



scottish
huntington's
association

SHAve



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SUMMER 2014



Spirit of Scotland...

To celebrate the Silver Jubilee of SHA, Wellbeing Volunteers are raising awareness of HD by producing some stunning photographs alongside some of Scotland's most famous landmarks.

Stuart King, pictured here, stands proudly at the iconic Eilean Donan Castle in the Western Highlands, as part of what we called our "Spirit of Scotland" event.



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Matters from the Chair

Philip Fox - Chairperson



Looking back over my diary these last 4 months since the spring SHAre, is all it takes to make me realise how active SHA has been during this celebratory time of 25 years existence!

We held a Business Breakfast (see story below); Family Branch tree planting events; HD Balloon releasing; HD Awareness week; Film Event; 'Roon the Kitchen Table' for staff. Our fundraising locally and nationally has grown out of all expectation. There was a huge achievement for our SHApp, securing £790,000 funding from the Big Lottery for its youth work. (see SHApp update page 8).

We also had achievements in Training, notably Linlathen Care Home Accreditation success and now going into autumn, we have expectations of the new Stirling University HD module course soon to start in September.

There has been continuing progress with the Wellbeing Volunteer service and we have a better control of SHA financial setup, both at family member and national levels.

What fantastic vibrancy we are experiencing with promise of much more to come. Small wonder that the June board meeting, which was our first since the start of our new financial year, was almost full of overwhelming reports of the Association's vitality and visions for the future, inspired, as always by the single-minded dedicated focus of John, our CE.

What will the next 25 years bring? Will we have a cure for HD; can we better our services; improve training and have a more comprehensive awareness of the needs of all affected by HD. May we be united in all the projects that lie ahead!!

Philip

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Cover picture.

Stuart King, stands proudly at the iconic Eilean Donan Castle in the Western Highlands

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Business Breakfast with Sarah & Katherine



The Business Breakfast meeting at the Corinthian Club in Glasgow on 11 June went extremely well.

The event was well attended and representatives from businesses were clearly engaged by the presentations. Our patron Sarah Winckless and her friend, Olympic Champion, Katherine Grainger were two of the delegates from SHA.

Sarah gave a personal account of HD, which was very moving. We received many offers of support and an initial £5,000 was raised by the event, with

a number of companies committing to fundraise for us this or next year and several indicating that they may consider us for their charity of the year. We also received offers of help 'in kind'. It was a great outcome and an important first step to building relationships with companies.

If you do have connections to a Scottish Business, please get in touch with Head Office on 0141 848 0308. We are happy to meet face-to-face with them to talk about HD and the work of the charity.



John Eden, Chief Executive writes...



“Monday 8 September will see the beginning of a Continuous Professional Development Module at Stirling University. The course is called ‘Supporting people living with Huntington’s disease; an empowering approach’. It may not be the snappiest title in the world, but it does capture a fundamental part of the ethos of the charity which is that enabling families to retain as much control over their lives and for care to be centred around them as individuals is an essential part of caring for people living with HD”

The course is an important milestone for the SHA. It sets out a programme of 200 hours of education and training at university level and will equip participants with an unprecedented level of knowledge and information about the condition.

In itself that’s an important goal because it can only serve to improve the quality of care that people living with HD experience. However the course does much more. It raises the status of Huntington’s disease as a condition

and signifies that our understanding of how to support people effectively has come far enough that it is now possible to produce an evidence based approach that enshrines the key tenets of care.

One of the most important things that this charity can accomplish is to increase the capacity of other agencies to provide good support and one of our most important tools is training and education, and within that we are establishing the ideas, concepts, key knowledge, models, approaches and unique learning of the HD community.

It will be the promulgation of these learning memes (ideas and concepts) that very powerfully will shift the landscape of understanding about HD in the coming years.

Working on the CPD module, we were acutely aware that there is much that still needs to be evidenced and understood better and the module must be a living, breathing entity that grows as our understanding of how to care for people living with HD and their families grow, but for the first time we have built a solid learning platform from which we can build a stronger national understanding of this condition.



