD. I partly did it because I want to support the work the research community is doing, but also because I wanted to gain an insight into the potential treatment for HD.

I hope everyone is now aware that 'gene silencing' or more accurately 'Huntingtin lowering therapy' is the treatment to watch. If you aren't familiar with it pop over to <https://en.hdbuzz.net/> and read our research update article on page 3.

When (there's that word again) it becomes available it is likely to require a series of monthly treatments that will involve a lumbar puncture that will be used to remove some spinal fluid and replace it with the drug. That sounds pretty daunting, but if my experience is anything to go by the idea of it is much worse than the reality.

I had my lumbar puncture at the rather stunning new Queen Elizabeth Hospital. Prior, the only thing I had to do was fast from midnight. The procedure involved a short neurological examination – something many people with HD have experienced. I then lay on my side, was given some local anaesthetic (no worse than having blood taken) and after the area was numb, the neurologist did the lumbar puncture; I did not feel a thing. I had to lie flat for an hour afterwards (although I was rewarded with a very welcome cup of coffee and some biscuits!) and after that I went back to work.

ENROLL can still benefit from volunteers willing to be controls so it's worth thinking about. My experience was positive and if I had to have a lumbar puncture in the future, it's not something I would worry about and that also reassures me for those for whom it might become a regular event when treatment becomes available to control HD.

## SHA Adult Clinical Service Update

**It has been a very busy summer for the HD Specialist services. They have been very productive despite staffing shortage in Lanarkshire and Glasgow. We are delighted to report that Jackie Webster has been appointed to replace Marta as admin support in Lanarkshire and started on 7 August. Marta wanted a full time post and left in Mid-July. We all wish her every happiness in her new role. Linda Lucas is still on maternity leave and Lindsay Wilson, HD Specialist form Tayside, is helping out in the Lanarkshire service one day each week until she returns.**

Claudia Lang was recently appointed to the Glasgow service as HD Specialist, and took up post on 7 August. This will now bring Glasgow up to full capacity.

The first three services to be involved in localisation of the SHA National Care Framework are Ayrshire, Fife and Grampian and a couple of meetings have now taken place with work now well underway.

In Ayrshire, we are pleased to report that Dr Johnstone, Consultant Psychiatrist/HD Clinical Lead, now has four contracted sessions for HD Management Clinic.

There was a meeting in Moray on 13 July with Jane Mackie, Head of Adult Care Services and Ann Mackenzie, Services Manager, to discuss future support of HD families in the area. Although SHA won't be offered a contract in Moray there was a commitment to offer a more streamlined service to the Moray families and there is

also the possibility of 'spot contracts' to meet need which cannot be met by Moray Health & Social Care Partnership (HSCP). This would include a 'named officer' to coordinate care and an improved multi-professional team approach. A local clinic space will also be made available in order to reduce travelling. There is also a plan to meet with family members to explore their needs more fully.

There are now several care homes who have expressed interest in undertaking the SHA accreditation process in order to be included on our register of approved care providers. This is positive news for families.

And finally, we are delighted to inform you our award winning Stirling University Module: Huntington's disease – An enabling approach to supporting families, will be running again this year, commencing on 4 September 2017 and will run for 14 weeks. There has been a great response with over 18 people signed up for the course.





**Ionis says its trial of HTRx, intended to lower huntingtin protein, is fully recruited and plans to extend it.** *by Dr Jeff Carroll 22 June, 2017*

## Huntington Lowering Drugs (previously called gene silencing drug)

Ionis Pharmaceuticals launched the first ever trial of a huntingtin-lowering drug in late 2015. In a significant update, the company has announced two important milestones:

- the trial is now fully recruited
- use of an 'open-label extension' (A trial in which the patient and doctor know what drug is being used)

### What is new?

News that the trial is fully recruited and the final patients are going through the procedures is a strong suggestion that even at the highest doses, the drug's safety looks good. Despite exhaustive safety testing before going into patients, any drug can produce unwanted effects, so that's really the best news we could be hoping to hear at this stage.

**"The safety and tolerability profile of IONIS-HTRx in the completed cohorts of the Phase 1/2a study supports its continued development".**

"Top line results" are expected around the end of 2017. In our experience, the results of a trial like this may not come out all at once. The safety data may come first, but information about whether treatment with HTRx lowered the level of huntingtin protein in the spinal fluid – a much-anticipated 'biomarker' (a test of any kind - including blood tests, thinking tests and brain scans - that can measure or predict the progression of a disease like HD. Biomarkers may make clinical trials of new drugs quicker and more reliable) outcome – may take a little longer to materialise.

### A recap on huntingtin lowering

The idea of 'switching off' the Huntington's disease gene was first considered when it was discovered in 1993.

**Huntingtin lowering drugs** reduce levels of mutant huntingtin by telling cells to delete the 'message molecule' from the huntingtin gene. To reach the brain, ASO (A type of gene silencing treatment in which specially designed DNA molecules are used to switch off

a gene) drugs like HTRx have to be injected into the spinal fluid using a thin needle.

