

25th
anniversary

scottish
huntington
association

SHAve



ISSUE NO. 71

SPRING 2014



Jubilee Year Celebrations...

John Eden, Chief Executive says.....
"Whether you are a family member, Trustee, staff member, volunteer, fundraiser, part of the growing network of friends and supporters of the SHA, or belong to the expanding number of organisations that support people living with Huntington's disease – this is your year!

SHA is built on the shoulders of the thousands of people that have contributed to its growth over the last twenty five years and you can be proud of your contribution. Our deepest thanks go to everyone that has and does make the SHA so unique.

In our anniversary year we want to celebrate our accomplishments, but also create a lasting legacy that will enable the charity to continue to grow and succeed in its mission of improving the quality of life for everyone who lives with HD."

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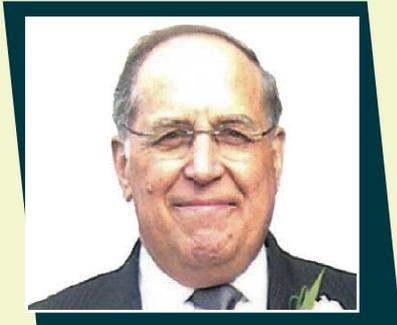
25th
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Matters from the Chair

Philip Fox - Chairperson



Well here we are - now celebrating 25 years, with the prospect of worthy and well-deserved celebrations to look forward to. Already we have in place a new logo and commenced plans for a range of other activities, building up to our annual conference booked for 31 October/1 November at the Glynhill Hotel, Renfrew. (please see page 11 for more details)

More than ever our board meetings, (two since our last SHAre - 7 December and 8 March) reflected the increase and depth of the Association's activities. I am happy to report a strengthening sense of stability as far as our finances are concerned, thanks greatly to the diligent efforts of our Treasurer, Jim Lochery, with the input of Paddy Mcanena, a retired Chartered Accountant, working with our finance and fundraising team. Their success in keeping our deficit down to a predicted £40k at the end of the year is to be applauded, as is the successful grant awards - topped particularly by the wonderful £102k from BBC Children in Need which will support our Youth Service over the next few years.

The presentation of a very comprehensive 'Fundraising Strategy' document has given us much food for thought, along with the dozen or so themes from the last 'Roon the Kitchen Table' (RTKT) report, forming the basis of future plans and actions for SHA. By the time this publication reaches you it will be augmented by another - emerging from a special RTKT on 26 March, designed specifically for staff.

The picture is one of continuous, lively, positive activity affording a role for everyone, board, staff, family members, volunteers - all visualised as having integral parts to play in creating the masterpiece. Long may there be strength to the artists arms!

Philip

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Cover picture. Hugh Henry MSP, pictured right, joins family members and SHA staff at Head Office for a Tea Party.

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Getting involved in our incentives

25th Anniversary Pin Competition

The lovely folk at the Lothian family branch have suggested that the charity adopts a new pin in our 25th Anniversary year and the Board of Trustees of SHA felt this was a really good idea. It was decided that we would love to invite members of the HD community to submit designs for a new pin with the best one being produced this year.

What pin do we use at the moment?

Our current pin is the Amaryllis flower which is the international symbol for HD. It's shown in the picture below.

Are there any requirements for the new pin?

The new pin should be of a similar size (3cm by 3cm maximum), but other than that you are free to use your imagination to come up with a new design.

Can anyone submit a design?

Yes, anyone with a professional or personal link to HD can submit a design.



When does the new design need to be submitted?

Your design should be submitted by the 30th May 2014 so that it can be considered with the other entrants at the board meeting on the 7th June.

In what format can I submit it?

You can send your entry by post or by e-mail to sha-admin@hdscotland.org

Is there a prize?

Your design will be turned into the charity's new pin and we will commission a special pin for the winner with their name engraved. The winner will also get 25 new pins to distribute to their friends and family. The winner will come to national office and be the first to see the new pin.

When will the pins be available?

After the board of Trustees make their decision on the 7th June, it will take about 6 weeks to produce the pin and so we expect them to become available around mid-August 2014.

What will happen to the current pins?

We still have a small supply of the current pins and these will remain available until they run out. Afterwards we will only produce the new pin.

GOOD LUCK!!!



John Eden, Chief Executive writes...



continued from front page

We have some fantastic events planned for our Jubilee year. Join us on 17 May in Aviemore (weather permitting) for our HD STAR project (see flier and more information below), when we will launch hundreds of messages of hope, inspiration and remembrance that will fly to 25 miles above the earth where they will be released and travel hundreds or thousands of miles; a powerful metaphor for our goal of raising HD awareness. It is our hope that HD STAR will inspire others to find innovative ways to raise awareness. This project is about the power of people to work together towards a common goal.

11 June; we plan to show a brand new film about life with HD called 'Alive and Well'

at the Grosvenor Cinema, Glasgow, which co-incides with our awareness week (9 – 14 June) our family branches will 'plant a tree for HD' creating a number of prominent sites that will help raise awareness and a fitting 'in memorium' for those that have fought with the condition.