Financial Wellbeing Service

Over the last few years during our discussions at ‘Roon the Kitchen Table’ thoughts have often turned to the many financial challenges that face families living with HD. Whether it’s navigating the complexities of the benefits system, dealing with debt, making financial plans or getting access to financial products like insurance - there is a great deal to cope with.

John Eden concludes....

“ It gives me great pleasure to announce that the charity made a successful bid to the Big Lottery Fund to set up a three year project called the Financial Wellbeing Service which will commence in January 2015. The £357,000 grant will allow us to employ three Financial Wellbeing Officers who will be based at National Office, Aberdeen and Edinburgh and who will have the capacity to visit at home as well as give advice by telephone and email. The service will be available to everyone living with HD in Scotland and we are keen to give support not just to people living with symptoms of HD and their carers, but also those living with the genetic risk; particularly in relation to financial planning and accessing financial products. ”



Sue Beevers HD Service Development Manager North/East

“At the time of writing, we are reaching the closing date for applications to study our exciting new University

Course on HD, commencing in September and running annually in partnership with Stirling University. (See article, page 3). We have exceeded our target for the course to run viably and we already have interest for the cohort next year.

Enormous gratitude to Alison Tonner, HD Specialist in Angus, who kindly took on extra hours to her part time contract in order to research and contribute to the learning materials which will be used for the HD University course. Alison has done a terrific job”.

News throughout the North East:

Highlands: The service is pleased to say that they have successfully undergone an annual monitoring visit from Highland NHS, with no recommendations or requirements for action. As well as this the service are actively involved in supporting local families with fundraising.

Grampian: A warm welcome to Liz Fraser as full time Senior HD Specialist who started in April. Liz has a wealth of experience in nursing and HD and has already made a hugely positive impression on the service.

Tayside: In conjunction with the Angus Service, the team has been working to develop further the Euro HD and symptom management clinic. The benefits of this include speedier access to specialist support and referral, reduced appointment waiting times, as well as accessible research opportunities for local clients.

Fife: The team are very pleased to be developing further support groups for the Fife area including early symptomatic, which is now well established. They continue to work with other providers in order to increase the range of support for those with HD, including training for 24 hour care settings.

Lothian: We were sad to see Carrie Ho leave the service for a new role with Lothian NHS; however we can announce that Trevor Law is the new HD Specialist and will be taking up his post in September. He will be joining Annette

and Graeme. In the meantime, Annette is doing a terrific job covering all clients, prioritising those assessed as most in need. Lothian Family branch had a fabulous evening cruising down the Union Canal in Edinburgh prior to their summer break. Carrie was invited along and was presented with lovely gifts from the branch.

Carrie pictured here having a great time with the group.



Please contact Sue Beevers for more information on the work of the North East services - telephone 019755 62186 or email sue.beevers@hdscotland.org

Karen Sutherland HD Service Development Manager, South/West

Ayrshire: The Ayrshire team has finally moved and settled into the

Douglas Grant Rehabilitation (DGR) centre, based within the Ayrshire Central Hospital site. This has proved to be a good move for the team, as they are in an excellent position to integrate and liaise with all the other allied professionals based within the centre. The HD Management Clinics will also take place at the DGR centre.

During awareness week, the team set up information stands at Ayr and Crosshouse Hospital and awareness of the service was raised by participating in NHS Ayrshire & Arran Road Shows held at various locations over a five week period during the summer.

Glasgow: Unbelievably, Sally and Liz have been with us now for nine months and have their feet firmly under the table. They were delighted to welcome Douglas Johnston to the team at the beginning of May.

Douglas has a nursing background and is already proving to be a great asset to the team. They have all worked extremely hard and have now completed the handover of all HD families throughout the Clyde Area. 32 new referrals were made to the service.

Glasgow City Council Mental Health Commissioning Team has recently completed an in-depth review of the service. Initial feedback has proved very positive. The Team continue to support the management and development of the Huntington's Disease Management Clinic (HDMC) who work closely with Dr Ritchie, presently supporting 21 individuals who attend the clinic. All four Huntington's Disease Specialists were involved in facilitating a Carers event during Awareness week.