This is called an **intrathecal injection**. While this may sound gruesome, it is a commonly-used method for treating the brain in other conditions like cancer. A closely related procedure – lumbar puncture or spinal tap – is very widely used, and indeed many hundreds of volunteers from Huntington's disease families have undergone this procedure to donate valuable spinal fluid to help with HD research.

The current HTRx safety trial involves patients with early symptoms of Huntington's disease. After extensive clinical evaluation, each volunteer receives four injections of the drug at monthly intervals, followed by a final spinal fluid collection.

In an **open-label extension** trial, or **OLE**, the volunteers from a blinded trial are invited to come back for further doses, and every volunteer gets the active drug rather than some receiving drug and some the placebo – usually at the highest dose that was safely tried in the blinded trial.

Ionis had previously said that an open-label extension **may** be implemented if the data from the safety trial looked good. We don't want to read too much into a brief announcement, but running an OLE isn't cheap for a trial sponsor, so this open-label extension study will only be available to volunteers in the current trial. That means it will run in the same study centres in the UK, Canada and Germany. The length and exact design of the OLE have not yet been announced, but it will provide a wealth of information that Ionis and its partner, Roche, can use to plan their next steps.

This announcement certainly gives us optimism about the whole HTRx programme.

*For an unedited version and further information on the latest HD research, please go to [www.hdbuzz.net](http://www.hdbuzz.net)*

## Pope Francis in Rome

**Pope Francis gathering on 18 May 2017 with the global Huntington's disease community was a major inspiration for those seeking to increase awareness and research about the condition. The Pontiff stayed for nearly an hour after the audience at the Vatican to offer individuals a hug and a greeting. He is the first world leader to publically recognise the plight of those of those with Huntington's disease.**

Family member Dina De Sousa felt privileged to be one of the individuals invited from around the world who travelled to Rome for this unique occasion.

### Dina recalls her visit

It will be a day to remember for the HD community. It marked the start of a global awareness campaign and the first time a world leader has recognised the difficulties of those who suffer from Huntington's disease. The aim of HD denmore was to raise global awareness and stop the stigma HD families have faced for so many years.

About 1,500 people attended and I was honoured to be among the 150 who met the Pope personally. His speech was very moving and brought tears to my eyes when he uttered the words:-

**"May none of you ever feel you are alone. May none of you feel you are a burden. May no-one feel the need to run away."**

It was a day filled with different emotions. Seeing so many people affected by HD brought back memories from my father and feelings to what I will face. Most people are unaware of the complexity of this disease and it reinforces my goals for strong patient advocacy. I am fortunate to have such a large HD family/community.





## Firstly, a huge congratulations to Pete Carruthers, who has recently

been awarded an additional 3 years funding for SHAYP's Fife and Lothian service from BBC Children in Need. With this funding secured it ensures that the national SHAYP service can continue to grow and develop and the award signifies the tremendously high level of work which Pete has put into developing the service over the past 3 years. We are extremely grateful to BBC Children in Need for recognising the value of SHAYP and thankful to Pete for all his dedication and hard work.



## Summer Camp was recently held from 10 - 14 July 2017

at our favourite venue, Lagganlia Centre for Outdoor Learning near Aviemore. 35 young people joined us for 5 days of high jinks, hospitality and hope building. The young people loved the daytime activities with ski-ing, archery, woodland exploration, kayaking, mountain biking and gorge walking. In the evenings

we had a games night which included football, rounders and board games; Outdoor Discovery which had trampolining, tubing, reverse bungee; laser quest and high ropes courses to burn off some energy; swimming was a firm favourite with fun and games in the pool.

The young people who are first year high school and older attended the festival aspect of the camp. The theme for the festival was 'Back to the Future' and the young people worked through sessions on HD which educated them on the past, the present and the future. The aim of the festival was for the attendees to learn about Huntington's disease and service provision throughout the generations and ascertain what the young people's hopes are for the future. The festival went incredibly well and as one young person noted:-

**'I hadn't realised how things had changed and how good we have things in Scotland for HD. I've learned loads about HD in the past and present and my hope for the future is that the treatments they are experimenting with at the moment actually work.'**

**HD's Got Talent** showcased the tremendous flair our young people have, whilst the week was finished off with a party and celebration. It was a fabulous five days and everyone really enjoyed themselves. Next year's camp is already booked from 9 - 13 July 2018!



## HD Routes: Phase 2

is currently under construction with two new chapters completed and heading to the designers in early autumn. David Drain has worked tirelessly to complete the chapters on Family Planning and Being a Young Carer. These new chapters will complement and enhance the previous chapters of HD Routes and will be a great tool for young people growing up in families impacted by HD. Watch this space for further updates!