18 June; at the Corinthian Club we are holding a special business breakfast. Our Patron Sarah Winckless and her close friend and fellow Olympian Kathleen Grainger will be speaking to around 40 specially selected companies about the work of the SHA. This is one of our 'legacy' events which we hope will enable us to create lasting relationships that will help support the work of the charity into future years.

In early September we will launch the first accredited training course in the care of people living with HD with our partners, Stirling University. This landmark course,

the first of its kind anywhere in the world, will contribute to the improvement in the standards of training of health and social care staff and significantly raise the profile of HD as a condition.

31 October; our two-day national family conference will take place at the Glynhill hotel in Renfrew where we last held our 20th Anniversary in 2009.

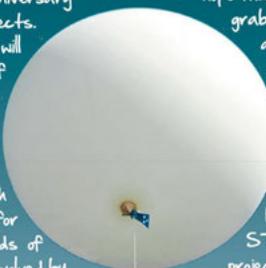
28 November; we are planning a special reception, on the 'actual anniversary of the SHA' and we will share further details about this in due course.

We hope the range of events will provide you with the opportunity to celebrate and contribute to the continued success of the charity and we look forward to sharing many more years as we continue to work together to make a significant difference to everyone who lives with HD.

HD Star

Empowering ordinary people to meet extra-ordinary challenges!

Inspired by the 'Huntingtin in space project' HD STAR is one of the SHA's 25th anniversary awareness raising projects. On the 3rd May SHA will send 500 messages of hope, inspiration and remembrance into orbit in a weather balloon and when it bursts at 25 miles above the earth they will be scattered for hundreds and thousands of miles. You can also get involved by joining our search and recovery teams whose job will be to hunt for the balloon when it floats back to earth on a parachute. This essential job will enable us to recover the two on board cameras that we hope will capture amazing footage of the Earth from



space! Be part of the first team to recover the Balloon. It is our hope that the whole project will grab the attention of local and national media enabling us to raise HD awareness. The more people who get involved, the more awareness we will raise. Would you like to become an HD-STAR? We hope this project will inspire you to find innovative ways to raise awareness about HD and we would love to hear about them! If you would like to get involved, send a message to space or help spread the word, contact us on the numbers and e-mail below.

scottish huntington's association
Scottish Huntington's Association,
St. James Business Centre, Linwood
Road, Paisley, PA3 3AT

"Become an HD Star!"



Charity number:
SC 010985

Call +44(0)141 848 0308 Email sha-admin@hdscotland.org

HD STAR

Inspired by the 'Huntington in space project', HD STAR is one of the SHA's 25th anniversary awareness raising projects. Would you like to help awareness of HD reach the stars?

On 3 May SHA will send 500 messages of hope, inspiration and remembrance into orbit in a weather balloon and when it bursts at 25 miles above the earth they will be scattered for hundreds and thousands of miles. Each message will have return information on it so that we can discover just how far our awareness raising reaches!

You can also get involved by joining our search and recovery teams, whose job

will be to hunt for the balloon when it floats back to earth on a parachute. This essential job will enable us to recover the two on-board cameras that we hope will capture amazing footage of the Earth from space!

Would you like to become an HDSTAR? We hope this project will inspire you to find innovative ways to raise awareness about HD and we would love to hear about them! If you would like to get involved, send a message to space or help spread the word contact us on **0141 848 0308** or email: sha-admin@hdscotland.org



Sue Beevers HD Service Development Manager North/East

Further to the last issue, we are delighted to announce that Bridgeview, the HD unit

in Broughty Ferry, which is part of the Huntercombe Group, has been successful in achieving registered providers status. Bridgeview agreed to work on a pilot of the accreditation, which has been developed by the Association in order to signpost to individuals and families, care providers that have developed a range of standards and strategies with ongoing continuous improvement towards meeting the specific care needs of people with HD. This means that they are the first setting to achieve this recognition. The staff team at the unit have worked incredibly hard for over 18 months developing and evidencing standards of care for individuals with HD. It has been a process that has required partnership working and dedication.

As we reach the end of our reporting year the North East services received **86** new referrals and here are some other statistics from our regional services;

Local news includes;

Highlands: Throughout the last 12 months the service has worked with **87** individuals affected by HD along with **14** young people supported by the Youth Service. Gordon Bogan has also delivered 6 training sessions to professionals.

Grampian: **77** individuals have received our support as well as **19** young people. **7** training sessions have been delivered. We are pleased to announce that we will have a new recruit starting in April to fill the current HD Specialist vacancy; more news in the next issue.

Angus: Our part time service in Angus has worked with **43** individuals as well as **4** young people. Alison Toner has delivered **8** training sessions.

Tayside: **64** individuals have received support throughout Dundee and Perth during the year as well as **6** young people. Paula McFadyen has been busy delivering **11** training sessions. Jointly Angus and Tayside have also had **185** places taken up at support groups run by Alison, Paula and Lindsey.

Fife: The team currently support **120** clients and **17** young people are supported by the Youth team. **18** training sessions have been delivered.

Lothian: Welcome to Graeme Sutherland-Lockhart who joined us in December as our new admin/resource worker and is the calm, friendly voice on the phone. The team have supported **233** clients in the last period. **24** young people are supported by the Youth Team. **22** training sessions have been delivered.