Lanarkshire: Great news - As a result of some boundary changes taking place across Glasgow and Lanarkshire NHS, the areas that the Lanarkshire service provide support to will change and increase the number of

people requiring support. Some money has been made available to fund these changes, which means that we will now be in the position to fund an additional part time (29 hours) Huntington's Disease Specialist (HDS) post.

It is hoped that the recruitment process can take place soon and the new HDS will be in post by October.

A great deal of partnership work has taken place over the last few months, with North Lanarkshire Social Work Local Planning Groups resulting in improved networking and integration of the Lanarkshire HD service, which will benefit the HD families as this will result in faster, more streamline referral pathways to other support services.

On behalf of the SWT, I would like to take this opportunity to wish you all well for the forthcoming months and look forward to seeing you all at the Family Conference on 31st October/ 1st November.



HDBuzz Research extracts

The following extracts from HDBuzz bring you links to the latest HD research online. If you do not have internet access and would like to find out more about any of the articles below, contact Isobel on 0141 848 0308 and she'll be happy to print out the entire article(s) and post them to you.

2CARE study of coenzyme Q for Huntington's disease ends in disappointment

<http://en.hdbuzz.net/171>

The largest ever therapeutic trial for Huntington's disease was halted early this week because an analysis of the results to date showed that it was very unlikely to show positive results. The study, called 2CARE, was designed to test whether a treatment called coenzyme Q10 could slow the progression of HD.

New results bring BDNF (brain-derived neurotrophic factor: a growth factor that may be able to protect neurons in HD therapies into focus)

<http://en.hdbuzz.net/172>

Cells in the brain depend on support from one another to stay alive. Nutrients called trophic factors act like brain fertilizer, keeping neighbouring brain cells healthy. This process has long been thought to go wrong in HD, and exciting new mouse research paints a very clear picture of exactly what's happening.

A starring role for astrocytes in Huntington's disease?

<http://en.hdbuzz.net/170>

We know those famous cells called neurons are important in Huntington's disease. But the brain has other cell types with 'supporting actor' roles. New research has shown that brain cells called astrocytes may misbehave in HD, allowing the neurons to malfunction.

Illuminating the progression of Huntington's disease

<http://en.hdbuzz.net/168>

Huntington's disease (HD) progression is a long process in which the first changes in the brain happen well before we even see symptoms in patients. It makes sense to focus our efforts on treating the earliest changes, to nip the problem in the bud. But what are these changes and how can we target them?

A recent study has literally shed some light on this question. By creating HD mice with glowing brain cells, researchers at the University of Nottingham Medical School and the Babraham Institute in the UK have found that some of the earliest changes happen before these cells start to die, in a region of the brain where HD researchers have never before thought to look.

Jumping genes: Huntington's disease protein invades brain transplants

<http://en.hdbuzz.net/167>

Huntington's disease is caused by the malfunctioning and early death of brain cells.

Replacing those dead and dying cells with stem cells has long been a goal of some HD scientists. A new study investigates the long-term health of some of the earliest cell transplants into HD patient brains - and finds a surprising result.

NUB1: enhancing clearance to decrease mutant huntingtin

<http://en.hdbuzz.net/165>

Huntington's disease is caused by the accumulation of the toxic mutant huntingtin (mHTT) protein. This means that decreasing levels of mHTT, by boosting its breakdown, could be therapeutically beneficial.

Palacino and colleagues have identified a possible contender for this role: negative regulator of ubiquitin-like protein 1, better known as NUB1.

Raptor announces results of cysteamine trial for Huntington's disease.

<http://en.hdbuzz.net/163>

A chemical called cysteamine has long been of interest as a potential therapy for Huntington's disease. Now, Raptor Pharmaceuticals has announced the interim results of a study of cysteamine in HD patients. The trial failed to meet its pre-specified goal, but there are some interesting details in the data suggesting the ongoing trial deserves attention.

Could HD be caused by amino acid deficiency?

<http://en.hdbuzz.net/164>

This article is related to the 'cysteamine' article above.

All the proteins in our body are made of tiny chemical building blocks, called amino acids. The internet was recently buzzing about a newly discovered link between one of these amino acids, cysteine, and Huntington's disease. Is it true, as some headlines suggested, that "Brain Degeneration In Huntington's Disease Caused by Amino Acid Deficiency"?



