

SHAre

Spring 2019

The Magazine of Scottish Huntington's Association - Issue No.86

scottish
huntington's
association



Let's talk about You, Me and HD

Over the course of our 30th anniversary, we are recruiting thirty volunteers who will reach out to community groups in their local area using an education and engagement model. Essentially they will give groups the facts about HD, and will also share their personal story.

Former SHA staff member, Liz McConnell, and Tayside HD Specialist, Lindsay Hughes Wilson, are leading the awareness-raising project.

The first task has been to promote the opportunity to participate and to recruit the 30 volunteers – you might have seen the ongoing promotion on social media already? We've had a great response but there's still time to get involved. Thank you!

One of our volunteers is Gillian McNab, who speaks so powerfully about her own HD journey in the [You, Me and HD recruitment video](#), which was filmed to inspire others to become involved.

Gillian says: **"It's just a huge relief to be able to talk about it after keeping quiet for so long. I tell everybody who will listen and have become involved in the fundraising and research. We need to play a role and help people to understand."**

Barbie Short, who is also featured in the video, adds: **"It's very important that we have people who can speak up about HD and explain that there's hope for the future. We're all very excited about the research projects. HD needs to be brought out into the open and talked about much more."**

You, Me and HD volunteers will engage with local community groups and promote their efforts through social media on the dedicated Facebook page that has been set up.

Full training will be given and out of pocket expenses will be reimbursed. We are thankful to the James Tudor Foundation for the £5000 grant that has made the campaign possible.

"This is a great opportunity for people to help us make a real difference to how HD is understood. It is a chance to really move forward people's understanding of the condition and the impact it has across generations of families," said John Eden, SHA Chief Executive Officer.

If you're interested in volunteering as part of the You, Me and HD campaign, please contact Liz McConnell at 07916062120 or email elizajane54@hotmail.co.uk



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SHA Chairperson Catherine Martin pictured in Boston with two researchers from WAVE Life Sciences. From second left, Wendy Erler, former Vice President Patient Advocacy and Commercial Market Insights; Huntington's Disease Youth Organisation staff member Chandler Swope; and Catherine Martin of SHA. WAVE Life Sciences is heading the Phase 1 trial for antisense oligonucleotides (ASOs) and Glasgow is one of their sites.

SHA Chairperson, Catherine Martin...

30 years ago, a group of families impacted by Huntington's disease wanted to ensure that all families have access to education, support, care and advocacy. They also wanted to ensure that any money raised in Scotland, stayed in Scotland. Since those years we have come a long way. The gene was identified, multiple international collaborations established, science and research advance has surpassed expectations and we have multiple clinical trials for possible treatments of the **WHOLE** disease active currently.

The journey hasn't always been easy, but SHA has grown over the years and kept our original focus as our guiding principle; families first. As the Board of SHA begin work on the next phase of the organisation's strategy, we are excited to be envisaging a future where we are making sure that families not only

continue to have access to the care they ALL need and that treatments, as they come on board, are accessible, affordable and appropriate for those who need them. To achieve this, the voices, testimonies and experiences of all members of families impacted by Huntington's are going to be invaluable. We need to step out of the shadows and proudly tell our stories. We shouldn't be hiding or ashamed of Huntington's, but be open to telling others that this is our reality. It might not be pretty, but it is part our family history and with the hope new treatments and scientific developments bring, it will not be our legacy.

In the words of many of the world advocates for Huntington's disease, Scotland is THE best place in the world to have HD, we need YOU to make sure moving from our 30th Anniversary as an Association, we lead the way by making sure that Scotland is the best place to get treatment for HD now and in the future.

John Eden, Chief Executive Officer...



A few issues ago, I wrote about the challenges families affected by HD, face in accessing protection insurance (life and critical illness cover). We worked with our colleagues in the Huntington's Disease Association of England and Wales, seeking to influence the Government at Westminster and the Association of British Insurers. We wanted them to remove HD as the only exception listed in the Code of Genetics and Insurance. To recap, this is the national policy that governs when insurance companies can ask for genetic test information when applications for

protection insurance are greater than £500,000 for life cover and £30,000 for critical illness cover. Over these limits insurers can ask for genetic test information, but only for one condition: HD.

