



Thumbs up for new Clyde Service



John Eden, SHA Chief Executive

Since families started SHA in 1989 the most important goal of the charity has been to establish specialist support services across Scotland. Today sees us take one giant step closer to making this a reality by securing funding to expand the support we provide in Glasgow to the whole of the Clyde Valley. With a population of 1.2 million and an estimated 240 people living with symptoms of HD, the region is the largest and most populace in Scotland.

East Renfrewshire Community Health and Social Care Partnership (CHCP), West Dunbartonshire CHCP, Inverclyde CHCP, Renfrewshire

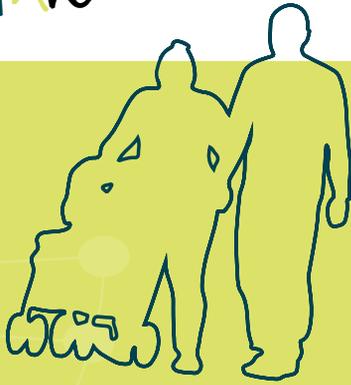
Council and East Dunbartonshire Council will all contribute funding to two brand new Huntington's disease Specialist posts (one full and one part-time). The new staff will be based with our existing Glasgow team, but will provide an outreach service to all parts of Greater Glasgow and Clyde.

We expect to commence recruitment in September and aim to fill the posts by early December so that by 2014 families living with HD across the region will benefit from the same support.

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Get Involved

If you would like to get involved and help us make a difference, then give us a call on 0141 848 0308 or email sha-admin@hdscotland.org



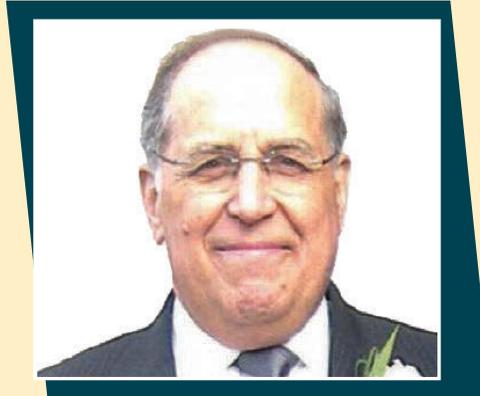
Matters from the Chair

Philip Fox - Chairperson



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What an amazing organisation SHA is when one considers the spectrum and depth of its activities.

Whenever the board meets one is reminded of this, never more so than at our meeting this June, when all 11 members, along with John Eden, were present.

The breadth of the agenda was almost overwhelming. We reflected on the SHA Business Plan; the Communications Plan which encompasses stakeholders, healthcare professionals, politicians, media, and local authorities; the latest Operational Report highlighting the forthcoming Annual Family conference which is being held in Aviemore. We also discussed the progress on the new Glasgow and Clyde Post, the £44k funding for the Youth Service, Wellbeing Volunteer development, links with Stirling University where we are currently formulating an HD training module and the growth of Branch and Peer support.

The occasion was made even more special by lunching together before spending time in discussion, sharing something of our backgrounds, what we felt we could contribute as board members, what were SHA's weaknesses and strengths and what each of us would like to see in its future.

However, all this was eclipsed throughout by good wishes and gifts to one due to enter the 8th decade (June 9th). A day I will not forget. Thanks and Blessings to all of you!

Philip



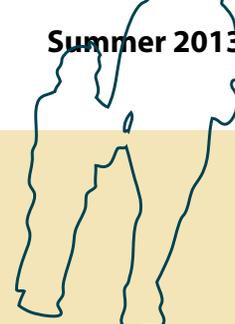
Cover picture: back row l-r Jane Williams, Lindsay Davis, Jade Gemmell, Daniel Frame, front row - Isobel Darroch & Sadie Clark.

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

t: 0141 848 0308
sha-admin@hdscotland.org
www.hdscotland.org

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John Eden says,

“ An enormous amount of behind the scenes work has gone on to get to this point and we are immensely grateful to our statutory partners across Clyde for recognising the very real need for this service. I am personally delighted that the charity has been instrumental in removing a significant inequality. ”

This development will also ensure that families will benefit from other key support that includes our National Youth Service (SHAYP) and our new, but growing, Wellbeing Volunteer service.

While we celebrate the fantastic news in Clyde, there are still other areas of Scotland where there is a need for a specialist service. Forth Valley is now the single largest region without a specialist service and the charity will continue to campaign for better support. However, the news in Clyde can only strengthen the case for families living in Forth Valley even further.

John says, “The day is in sight when everyone can access the specialist support they need regardless of where they live. Upon that foundation we can improve the quality of care for everyone living in Scotland.”



The Scottish Disabled Supporters Association (SDSA) was launched in October 2010 and supported by CAFE - Centre for Access to Football in Europe

UEFA announced that its Monaco Charity Award for 2009 would be dedicated to the creation of a new organisation to establish equal access for disabled supporters across Europe. CAFE was created to ensure disabled fans across UEFA's member associations can enjoy a football match as a problem-free experience. CAFE's aim is inclusivity and equality of experience and because football embraces diversity in all its forms, CAFE will also work with the football family to raise disability awareness more widely throughout Europe. The aims of SDSA are a mirror image of those of CAFÉ:-

- **to enable disabled people to follow football in Scotland**
- **to achieve equal access for all football supporters in Scotland**
- **to increase disability awareness and improve the lives of disabled people using the special influence of football within Scotland**
- **to establish a Scottish network of disabled football supporters**

The SDSA is active in the recruitment of new members. Recently Keith Ferguson (Chairman of the SDSA) met with John Eden, Chief Executive of SHA, and discussed the issues surrounding football fans with Huntington's disease attending matches.

