

## Financial Wellbeing Service exceed all 1st year expectations

The Scottish Huntington's Association's three strong Financial Wellbeing Service was set up with help from the Big Lottery Fund in early 2015 and since then have worked with 250 HD families in Scotland, securing an extra income for them of over £2,000 on average. At the start of April 2016, the service reached £610,000 in known financial gains for them.

These gains include awards or increases of: Attendance Allowance, Employment Support Allowance, Disability Living Allowance, Personal Independence Payment, Council Tax Reduction, Housing Benefit, Carers Allowance and Pension Credit. In addition to this, the team have provided information and advice on debt issues, guardianship, power of attorney, pensions, insurance and financial planning. The service receives invaluable support from the HD Specialist Services, our Volunteer Support Team and a mixture of local Independent Financial Advisers.



## SHA Appoint New National Care Framework Lead

The Scottish Huntington's Association has appointed a National Care Framework Lead. Alistair Haw joined SHA in January from Prostate Cancer UK where he led the charity's award winning communications and public affairs work in Scotland.

The role - which is funded and backed by the Scottish Government - will be to coordinate the development of a National Care Framework for Huntington's disease to help ensure families affected by the condition are given the best possible care, information and support regardless of where they live in Scotland.

The appointment builds upon extensive preparatory work undertaken by Scottish Huntington's Association, its supporters and partners over several years - including the publication of draft local care frameworks in two NHS Board areas. A central part of the work will be to build upon these solid foundations by consulting with and pulling together the expertise of everyone who has an interest in making a success of the National Care Framework, including HD families and a full range of health and social care professionals and organisations.

As part of a series of initial discussions, Alistair attended a recent Glasgow Family Branch meeting to listen to the views of members from an HD family perspective.

Alistair said: "I am delighted to have been given the opportunity to work on this extremely important project and look forward to listening to, and working with, all interested parties to ensure that the framework is the best it can possibly be for families affected by this devastating condition."

It is anticipated that it may take a year to develop and launch the overarching National Care Framework for HD, and a further two years to develop more detailed localised Frameworks for each NHS Health Board area thereafter.



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## SHA Treasurer, Jim Lochery



### A view from outside the kitchen window...

**My first involvement with SHA was in May 1999, when I was carrying out the audit of the accounts. I remember asking my boss what the Association did, and the answer I received was "some sort of health thing!"**

So, in addition to carrying out the audit, I tried to find out as much as possible about the Association, and what it represented. I was given some leaflets by Patricia McLaughlin, the then Chief Executive. I read those, and gained a little understanding of HD.

On my next visit to National Office (in Elderslie), I was shown a video of a man in the later stages of HD, the effects on him and his family have remained with me to this day.

I was co-opted on to the Board of Directors in 2000, and appointed as a director in 2002. My first job was to implement a more robust accounting and payroll system as the Association grew from three services to the present day total of nine, with Youth and other services being added. It is pleasing to note that the Association has grown five-fold over the past fifteen years.

I recall attending a family conference in Perth, and giving a lift to one Glasgow family member who shall remain nameless, but she knows who she is, don't you, Jan?? Oops. For almost the whole journey back to Glasgow, she talked non-stop. The message was not one of despair, but rather, one of hope. Over the years I have found the same hope and belief in all the family members I have been

lucky enough to meet. The family conference in 2015 in Fife, and the little babies born and not at risk of HD was very moving. I can say confidently to all members "You are truly an inspiration."

Recently I was diagnosed with type 2 diabetes. This will present some challenges to me over the coming months and years. I know I cannot only improve the health conditions which have led to this diagnosis, I am confident that I can reverse it to the point where I shall be diabetes free. While living with diabetes doesn't compare to living with HD, I do draw inspiration from all those wonderful people I have met about living with a long-term condition. (For the record I have lost 6kg and two inches off my waist line since diagnosis, but I could murder a Mars bar and a can of Irn-Bru).

The Association is in a fairly healthy position, in terms of its finances. It remains the leading deliverer of services to family members (as can be demonstrated by the National Care Framework work being undertaken by Alistair), and we are so fortunate to have a staff group that are totally committed to the needs of family members, and carers.

I have thoroughly enjoyed my time as a director, and grateful to my fellow Board members for their support, and I would hope to be here for a few more years to come. I look forward to meeting old friends and new at the Carers' conference in Stirling and at the Family conference later this year.

**Best wishes and Kind Regards**



Jim pictured here at a Family Conference with former SHA Chairperson, Philip Fox, Sarah Winckless, SHA Patron and Scottish First Minister, Nicola Sturgeon



## John Eden, Chief Executive...

### SHA investing in building effective partnerships to improve services and support to families

**Partnerships are an important vehicle in many aspects of life for facilitating new ventures and this is very true in the world of charities. SHA has invested heavily in building effective partnerships that improve services and support to families living with Huntington's disease.**

We have a long standing partnership with Breathing Space Scotland who provide a free, confidential and safe out of hours telephone support service that helps to ensure that families have a point of contact outside of normal office hours.