We argued this policy unfairly discriminated against people with HD. We explained that the basis on which this decision had been made was scientifically wrong (insurers still think having the gene means you will always get HD). We told them every other country, including those who have this type of voluntary agreement between Government and the insurance industry, opted for an approach that did not select particular conditions. We challenged them to justify why HD should be the only listed condition when other late onset, autosomal dominant conditions like CADASIL (in which the brain is damaged as a result of repetitive strokes) or Familial Hypercholesterolaemia (which greatly increases the risk of heart attack) are not. We

explained the consequences of the policy were to perpetuate the myth that people with HD cannot be insured and in effect institutionalise that bias within the industry. We proposed a better alternative where, instead of selecting particular conditions, insurers should carry out an anti-selection risk assessment. In other words, when someone applies for insurance above the thresholds and they have a family history of a genetic condition, insurers can only ask for genetic test information if they can show it is necessary to make a fair decision about providing insurance cover and we also proposed this be monitored by the Government's Treasury department with oversight of the industry.

While we have yet to persuade the ABI and Government to change their policy, our engagement has been useful. For the first time we are engaged in an active and generally positive dialogue with the insurance industry and I remain optimistic this will result in improvements in the way insurers approach HD.

The work we have done so far has resulted in some tangible benefits. Our engagement with the industry has helped identify a new insurance product that benefits those living at genetic risk of HD (see last issue). We have also received support from the Insurance Industry Disability Champion who supports our position and the ABI has acknowledged we have made a fair challenge to the code and it is this admission in particular that persuades me, we should continue to engage with them. I believe this is very much a case of the tortoise and the hare, where perseverance will pay off.



Karen Sutherland, Operations Manager, and Lynn Garrett, Assistant Operations Manager, bring you up to date with the work of the Adult Clinical Service teams across Scotland.

Spring has sprung here in SHA and the Adult Clinical Service teams are looking forward to the all the exciting challenges and celebrations our 30th anniversary will generate. The buzz of last year's news relating to the clinical trials is still enthusing staff and families alike, although it is having an impact on the workload of staff who are supporting people through the trials, not that they are complaining it is a great honour for them to be involved. Many of the services have had an influx of new referrals since the start of the year, keeping them very busy and on their toes.

The Wave Life Sciences trial being led by Dr Ritchie at the Queen Elizabeth University Hospital is well under way and we are all very excited that Roche have selected Aberdeen Royal Infirmary and the Queen Elizabeth University Hospital in Glasgow as sites for their phase three clinical trials, which are due to begin in the very near future. We wait with anticipation to begin the recruitment process as soon as Roche give the go-ahead.

The Fife team are eagerly awaiting to see what the future holds with the Clarity trial, now that they are an approved site. After 12 years of HD families participating, it is fantastic that we can now offer them something.

Nicola Johns, Fife HD Specialist says;
"Now that Fife are a certified Huntington's Disease Clinical Trial Site, and have been officially accepted for the HD Clarity trial, we are eagerly awaiting a start date."

Highland service are almost ready for the joint work with the genetics service across Highland and Grampian areas. The Lothian Team facilitated a very successful training session for Social Care Staff on the 6 March, "Caring for a person living with Huntington's Disease". The feedback was awesome!

"I wanted to score more than excellent!"
"Powerful presentation – brought me to tears."
"Clear, practical approach and no misunderstanding."

The Lanarkshire team have also had huge success in recruiting large numbers of H&SCP staff in attending their monthly training session since the beginning of the year, all of which

have evaluated extremely well. Tayside, Fife and Lothian are looking forward to supporting the bench events taking place in their areas as part of the 30th anniversary celebrations.

The Ayrshire team have welcomed a new member of staff to their team. Lynn McCormack joined them on the 4 February, taking up post as admin/resource worker and has already got her feet well under the table.

Also as part of the 30th year celebrations Lindsey Wilson, Tayside HD Specialist, alongside former staff member Liz McConnell will be working over the summer working on the **You, Me & HD campaign**, to recruit 30 volunteers, who will then provide training and support to enable them to go around the country speaking to groups to raise awareness of HD.

Most staff have been involved in developing the localised version of HD Care Framework in their areas and it has now been successfully launched in Grampian, Fife, Ayrshire, Lanarkshire and Lothian, with Glasgow following suit in the next few months. Second phase is now under way in Forth Valley, Dumfries & Galloway and Highlands, with the final phase commencing in Tayside and the Borders in the summer.

This year's Carers' Conference is at Balbirnie House Hotel, in Fife scheduled for Tuesday 14 and Wednesday, 15 May. We have a stimulating programme arranged and look forward to seeing you all there.

Thankfully it is not all work and no play, staff had fun whilst improving their skills and knowledge at their last team training event.