Our thanks to HD buzz for these articles. If you would like to read them in full, please go to www.hdbuzz.net



Family Branch/Support Group Update

Isobel Darroch - Branch/Support Development Officer

What a summer it's been for family branches. They all took part in our Tree Planting Events in June to celebrate 25 years of SHA. The first took place on a very dreich day at Bandrum Nursing Home in Fife, which did not dampen the spirits of our Fifers. They continued round the country and finished with Tayside branch holding theirs at the Neurodisability Unit in Dundee. It was a superb effort by all the branch members. We were joined on each occasion by an invited guest to officiate over the ceremony, each performing their task with great enthusiasm. Lothian branch were joined by local MSP Colin Beattie, who said;

“ SHA remains the only one of its kind in the country supporting individuals and families living with HD. Without their help, we would not have made the incredible strides in treatment that we have seen over the past two decades. Their huge commitment in raising public knowledge of HD is to be congratulated. ”

Two pictures from the Tree Planting Events



Top image: Fife pictured with MSP Cara Hilton at Bandrum Nursing Home And
Bottom image: Michael Matheson, Public Health Minister for Scotland helping to plant the Forth Valley tree at Larbet Woods, beside Forth Valley Hospital

Fife held their third year at Culross Fayre and what another resounding success it was! The three tabled Tombola made just shy of £900 which will go to the Fife Family Branch to help local families. A massive thank you to Sue, Gemma, Susan F, Susan, Tina and Nicola for making the day fun and productive and also to everyone who donated goods for the stall. Susan and Tina kick started the day with £143 which they had made at their raffle at MGM Timber.



Culross Fayre

The Edinburgh Branch of SHA invites you to join them for a morning of exercise, relaxation and friendly fun at their weekly Tai Chi sessions. Mary Johnston, the branch treasurer, makes delicious sandwiches, buns and biscuits, which are enjoyed after the session. The Tai Chi takes place at Laichfield Community Centre, Chesser Loan,

Edinburgh, EH14 1UR from 11-12pm every Friday. Please contact Mary on 0131 660 5906 for more information. The family members who go along feel great benefits from this very gentle exercise and highly recommend it to others to come along and try.

Support Groups

East Dunbartonshire held a cinema evening during our awareness week and raised £900. Thanks to Lynne Baillie for organising the event. The group are also holding a cabaret fun night in the Kirkintilloch Miners' Club on Thursday 9 October. Tickets priced £5. Call Isobel for more information on 0141 848 0308.

Isobel concludes:

“ Most of our support groups took a break over the summer and are now starting up again. All are continuing well, but would like to see more family members join them at their meetings. These are very informal and offer friendship and mutual support. Please contact me for details of times, venues etc. for groups held locally to you on 0141 848 0308 or email isobel.darroch@hdscotland.org. ”

News in Brief

The SHA Lucky Lotto



Our monthly in-house lottery (formerly The 500 Plus Club) is about to get a lot more exciting! With a complete revamp underway, including a new name and new prizes, 'The SHA Lucky Lotto' will have someone winning big in time for Christmas! Subscriptions cost £6 per month and each month players have the chance to win £200, £50 and £25 for 1st, 2nd and 3rd place respectively.

But wait, it gets better...

To celebrate the official launch in December, the Christmas 1st place winner will bag a massive introductory prize of £300!

So if you're feeling lucky, you can sign up now by clicking 'The SHA Lucky Lotto' section under the fundraising tab on our website www.hdscotland.org or call Jim on 0141 848 0308 for more information.

A fond farewell with Gordon Brown, MSP. New to Fife, Bluebird Care describe themselves as specialists in care-at-home providing a 'good old fashioned' service.

This is mainly due to their flexible approach and willingness to work around any customer difficulties. On Friday, 4 April, Bluebird Care promoted their service by inviting Gordon Brown, MSP to their Head Office in Kirkcaldy, Fife.