We have worked in partnership with Stirling University to develop a continuous Professional Development Module that delivers 200 hours of in-depth training and education to health and social care staff involved in the care and support of people living with the condition. There are a few

more powerful things we can do to enhance quality of care.

We work in close partnership with the European Huntington's disease Network and several of our staff are directly involved in the ENROL study. EHDN is a significant platform for current and future clinical trials and an important way for us to be engaged with and participate in the research work required to find treatments for HD. Similarly we also partner with HD Buzz to ensure that there is high quality information about all of the current research that is written in a way that non-scientists can understand.

Our Youth service partners with HDYO who have the most comprehensive web site providing information to young people and parents about living with HD.

The most significant and long-term partnerships the charity has are at a local level with NHS and Local Authority colleagues. Where would we be without the clinicians who run clinics throughout the country and play such an important role in symptom

management. This year we are developing a National Care Framework for Huntington's disease and one of the foundations that will help to ensure that it is successful are the myriad of local partnerships that our network of staff have built over the years.

In April a small contingent is travelling to meet our colleagues at the HDA of England and Wales where we will discuss joint fundraising, awareness raising and other areas where we can work together to increase the impact of our work for everyone living with HD.

Partnerships work means that our small charity can have a much greater impact, but for me the most important partnership of this charity is the one that exists between the staff and families that comprise SHA. At the heart of everything we do, it has always been that unique synergy which has driven the success of SHA.

## Karen Sutherland, Operations Manager, Adult Clinical Services



**The Adult Clinical Service Team's (ACST) have all been working very hard developing services and supporting families within their local communities. Despite a few of our staff having to take unplanned extended sick leave this year, the teams have admirably kept things going.**

We have recruited a further two new members of staff since the last issue of SHAre. A warm welcome to Elizabeth Farnham (Lizzie) the new admin / resource worker who joined the Lothian team at the beginning of March and to Lindsay Wilson our new Huntington's disease Specialist for Angus, who took up post recently. Lindsay comes to us with vast experience in HD having been a senior staff nurse at Linlathen Care Home. She replaces Alison Tonner who left in December. We wish Alison well in her new venture.

Liz McConnell and John Eden met with Contracts Managers from Perth and Kinross Council, Dundee City Council, Angus City Council and Tayside Health Board to discuss amalgamation of Tayside and Angus Specialist Clinical Services for Huntington's disease. The result being that the proposal was accepted, therefore Angus and Tayside will now function and be managed as one service, namely Tayside.

We are planning a SHArp event early in the summer and will be inviting all nursing home managers to attend with the intent of sharing information on our SHArp (SHA Registered Provider) accreditation scheme. Invites will be sent out this month.

## Youth Service



One young person stated **"It was great to spend time with friends, and getting to know and meet new people!"**

The session was a great mix of activities and structured group work sessions where the young people could learn about 'Positive Mental Health'. In the afternoon, staff from Low Port took the group "Pioneering" – where they found out how to build a bridge, use a compass to find their way around the Forrest, and build a stretcher.

In the evening, a Complimentary Therapist joined us for a session teaching the young people mindfulness and relaxation techniques.

**During the Easter Holidays, seven young people from Edinburgh and Fife visited Edinburgh Zoo. It was the first visit to the Zoo for some of them and they all had a great day out. They had excellent weather and everyone enjoyed watching the animals, with the penguins taking top billing, especially the 'penguin parade'!**

### SHAYP's 8-12 Group residential

For the first time ever, 12 young people were offered the chance to attend SHAYP's 8-12 Group residential, which was held at the wonderful Low Port Outdoor Centre in Linlithgow. The young people had a great time.

Another young person commented **"I have learned loads - I learned relaxation techniques that I can take home and use to feel better!"**

This residential was a great opportunity for the young people to have a break from their caring responsibilities and having fun with others who understand their situation. SHAYP would like to thank all of the young people for coming along and making it a huge success. We would also like to thank Starbuck's for their funding contribution for this event!

The next 8-12 Group is on Monday 2nd May and SHAYP would be delighted for anyone aged between 8-12 to come along and join us for the session. Contact Grant Walker [grant.walker@hdscotland.org](mailto:grant.walker@hdscotland.org) for more information.

## Highlighting the work of the SHA Youth Project at Westminster

**Fife MP, Roger Mullin, recently highlighted the work of the SHA Youth Project at Westminster.**

Chloe Mullin, pictured here with Mr Mullin and Peter Carruthers, Specialist Youth Advisor, gave an overview of group work and individual support she has received through SHAYP to Mr Mullin at a meeting in Fife. As a result of the meeting, Mr Mullen raised an early day motion in parliament to support the work of SHA.

Chloe said at the meeting **"The more people who know about HD, the more awareness there will be about how it affects people"**

Mr Mullin's motion attracted signatures from 27 MPs.