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



Karen Sutherland HD Service Development Manager, South/West

Ayrshire: funding has been agreed by the three local authorities for a further year until

March 2015. It is likely to be concurrent on a year to year basis. Changes are being made to the Huntington's Disease Management Clinic (HDMC). Dr Nitu, Specialty Doctor in Psychiatry will be taking over the clinic as of 1 April. The days and venue of the clinics are currently being negotiated, as is the accommodation of the service staff. The patient satisfaction audit is almost complete. Results are due in the next few months. The joint professional study with Motor Neurone Disease and Multiple Sclerosis is scheduled for 15 May at the Gales Hotel, Irvine. Ayrshire is currently supporting 96 people, 49 of which are symptomatic.

Glasgow: the new Glasgow team has completed their induction and are now in the process of meeting all existing Glasgow clients. They are working really hard networking with all health and social care professionals across Glasgow and Clyde. Sally, Liz and Beverley have been working in partnership with Patricia McLaughlin from the Single Genes Complex Needs Service (SGCNS). Patricia has been introducing them to everyone in Clyde.

Sally and I were invited to attend the Long Term Condition (LTC)/Macmillan Project steering group meeting on 3 March. They have allocated two dedicated LTC advisors to work with HD clients (who will deal with all welfare benefit issues plus much more) both have been given training by SHA and so far 6 referrals have been made to the team. The service will be based at the Southern General Hospital.

Forthcoming Training dates for Glasgow: Wednesday 4 June 2014 and Wednesday 29 October 2014 Time: 9.30 am - 12.30 pm. Venue: Training Room, ASDA, Parkhead Forge. Course title for both dates: An Overview of HD.

Lanarkshire: is just getting busier and busier, with new referrals continuing every month. A review of service delivery and client support is being carried out every few months to assist Linda Lucas and Dr Gordon to meet the ever growing demands on the service. Despite this, 137 people were seen at the HDMC between 1 April last year to date. This is a fantastic achievement. An audit of client and professional satisfaction of the service is currently underway. The results should be available early May. The SHA is still trying very hard to source further funding for an additional Huntington's Disease Specialist. A meeting with our funding partners took place

on 26 March. Lanarkshire has been buzzing with SHAre Tea for HD parties this month. Well done family members and everyone involved.

Forthcoming Training dates for Lanarkshire; Monday 24 April 2014 2pm to 4pm Introduction to HD. Monday 27 October 2014 2pm to 4pm. Course title is; Challenges in Caring for People with HD. The venue for both is The Boardroom, Udston Hospital, Farm Road, Burnbank, Hamilton.

Forth Valley NHS: David Thomson, neurology nurse at Forth Valley appears to be settling well in his new post. He has now seen ten families in their own home and several at the clinic. He is working in partnership with Kirsten Paterson, SGCNS. There will now be a HDMC every two months held at Forth Valley Royal Hospital with Dr Neumann continuing to take the lead role. David is also working on a web based educational package, providing basic information on HD for nursing staff, to be rolled out across Forth Valley as soon as possible.

On behalf of the South West Team, I would like to take this opportunity to wish you all a happy, warm sunny Easter.



Sarah Kernahan Trusts & Grants Fundraiser

It has been another successful year for trusts and grants with over £126,000 raised in 2013/14. This year has seen an increase of 35% on the number of donations received from charitable trusts and foundations, which shows that our success rate with trust applications is improving each year. Notable successes this year have included:

We have received £10,000 towards our 2014 Summer Youth Camp which will provide young people, aged 8 - 25 years old, living in a family affected by Huntington's disease (HD) the opportunity to enjoy a fun filled 5 day retreat at Lagganlia Centre for Outdoor Learning in Glen Feshie.



2013 Summer Youth Camp



In 2012 the **Robertson Trust** gave an award of £65,000 over 3 years towards the Wellbeing Volunteer Service. This year we received an instalment of £16,000 from the Trust.

We also received a grant of £10,000 from the **Garfield Weston Foundation** towards our core services.

The majority of our funding comes from small Scottish trusts who give to us regularly and with whom we have a good relationship. Our plan for the year ahead is to focus on targeting national trusts by 'packaging up' our core services with a view to applying for larger grants. This will provide us with a great opportunity to grow our income within this area and secure multi-year funding for our services.



Wellbeing Volunteers

Bob Bogle - National Volunteer Co-ordinator

never run out of things to talk about because it's a good match"

Andy is a retired engineer and ex-serviceman who really enjoys his mornings out with Willie. To Andy, it's more than volunteering - it's an opportunity to have some quality time with someone with whom he has much in common.

Building on the success of partnerships like this, the SHA Wellbeing Volunteer service is now distributing information leaflets detailing how to access the service across the south and west of the country - featuring these two likely lads on the front!

Could you or a HD family member you know benefit from the following?

- Provision of carers respite for short periods
- Help accessing additional services or filling out forms
- Safe and good company for social activities
- A friendly and understanding ear
- A wide range of other person-centred support

Currently, to receive this service the HD family member must live in Glasgow, Renfrewshire, Inverclyde, West or East Dunbartonshire, East Renfrewshire, Lanarkshire or Ayrshire (other areas to follow as the service is rolled out across Scotland).