Last, but not least, in Grampian we are keen to build on the great work created with the launch of the Huntington's Care Framework last year, and are looking to support Moray family group as it grows and develops.



Staff really enjoyed our recent team training days, building their skills and knowledge – and having a good time!



Roisin joins the team

Welcome to Roisin Eadie, our new communications officer, who joined us in March. A former Head of Communications at Mary's Meals, Roisin is working part-time in the national office. Her role involves working with the media to raise awareness about HD and the work of SHA, writing for newsletters and publications, including SHAre, supporting the fundraising team, and exploring ways to grow the SHA supporter base. Roisin is really looking forward to getting out and about and meeting as many people as possible over the next few months!



Carers Toolkit SHA Carers Conference 2019 Tuesday, 14 - Wednesday, 15 May

As part of our 30th anniversary celebrations, we are holding our annual Carers' Conference in an extra-special location. Balbirnie House Hotel <https://balbirnie.co.uk/> is an award-winning luxury country house nestled within 400 acres of beautiful parkland in the heart of Fife. The Georgian mansion was built in 1777 and is near the village of Markinch, between Edinburgh and St Andrews. Without the support of Balbirnie, we wouldn't have been able to secure this lovely venue and we thank them very much.

A limited number of rooms will be available for carers to stay overnight on the Tuesday, complete with breakfast served in The Orangery Restaurant. Overlooking the front of the house, it is a wonderful place to start your day before the full and entertaining conference programme begins.

Entertainment will also be provided on the Tuesday evening, starting with a relaxing yoga taster session, followed by dinner and a 'Hounds for Huntington's' fun event with prizes aplenty.

Our conference agenda is packed full of speakers who hope to help expand your toolkit of resources to support you as a carer of someone with HD. Lunch will be provided, and we aim to secure a minibus for those who require transport back to the railway station at the end of the conference.

Invitations were sent out in mid-March, but if you haven't received yours, please contact Christine Malhan at shahighland@hdscotland.org or telephone 01463 729958 and leave a message. We look forward to seeing you there!

National Care Framework

The Lothian Care Framework for HD has been formally launched at an event in the University of Edinburgh.

Dr John Harden, National Clinical Lead for Quality and Safety at Scottish Government, said:

"Scottish Government has been hugely encouraged by the National Care Framework and the localised versions are now being rolled out."

"Not only does it stand to benefit families impacted by Huntington's disease but we are hopeful it could in due course be used as a model to help people affected by other neurological and long term conditions. This is a really exciting prospect."

Dina De Sousa, Chair of the Lothian Huntington's Disease Support Group, said:

"Having the Framework allows families to access information and help all in one place."

The national and available local Frameworks can be viewed at care.hdscotland.org. The Greater Glasgow & Clyde Framework is due to be launched next, and work is taking place to develop Frameworks for Highland, Forth Valley and Dumfries and Galloway. Work to develop Frameworks for Tayside and the Borders will begin in the summer. Once complete, all mainland Health Boards will have a localised version in place.





Civic Reception, Paisley

Renfrewshire Council is to mark the charity's 30th birthday with a civic reception hosted by the Provost, Lorraine Cameron.

This is a wonderful opportunity to bring together family members, donors, volunteers, SHA staff and trustees, local businesses and influencers to raise awareness about Huntington's disease, the work of the charity and how we are transforming the landscape of care for people with HD.

The event will place on Friday, 10 May 2019 at the Glynhill Hotel, Renfrew. Up to 70 guests are expected to attend, and speakers will include SHA Chief Executive John Eden and SHA Chair Catherine Martin.

Pupils get top marks in philanthropy challenge

A big shout-out to Braes Academy, Polmont, for taking part in the Youth and Philanthropy Initiative (YPI), a global citizenship programme to raise awareness among young people about philanthropy and their local community.

Pupils were challenged to give a presentation about a charity of their choice – and the winning team decided to highlight the work of SHA and its youth services in their innovative and inspiring performance.

SHA fundraising officer Linda Winters and specialist youth advisor Grant Walker attended the event, and were full of praise for the pupils' creative approach and commitment to raising awareness about Huntington's disease.

The YPI programme is principally funded and managed in Scotland by The Wood Foundation, and a £3000 grant has now been awarded to SHA in recognition of the pupil's success.



In Memoriam Annie Mackenzie

We were sad to hear that Annie Mackenzie passed away in February 2019. For those of you who remember Annie, she was part of SHA for many years before going on to create her own charity, Live for Life Foundation, which was founded in April 2011.