Our long overdue literature for early years, 8-12 and 13+ is also nearing completion. Grant Walker has put a tremendous amount of effort into ensuring the content is correct and worked closely with a designer to develop themes which is young person friendly and engaging. The booklets are nearly completed and will be launched before Christmas.

Laura has worked incredibly hard holding the team together and this is often no easy feat with staff based throughout Scotland. However Laura is now so experienced in doing so that she recently celebrated her 10 year Anniversary with SHAYP. As a token of our thanks for all her hard work and being the hero behind the scenes we presented Laura with flowers as a token of our gratitude.

SHAYP are looking forward to another exciting few months and hopefully seeing you all soon!

## Referring to SHAYP

If you are a young person aged 8-25 living in a family impacted by HD (this can be a parent, step parent, grandparent, auntie, uncle, cousin, sibling etc) then you can become involved with SHAYP. Simply call **SHAYP HQ on 0141 556 2136** and we can arrange to visit you.



- **Over 18s weekend**  
29 September to 1 October 2017
- **8-12 group**  
9 October (date may change) 2017
- **13-17 Residential**  
17 to 19 October 2017
- **Christmas Activity**  
January 2018 (date to be confirmed)
- **Summer Camp 2018**  
9 to 13 July 2018



## Social media

To be kept in the loop of SHAYP updates remember and add SHAYP to your list of liked Facebook pages.



# Family Branch/Support Group

Isobel Darroch - Branch/Support Development Officer

**Fife** branch is holding a meeting on 11 September at the Day Room, Glenrothes Hospital, from 7.30pm to discuss the future of the branch, where they hope to elect a new chairperson and secretary. They extend a warm welcome to family and friends in Fife to come along and join them and offer their support for the continuance of the branch. Tea and coffee is on offer with an opportunity to catch up with fellow HD families.



**Glasgow** is continuing well and meets on the last Tuesday of the month at the Wedge in Pollok. They meet from 6 – 8pm, extending a warm welcome to everyone in the Glasgow area.



**Tayside:** Whilst enjoying a fun day out in June, travelling through from Tayside and catching the ferry to Rothesay, the branch were keen to offer support to the Bute Kidney Patient Support Group, who are running a Kidney Dialysis Unit Campaign to raise £300,000 to create a Dialysis Unit on the Isle of Bute. This will mean that those on the island who rely on dialysis will not have to make the three-times weekly trips to Greenock. The branch have had a huge success running their pop-up-shop, and the funds raised goes to both SHA and Kidney dialysis.



**Lothian:** The group has continued to meet every month. This year they had a visit from Wiltshire Farm foods, held a bingo night and a fish supper evening in June. Some of the members are planning a weekend break again in Fife. They look forward to starting again in September with their new schedule for 2018/19.

## Support Group Information

Current groups are: **Ayrshire Carers; Ayrshire early symptomatic; Grampian; Highland; Glasgow Symptomatic; Lothian Carers; Renfrewshire and Surrounding Area; South Lanarkshire Carers; Tayside Carers; West Dunbartonshire.**

**Ayrshire Carer Group** enjoyed a lovely lunch at the Lido Restaurant in June. Meetings start again in September

**Ayrshire Early Symptomatic** is a new group. They had a day out in Millport in June, and went walking at Loch Lomond in August. Alan McGill, Senior HD Specialist, Ayrshire took part in a charity day with the group using an exercise bike to cycle the distance from DG Ayrshire Central to Scottish Huntington's Association National Office in Paisley (50 miles). Betty Anderson joined in the fun as she is training for her cycle around Millport on 10 September 2017.



**Renfrewshire and Surrounding Area** are having their annual walk along the River Clyde on Saturday 16 September. Call me on **077 222 42076** for meeting times. Everyone welcome to join this walk and afterwards meet at Morrisons café in Erskine for lunch.



The support groups are less formal than the family branches, and their dates vary. Please contact Isobel on 0141 848 0308 for more information.

**Grampian group** held a lunch in the committee room of the Central Library in Aberdeen and were joined by the Grampian Team.

## Highland Support group

meeting in Inverness had a First Aid presentation from Kirsty Jarvie, Education Co-ordinator at the British Red Cross, and happily took part in the demonstration.



# SHA NEWS UPDATE

Our raising awareness campaign from 8 - 14 May 2017 gained momentum with SHA taking part in another 'Light Up for HD', a worldwide event which was held throughout May to raise awareness globally of HD.



This year the weather was kinder to all SHA supporters, as they travelled to the Kelpies in Falkirk and the Titan Crane at Clydebank. Both were lit spectacularly with the international HD colours, illuminating the night sky. This event also drew attention through local media. Many thanks for everyone who came along to support us during our weeklong awareness campaign, both at the 'Light Up for HD' and the Holyrood reception on Thursday 11 May 2017.