For more details and to arrange a home visit and chat about your needs and possible Wellbeing Volunteer support please contact:

Bob Bogle: - National Volunteer Co-ordinator
Tel: 0141 848 0308
bob.bogle@hdscotland.org

Another successful Wellbeing Volunteer partnership goes from strength to strength. **Andy McArthur and Willie Logan** have been visiting together the coffee shops of Lanarkshire's garden centres for some months now.

"I really enjoy the friendship and the banter too of course!" said Willie.

Willie greatly appreciates being able to get out and about, still doing some of the things he enjoys and knowing that Andy understands HD and at least some of the challenges Willie faces. It also means that Willie's wife is able to have some valued time for herself.

"It's good to get out, even when sometimes you don't feel like it at first - it keeps my drive going"

Willie explained.

Andy said **"It's not just about giving something back - it's a two way process and a partnership. We**



Willie & Andy

Fundraising



Linda Byars, Community Fundraising Officer, writes,

“Good news, I will be taking on the full time role of Community Fundraising Officer across Scotland from the beginning of April as Paddy Ryan has now left SHA to further his career in England.

Over the last financial year 2013/14 our community fundraising has steadily grown and has increased to over £200,000, an amazing total... My sincere thanks to all involved!

We have many exciting ideas for the year ahead and I am keen to hear from anyone looking to get involved in fundraising for SHA.

So, no matter if you want to fundraise as an individual, a team, with work colleagues or family and friends, I would be delighted to offer fundraising information and support to help make your event a success.

You can contact me on **0141 848 0308** by email linda.byars@hdscotland.org or via our Facebook page www.Facebook.com/ScottishHuntingtonsAssociation “



We had fundraisers hosting tea parties throughout Scotland. Not only did these parties raise funds, we received Scotland wide publicity. The map shows the areas in Scotland where Tea Parties were held and to date a total of £3,000 has been raised.

It's a great step towards supporting families affected by HD, reducing isolation for families and educating local communities about HD. We plan to make the tea parties an annual event and hope more fundraisers will come on board and host this simple to plan activity. Everyone can get involved with a tea party and is fun for the whole community. Watch this space for future dates!

A massive thanks to all our tea party hosts.

- Denise Easton and Work Colleagues, Highland, SHAre tea for HD
- The Kitchen Inverness
- Mustard Seed Inverness
- Denise Easton and Friends, Highland
- Ladies Circle, Callander
- Wilma & Aidan McCallum and friends, Star of Markinch
- Jam Jar - Bridge of Allan
- Head Office, Renfrewshire
- Riverhouse, Stirling
- Julia Kelly and Friends, Kirkcaldy, Fife
- Forth Valley Tea Party

Fundraising



Kerry having a well-earned break after tackling the Forth Road Bridge.

Go Kerry Go!! Thirty nine year old Fifer, Kerry Russell, loves to fundraise. Over the past year she has spent a lot of her time thinking of new ways on how to raise funds for the organisation. Very recently, and with support, Kerry travelled over the Forth Road Bridge and raised funds for families in Fife affected by Huntington's disease. Kerry also organised a few car boot sales last summer and feels that she wants to do so much more. To date, Kerry has raised an impressive £154. Well done Kerry!

Another Fifer, Caroline Maxwell took on a 5K-50 day challenge and raised £510. Her employer Diageo has kindly offered to match her funds and donate a further £510 making the total an amazing £1,020. Caroline said "I was delighted to support such a great cause" adding she was thrilled to raise money for the charity and losing a stone in weight in the process. An all over 'FLAB'ulous success story.

A Funday at Douglas Arms Methilhill raised almost £670. Moira Izatt, along with Joan Thomson organised a day with tombola, raffle, stocks, hampers and a silent auction. Prizes were donated by local business and people in the community. A huge thank you to all that helped and contributed.



A Christmas raffle was organised by the Auld Classic Pub in Dunfermline. A total of £405 was raised by the Armit family and clientele.



80s Night in Fife
Joanie sings the 80s.
After the success of last year's event, Joanie and Alan again organised an 80s fun night on Friday 14 March in Lodge Balfour, Methil and asked everyone to dress up in their 80's gear. The night held a raffle, 80s music and buffet, raising a fantastic £1,402. Our sincere thanks to everyone

who came and supported the event, and to the businesses who made a donation towards the raffle and buffet.

Do this Fife team ever stop? Apparently not. They have already started planning for next year. **Dates to follow!**

Dedicated fundraisers Linda and Neil Scobie are organising a thrift shop for a week in Methil and are asking for any unwanted items they can sell in the shop. All proceeds will be donated to SHA. You can contact Linda or Neil on 01333 631312 to make a donation.



Coatbridge Student Coffee morning

A big thank you to the hair and beauty students of Coatbridge college who presented Linda Byars, Fundraising Officer, pictured left, with Linda Lucas, Senior HD Specialist (right) with a cheque for £370.44. The funds were raised from a coffee morning organised by the students in the college.