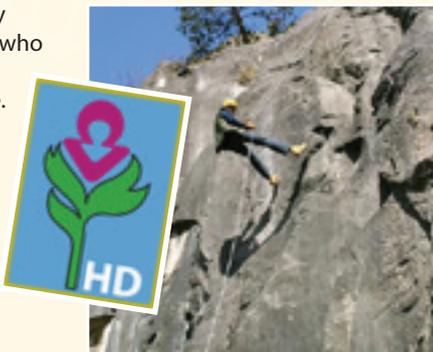
Whilst visiting, Mr Brown spoke to Elma. Elma has Huntington's disease and has just gone into long term care after receiving several months of excellent, quality support from Bluebird Care. She, along with her husband Brian, expressed their gratitude to Bluebird Care, but with regret that it had, sadly, come to an end. As a fond farewell, Mr Brown presented Elma with a bouquet of flowers from Bluebird Care. A wonderful display of cakes and biscuits, baked by Linda Forrester, Care Manager, completed the event.



Photographed with Mr Brown are Elma and Brian McLennan, Bluebird Care staff and Nicola Johns, Huntington's Disease Specialist (Fife).

Pin Badge Competition.

Congratulations to family member, **Philip Jobling** who submitted the winning design of our SHA badge. Philip Pictured here, also did an abseil down Avon Valley Gorge, Bristol and raised over £925 for SHA.



The eagle has landed and we found it! Thank you to all who were in attendance at our balloon launch, especially the Short family who were the successful rescue team! The launch took place at Lagganlia Adventure Centre near Aviemore, where the youth summer camp was held.

The young people, staff and family members were so enthusiastic and had a terrific day to remember. The balloon and its payload rose to over six miles and travelled 59 miles to the East. The 100 messages were successfully released. We got some excellent footage of the event which was compiled into a short video story and uploaded to our website:- www.hdscotland.org/media



Finders Keepers! Marie Short with the balloon

New Website...

We are pleased to announce our new vibrant website is up and running. Information is uploaded regularly and continues to be a work in progress. Please go to www.hdscotland.org to view. We value your comments, please send them to sha-admin@hdscotland.org



Follow the link to read **Sarah Winkless & Katherine Grainger's** interview by the BBC www.bbc.co.uk/sport/0/rowing/28298127

Good coverage of some of the issues facing HD families in The Scotsman. Big thanks to Glasgow family member Jan McMenemy. Read it here www.hdscotland.org/news

Family Conference:

Notification has gone out for the family conference. Held again this year at the very friendly and accessible Glynhill Hotel in Renfrew.

Contact **Lindsey Buchanan** on 01382 425 549 if you have not yet received an invite.

During our awareness week in June, we held a UK premier showing of the documentary **'Alive and Well'** which documents the resilience of seven people living with Huntington's disease and were pleased to have a packed audience of professionals and family members.



Kirsten Walker... Reports on Funding for Youth Service

In mid-2013 SHAYP started the long and arduous journey of attempting to secure funding to continue the service, as the current funding streams were due to end. Various applications were made and we are delighted to announce our success in receiving 5 years funding from the Big Lottery Fund.

This will cover the majority of the costs of SHAYP. Within this funding (and additional funding from Young Start Fund) it has enabled SHAYP to employ 3 full time staff members. Over and above this we have secured additional funding over 3 years from Children in Need, which will allow us to employ a new staff member, who will cover the Fife and Lothian areas. This means that SHAYP now has 4 full time specialist youth advisors covering Scotland and one part time admin/ group support officer.

An incredibly exciting time, with the project going from strength to strength and with 5 years funding secured it will allow SHAYP to focus on further developing the service to meet the needs of young people growing up in HD families. A huge thank you to all the funders for recognising the need of the service in supporting young people in HD families.

“ It was my first time and it was one of the best trips of my life.”

40 Young people from across Scotland, plus staff and volunteers, joined together for another hugely successful SHAYP annual Summer Camp and Festival in June at Lagganlia, just outside Aviemore. What a fun filled, action packed week everyone had! Daytime activities included; mountain biking, walking, skiing on the centre's artificial slope. Everyone had a brilliant time and thoroughly enjoyed all of the activities they took part in.