Mr Mullin added **"It was a privilege to hear their stories and understand how I could raise awareness of the benefit youth work in SHA has for young people."**



## Exciting News for Carers

Our unique online support forum for HD carers was launched at the end of February with an initial pilot in Lanarkshire. This provides a confidential, secure and anonymised forum for carers to share and support one another as well as interact with related SHA staff. So far, it has proved to be a growing success, especially with those carers who are unable to physically attend their local support group meetings. Thanks are due to the carers who use the forum and to our Lanarkshire HD Specialist service, Isobel our Peer Support Officer and to two of the volunteers from our Huntington's Online Services Team (HOST). Craig and Mark (pictured here) are responsible for the design, development and the on-going technical support for this great resource - thank you both!

We will be evaluating the forum soon and reporting back at the forthcoming Carers' Conference in May. If you're going to the conference, keep a look out for Mark and Craig - great lads!



# Writing Out of the HD Shadow



At Scottish Huntington's Association, we believe that one of our biggest challenges is just being heard. In a recent study, we discovered that only 23% of Scots know what Huntington's disease is. We aim to change that. We want to give the HD community a voice and get the rest of the world to sit up and think about HD. We're starting in HD Awareness Week 2016 with our brand new campaign; Writing Out of The HD Shadow.

Working in conjunction with the Scottish writing community and the Scottish Association of Writers, we are launching a flash fiction competition. Flash fiction, or "drabbles" are very short pieces of fiction, no more than 150 words, which really test the writer's ability to concisely tell a story in a powerful way. We will be challenging writers to tell an HD related story through flash fiction, and will be giving out cash prizes of £500, £300 and £100 to the winners, along with framed copies of their entry. We are also running a parallel competition for under 16s with a prize of £100.

The competition will be open to anyone, whether they are writing from their own experience, or learning about HD as they write. We want to use the power of fiction to get people talking, and make people really care about Huntington's disease and we hope that the HD community will be able to help us do this by supporting our campaign. We'd love for you all to write for us, and if you don't want to do that, then talk to your friends, neighbours, colleagues and family. Spread the word, because the more people talk, the more awareness goes up!

The competition will go live in HD Awareness Week, which runs from 6 -13 June 2016, when we'll launch our competition website at a special event, and will run through until September 2016.

If you want to find out more, then email Sally at [sally.brewer@hdscotland.org](mailto:sally.brewer@hdscotland.org) or call on 0141 848 0308.

## Flash Fiction

written by a young person affected by HD.

### Blue Eyes

I stood beside Dad at the door; the two of us stifled tears as two care workers helped Mum into the ambulance

'You're my Patrick Swayze,' she said.

'You're my Madonna. You're three times a lady,' Dad said, the words catching in his throat. Grief welled inside me.

We watched until she was out of sight and went into the kitchen where he lifted a glass of milk; we both pretended to ignore the smell of vodka.

'You are so like her Blue Eyes.'

'Don't say it. Not again.' Every time is like a punch in the chest.

He turned away and banged his fist on the kitchen table.

'I can't help that I look like her,' I yelled and ran to my bedroom, throwing myself onto the bed and sobbing.

I hear him crying too. My family will never be the same again.



## Royal Honour for SHA's Patron

Olympic champion rower and our Patron Sarah Winckless has been made an MBE by the Queen. The honour, for her services to sport and young people, was presented at a ceremony in December.

Sarah said "Firstly, receiving the MBE still feels unreal. I have been supported by so many people over the years and it means it really is a team effort. Getting my MBE from the Queen at Windsor Castle was really special. Mum was one of my guests and we got to see some unusual parts of the Castle while we found a lift that would fit her wheelchair in, then, waiting to meet the Queen was a little like waiting for a race, both wanting to savour the moment and not wanting to get it wrong. As it was she was kind and interested and she wanted to know about Huntington's and our community and how I thought sport and activity might help us. My medal will be something I treasure, but the memory of the day and those who have been part of the journey are the most important part for me."

John Eden added

"This is a well deserved recognition for the work Sarah has done to encourage young people in sport. We are extremely lucky to have her as Patron and for the work she carries out on our behalf both to raise awareness of the work we do and for her fundraising efforts."



# Research Extracts



**The 11th Annual CHDI (Cure Huntington's Disease Initiative) held its HD Therapeutics Conference in February in Palm Springs. It is the biggest gathering in the world of leading scientists who are trying to develop new treatments for HD.**

**Tom Vogt**, vice president of Discovery and Systems Biology at CHDI, updated the audience on CHDI's efforts to better understand HD, reminding everyone of a huge study published this year that revealed genes which modify HD age of onset. (Even though every patient with Huntington's Disease has a mutation in the same gene, the age at which HD patients develop symptoms varies widely). He said "These genes

might help us better understand how HD happens, but also provide important "targets" for drug hunters. To make this breakthrough, the research team required DNA samples from literally thousands of HD patient volunteers."