The wonderful children of Lecropt Kirk Sunday School in Bridge of Allan

have been star supporters of SHA this year, and raised a fabulous £208 by organising a raffle and donating the proceeds of their Brown Penny collection.



Thanks to everyone in Forth Valley who fundraised and dipped their 'soles' in the burning embers. £3000.00 has been raised to date.

A huge thanks to Walter & Isobel Barr

who raised £550 at their Diamond Wedding Anniversary in lieu of presents.



An amazing £4,685.00 has recently been donated by the fundraising force that is The Scott family!

All members of the family got involved with the mission to raise funds, not only for SHA but for other charities as well: coffee mornings, jam making, quizzes, baking, growing, arts & crafts, to name only a few. What a fantastic effort, thank you so much.



An SHA Charity Shop in Inverness raised £1,747.00!

Thanks again to everyone who supported in any way.

Fundraising continued...



Graeme Reid had a heart attack during an Off Shore visit and medics shocked him back to life. Doctors told him he couldn't go on his planned India Trek, so..... he just did 6 months-worth of activities in the

UK to make up. See his story at this link: <http://www.sponsorme.co.uk/bibby-graemereid/graemes-india-dalai-lama-trek.aspx>
Graeme's fundraising was matched by Bibby Linegroup. He gave half to SHA, which was £1,520 and half to HDA.

Volunteers helped Paddy Ryan on Boxing Day to raise £796.50 at a bucket collection at Aberdeen Football Club. Thanks to everyone.



Thanks also to

- Caroline Maclellan**, who held a soup and sandwich day and raised £934.00
- Lynette Rose** held a Christmas party fundraiser with match funding from who? And raised a total of £1,812.50.
- Mary Wood** held a fashion show in Inverness and raised £800
- Caber Coffee Company**, who raised £265.00.



Firewalk successes in Aberdeen & Inverness. Thanks to all our brave soles! A total of £8,311.65 was raised.



Elaine Watt and her niece Nicole Murray ran the Santa Fun Run in Aberdeen and raised £1,012.

A huge thank you to Williamson Food Service who are sponsoring us for the whole of our anniversary year; www.williamsonfoodservice.co.uk/scottish-huntingtons-association

2014 DATES FOR YOUR DIARY

New exciting ways for fundraisers to help us raise awareness and funds in our Jubilee Year.

May - Sat 17 - Strathclyde Country Park 10K: This event is being organised by Funding Neuro who are asking participants to pay £15 to register - with all further funds donated to SHA. The 10k race is part of the Strathclyde Park racing weekend and in conjunction with Glasgow Triathlon Club at the refurbished Commonwealth Games venue. Go online at www.entrycentral.com to register and then call Linda on **0141 848 0308** to receive your SHA fundraising pack.

May - Sat 24 & Sun 25 - Edinburgh Marathon Festival - we still have a few places available for all of the races. To register go online to http://www.edinburgh-marathon.com/?charity-information&charities_id=198 and contact Linda on **0141 848 0308** to receive your fundraising pack.

May - Glencavie challenge event, visit the website on www.rotarychallenge.co.uk

June - Sat 7 - Lillias Day, Kilbarchan - We are planning a stall of events to raise awareness and funds. If you can spare a few hours to help out on the day or if you can make a donation to the raffle. Please call Linda on **0141 848 0308** or email linda.byars@hdscotland.org

June - Sat 21/Sun 22 (one night) Edinburgh Night Ride - A Magical Moonlit City Cycle - A 50 mile night ride through the streets of Edinburgh, see the sights like never before...Join this 50mile cycle with other like-minded cyclists whilst taking in the iconic sights of the beautiful city of Edinburgh. You will cycle past places such as, The Royal Mile, The Castle cycling past the Scottish Parliament building and Holyrood Palace. To register go online to <https://www.globaladventurechallenges.com/booking/?id=3367&d=ENR14062014&r=1&charity=5533> and call Linda on **0141 848 0308** to receive your fundraising pack.

July - The Stand Comedy Club, Benefits Show, Glasgow - date to be confirmed.

Oct - Sat 25 - Fright Hike - 18 Mile Night Trek Challenge through the Queen Elizabeth Forest Park, Stirling. Ghosts are abundant throughout Scotland and Stirling is no exception; look out for the old ruined Kirk in Aberfoyle, with two large mortuary weights, used to stop thieves from making off with freshly interred bodies. Pastor Robert Kirk's spirit is said to be imprisoned in a pine on the nearby Doon Hill. Tie your laces tight, this is going to be one scary challenge! To register go online to <https://regonline.activeeurope.com/FH14-QEFPHUNT>

In Planning - Walk of Hope and Girls Night In/Boys Night Out. Date and further details to be confirmed

giftaid it Gift Aid Reminder,

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!**



Family Branch/Support Group update

Isobel Darroch - Branch/Support Development Officer

SHA Family Branches will be commemorating our Silver Jubilee

during our Awareness Week from 9-14 June. A few suggestions were made by them and they chose the idea of planting a tree. A tree is symbolic of putting down roots; contributing to the future; and of remembering others. They will also hold a balloon send off at the same time. New branch/support group leaflets have recently been published and each branch plan to do a 'drop off' at local health centres, hospitals, etc. We thank them for their time and commitment to mark this occasion which will also raise awareness throughout Scotland

Last year we held a 'Reaching Out' event for family branches to get-together. It was a great opportunity for them to meet up and discuss branch issues. Another one-day reunion has been planned for Tuesday 19 August at Crieff Hydro. Branch members were offered use of a room at the hotel by Carrie Ho, HD Specialist, Lothian. Carrie has organised a few days' break for Lothian family members at the hotel, which is being held the week commencing 18 August. This offer for the branch meeting is great appreciated.