Kirsten continues:-

“ On the Thursday morning, those aged 1st year high school and older, took part in SHAYPs annual Young Person Festival which this year focussed on the UN Convention on the Rights of the Child (UNCRC). The festival offers the young people a safe, protected semi- formal environment to learn more about issues around HD. This year Matthew Ellison from HDYO.org joined the group to record a short video around the UNCRC and how some of the rights relate to a young person growing up in a family affected by Huntington's disease. The video should be on HDYO's website soon and we will post a link on our Facebook page when it is. Why not keep an eye out for it? ”



National Quality Award for our Wellbeing Volunteers



Volunteer Friendly Award

We are delighted with the news that our Wellbeing Volunteer Service has just been awarded the Volunteer Friendly Award, Scotland's national quality award for volunteering

management and practice. Every aspect of the Volunteer Service was scrutinised by two independent external assessors to ensure that we meet the highest standards in terms of policies, procedures and support for our Wellbeing Volunteers. The entire process can take an organisation as long as a year or more with ourselves SHA achieving the standard in only six months.

John Eden says

“I'm delighted to have received this award for our innovative approach to volunteering.”

We see volunteering as very much a two way process, our tailor-made programme means people thinking about giving up some time can build it around other work and family commitments and still learn a new skill.

The Wellbeing Volunteer Service remains active in the South and West of the country but plans are afoot to expand into the East and then into Grampian and Highlands once the necessary resources are secured.

John is also very clear on the vital and ongoing contribution of the service -

“Volunteers play an increasingly important role within the charity and without them we would not be able to offer the range of support that we do.”

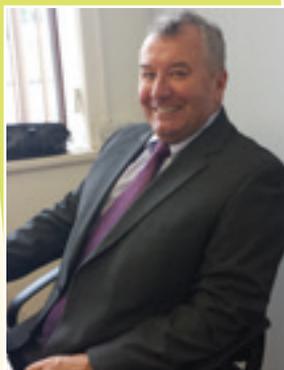
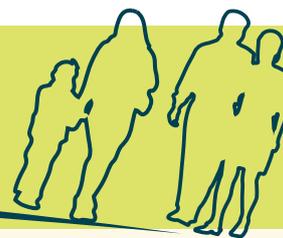
Another milestone for the Wellbeing Volunteers is that they have freely given support to HD family members and the SHA

to the tune of the equivalent of nearly 120 full working days since the service went “live” just over a year ago, with that total increasing every week.



Chief Executive John Eden, Wellbeing Volunteer Rahil Sheikh and National Volunteer Co-ordinator Bob Bogle.

Fundraising



Dougie Peddie Fundraising Manager

Dougie joined the Fundraising Team in August 2014 and brings a wealth of experience gained over the past 38 years in the field of youth and community work. His previous posts within both statutory and voluntary organisations have provided him with a wide range of knowledge and skills in fundraising for services, team management and strategic planning.

Although Dougie is a new member of staff at Scottish Huntington's Association, he remembers working with the organisation in the late 90's, in his role as the Head of West of Scotland Services for the Scottish Council of Voluntary Organisations, providing impartial advice to Scottish Huntington's Association on their developing fundraising strategy.

Dougie says, “I'm already impressed by the commitment and enthusiasm from the Fundraising Team at the National Office and I will be able to make a valuable contribution to the work of the Team and Scottish Huntington's Association over the forthcoming months and years.”

Wills, Legacies and Bequests



Jim Opfer Individual Giving Fundraiser

As Individual Giving Fundraiser, Jim's task is to increase the amount of donations raised from individual supporters, whilst also raising awareness for the charity. It's an area of fundraising that has never been properly concentrated on before at SHA, which makes the role both challenging and exciting. By focussing on individual giving we now have tremendous potential to raise the charity's public profile and ultimately gain more supporters than ever before.

Jim says, “During my first year in post, as well as revamping the established 500+ Club, there are many new fundraising campaign ideas that I intend to launch. As part of my role I will also be in charge of legacies and bequests and will make information on how to donate in your Will available through the website. I'm looking forward to raising funds for Scottish Huntington's Association and I hope that my work will ultimately help us to provide

greater support to those people affected by HD in Scotland.”

He concludes “In the four months that I have been with SHA, I have learned a great deal about Huntington's Disease and the fantastic work that we do to support people living with the condition in Scotland. I have been amazed by the dedication of my colleagues and their passion for the services we provide.”