## Grampian HD Service



L-R Katrina Lovie, Liz Fraser and Mary Cho

Liz Fraser, Senior HD Specialist, Grampian, gives an update on the SHA Grampian service;

**"We cover Aberdeen City and Aberdeenshire and during the last year, we have offered committed, informed, honest and practical support within the HD community which has included:-**

- 73** service users seen by Liz Fraser, Senior HD Specialist
- 18** youths seen by David Drain, Specialist Youth Advisor
- 49** families seen by Katrina Lovie, Financial Wellbeing Officer

**Grampian has been chosen as one of the first areas to begin the process of rolling out the National Care Framework, where more detailed localised versions are expected to be in place by the beginning of 2019. This means here at Grampian we have been given a unique opportunity to significantly drive up health and social aspects of care and support provided to HD families."**

We are now at the stage of seeking the views of those living with HD and their families, and if you would like to become part of a focus group where you could share your thoughts on the National Care Framework, please contact **Liz Fraser, Senior HD Specialist**, or **Alistair Haw, National Care Framework Lead** on either Tel: **0141 848 0308** or Mob: **07736 457247**.

Liz Fraser, Senior HD Specialist  
T: 01224 550062  
E: [elizabeth.fraser10@nhs.net](mailto:elizabeth.fraser10@nhs.net)

Katrina Lovie, Financial Wellbeing Officer  
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E: [katrina.lovie@hdscotland.org](mailto:katrina.lovie@hdscotland.org)

David Drain, Specialist Youth Advisor  
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Mary Cho, Administrator  
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## Financial Wellbeing Service

The service is as busy as ever, having now advised over 500 individuals across Scotland and generated over £1.78 million of financial gains for these families. We have continued to provide advice on a range of money issues including benefit checks and claims; debt issues; financial planning issues - including Power of Attorney Advice and care costs; financial products and other areas such as blue badge, bus passes, and reducing energy costs.

We are continuing to roll out our 'Financial Health Check' programme to ensure that every HD family across Scotland has received a personal invitation for a financial review. At the same time we continue to accept referral's both from HD specialists or other professionals, as well as responding to requests from individuals directly.

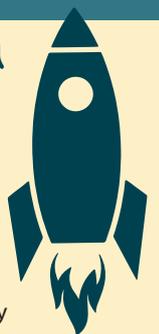
An independent evaluation of the service has recently been published which was based on a series of interviews with families and staff members, as well as an analysis of the project outcomes and statistics. Based on the hugely positive feedback, it was felt that the service has been delivered effectively from the point of view of clients, with the Financial Wellbeing Service seen to be expert, hard-working and effective, as well as delivering a holistic, caring and personal service. The close working relationships between the Financial Wellbeing Officers and Huntington's Specialists was also praised and seen to be a key part of the project's success. The evaluation concludes that the service has had a significant positive impact on people affected by Huntington's and that there is therefore a strong case for continuation of the service. With our current funding period ending in March 2018, the ongoing challenge will be to secure continuation funding for the service, and we continue to work towards that goal.

If you would like further information on the Financial Wellbeing Service, please contact Jo on **07710 391622** or email [joanne.baldock@hdscotland.org](mailto:joanne.baldock@hdscotland.org)

## SHA Carers' Forum has been relaunched

The SHA online Carers' Forum has been redeveloped and will now give carers set topics to discuss. Carers can feel very isolated, and we hope this upgraded version will be more appealing for them to engage with other HD carers.

It is a web-based, secure and confidential discussion forum in which carers within HD families can anonymously discuss issues and difficulties facing them. With 24/7 access, and designed for easy use with just a login and password, they can sign up directly through our website: <https://www.hdscotland.org> or go to [forum@hdscotland](mailto:forum@hdscotland) for further information.



# SHA NEWS UPDATE *Cont...*

## New SHA Staff



**Jessica Muscatt**  
HD Specialist,  
Glasgow

Having worked as an Occupational Therapist in the NHS for many years, it's great to gain experience within the charity sector. I have been so impressed with the genuine passion and commitment shown by everyone within the organisation to improve the lives of those affected by HD. Since starting I have visited several SHA services and external organisations and met the clients and families I will be working with. I have already learned so much and look forward to continuing the amazing work carried out by SHA.



**Kim Haran**  
Senior Bookkeeper

I joined the SHA team at the end of July as Senior Bookkeeper. I have experience in both corporate and non-profit organisations and previously worked in practice for over 5 years. Throughout this time I completed professional qualifications in accounting. I have already learnt so much about Huntington's disease and the impact that the SHA has in helping those with the disease and their families. Everyone has been very welcoming and I have been inspired by the dedication of staff, members and volunteers to the charity and look forward to being part of the team.



**Claudia Lang**  
HD Specialist,  
Glasgow

I joined the Glasgow team as an HD specialist at the beginning of August. I qualified as a social worker in 2000 and have worked within the voluntary and health sectors in brain injury services, cancer support and children and families services. I'm taking the time to visit different SHA teams across Scotland as part of my induction and have been inspired and encouraged by the breadth of experience, skills and dedication that the staff, volunteers and families share in their work with SHA.