More branch news:

Fife branch has just held their annual ceilidh at Fort William on 8 March. It was a huge success and raised £1,200. Many thanks to the organisers, Heckie and Belle Henderson and Brian Gray pictured here with Brian Mackenzie, Fife Chairperson (Curstey of Oban Times) Their other yearly event to Millport is planned for 25 May. Contact Isobel on **0140 848 0308** for more details.



Forth Valley Family and Friends; David Thomson, the Forth Valley neurology nurse was warmly welcomed to their meeting in February. The branch also held an impromptu SHAre tea for HD at the meeting and made a donation to the organisation; The group are holding a bag-packing event at Morrisons in Stirling in July. Any help from family members would be greatly appreciated. Call **0141 848 0308** for more information.



Glasgow joined us at our tea party on 14 February, which was also branch chairperson Irene Brown's birthday. Irene is pictured here blowing out her candles. Thanks for your support on the day, Glasgow, we all had a lovely time.



Lothian shared a very successful Duck Race in January with Children 1st and each charity raised £800. Many thanks to the organisers. The Tai Chi sessions are continuing well. The branch held a belated Christmas lunch recently, at GiGi restaurant in Bonnyrigg. Twenty two people attended from Lothian and they all had a wonderful time. They had a very informative visit from Stan Pearson, an SHA director to their branch meeting. They are looking forward to the Lothian trip away to Crieff Hydro. There are many families going and everyone who requested a place will be going.

Tayside branch are continuing every month and were delighted with the response to the Huntington's disease research event in January at Ninewells Hospital. Dundee University has joined forces with pharmaceutical company GlaxoSmithKline to further the work of local scientists. David Husband, branch chairperson commented "They spoke about students developing a device that's attached to the wrist to measure involuntary movements. A well attended and informative evening, which was enjoyed by all".

North / East Support Groups

Nicola Johns, Fife HD Specialist who set up the new Fife Early Symptomatic group commented.



"The group were joined on 30 January by Isobel Darroch, Branch/Support Development Officer. She gave a resume of her role and updated the group on forthcoming events within the association. As part of her remit, Isobel will join us again later in the year."

East Fife Carers support group is continuing well in the community room at Asda in Glenrothes on the 4th Monday of the month from 6.30-8pm. It is hoped to hold a West Fife Carers support group in Dunfermline. Please call Isobel on **0141 848 0308** for more information.

Highland support group is continuing to meet quarterly. They have a speaker coming to give a talk on Self Directed Support on 25 April.

Tayside support groups are well attended. The carers group meet every 2 months at Carnoustie. Their next meeting is on 23 April and the symptomatic group meet 3-4 times at year. Please contact Paula McFadyen on **01382 425 549** or Alison Tonner on **01241 437 247** for more information. Thanks to Mary Cunningham, family member and her helpers who recently held a fundraiser at a charity shop and raised £2,500.

South / West Support Groups

East Dunbartonshire; is continuing well and are planning a few events this year.

Glasgow East; meet in the Milnbank Housing Association. It has been decided to hold the meetings on the last Tuesday afternoon of the month. Please come along and support them.

Renfrewshire and Surrounding Area; hold their regular monthly meetings on the second Monday of the month. New faces are most welcome.

South Lanarkshire are now meeting at the Lifestyle Centre (also known as -Murray Owen Centre) 1 Liddel Grove, East Kilbride, G75 9AD on the fourth Monday of the month at 10.30am. In March Helena Kelman from the South Lanarkshire Princes Royal Trust came along to give a talk to the group. It was greatly appreciated.

West Dunbartonshire needs more support from family members and the next meeting date has been set for 6 May at Asda Clydebank.

Accreditation

We are delighted to announce that the Bridgeview unit, which is part of the Huntercombe Group in Broughty Ferry, has been awarded with SHArp (Scottish Huntington's Association Registered Providers).

In a process that has taken over 18 months of partnership working and dedication, the team at Bridgeview received the news after the accreditation was approved by the SHA Board in December.

SHA has been working closely with the care home sector to develop the scheme; accreditation is carried out through a process of self-assessment, desk and site visit and is fully audited by SHA specialists. Bridgeview's site

audit was carried out by Karen Sutherland, Alison Tonner, family member Margaret Hutchison and Sue Beevers.

Sue Beevers, service development manager, north east, said **"Currently only a small handful of nursing homes have any significant experience of caring for someone with HD. The experience of many families is that the quality of care provided is frequently highly variable, sometimes inappropriate and occasionally inadequate, this new accreditation system will change that. Now families will be able to tell exactly what levels of expertise care homes have in HD simply by looking at the register of homes we will be**

developing, Bridgeview is just the first."