You can make a donation to Scottish Huntington's Association by visiting our website and clicking on the 'DONATE' button at the top right of the page.

Fundraising Continued...



No fuss, just a Fun Night In..! Join other fundraisers during the month of October and organise a Fun Night In.

Having a "Night In" is as simple as this: invite everyone round to yours to eat, drink, laugh, catch up and do something magnificent by donating the money you would have spent on a night out to Scottish Huntington's Association.

Saving £3 on a bag of chips on the way home would pay for a 5 minute call that can change a life

Saving £16 on a round of drinks would provide One to One counselling to a young person affected by HD

Saving £30 on your taxi home would pay for a home visit to someone affected by HD

Saving £350 on the group's total bill on a meal out is the cost of an HD Specialist's day, which is literally a lifeline for families affected by HD

You can even set up a Facebook event and invite all your friends.

Call your night a cosy catch up, team building, come dine with me, movie night or why not add a theme. The possibilities are endless and it's so easy.

It's a perfect time of the year to stay home with special people and really catch up on that quality time together.

Because of you and the funds you raise, you will make a huge difference to families affected by Huntington's disease.

So, whether you raise £50, £500 or £1000, every penny and pound will be put to good use and this is the difference your savings will make...

Please contact Linda on **0141 848 0308** or email linda.byars@hdscotland.org to receive your fundraising pack.

Paris to Geneva Cycle September 2015

We would like to inspire fundraisers to register for the Paris to Geneva overseas cycle challenge organised by Discover Adventure from the 6 - 11 September 2015.

This cycling event runs over six days and although it seems like a long way off, you do need to plan, book holidays and raise sponsorship. This is an exciting opportunity to join other likeminded people raising funds for their chosen charity.

You will pass through famous landmarks of Paris to quiet lakeside Geneva. Surrounded by mountains, this is a wonderful challenge linking two different cities. Leaving from the Eiffel Tower you will travel through Paris into the fields of wheat and sunflowers of rural France.

Your cycle culminates in the crossing of the beautiful Jura Mountains. The gentle rolling hills that form much of the landscape en-route provide you with the perfect preparation for the hair-pin bends of the Col de la Faucille (1323m), a climb that has featured many times in the Tour de France.

A wonderful descent takes you down the mountain into Switzerland. After long days in the saddle and a challenging day in the Jura Mountains you will be happy to see Geneva and its beautiful lake.

The registration fee is £149 with a further £1650 to be raised in sponsorship. You have a full year to raise your funds and this can be done in a variety of fundraising ways. If you want to find out more, please call Linda on **0141 848 0308** or email linda.byars@hdscotland.org.



giftaid it

Please help us claim the sponsorship gift aid.

In order to claim GiftAid on sponsorship forms we need the full postal address (at least house name, number and postcode) of each donor. We can then claim 25% on every £1 raised. So a £1 becomes £1.25!



We have a two day Bag packing opportunity at Marks & Spencer, Braehead on Saturday 6 and Sunday 7 December and desperately need volunteer support. If you can spare a few hours please call Linda on 0141 848 0308.

Thank you Fundraisers...

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



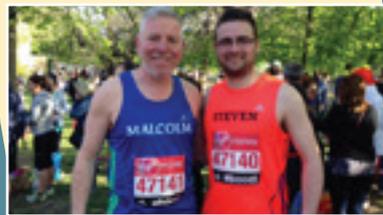
Stan & Laura Ward, Ecotune Hillington & employees, Specialised Car tuning day and Raffle raised £2,500



David Drain (Specialist Youth Advisor) & Nicola Henderson (Executive Assistant), Prosource, Coffee Morning raised £303



John Lewis - Carol Halliday (Leisure Benefits Coordinator) & Annette Brown (Senior HD Specialist), Community Matters Project raised £900



Malcolm Binnie & Steven Cliffe, London Virgin Marathon 2014 raised £3,168



Sheila Keenan & friends, Great Scottish 10k raised £100



Ruth Chapel & Sarah Kernahan (Trust & Grants Officer), SOSJ Grand Priory Trust donated £1,000



Sheena Assiph & Franck Pauly & competitors, Ceroc Dance Competition raised £5,000