## Carer Conference 2017

Our Carer Conference this year was held at Inchyra Grange, Falkirk. Over 40 carers attended the two day event. Relaxation sessions were offered after registration on the first day and many of the delegates welcomed having some time out to unwind. An evening dinner and quiz gave everyone an opportunity to relax and get to know each other. A full conference programme was introduced by SHA National Care Framework Lead, Alistair Haw, and presenter Kathryn Valentine spoke on Personal Reflections on Dilemmas Encountered. A choice of five workshops with a wide range of topics was organised for delegates.



**"It is good to get an opportunity to discuss common topics with people in similar situations. This is a very valuable part of the conference."**

**"Always love joining HD Conferences, it has helped me greatly over the years."**

**"It was good and informative and always great to meet new people there."**

## Family Conference 2017



This year's family conference will be held at the Crowne Plaza, Glasgow, on Saturday 28 October 2017. This is a one day event and we have a packed programme to offer. Charles Sabine, former NBC New Journalist, will be speaking on the Challenges for Families living with HD. Alistair Haw, SHA National Care Framework Lead, will be updating us on the National Care Framework and Dr Ed Wilde, MCR Clinical Scientist, is giving a talk on the latest HD research. Invitations have been posted out. If you have not received a copy, contact Kim Kemp on **0141 848 0308** or email [kim.kemp@hdscotland.org](mailto:kim.kemp@hdscotland.org)

## UK HD Network

Dr Michael Armanyous and HD Specialists Jillian Foster, Nicola Johns, Paula McFadyen and Lindsay Wilson joined the Enroll-HD team on Friday, 16 June 2017 for the annual site investigator's meeting in Birmingham.

The meeting encompassed several interesting topics, including alcoholism in HD study, social economics in HD, HDA care home accreditation scheme and functional/cognitive training. Without doubt, the highlight of the day was Professor Sarah Tabrizi's presentation which gave an update on the IONIS trial.

The IONIS trial is aimed at lowering the huntingtin protein. Already looking very promising, if successful and evidenced, a major pharmaceutical company is interested in taking this trial into the next phase, hopefully, as early as the beginning of next year.

The Fife service is currently working on site certification in the hope that they will be selected as a study site should IONIS move into the next stage.

## Scottish Young Carers Festival 1st - 3rd August 2017



SHAYP took 4 young people to the Scottish Young Carers Festival, a two-night event which has over 500 young carers from all over Scotland attending.

This year, one of our group, Cameron, was part of the Festival Media Team, which involved running the festival radio station, interviewing young carers and taking part in an interview with MSPs on Facebook Live.

The group enjoyed watching live bands, dancing the night away at the disco and outdoor activities. They also contributed well to the number of consultations that took place to help direct how decision makers can make things easier for young carers. Despite the poor weather, the entire group enjoyed the event, especially just hanging out with other young carers.

**"I loved meeting new people and the casual atmosphere of the festival"** – Barry



## Writing Out Of the HD Shadow

One of last year's biggest successes in the fundraising department was our inaugural writing 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.

We now intend to continue this competition in 2017-2018 with a poetry competition - Writing About HD: The Light Beyond the Shadow. We are thrilled to be partnering with former Edinburgh Makar, the Scottish Rivers' poet, Valerie Gillies with our theme for 2017. Huntington's disease (HD) is a neurological condition that is still hidden from many and this year we want to use the power of poetry to look beyond the shadow.

Valerie said **"Poetry is such an expressive medium and I'm really looking forward to learning more about HD through this powerful form"**

We are inviting poets from across Scotland and beyond to submit their work.

We will accept any form of poetry, from haiku to iambic pentameter to free verse, as long as it's about Huntington's disease. Each poem should be no more than 24 lines. The competition will be judged by Valerie Gillies and prizes presented to three talented poets at the winners' event in December 2017.

The competition this year will open on Friday 1st September 2017, so you have plenty of time to get your quills and nibs sharpened.



## Christmas Hamper

We're looking forward to making one lucky SHA supporter's festive season a little bit brighter with our Super Tasty Big Christmas Hamper. Made up of donations from SHA supporters and staff members, we will be raffling off a delicious basket of wine, food and treats throughout October, November and December. You should get your raffle tickets soon - each ticket is £2 and means you'll be in with a chance to win our fabulous hamper. Don't miss out! Get your tickets back to us as soon as possible!

## Christmas is coming

### Carols or Christmas Songs by Candlelight

We'd love to hold a candlelight event in late November or early December, but need a community/church venue and a choir. Donations of candles, mulled wine, mince pies and tea/coffee, would also be greatly appreciated.