Annie worked hard to develop all the events for the Foundation and, along with a team of volunteers, delivered numerous successful events, mostly around the Glasgow area, to raise vital awareness about HD.

We send our deep condolences to Annie's family.

SHAYP



SHA Youth Service – SHAYP – has been awarded £249,708 by the National Lottery Community Fund – great news as the funding means vital services supporting young people will continue for a further two years.

Kirsten Walker, Senior Specialist Youth Advisor at SHAYP, said:

“Growing up in a family impacted by Huntington’s disease is incredibly challenging and without this award from The National Lottery Community Fund we would have been faced with the real prospect of cutting services which would have had a devastating impact on the children and young people we work with so we are eternally grateful!”

SHAYP is now developing the service plans for the next two years, so watch this space for more details!



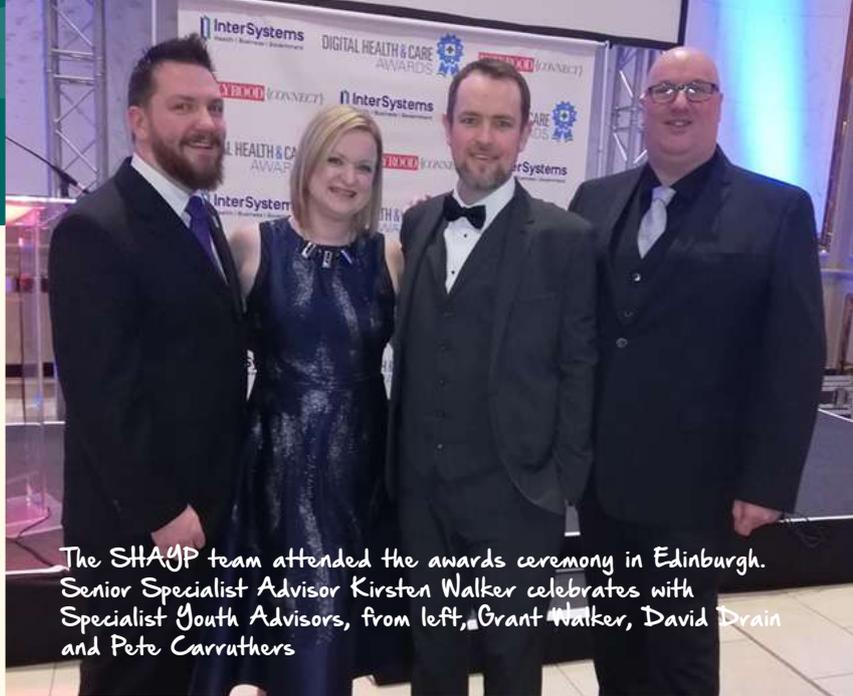
Research Review

SHAYP is continually striving to improve their services to children and young people. Following consultation at Summer Camp 2018, the young people informed SHAYP staff that they didn’t know what was happening in the world of research. Since then, SHAYP has spent time developing a young-person centred newsletter, and the first Research Review was published on SHAYP’s Facebook page in February.

Each month SHAYP staff will look at pertinent research and provide a young person friendly explanation which will be shared on SHAYP’s Facebook, so please make sure to ‘Like’ our page.

As an adult, if you are looking for further detailed information, remember to subscribe to SHA Headline.

<http://hdscotland.org/headline/>



The SHAYP team attended the awards ceremony in Edinburgh. Senior Specialist Advisor Kirsten Walker celebrates with Specialist Youth Advisors, from left, Grant Walker, David Drain and Pete Carruthers

DIGITAL HEALTH & SOCIAL CARE AWARDS 2019

SHAYP’s work gained further recognition at this year’s Digital Health and Social Care Awards.

The team was absolutely delighted to be shortlisted in the Empowering Children and Young People awards category – judges were impressed by the digital literature and innovative resources developed by SHAYP to support children on their Huntington’s journey.

Kirsten Walker, Senior Specialist Youth Advisor at SHAYP, explains: **“To have the hard work and endeavour of SHAYP highlighted is an honour in itself. Whilst it would have been amazing to win the award, SHAYP is delighted to have been recognised and to have improved the range of digital information available to children growing up in families impacted by HD – being runner-up has only spurred us on further!”**

SHAYP Talks

#LetsTalkAboutHD #YouAndMeAgainstHD

SHAYP are delighted to announce the launch of SHAYP Talks, a new online video series to help our young people, parents and professionals understand more about HD. This series will engage with experts within the HD community to focus on a specific topic around HD, and will follow a question and answer format.