Members of Rotary of Culloden Inverness, Glencalvie Challenge raised £1,000



Marie McGovern & her team, The Gunner Pub Night & Tesco Bag Packing raised £1,650



Gordon Murray, Belfast Marathon raised £2,056



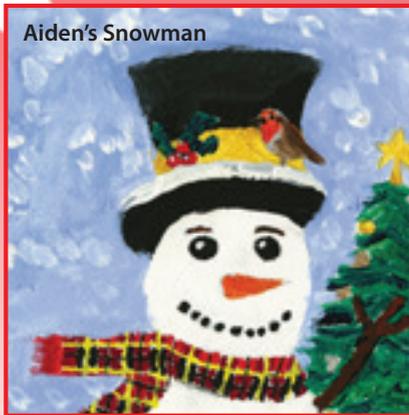
Mary Cunningham & Jessie Smith and their group, Blairgowrie Charity Shop & Ukulele Night raised £3,000



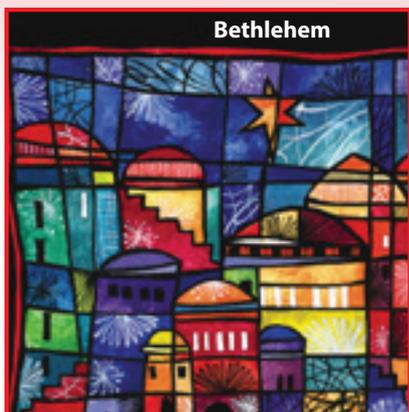
Fiona Gray & Judith Scott, family and friends, Tattie Barn Dance, Aberdeen raised £4,160

Andrew Hannah & Jim Reid, Strathclyde Park 10k, Andrew raised over £950 and Jim £150

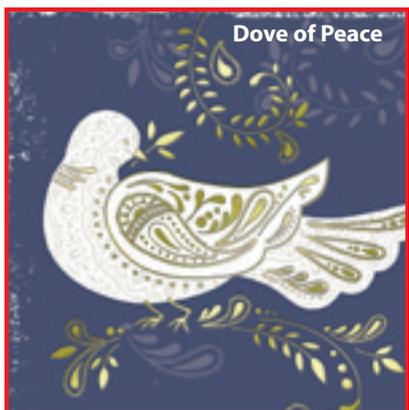
Do you have an interesting fundraising story to share and would like to be included in the next newsletter, please send your photographs and event details to linda.byars@hdscotland.org We will try our best to print as many stories as we can.



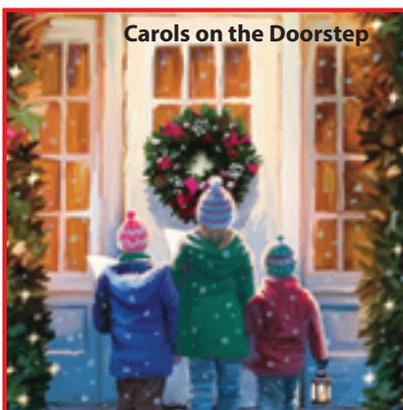
Aiden's Snowman



Bethlehem



Dove of Peace



Carols on the Doorstep



Variety Pack

Christmas Cards...

Christmas may seem a long way off but really it's on the way. This year we have a lovely new selection of cards for you to choose from and there is something for everyone.

If you want an extra special card, then why not purchase a pack designed by our own little star, Aiden McCallum. Aiden is an extraordinary boy and dedicated to supporting us and has especially designed the snowman card.

Please complete the form below and return to us with payment and we'll help get Christmas underway!

2014 Christmas Cards Order Form

Name:		Address:		
Telephone:		Postcode:		
Ref	Card Name	Cost Per Pack (10)	Number of Packs	Total
1	Aiden's Snowman	£3.50		£
2	Bethlehem	£3.50		£
3	Dove of Peace	£3.50		£
4	Carols on the Doorstep	£3.50		£
5	Variety Pack	£2.50		£
SUBTOTAL				£
POSTAGE				£2.50
DONATION				£
TOTAL				£

Please complete and return to us at Scottish Huntington's Association
St James Business Centre, Linwood Road, Paisley, PA3 3AT