It would be a family event, in a calm and peaceful setting, with the time of day to be agreed. If you can help out or can suggest some venues, please get in touch by calling Linda on **0141 848 0308** or email [linda.winters@hdscotland.org](mailto:linda.winters@hdscotland.org)

# Fundraising

## New Volunteer to help in the SHA eBay Online Store



SHA is delighted to welcome aboard a new volunteer, Ermias Takele from Ethiopia, who is supporting Jock McKechnie in our eBay online store. Ermias has a wide range of skills in IT, retail and photography and has already started to take on tasks from Jock. Ermias is a local lad and being a keen cyclist, he cycles to the National Office from his home in Paisley. He also has his own online accessories web site, selling items such as sunglasses and wrist watches, so everyone at SHA is hoping he can transform our very own eBay site. Watch this space and don't forget if you have any unwanted items you would like to donate to the eBay store, just give us a call on **0141 848 0308** to arrange collection.

## SHA Art Exhibition, Sale and Auction

The first entry for the SHA Art Show has arrived at the National Office, but there is still time to take part if you haven't requested your artist canvas yet. To date over 50 artists have confirmed that they will be submitting a piece (or two) for the exhibition and it is hoped this number will increase over the next two months.



Jane Ross from New Cumnock was our first entry and she has set the bar high.

The exhibition is taking place in the Awestruck Art Gallery, 71 Kilbowie Road, Clydebank G81 1BL on the evening of Thursday 9 November 2017 from 18:30 onwards. All artists submitting entries will be on the guest list, so get painting. All we ask is that you donate your time, skill and paint. SHA will raise much needed funds on the night to support its teams of HD Specialists across the country who provide lifeline services to individuals and families impacted by Huntington's disease.

## #JeansForGenes day

We are so excited! This year Scottish Huntington's Association is a part of Genetic Disorders UK's annual **#JeansForGenes** day in September. Jeans for Genes Day is an annual fundraising event when school children and office workers wear their jeans in exchange for a donation. This year it will be taking place on 22nd September 2017.

Funds from Jeans for Genes Day are granted to specialised charities to provide care and support for children affected by genetic disorders. This year, Scottish Huntington's Association's Youth Project is one of the charities who will be lucky enough to receive support.

If you'd like to get involved with #JeansForGenes this year, then why not visit their website at [www.jeansforgenesday.org](http://www.jeansforgenesday.org) They have some great educational resources, loads of ideas for activities to raise money, and some lovely wee bits and pieces on sale to raise money for the cause.

## Made with Hope

Scottish Huntington's Association is launching a new craft project, 'Made with Hope.' This project hopes to bring all of our supporters who have an interest in crafting to do something amazing together! We hope to bring people together to craft various items including bracelets, plush toys, knitting, cards etc.



No degree of skill is needed to begin with as we all learn from each other. - No set time commitment is required - craft as and when it suits you! - Link up with other crafters local to you! - Turn your hobby into something productive!

All of these items will be sold via our fundraisers, the SHA eBay store and the SHA website and profits will go towards paying for things like the SHA Family Conference which brings the HD community together on an annual basis.

Please email [gemma.powell@hdscotland.org](mailto:gemma.powell@hdscotland.org) to register your interest and share the news with all the crafters you know!

# CALENDAR OF EVENTS

Your support will help us continue improving the quality of life for people impacted by Huntington's disease (HD)...



**Great Scottish Run, Glasgow 1st October**  
<https://greatscottishrun.com/events/>

More than 25,000 runners will pound the streets of Glasgow on 1 October, taking part in the Great Scottish Run, Scotland's largest mass participation event. Can you run to raise money for Scottish Huntington's Association?

There's a fantastic atmosphere with thousands lining the streets to cheer everyone on.

There's no minimum sponsorship required, but be assured that every penny you raise goes towards providing a gold standard of care.

**Baxter's Loch Ness Marathon - 24 September 2017**  
<https://lochnessmarathon.com>

The Baxter's Loch Ness Marathon is quite possibly one of the most stunning marathons in the world. With spectacular scenery, fantastic atmosphere and a truly memorable experience - definitely one for the 2017 bucket list!



Loch Ness

**SHA Family Car Treasure Hunt Saturday 14 October 2017**

From 11:00 to 16:00 hours meet in The West End Car Park Station Road Pitlochry PH16 5BN Bring the children and seniors too. £40 per car Info packs available from Dougie Peddie, Fundraising Manager



**Supernova Kelpies 10th-12th November 2017**  
<https://supernovarun.com/>



**Hogmanay Loony Dook 1st January 2018**  
<https://edinburghshogmanay.com/whats-on/loony-dook>



**SHA Art Exhibition, Sale and Auction Thursday 9 November 2017**

From 18:30 to 21:00 hours in the Awestruck Art Gallery 71 Kilbowie Road Clydebank, G81 1BL Call for entries is still open.