SHAYP has already launched two episodes – SHAYP Talks: An Introduction and SHAYP Talks: Talking with others about HD. Both are available on our YouTube channel, and are also shared to our Twitter and Facebook feeds. We are hoping that they will be as interactive as possible so please Like, comment, share, or subscribe to help get everyone talking about HD!

SHAYP are also keen to hear from anyone who has an idea for a SHAYP Talk or would like to take part. Please get in touch with Grant Walker - grant.walker@hdscotland.org.



Kim Kemp, SHA Administration Assistant and Gavin Neate

Getting out and about can be very difficult for some people. We hope the information below may be useful to you.

Kim explains how the Neatebox Welcome app has changed her life.

“ I came across the Neatebox Welcome app at the Scottish Muscular Dystrophy Conference in November 2018, when I attended a workshop called ‘Getting around using technology’.

Neatebox Welcome aims to ensure better customer service experiences for those with a physical or hidden disability.

The app enables you to request visits to participating venues, indicating the areas you need customer service to have awareness of and the specific assistance you require. Venues are notified of the visit request and receive an overview of your condition and top tips to aid their interaction with you.

I was interested but sceptical at first - these gadgets, despite changing your life for good, are usually VERY expensive. However, Neatebox Welcome is FREE to use.

Gavin Neate, CEO and founder, was inspired to devise it during his years training guide dogs for the blind. Acutely

aware of the challenges faced by disabled people, he decided to give up his job to develop an innovative solution – and Neatebox Welcome is the result.

I was completely sold! I approached Gavin after his presentation at the conference, shook his hand and said: “Where have you been all my life?”

The Neatebox Welcome app is simple to use, but revolutionary. It’s a real game-changer that has given me, as a disabled person, customer service at a level that I’ve never experienced before.

No more worrying about how staff will treat me. No more staff not answering my questions and talking directly to my carer instead of me. Now, when I visit venues that use the Neatebox Welcome app, I receive excellent customer service and I leave feeling like a VIP.

Now I’m on a quest to get as many new users as possible. After telling CEO John Eden about Neatebox Welcome, SHA is

now on board and HD is on the app!

I hope that people living with HD, their families and carers, and those who work with and support those with HD, will see the value and potential of this app.

I have been Tweeting, Facebooking (I’m editor of the Welcome App Friends Group on Facebook) Instagramming, e-mailing, visiting organisations and attending conferences to get the word out there.

I am also learning to blog and have written a few pieces about my Neatebox journey. I am also part of #AXSchat on Twitter.

It is easy to use, but if anyone wants help to download or use the app, Gavin and I are both happy to help. Just get in touch!

Why do I do all this? Because somewhere out there, there is a person who is isolated and desperate to be a part of society. I know Neatebox Welcome can help to change their life. **”**

MyBus
Getting you around

MyBus is a bookable bus service offering door-to-door transport in your area. MyBus can be used for shopping, GP appointments, visiting friends, attending local clubs and much more.

MyBus will pick you up and drop you off as close as possible to your destination. All vehicles are low-floor and wheelchair friendly. The driver will give assistance to board

the bus from the pavement. Please note, however, that the driver is unable to provide assistance from your home to the bus.

To speed up the registration process, you can download, print off, fill out, and send in the MyBus fast track booking form http://www.spt.co.uk/cms/wp-content/uploads/2018/06/MyBus_FastTrackBookingForm_June2018.pdf.

You can also apply for membership of the MyBus service by calling its information line on 0345 128 4025, Monday to Friday between 08:30 and 16:45.

To find out more about MyBus in your area visit MyBus <http://www.spt.co.uk/bus/mybus/>



Family Branch/Support Group

Isobel Darroch - Branch/Support Development Officer

I have travelled across the country for nearly eight years now in my role as SHA Branch/Support Officer. Whilst driving along a road just after Christmas, I came to a crossroads - which way to go?

Left to HQ, right to Support Meetings or straight ahead to Retirement?

I have decided to take the road not yet travelled and will retire at the end of April. I have been privileged to travel hundreds of miles to meet thousands of people and now have a million memories to cherish. It's been an amazing, life-changing journey these last 23 years, watching SHA grow and flourish into its 30th year. For eleven years I have also been the editor of SHAre newsletter, always looking for stories and meeting deadlines, with a constant cry for more pictures please!