## DNA and RNA (ribonucleic acid)

**Steve Horvath**, from UCLA (University of California), discussed the chemical changes in DNA that happen in ageing. One of these chemical changes is so reproducible that he has shown it can be used like a clock to predict the age of a cell. Using this genetic clock, he found that different parts of the body "age" at different rates. So what about brain samples from people with brain diseases like HD? Do brains of HD patients age faster than people without HD? Using this method, he did find they look older than they should.

**Ray Truant** (McMaster University) is interested in understanding what the huntingtin protein does normally, and how the mutation that causes HD changes this. Truant has discovered that a chemical called kinetin helps keep mutant HD cells healthy. In his lab, they have done extensive experiments which suggest that the Huntingtin protein might be involved in DNA damage. His hypothesis is that kinetin helps the mutant huntingtin protein do its job better in responding to DNA damage. He hinted that the huntingtin protein might play some role in DNA damage and proposes to study kinetin as a potential therapy in HD.

## Research Request



**Rosie McLean, PhD student, School of Life, Sport and Social Sciences, Edinburgh Napier University.**

Rosie wrote to SHA requesting that we ask if anyone who is **at risk** of developing Huntington's disease would like to participate in a research project.

Through this project they are investigating symptoms of Post-Traumatic Stress Disorder (PTSD) and potential protective factors against the development of these symptoms, as well as at substance use in the at risk population.

Participants must be at least **16 years old** and have **one parent who is confirmed as having HD**.

The study involves completing one questionnaire which asks about stressful life experiences, psychological resilience (coping), anxiety & depression symptoms, and substance use. Participation should take approximately 15-20 minutes.

All questionnaires are anonymous and the results are completely confidential.

If you are interested in participating in this study, please contact the primary researcher (Rosie McLean), who will provide more information and arrange for the questionnaire to be sent either by post or by email.

If you have any questions you would like to ask or just require further information, please get in touch with Rosie directly on:  
Email [40188064@live.napier.ac.uk](mailto:40188064@live.napier.ac.uk) Telephone - **07944292463**

## Research Report

### The Third Sector and the Shaping of Services for Huntington's Disease in Scotland

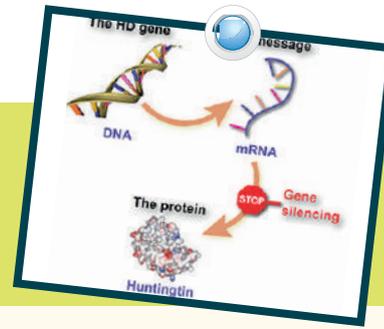
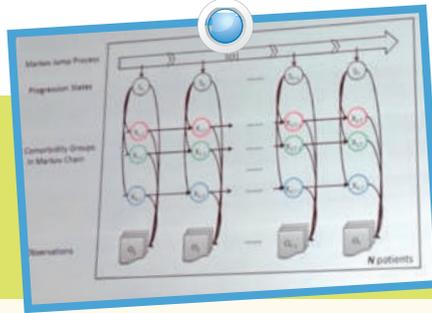
This research explored the role of 'third sector' health organisations – not-for-profit patient organisations. In recent decades, social scientists have been interested in the growing involvement of third sector groups within all aspects of health and health care. In particular, it focused on the case of services for people with Huntington's disease.

Huntington's disease services are an area within which multi-professional, multi-sector services exist to provide clinical support and community care for people living with HD within a small and closely connected health system. It involves the intersection of numerous types of specialist expertise, professional roles and organisational cultures under health policy that strongly encourages 'partnership'.

### HD as a Case Study

A multi-methods qualitative research framework was used to gather perspectives of key individuals working in the Scottish HD and wider health scene. Fourteen semi-structured qualitative interviews were carried out with professionals and an individual connected to HD over the period of 2012-2014.

While the focus of this research was solely on formally provided services, it should also be acknowledged that informal, unpaid caregiving involving friends and families is a significant and valuable part of care for many people with HD and other long term conditions.



### Gene Silencing trial - Trial Design

Sarah Tabrizi (University College London) spoke about the HTRRx-CS1 'gene silencing' study that she's leading with Roche and Ionis. This trial is investigating whether "antisense oligonucleotides" (ASOs) that reduce levels of the huntingtin protein are safe. Because ASOs can't get into the brain on their own, they have to be delivered by infusion into the spinal fluid around the brain. This is done by infusing the drug into the spinal fluid using a thin needle every four weeks. The estimated study completion date is September 2017.