Falkirk

Glasgow

Edinburgh

**Great Edinburgh run 13th January 2018**  
<https://greatrun.org/great-winter-run>



Robert Burns

**SHA Fashion Show Saturday 11 November 2017**

Wynd Centre, Paisley  
<https://hdscotland.org/shamazing-ladies-night/>



**The "BIG GIG" with KIOKO Saturday 3 February 2018**

From 19:30 to 23:30 hours In Community Central Hall 304 Maryhill Road, Glasgow G20 7YE Ticket Prices £10.00



**Clyde Rowing Race Saturday 17 March 2018**

The Boathouse River Clyde, Glasgow Green TBC



**Ride the Clyde Bridges Sunday 25 March 2018**

From 10:00 - 16:00 hours From Dalmarnock Bridge to Erskine Bridge returning along the Forth & Clyde Canal to Port Dundas - a total distance of 25 miles **Can you raise £100 sponsorship to support people with Huntington's disease?**



**IS BACK in February 2018**

You can host a tea party from your own home, garden, your place of work, or a local café, bar or community centre. Once you have the venue you can then start inviting your family, friends, neighbours, colleagues or even the local community.

Email [fundraising@hdscotland.org](mailto:fundraising@hdscotland.org) or call 0141 848 0308 for more information!

If you would like to get involved in any of our fundraising events, or would like to plan your own, contact the fundraising team on [fundraising@hdscotland.org](mailto:fundraising@hdscotland.org)

# Thankyou Fundraisers

## 3 peaks challenge

Lucy Frazer and team impressively completed the 3 Peaks Challenge and raised **£5,000!** That's three mountains in a day!



## M&B Kiltwalkers

Ashley McDougall and friends took part in the Glasgow Kiltwalk and raised a fantastic **£2,169!**



## Colour Me Rad

A massive thank you to everyone who took part in Color Me Rad and raised over **£1,600**



Cally Mackenzie, Sandie Henderson and Siobhan Binnie



Both Louise's sons Cameron & Jack looking happy at the finish

Louise Reid with son Cameron

## ALLOA ROCKS

A magnificent £700 was raised at a Memorial Concert for Ian Small in the Royal Oak Hotel, Alloa on Friday 24 March 2017. Over 60 of Ian's friends and family members rocked the night away to "The Solid Gold Band" performing songs from the 70s, ABBA and the Solid Gold Scotland collection. DJ Jamie Keane and his Beatz Disco kept the party jumping into the wee small hours. A huge thanks to Tam Cassidy and his colleagues for staging the event which was a fantastic success. Alloa, we can wait for the next one!



## Heineken Race to the Broadway Tower

Could you run a distance of 52 miles? (imagine running to Edinburgh from Glasgow). We know without a doubt we couldn't do it. Super fundraiser Scott Waddell however did just that taking part in the Heineken 52-mile Race to the magnificent Broadway Tower in the Cotswolds over 2 days in June. Raising a fabulous £1,980. What a fantastic effort!



## Skydive

Daredevil fundraisers raised over **£9,000** by jumping 10,000 feet from a plane. Participants who took part came from all over Scotland. Huge thanks!



## Edinburgh Night Ride

Rachel Duff – Raised over **£800**



## Stirling Marathon

Layna McKechnie raised over **£1,000**



## Perth Charity Gig

raised over **£3,500** including sales from the Trendies CD



## Plain(ish) sailing for White Water Rafter

We introduced a White Water rafting event to the fundraising calendar this year which was a great success! 13 fundraisers set sail down the rumbling rapids of River Tummel and 13 fundraisers fell in the river at some point or other! Everyone seemed to have a blast at this event and raised over **£2,000** between them.



## Amazing lady Janice Forsyth

took on a 60/60 challenge i.e. 60 days of sports for her 60th birthday. With activities ranging from rowing, darts, sumo suit racing (yes, really) to 10K runs and fresh water swimming. There was no challenge too great for Janice! A lot of time and effort went into this challenge and certainly paid off with a fundraising total over £9,500 split between ourselves and very worthwhile cause Sue Ryder. 60 challenge 2.



# In Memoriam

**We sadly lost two of our Family Branch members recently. Brian McKechnie, Fife Branch Chairperson, and Caroline Duncan, Tayside Branch Treasurer.**

## *Brian McKechnie - An appreciation by Isobel Darroch*



We were saddened to hear of the untimely passing of our dear friend, Brian McKechnie, who died suddenly in May. Brian is survived by his wife Rena, daughters Claire and Heather and two grandsons. We send our condolences to Rena and her family.

Brian worked at Blackwater Manufacturing company as an engineer for 29 years. A devoted husband, father and grandfather, Brian's passion was playing in a Kings of Leon tribute band as a drummer and was hugely involved with the group scene in Fife, where he stepped in to play drums with other bands if needed. His work colleagues and friends in the bands were deeply saddened and shocked to hear of his sudden death.