So, as I sign off with a HUGE thank you to everyone I've met and worked with, I send my heartfelt wishes to you all. Slan go foill - Isobel

Now for my final hop around the country with the family branch and support groups.

Family branches

Fife enjoyed a Christmas lunch at Gilvenbank in Glenrothes in December and were delighted with 40 people attending. The branch is also busy getting ready for the launch of its pop-up thrift shop in Wellesley Road, Methil, which will be open from Saturday, 4 May to Friday, 10 May. Pop along to pick up a bargain – and to drop off donations! Finally, preparations are underway for the upcoming installation of the 30th anniversary bench, which will be sited at Bandrum Nursing Home in Dunfermline.

Lothian enjoyed a visit from author and storyteller, Millie Gray, in February, who regaled them with stories from her books and life. They will be holding their AGM in April and are busy preparing for the installation of their 30th anniversary bench next month.

Tayside made up hampers in December for people living on their own at Christmas and carers received a bouquet of flowers. Hampers were also sent to each specialist unit. They also had another hugely successful pop-up shop in February in Coupar Angus and are putting arrangements in place for the siting of the Tayside 30th anniversary bench.

Branches extend an invitation to all family and friends to support them. Over the years they have provided a forum to discuss problems associated with HD and how it affects the individual, their carers, friends and family.

Support Groups

Ayrshire carers enjoyed a First Aid Demonstration from British Red Cross Adult Co-ordinator, Marc Begley, who explained techniques on choking and CPR.

Glasgow Carers also had the same demonstration at their meeting. Both groups found the presentation very informative.

Glasgow Symptomatic group was joined in March by Grant Walker, Youth Specialist Advisor, who updated them on current HD research and presented the new youth literature to them.

Grampian group is continuing well at the Health Centre in Aberdeen, where the Grampian Senior HD Specialist joins the group regularly for information sharing.

Highland had a busy group meeting at the Spectrum centre in Inverness, where they continue to be very supportive of each other's HD journey whilst enjoying the camaraderie of Highland hospitality in the form of baked cakes and brownies.

Lanarkshire carers meeting numbers unfortunately have now dropped considerably and will have to consider the future of the group.

Moray had a great turnout to their meeting in February. As ever, there is huge support there. Thanks to Michelle Fleming, from Moray Council, who gave an update on Self Directed Support (SDS). Tony Cantlie and Dave Powney explained how facilities at Moray College gym include an Alter-G anti-gravity treadmill – a specialised treadmill with an air bubble underneath can support your bodyweight and helps people with neurological conditions.

Tayside carers meet every two months, however there is currently no symptomatic group as they are struggling with transport issues.

Dianne Anderson brought an embroidered cushion to the Moray meeting which she raffled off. £220 was raised. Thank you Speyside Quilters, of which Dianne is a member - your creations are fabulous!



Dianne Anderson and Isobel Darroch pictured holding the cushion with the Moray support group enjoying the moment.

Fundraising News



Wonderful gift from The Hospital Saturday Fund

Scottish Huntington's Association was delighted to receive £3000 from The Hospital Saturday Fund at a special reception hosted at Glasgow City Chambers on 21 February, 2019. The donation will be used towards our Glasgow & Clyde HD Specialist Service.

In total, £80,000 was gifted to the charities at the event, which was hosted by The Rt Hon Lord Provost of Glasgow, Councillor Eva Bolander, represented on the evening by The Lord Dean of Guild, Mr Ian Dickson.

Speaking at the reception on behalf of The Lord Provost, the Lord Dean of Guild celebrated the extraordinary work of all the charities receiving donations from The Hospital Saturday Fund.

Paul Jackson, Chief Executive of The Hospital Saturday Fund, said: **"We are delighted to continue the tradition of supporting many wide-ranging charities in Scotland, many of which are less well-known. The Hospital Saturday Fund is honoured to support the efforts of such deserving charities and help in some way towards the exceptional, tireless work that they do in making such a huge and positive difference to people's lives."**



Join fundraisers from across the world embarking on a Walk of Hope! These walks of hope have raised awareness of Huntington's disease across the globe from Australia to America and lots of countries in between!

Put your best foot forward by taking part in an organised challenge, or set your own walking route, recruit your team mates and go!

Find an event near you!

Sunday 28 April – Glasgow Kiltwalk

Saturday 8 June – Ben Nevis Trek

Sunday 2 June – Aberdeen Kiltwalk

Friday 16 August-Sunday 18th August – Three Peaks Challenge

Sunday 18 August - Dundee Kiltwalk

Sunday 15 September – Edinburgh Kiltwalk

Any date – organise your own!