Families making a decision about long term care will now be able to make a balanced decision based on hard evidence that a care home has the required expertise and experience to offer outstanding support to anyone living with HD. Being on the register will indicate to families that a particular home has demonstrated that it meets a range of requirements that people with HD need to ensure a high quality of life.

Suzanne Wilson, centre manager added **"The Bridgeview unit has been established for around five years and the team have been passionate about meeting the specialist needs of people with HD from the outset. We were really keen to work towards accreditation by the SHA and the process was both challenging and rewarding for the staff team as it provided a great deal of insight into the rationale behind the care we provide."**

Any care homes interested in finding out about HD accreditation should contact Sue on **01975 562186**.



Bridgeview

SHAYP

New Huntington's Disease youth project launched

Young people living in families with the degenerative brain disorder Huntington's Disease (HD) are set to benefit from a new support project. The Scottish Huntington's Association (SHA) youth services team will be spearheading a national programme called 'HD Generations' to improve the lives of children living in families affected by the condition.

The project will develop an online workbook that the team will use with teenagers to explain the implications of being diagnosed with HD. It is being developed in collaboration with Huntington's Disease Youth Organisation – the international support organisation for young people around the world impacted by HD - and funded through a Young Start award. Run by the Big Lottery Fund Scotland, Young Start awards money from dormant bank and building society accounts that have seen no customer activity for 15 years.

"Through this project we want build a resource that will make learning about HD interesting, understandable and relevant for young people," said SHA chief executive, John Eden. **"Being a hereditary condition means it's not just the person diagnosed affected by the condition, it impacts on the whole extended family. Learning about HD at an early age better equips young people for some of the difficult life decisions they may have to take when they're older."**

He added that HD Generations will ultimately encourage better co-operation between generations, break down preconceptions and lead to better understanding within families, all helping to get over the stigma that often surrounds an HD diagnosis.

Big Lottery Fund Scotland Director, Jackie Killeen said: **"Young Start funding can help children and young people gain the abilities and confidence they need for positive and healthy futures."**

On Saturday 7 December, 25 young people took part in SHAYP Life's Christmas Activity in Glasgow. The fun filled day involved a trip to the Chocolate Factory, a yummy lunch and an ice skating session. All in all it was a great day as can be seen from the positive comments below:

SHAYP are also planning a break at Lagganlia Activity Centre in Aviemore again from 14 - 18 July 2014.



"Met old friends and made new ones. All of the activities were great"



"The activity made me feel relaxed and I was able to talk about things"



"Being with others who were in my situation helped a lot!"

News

The Carer Conference

is being held once again at our favoured venue, The Golden Lion Hotel, in Stirling, on **Wed 28/Thurs 29 May**. Invitation letters will be sent out to HD carers shortly.



The Family Conference

is again heading to the very family friendly and accessible Glynhill Hotel in Renfrew on **31Oct/1Nov**. The exciting programme is currently being prepared and notification will be sent out in a few month's time.



News in Brief...

SHA Website; in response to an appeal in the Paisley Daily Express for someone to re-design our SHA website (which is currently not working as it was hacked) we have recruited a Glasgow based company who have agreed to provide us with a new web site with the majority of the work being done free of charge. The aim is to have a new site up and running as soon as possible.

Strathclyde University invite you to; - Images of Research 2014 - Opening Night Professor Sir Jim McDonald (Principal) invites you to a drinks reception with colleagues, guests and entrants from this year's Images of Research Competition at the launch of the exhibition at The Scottish Universities Insight Institute. The exhibition showcases the University of Strathclyde's innovative work, offering a glimpse of the pioneering research undertaken across the University, and an explanation of how important working with others is to their research. **5.30pm arrival, event starts 6.00pm, Monday 28 April 2014.**



Remarkable Rose... Many of you will know Rose Knight and will have heard that she was involved in a serious road traffic accident which left her with multiple fractures and extensive injuries to both legs. The Fife Specialist Service would like to share with you that Rose is making a remarkable recovery. Her bubbly nature has helped her through this extremely difficult trauma.

Rose recently said, **"I am not letting this bring me down. I am going to make this into a positive"**.

We wish Rose all the best for a speedy recovery and she would like to thank everyone for their support and kind thoughts.

Text to donate; As part of our 25th anniversary celebrations we want to raise an extra £25k over the course of the year to improve the way we tell the HD story through a range of new information platforms. To help us achieve this text SHA1 to 70707 to make a £3 donation.

A Clyde2 Sunday Talk In radio programme with Ally Bally discussed End of Life Planning. Jan McMenemy, family member, telephoned into the show and was asked to give her opinion on the subject. To listen to Jan's interview please type www.soundcloud.com/scottish-huntingtons-ass/jan-mcmenemy into your computer search.

Thanks to Jan for sharing her views with us.



Join our Lottery draw; as part of our Silver Jubilee celebrations we want to reach 250 regular contributors to our lottery. Drawn every month there is one prize of £100, one of £50 and two of £25. All you have to do is pay through your bank account £5 a month or multiples thereof for a chance to win. Contact

mandy.nichol@hdscotland.org to register.