Brian and his father Bill were both part of SHA since its inception in 1989. Bill became a stalwart for many years as Ayrshire branch chairperson. Brian established and became the first chairperson of the Tayside family branch and in 1996 he then moved home and set up the Fife family branch, and remained as chairperson there ever since. Through Brian's support and dedication for over 20 years, the branch continued to be hugely successful. For many years they

held joint family outings with the Ayrshire branch in Millport, enjoyed overnight ceilidh dinner and dances at Fort William and still found time to fundraise and raise awareness of HD and SHA whenever possible.

My first meeting with Brian and Bill goes back over twenty years, when, at my first family conference two 'gents' appeared, adorned in highland regalia. They were quite a pair at these events, never missing an opportunity to support SHA where their infectious 'Joie de Vivre' never failed to raise everyone's spirits.

Jillian Foster, Senior HD Specialist in Fife, concludes:

**"I have never met such a man who would put the needs of so many before himself. His courage, determination, humour and selflessness was something that any person who was lucky enough to know him, felt. The Fife service and family branch mourn his passing and he is sorely missed by everyone. His shoes as chairperson will be very hard to fill. Brian McKechnie, you were a giant of a man and will be in all our hearts forever."**

SHA wishes to thank Rena and her family for kindly donating £809 from his funeral collection to the Fife family branch.

## *Caroline Duncan - An appreciation by Paula McFadyen*



Caroline was born in Singapore and brought up in England before she moved to Scotland where she studied Theology at St Andrew's University. Caroline held several jobs including work with mental health befriending projects and rape crisis before she had to give up work due to being diagnosed with Huntington's Disease. Despite her diagnosis, Caroline continued to do a significant amount of voluntary work and became an active member of the Tayside family branch, supporting their fundraising activities and giving up her time to be the Branch Treasurer.

Caroline was very open about her condition and regularly attended training events with the HD specialist to 'tell her story'. This allowed professionals to gain a huge insight into the challenges of living with Huntington's disease, but also inspired others by how positively she lived with her condition. Caroline helped to train a number of medical students about HD and they found her input invaluable.

She lived at home with her much loved cat Sylvester and was supported by a number of professionals who built up a close relationship with her. Caroline was diagnosed with cancer in May 2016 and had major surgery but unfortunately the cancer returned in March 2017. She continued to live for the day and made the most of the time she had left, enjoying time with family and friends and continued to think of others right up to the time of her death and her wish to donate brain tissue for research into HD was carried out.

Caroline will be missed by all her friends in the HD community and by those who worked with her. Our condolences go to her sister and dad and to her 'Dundee' family Tracey, Shaun, Nathan and Natasha, as well as her wider circle of family and friends. Many thanks to all who donated at Caroline's funeral where £500 was raised and donated to continue the work of the Tayside Family Branch.

Getting travel insurance is a common problem for people who have HD. We've had some discussion with Just Travel Cover who are an insurance broker who specialise in advising people with pre-existing medical conditions.



Here is their contact information:

<https://www.justtravelcover.com>

Telephone: **0800 231 5532**. If you contact the company and use the code: **HDSCOT8**, you will be given an 8% discount on your premium. There are other providers that you may wish to use and the specimen below is an example of quotes for someone with HD travelling to Spain for eight days. It's good to see even someone impacted could potentially still be insured. Obviously, these are only examples and premiums would be affected by a number of other factors e.g. co-morbid conditions.

## Huntington's disease example prices

### 1. Prices start at £14.50

Do you require assistance with dressing or eating or washing	Never
Has the condition caused any changes in behaviour	No
Has the condition caused any memory loss	No
How many unplanned hospital admissions has there been for this condition in the las 12 months	None
Has this condition caused any difficulties with swallowing	No

### 2. Prices start at £52.47

Do you require assistance with dressing or eating or washing	Sometimes, but not every day
Has the condition caused any changes in behaviour	Yes
Has the condition caused any memory loss	Yes
How many unplanned hospital admissions has there been for this condition in the las 12 months	One
Has this condition caused any difficulties with swallowing	Yes

### 3. Prices start at £100.74

Do you require assistance with dressing or eating or washing	Every Day
Has the condition caused any changes in behaviour	Yes
Has the condition caused any memory loss	Yes
How many unplanned hospital admissions has there been for this condition in the las 12 months	Two
Has this condition caused any difficulties with swallowing	Yes



## Congratulations to SHA trustee Marie Short

who was shortlisted for the Scottish Council for Voluntary Organisation (SCVO) Charity Champion awards on Thursday 22 June at the Edinburgh International Conference Centre ( EICC)

Marie says:

**"I was a bit surprised (=shocked) when Linda called to tell me I'd been shortlisted for SCVO Charity Champion. What does that mean?? It was simply to recognise the fundraising activities I'd been spearheading. How lovely! We had an amazing time at the award ceremony. So many inspirational people, I felt like my batteries were recharged as I soaked up their enthusiasm and humanity. I didn't even flicker when they announced Laura Young as the winner in my category. I was genuinely just blown away and humbled to be there."**



Snapshots from media stories



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