Email gemma.powell@hdscotland.org for more information and sign up.



Volunteers raise Thousands of Pounds for SHA

SHA relies so much on the efforts of local people who raise funds for the charity and this year we hope you can help too. Often we hear volunteer fundraisers say they would love to help the charity, but just don't know where to start. Well, that's where our very skilled community fundraisers can help. With a wealth of experience in fundraising, the team can talk you through event planning and delivery. They can demystify how to run a successful fundraising event and help you to help us in the fight against HD.

Perhaps you could run an event in your local community hall and give it a seasonal theme? Ever thought of running a Race Night? Well our new "Huntington's Hounds" Race Night package is available to borrow and the fundraising team will help make sure you deliver a great night.

Might a local venue allow you to take a bucket collection or a supermarket give you a date for a bag packing session? It's easy to take that first step and get involved; just call our friendly team on **0141 848 0308** for a chat about your ideas.

New corporate supporter for SHA!

Dundee Doubletree by Hilton has chosen SHA as one of four charities to support in 2019! Since March, they have been taking part in various fundraising events, from the sale of baked goods to a sponsored walk to raise funds and awareness of Huntington's disease. It's all very exciting and we're looking forward to seeing their success over the next three months. Thank you to all involved!



Fundraising News



A fantastic gesture from Ailsa and Andy

Ailsa, six, and her three-year-old little brother Andy Gilchrist from Fochabers, pictured left, shared a joint birthday party in February and raised a fantastic £222.50. They asked family and friends to put a donation in the HD bucket instead of bringing a gift. Their mum said that they had a wonderful party. What a great gesture, well done to them both (also mum and dad).

Elgin Rotary Club

Elgin Rotary Club chairman George Duthie presented a cheque for £1130 to Jock Anderson, for SHA Moray family support group. Group member Jock said: **"The Moray support group is delighted with such a generous donation."** Mr Duthie accepted a copy of the last SHAre newsletter, which will give the Elgin Rotary Club an insight into the challenges facing HD families in Moray.

Financial Support from Ross & Liddell Ltd

We were delighted to host a visit to the National Office by Fiona Church-Michael, Property Manager from Ross and Liddell Ltd who donated £500 towards the cost of printing new HD Services leaflets.



Plea for helpers at show

This year's annual Black Isle Show will take place in Muir of Ord, near Inverness, on Thursday, 1 August 2019. SHA will be represented at the show and we desperately need your help! Can you spare a couple of hours to staff our gazebo on the day? We will have HD information, balloons, collection buckets and fun items such as a raffle or tombola.

Gordon Bogan, our Highland Senior HD Specialist and Fundraising Manager Dougie Peddie, will be there all day. They'd be delighted to meet you and are promising a hot cuppa and home baking for helpers! Come along, volunteer for the charity and get into the show free – that's a saving of £18 on the entrance fee! Call Dougie on **0141 848 0308** or email dougie.peddie@hdscotland.org with your availability.

£9k Donation to SHA

HD Family and Board Member, Marie Short, is photographed handing John Eden, SHA Chief Executive, a hugely generous personal donation of £9000 on behalf of her sister Kathleen Celentano from Dunfermline in Fife. Part of the donation has been earmarked to help launch the new SHA My Zen Run event which can be accessed via the SHA website. A huge thanks to Kathleen for her financial contribution which will go along way to provide support to families impacted by Huntington's Disease across Scotland.



The Big Sing



What an amazing evening at the Orchardhill Parish Church in Giffnock on Sunday, 2 December 2018. The voices of the Military Wives and Falkirk Junior Gaelic choir filled the beautiful church building with joy and emotion for the 200-strong audience.

There are too many people to thank personally, but we are humbled by everyone who came along to support the work of SHA and volunteer their time. Chief Executive John Eden gave an insightful presentation about the charity's work and Huntington's disease (HD).

Not only did we raise awareness with people new to SHA, we also raised nearly £3000 towards supporting families affected by HD. Feedback was uplifting and positive – so much so that we have confirmed another date for Sunday, 1 December 2019.

Put it in your diary now!

Kelvin College link-up

SHA Community Fundraiser Linda Winters is working on a new project with additional needs students at Glasgow Kelvin College, who are working towards their National 1 Fundraising and Enterprise Award. The students created beautiful lavender bags, which were sold at SHA's annual ceilidh in March.