Professor Tabrizi said **"The safety board has allowed us to move to the higher dose of gene-silencing drug. This means there were no safety concerns in the first group of patients."**

### Genome editing

Via videoconference, Feng Zhang, Professor of Biomedical Engineering, addressed the meeting on the topic of 'genome editing'. Scientists once believed that we were stuck with the DNA we were born with, but new technologies make it possible to edit DNA. Zhang has conducted pioneering research with the most widely-used genome editing tool called CRISPR/Cas9, (The functions of CRISPR (Clustered Regularly Interspaced Short Palindromic Repeats) and CRISPR-associated (Cas) genes are essential in adaptive immunity in select bacteria and archaea, enabling the organisms to respond to and eliminate invading genetic material)

### Basal Ganglia

**Ann Graybiel** (Massachusetts Institute of Technology) is amongst one of the world's foremost experts on a part of the brain called the **basal ganglia**. The basal ganglia are important for HD because they're the most vulnerable part of the brain in the disease. The most obvious job of the basal ganglia is to help regulate movement - that's why HD patients have distinctive movement problems. But scientists increasingly appreciate that these bits of the brain also play an important role in regulating moods and emotions. Graybiel is interested in whether emotional problems in HD, like depression, might be due to dysfunction of the basal ganglia and is now making tools that will let her study how the circuits she's identified are affected by the HD mutation.

### Lab Notebooks Online

A surprise presentation with an exciting new effort from Dr Rachel Harding, of the Structural Genomics Consortium. She's interested in opening up the process of science - and has taken the very brave step of opening up her lab notebooks online. Anyone who wants to follow her experiments can catch up with what she's doing every day at her website **Lab Scribbles** or follow **@labscribbles** on Twitter. It's a brave adventure in "open science".

For the full feedback on this year's Palm Spring Therapeutics Conference, written by Dr Ed Wild and Dr Jeff Carroll, please go to [www.HDbuzz.com](http://www.HDbuzz.com)

### The three bodies at the core of the provision of Scottish HD services are

- 1) the public sector via the NHS
- 2) public sector local government social care services and
- 3) the third sector embodied through the Scottish Huntington's Association

### Main Findings

The research reveals that third sector organisations within Scottish Huntington's disease services have taken on extensive partnership roles and that alongside this it is evident that important aspects of the healthcare scene are being shaped.

Partnership arrangements such as those within Scottish HD services are also shaping concepts of health conditions themselves, through changing and expanding the way that conditions are defined. The combination of different types of expertise, a common feature within care for complex conditions such as HD, leads to multiple viewpoints of the same condition and the way it should be managed. The involvement of partners who have a wider remit and understanding of a particular condition - such as the third sector HD specialists within the current research - allows these individuals to expand and inform the realm of needs and support for people with that condition. This in turn is likely to affect some aspects of patient and family experience of an illness, through changing the nature of their encounter with care and support services.

The key themes of the findings that emerged around the shaping of 1) organisations, 2) identities and 3) conditions can be interpreted as being part of processes of boundary work between the different organisations in health. At all the different levels discussed within the research findings - organisational culture, individual professionalised identity and ideas of support - expertise was also being developed and used by the third sector professionals involved through their work with patients and their families.

### Implications of the research finding for future policy and practice

In focusing on the cultivation of expertise by third sector professionals, this research contributes a new perspective on the role of the third sector as a resource and an asset in complex care co-ordination.

Edited version of *'The Third Sector and the Shaping of Services for Huntington's Disease in Scotland'* by Tiorion Seymour

To obtain a copy of the whole report, contact [isobel.darroch@hdsotland.org](mailto:isobel.darroch@hdsotland.org)  
Or call **0141 848 0308**



# Family Branch/Support Group

Isobel Darroch - Branch/Support Development Officer



As ever a huge thanks to all our volunteers within the groups who do a tremendous job to ensure the much relied upon groups continue...

**Fife branch** held their annual ceilidh once again in Fort William's West End Hotel. After fifteen years of being the front runner in organising this event, Hector Henderson, known as Hecky, and his wife Belle, have decided to step down. To date the ceilidh dinner/dance has raised over £15,000. A huge thank you to them and everyone at the branch who have been so supportive over the years. The branch's next event is on 29 May, where they travel to Millport by bus and enjoy a day of fun and relaxation. If any family member would care to join them, please call Isobel on 0141 848 0308 for more details. The Culross Fayre where Fife have a stall is on 21 August from 10-3pm, please pop along to their hugely successful Tombola Stall. Thanks to family member Rose Knight, who held a T for HD and raised £620. And finally there will be an HD fundraiser at the Thrift Shop in Methil during our awareness week of 8-13 June. Volunteers willing to help out for a few hours and any donations of goods are more than welcome!



**Lothian Branch** 2016 started with a bang. The annual duck race in Bonnyrigg was the best yet. Organised by Bill MacDonald with half of the proceeds going to the family branch. The weather gods were very kind to them that day.



The group had its annual lunch out at Gigi's Restaurant, also in January. It was a lovely afternoon and everyone enjoyed it. Their AGM was in April, and their summer outing will take place once again on a barge along the Edinburgh Canal at the end of June. A very popular choice for the family group.

**Tayside Branch** David McNiven shares his visit to the Coupar Angus charity boutique in Tayside.

On Wednesday 30 March myself and Fundraising Officer, Gemma Powell, visited Coupar Angus to pop in and see the charity boutique, run by family member Mary Cunningham and her eager group of volunteers. I had heard so much about this boutique since I took up my post as eBay Co-Ordinator last year, but no amount of description could properly prepare me for seeing them in action. A lively and enthusiastic group of volunteers were more than happy to greet us. The shop has everything from books, clothing, ornaments and place settings; the boutique really does have something for everyone. Neither Gemma nor I left empty handed and even bought some home baked goodies to enjoy on the drive home.