You have to be in it to win it!

Partnership with Paisley Daily Express is continuing very well. In January we commenced a year-long partnership with the Paisley Daily Express, a newspaper local to Head Office, that has a wide readership throughout the Renfrewshire area. We aim to raise awareness of SHA and especially HD during our anniversary year. We hope to raise £25,000 throughout the year with various fundraising ideas geared to the newspaper readers.



Discussion on This Morning, ITV programme and the End of Life Planning. The link can be found on our Facebook page, or type <http://shows.stv.tv/this-morning/real-life> into your computer to follow the link and read the whole story.

News Starts



Mandy Nichol said; "I joined the Scottish Huntington's Association in June 2013 on a temporary contract and was successfully offered a permanent position as Bookkeeper in December. I am currently studying at the University of the West of Scotland towards a degree in Accountancy. I have been inspired by the dedication of the staff and

learned how Huntington's disease affects the whole family and the role the charity has to play in helping those with the disease".



Susan Sweeney said; "I joined the Finance Department of SHA on 20 January and have been warmly welcomed by everyone in the organisation I have met or spoken to so far. I have worked for non-profit making and charitable organisations in the past and am delighted to be back in this environment, as I find it immensely rewarding. I am very impressed by the dedication and passion shown

by everyone associated with this organisation and look forward to being part of the team moving forward".

Research



Huntington's Disease and Sleep

New studies shed some light on the function of sleep in animals, with interesting implications for HD research. By Graham Easton on 6 March, 2014. Edited by Dr Jeff Carroll.

Studies have shown that HD patients tend to get less efficient sleep, fewer hours of sleep, and wake up more times during the night. However, sleep in Huntington's is under-researched because historically scientists have investigated HD as a disease of movement impairment, and sleep problems don't seem to have anything to do with movement impairment.

Sleep - what is it good for?

The picture is a lot more complex now. Huntington's disease clearly involves more of the brain than just structures involved with movement. It now appears that sleep -that evolutionarily dubious activity that takes up one third of our lives - may come into play in important ways.

It's well known that sleep is indispensable to health and well-being, that with minor sleep deprivation, mood, reasoning ability, and learning suffer; with moderate sleep deprivation, our immune systems are less effective and even our hormones go out of whack. In HD, sleep deprivation may have an even more potent effect.

Sleep may be protective in HD

Some symptoms of HD, like thinking impairment and clumsiness, look a bit like symptoms of chronic sleep deprivation. Scientists now believe that sleep deprivation commonly occurs in HD, hidden among other symptoms, and possibly acting in the progression of the disease.

So far there have been no systematic studies to determine whether sleep deprivation is the cause of any HD symptoms. This is an exciting area of study because if dysfunctional sleep is indeed the cause of some HD symptoms, it becomes a strong contender to be the focus of a treatment. The treatment of sleep disorders in HD patients has also not yet been systematically studied, but there is actually some evidence that imposing a regular sleep schedule is "protective" in mouse models of HD.

A new study by Dr Nedergaard of the University of Rochester, New York, suggests that the value of sleep may lie in helping to clean out the brain. While not focused specifically on HD, the study raises interesting questions about the role sleep plays in diseases like HD.

This study is obviously very far removed from being a test of viable treatments in people - it certainly doesn't tell us that chemically induced sleep would improve the overall health of HD patients. What it **does** provide is a kernel of evidence that dysfunctional sleep is harmful in the progression of HD.

Sleep hormones help HD mice

One way the body naturally regulates sleep is with a "hormone," or chemical messenger, called melatonin. Release of melatonin by the brain signals that it's time to sleep and consequently we feel drowsy.

HD patients have been found to produce less melatonin at night, and in fact this may contribute to the dysfunctional sleep sometimes experienced in HD. To see how melatonin levels might be affecting HD patients, researchers injected Huntington mutation mice with extra melatonin every day. These mice lived longer and showed less brain deterioration than HD mice given a dummy injection.

Is this "protective" effect of melatonin related to its ability to regulate sleep? This is one possible explanation, although a protective effect of melatonin was observed in a plate of HD cells as well, which do not technically sleep. For a more in-depth discussion of this melatonin research in HD, you can read this <http://en.hdbuzz.net/057> article on HDBuzz.

We know that in HD, clumps or "aggregates" of a specific protein called "Huntingtin" build up inside brain cells, where they disrupt important cellular processes. For cells, especially the long-lived cells of the brain, getting rid of old and damaged materials is vital, and it seems like this job is not getting done correctly in HD.

Our thanks to HD buzz for this article. If you would like to read it in full, please go to www.hdbuzz.net

Each year at the HD Therapeutics Conference

they put together a video "postcard" to convey to patients and families some of the major themes from the conference that are most relevant to them. The idea is to foster a sense of progress towards therapeutics for HD and set realistic expectations among families about new developments that might be coming soon. The 2014 video, presented as always by Charles Sabine, family member and television journalist, who worked for NBC News for 26 years, before becoming a spokesman for Huntington's disease. You can view the video on CHDI's website on <http://chdifoundation.org>

Thanks to Simon Noble PhD
Director, Scientific Communications
CHDI Management/CHDI Foundation