The 2020 SHA Rickshaw Challenge

SHA is recruiting a team of community fundraisers for the 2020 SHA Rickshaw Challenge, which will take place in India next February/March. Each member is asked to raise £2500 in sponsorship for SHA, which includes return flights, accommodation and catering.

Participants will be away from the UK for 10 days, flying to Mumbai and taking the train to Goa. Once there, the Challenge begins! Four days in India will be spent cycling the SHA Rickshaw from town to town along the coast, staying in various accommodations along the way. Expect to be cycling/walking for four hours per day.

Fancy ten days in India with some time on the beaches of Goa?

SHA Rickshaw challenge

SHA Rickshaw Challenge
which will take place in Feb/Mar 2020. All you need to do is go to the SHA website www.hdscotland.org and register an interest at this stage, as the final details won't be confirmed until we know how many supporters sign up.

30th scottish huntington's association
Part of the HD Family Worldwide
Institute of Fundraising

If you would like further information please call
Dougie Peddie on 0141 848 0308
or email Dougie.peddie@hdscotland.org

The final couple of days in India will be spent relaxing in Goa before returning to the UK.

At this stage, we are only seeking expressions of interest to ascertain if such an event will be supported. If we can get a group together, then you would need to have a passport, apply for an Indian Tourist visa, arrange travel insurance and start training!

Contact dougie.peddie@hdscotland.org for more information or if you want to have a chat about the challenge call Dougie on **0141 848 0308**.

DATES FOR YOUR DIARY

- 30th anniversary civic reception, Glynhill Hotel, Renfrew
Friday, 10 May, 2019
- Strathallan Skydive,
Saturday, 11 May 2019, Auchterarder
- Carers' Conference,
Balbirnie House Hotel,
Fife, Tuesday 14 May to
Wednesday, 15 May 2019
- Dancing through the Decades
Saturday, 21 September 2019,
Pollokshaws Burgh Hall, Glasgow,
with Party People Video DJs.
- The Big Sing, Orchardhill Parish
Church, Giffnock, Sunday, 1
December 2019
- SHA Rickshaw Challenge,
February/March 2020

Research



Roche make significant changes to the GENERATION HD1 study

Roche have temporarily halted recruitment to the GENERATION HD1 clinical trial (for the huntingtin lowering or gene silencing drug RG6042, initially developed by IONIS). They have decided to do this because analysis of data from the group of people who took part in the phase one trial for the drug and who continue to receive it may suggest less frequent dosing is possible.

The trial was designed to include a placebo or dummy treatment group, of approximately one third of the trial participants. This group is necessary to cope with the placebo effect – the fact that participating in a trial makes people feel better, and even function better, even if the drug doesn't work. The other two thirds of the participants were intended to be split into two groups, both receiving the active drug. Half of the treated group would receive the drug every month, and the other half every other month. This part of the clinical trial has not changed.

Roche has announced they are adding a third 'arm' to the trial in which participants will receive treatment of the drug just three times in a twelve-month period.

Roche are being quite tight lipped about the reasons for this, but it seems the data being collected from those still receiving the drug has given them enough confidence to explore extending the interval between doses.

It is exciting news because, if this approach proved successful, it would be a step towards a manageable and much more affordable way of treating HD.

Scotland has two sites involved in this study: Aberdeen (ARI, Forrester Hill) and Glasgow (Queen Elizabeth Hospital).

uniQure gets green light from the FDA

Dutch-American company uniQure has received approval from the US drug regulator the FDA, to begin the first ever gene therapy trial in Huntington's Disease. Their plan is to use a virus, injected into the brain, to turn cells into a factory that makes a molecule to lower the harmful huntingtin protein. In effect the artificial virus will make strands of micro RNA (a very specifically designed molecule that binds to messenger RNA) and interferes with the production of the huntingtin protein. What makes this therapy so different is, it requires a one-off injection into the brain. As with all drug development the first phase is to test how safe it is to give to human beings, but it's exciting to see new approaches being developed.

Do cannabinoids improve Huntington's disease?

You can hardly turn on social media or the news today without hearing anecdotal tales of the benefits of cannabinoids (compounds extracted from the cannabis plant, but which don't have the component that causes 'highs'). We get regular questions about whether people with HD should take them which we are unable to give a definitive answer. It's good news then that MMJ Holdings has been given approval by the FDA to run a clinical trial into the effects. Through proper clinical trials, researchers can prove whether a potential treatment is both effective and safe. This is the standard that all other medicines are held to, and it shouldn't be any different for cannabinoids.