The level of dedication from each person involved really is inspiring. The hard work really does pay off as the boutique has raised over £25,000 to date! A huge thank you goes to Mary and her team.

The SHA charity shop which operates five times a year for one week, will be opening again on Monday 20 June at 9 George Street, Coupar Angus. Always worth a visit!

**Forth Valley Family and Friends** had hoped to have a well deserved evening out, but unfortunately due to group member's circumstances, have not been able to organise a date yet. Their next meeting in May is when they will be holding their yearly AGM and will have pizza and nibbles to enjoy. Any family member within the Forth Valley area is more than welcome to go along to the meeting at the Heritage Rooms, Milton Row, Duncaple on 3 May from 7-9pm



**Glasgow branch** enjoyed meeting Alistair Haw, National Care Framework Lead, at their meeting in February. (see front page article) Hugely supportive to each other, as ever, they welcome family members from Glasgow to join them at their monthly meetings on the 4th Tuesday of the month. Contact Isobel at Head Office on **0141 848 0308** for details.

## Dates for your Diary

### The Carer Conference...

Invites have gone out for the Carers' Conference, which is being held for the 5th year running at the Golden Lion Hotel, in Stirling on 18/19 May 2016. Contact National Office on **0141 848 0308** if you are an HD carer and haven't received your invite yet.



### The Family Conference...

The Family Conference is on Saturday 22 October 2016 at Inchyra Grange Hotel, Polmont. This will be a one day event and notification will be sent out in due course.



# Another Successful Fundraising Year



## Dougie Peddie Fundraising Manager says...

Looking back on the past twelve months gives us all great hope for fundraising in the new financial year. The contribution our community fundraisers, led by Linda Winters and Gemma Powell, have made to the excellent year end results is testimony to the hard work and dedication of the hundreds of individuals raising money to help families living with Huntington's disease. The new community fundraising strategy is proving to be enormously successful and a big, big thankyou is extended to everyone who organised an event to raise much needed funds for the Association.

A huge range of fundraising events are on offer over the next 9 months; such as SkyDives, Zip Slides, Abseiling from the Falkirk Wheel and a SHAvengers themed Bootcamp! Information on all of these can be found in our latest fundraising leaflet. Call the Fundraising team on 0141 848 0308 to obtain one.

The Lucky Lotto membership increased during the year. Regular Giving and new PAYE donors signed up following our Leap4HD campaign on 29 February 2016 which as you know was Leap Year day.

Individual giving was boosted enormously in 2015 by the £200,000 donation from an anonymous donor in England. Legacy and Life Celebration donations remained steady throughout the year. The 2015 Christmas Tree Appeal was very successful and the next appeal, a Grand Summer Raffle, is already in the planning.

## Sarah Kernahan

Trusts and Grants Officer, commenced maternity leave and wee Jeanie arrived in January 2016.

While Sarah is away until October 2016, Dougie, Sally and Gemma are continuing with trusts and grants applications, which so far is proving very beneficial. Two really exciting grant awards were received from Scottish Government recently - £73k from the Adult Community Care Grant Scheme, Section 10, for core costs and £40k from the Children, Young People and Families Fund for SHAp. These awards are payable annually over the next three years, which ensures healthy financing for the Association.



## Handover for Huntington's

An easy way for people to help out is by taking one of our Handover for Huntington's Huts (which I hope most of you will have seen or heard of!) Last year we had 150 of them especially made for us and I'm happy to say that to date we have more than half out in the community, to companies and homes, but we are always happy to 'Give a Hut a Home'. Contact [david.mcnicven@hdscotland.org](mailto:david.mcnicven@hdscotland.org) or call **0141 848 0308**.



It has now been over a year since the eBay@SHA store first began. What started as a trickle of goods in March last year has now grown out of all expectations. So much

so that my role has been made permanent. I will be running and developing the eBay shop further; setting up pop up shops and managing bucket and can collections. It has been a wonderful experience coming in to SHA and meeting so many dedicated and hardworking individuals, volunteers and colleagues. I look forward to continuing another year of fundraising for such a good cause!



David McNiven pictured above.

Erin McCarthy's six month Community Job Scotland placement came to an end on 31 March 2016 and everyone was saddened to say farewell. Erin developed a fantastic skill in digital design and provided really creative artwork for the fundraising team to advertise events.



**Kim Kemp** the new Administrative Assistant at the National Office joined the team on Wednesday 6 April 2016. Kim has a wealth of experience in the field of disability after working with the charity **Momentum Skills Scotland** as a Senior Administrator in Clydebank for over 9 years. Kim also acted as a PA for **Scottish Paralympian, Michael Kerr** and was actively involved in volunteering and fundraising with the **Glasgow Wheelchair Rugby Club** scene for a couple of years. She was also a volunteer administrator with **CancerBacup**.

# An Appeal to Share your HD story



## Sally Brewer Fundraising Officer explains

"Each year, the fundraising team raise around £500,000 for Scottish Huntington's Association. Of course, huge amounts of that come from you, our supporters, who we are endlessly grateful to, but about £200,000 comes from a totally different source; charitable trusts.

Each year, we apply to hundreds of Trusts & Foundations; generous organisations who give money to support charitable work. Each time we apply to these organisations we are competing with other charities, often for limited pots of money. The trustees of these charities, who make the decision about where to allocate funds, often know very little about Huntington's disease or the work we do before we contact them.

It is therefore incredibly important that we make the strongest case possible to win their support. The best way to do that is to provide real stories about what it is like to live with Huntington's disease and examples of the difference support from the charity has made.

## Could you share your story with us?

We are looking for family members who are willing to tell us their HD story and to talk about the difference support from the charity has made. It will be up to you to decide how we use your story and we know that not everyone will feel comfortable sharing them publicly.

When supporters offer to share their stories with us, we will ask them to fill in a form, which records the purpose they want us to use their stories. Some people may prefer that we only use their stories for Trust applications. This means that we will only send your story with funding applications and only Trustees of the Trust or Foundation will see it. If you are comfortable, we would like to use your story for more public documents, for example, our fundraising handbook, which is distributed to our supporters to support them raise funds for our work.

If you prefer to remain anonymous, your story would be used in confidence. It really would make a difference to our applications.

To share your story, just give me a call for a chat on **0141 848 0308** or email Sally at [sally.brewer@hdscotland.org](mailto:sally.brewer@hdscotland.org)

Thank you so much for taking the time to consider this request".

## Que Sera, Sera...

**Our volunteers couldn't really say anything else on Saturday 2 April when we all turned up raring to go on the zipline to find out the crane hadn't even arrived yet.**

However what appeared to be a bad situation turned out yet another fantastic day.

While they waited to hear news of whether it was going ahead, the jumpers made most of the time grabbing a Starbucks and sharing stories of previous fundraising fun. The participants eventually whizzed across the Clyde about 6 o'clock with great success and everyone went home in high spirits.

The next zipline is on **10th September**.



## Dates for your Diary...

### Skydive

Fife Airport Glenrothes, Saturday 4 June

### SHA Walk of Hope

Throughout August

### SHA Avengers Skydive

Fife Airport Glenrothes, Saturday 13 August

### Abseil

Falkirk Wheel, Saturday 3 September

### Zipline

River Clyde Glasgow, Saturday 10 September

### SHA Avengers Bootcamp

Catrine House, Mauchline, Saturday 17 September

## Our Achievements...

- SHA secured funding from Community Health Partners to extend our Glasgow HD Specialists to include all Greater Glasgow & Clyde.

- SHA secured five years funding from the Big Lottery Fund for our National Youth Service (SHAYP).

- SHA secured three years funding from the Big Lottery Fund to deliver our new Financial Wellbeing Service.
- SHA partnered with Stirling University and developed an innovative Continuous Professional Development Module, the first in the world.
- SHA won the Scottish Council for Voluntary Organisations, Charity of the Year 2015. Partnership Working Award for our work with Stirling University.
- SHA partnered with the Chief Scientists Office Scotland and the R S Macdonald Trust to develop a three year clinical research fellowship.
- SHA secured £60,000 of funding from Scottish Government to construct a National Integrated Care Framework for Huntington's disease in Scotland.

- SHA created a new Short Breaks Fund to enable people living with HD to reduce stress and improve quality of life;
- SHA created and piloted a Nursing Home accreditation scheme and our first nursing home was accredited in May 2014.
- SHA achieved the Volunteer Friendly Award; The Scottish Quality mark for volunteering services.
- SHA secured £40,000 for the next three years for SHAYP from the Children, Young People and Families Fund.
- SHA Secured £73,000 for the next three years from Scottish Government's Section 10 funding for core services.
- SHA initiated an eBay On-line Store which has raised £9,000 in the first year and will be developed over the next twelve months.
- SHA's Community Fundraising Strategy has seen the greatest increase in generated income since the charity started in 1989.
- SHA created the volunteer led Huntington's Online Service Team (HOST) to redesign and manage the web site.

# Thank you Fundraisers

We would like to thank everyone who has helped in many ways and raised awareness of Huntington's disease and vital funds; unfortunately we cannot include every photograph. Here are a few of our wonderful fundraisers and what they have been up to...



**Philip Lister, Great Wilderness Challenge raised £1,500**



**Lisa Carrigan, New York Marathon raised £1,800**



**Elka McLean, M&S Bag Packing raised £350**



**ABC Minicoach Hire Edinburgh, Car wash raised £250**

## Thank you Sarah Pringle...

A Glasgow City College student has recently chosen to support us alongside her events course students. Sarah has also signed up for our zip slide event and to volunteer at any future events. This is a great way for her to gain event experience and improve her career prospects.

If you would like to find out more about how you can get involved, please contact Linda Winters on **0141 848 0308** or by emailing [linda.winters@hdscotland.org](mailto:linda.winters@hdscotland.org) who will be delighted to meet up.

## A Wheely Great Abseil event...

We are organising our first ever abseil event off the Falkirk Wheel on Saturday 3 September and are nearly at maximum participation with only a few spaces left! All that we ask is that you raise a minimum of £175.

There is something for the whole family to get involved with and everyone taking part will receive a free pass to the wheel, along with a certificate and medal.

We are running the event in partnership with Muscular Dystrophy UK.

An exciting challenge for SHA so please contact Linda on **0141 848 0308** or by emailing [linda.winters@hdscotland.org](mailto:linda.winters@hdscotland.org) to book your space!



**Do you have an interesting fundraising story to share and would like to be included in the next newsletter?, Please send your photographs and event details to [linda.winters@hdscotland.org](mailto:linda.winters@hdscotland.org) We will try our best to print as many stories as we can.**



## Overseas Challenge to Nepal

Well its official, three amazing like minded women are embarking on a life changing experience and heading for the Himalayas in Nepal on Sunday 13 November 2016 ...

Linda Winters (Community Fundraiser) Marie Short (SHA Trustee) and friend Sharon Kinning are organising an 8 day trek of the Himalayas and raising funds for Scottish Huntington's Association. Both Linda and Sharon will split their funds 50/50 between SHA, Diabetes UK and Cancer Research.

Marie said "My aim for this year is to include some challenging fundraising. Sharon Kinning & I had committed to do a marathon last year. It didn't happen; her dear partner Chris was stopped in his tracks with a very cruel lung cancer that killed him in a matter of weeks. For me, I'm still HD positive, on the Board of Trustees at Scottish Huntington's Association and still working hard to stay on top of my mental health. The key, I believe, is that it goes hand in hand with the physical. So, I am taking on a big, fat Himalayan trek in Nepal. I'm thrilled to tell you Sharon agreed. And Linda Winters (SHA Community Fundraiser) is coming too".

You can sponsor me on Just Giving: [www.justgiving.com/Marie-Short2/2](http://www.justgiving.com/Marie-Short2/2) or Text MSLN99 £xx to 70070. HUGE thanks for your support.

Sharon said "I have two motivations; the first is Marie Short, what an inspiring friend. I know it's a hard journey for her but she does so much for others and takes such a positive view on life. She is someone who is a pleasure to know. My second reason was the loss of my partner Chris to cancer last year; he was 44 and had such a lot to live for".

[www.justgiving.com/teams/BigNepalChallenge](http://www.justgiving.com/teams/BigNepalChallenge)

Linda said "I have two motivations. Firstly, from my personal point of view, due to research funded by Diabetes UK, my daughter has a life saving insulin pump and I am passionate about everyone who needs one gets one. In my professional life, I have witnessed first hand the impact that Huntington's disease has on families living with the condition and the lifeline services the charity offers. I believe by taking on my biggest and life changing challenge, I can do a little to help by giving something back to both charities. I feel truly honoured to be joining these inspiring women on this incredible journey".

Exciting times ahead! You can follow our journey on [Facebook](#), [Instagram](#) and [Twitter](#).



## Some good news about Leap4HD!



**Dougie, SHA Fundraising Manager, and his wee brother "Oor Willie", Leaping for HD in the Italian Alps on 29th February 2016.**

We have some fantastic news. The first three

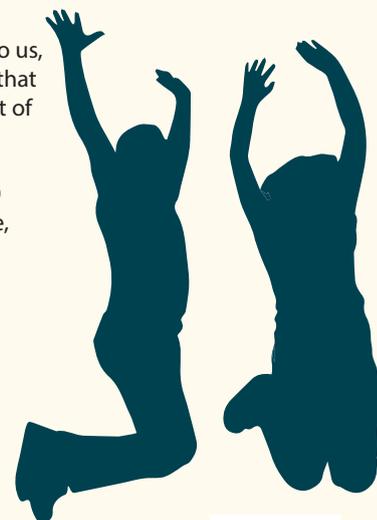
donations from the people who made the Leap4HD have come in! Three of our fantastic supporters approached their employers and asked if they ran a Give As You Earn Scheme.

Those employers did, and those donors now give to us, direct from their pre-tax pay packet, which means that that the tax that would have been paid on that part of their income is coming to us instead!

Scottish Huntington's Association will receive £840 over the next year from those new donations alone, which will make a massive difference, and we're hoping this is just the start.

Thank you to those who made the leap. And remember, if you work, there is still time. Ask your employer to help you Leap4HD!

For more information, email [sally.brewer@hdscotland.org](mailto:sally.brewer@hdscotland.org) or call Sally on 0141 848 0308.



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