The SDSA would love to hear from any members of SHA who are regular followers of football. For more information contact either:

Neil Strevens, Administrator,
neil.strevens1@gmail.com
 tel 07752830921 or
Keith Ferguson, Chairman,
keithferguson@btinternet.com
 tel 07743780913



Grass roots football in Scotland

SHAre Newsletter

We are pleased to announce that Stephen Dunn, Pre Press Design Technician from The Student Loans Company will now be designing SHAre newsletter.

The company is also affiliated through a family member and last year we were delighted to be their Charity of the Year.

Stephen, a keen cyclist also took part in the Borders Ciclista event in May and raised £420 for Scottish Huntington's Association.

Our thanks to the Student Loans Company and Stephen for their continued support.



Stephen Dunn



Sue Beevers HD Service Development Manager North/East

A development that we are very excited about is our new collaboration with Stirling University. We intend to work in partnership to launch a new higher education module in Huntington's disease. Two of our team members

from the North East, Alison Tonner and Jody Dexter, along with myself, are to form a small project group to write the content. We will have support from the university in this to ensure that it is compliant with all the necessary standards. The first course is expected to run in autumn 2014.

More news from each area;

Angus and Tayside Services: Alison, Paula and Lindsey have boldly volunteered to organise this year's annual team training event. This is when all of the staff get together to discuss service developments, effective team working and receive training vital to their roles to ensure that the support you receive is as up-to-date as possible.

Fife: Due to a keen eye for detail and evaluation, the Fife team have been refining their approach to carrying out their research clinics. Attendance is up and time management has improved. Jillian was able to present on the team's success recently at a meeting in Birmingham with an audience from across Europe and beyond.

Lothian: It's business as usual in Lothian with the exception of our much needed new second HD Specialist, Annette who has completed her first few months. Annette is enjoying meeting all the clients and becoming more familiar with the role. We are looking forward to some great developments for the whole service with our Health and Social Care colleagues.

Highland: Plans and final details are in place for this year's family conference which is hosted by the Highland Service. We're hoping for a high attendance to what promises to be a truly international event in Aviemore with guests from across the globe.

Our thanks to Kimberley Leslie, pictured here on left, with friends Lucy Macdonald, Jeni Macdonald and Allana Mackay who raised £835 for the Highland service by climbing Ben Nevis. Judging by the smile on their faces, they had a very enjoyable experience. Well done to all.



Grampian: Of greatest note in Grampian is the four information events that Jody held recently in the run up to Awareness Week. These were well received and there is support for a regular bi-annual meeting. Thank you to everyone that helped make these sessions successful.

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 service held several successful promotional events during Awareness Week. Both Eileen and Julie hosted stands in Ayr and Crosshouse Hospitals providing advice, information and literature relating to HD. New referrals have been coming in steadily over the past

few months and as always the service is working full steam ahead to provide the people of Ayrshire with an excellent support service. The client and carer's outing to the People's Palace in August was successful. The date to launch the Care Pathway took place in August at the MacDonald Education Suite in Ayr Hospital.

Glasgow: Teresa, Beverley and Anita have also been working hard providing a service to over 117 people and are very excited about the recent news that we have finally secured funding for Clyde. This will enable SHA to expand the Glasgow team by employing a further two Huntington's disease Specialists (one full and one part-time). The team look forward to being able to provide a much needed service throughout Glasgow and Clyde, thus reducing the post code lottery system which is currently in place.

The Glasgow service also had a very successful Awareness Week. Teresa and Beverley set up stands in their local Asda store, Stobhill and Victoria Hospitals. Beverley stated that over a thousand people passed her stand at Asda. Teresa once again supported the Youth Team by volunteering to help out for the week at the Youth Summer Camp.

Lanarkshire: Linda remains busier than ever in Lanarkshire. The service has had over 18 new referrals since January. That's more than the whole of 2012. This takes her caseload to well over 127.

Valerie Ross, our former Fundraising Officer worked hard to submit Trust and Grants applications to try and access monies to help us fund a part time Huntington's disease Specialist. The launch of the Care Pathway on 11 June during Awareness Week was very well attended and it highlighted the success of the Partnership working of the NHS, SHA, North and South Local authorities throughout Lanarkshire, providing a cohesive and effective service for individuals and their families whose lives are affected with HD.



(pictured At the launch of the Care Pathway (l-r) HD Specialist Linda Lucas, Dr Alison Gordon and SHA chief executive John Eden)

On behalf of the South West Team I hope you have all been enjoying the lovely warm weather this summer and it continues for many months to come.



Wellbeing Volunteers Are Go!

Bob Bogle - Volunteer Co-ordinator



After a hectic year of planning, preparing, publicising, recruiting and training, the very first of our Wellbeing Volunteers are now going out to support HD

family members across the south and west of the country. The volunteers are being carefully matched with family members through each service's HD Specialists. The intention is that this will result in a match between both parties and bring real improvements to the lives of those affected by HD as well as the volunteers themselves.

A unique feature of our Wellbeing Volunteer service is that it is tailored not only for the HD family member, but the volunteer as well. The volunteers come from a wide range of backgrounds but all come with very useful experience, skills and real enthusiasm for the role.

To help illustrate this, two of them have agreed to introduce themselves and explain why they have decided to become Wellbeing Volunteers:

Jade Gemmell, Glasgow

Jade has a very special reason for becoming a Wellbeing Volunteer – her mother was diagnosed with HD five years ago and there is a 50% chance the faulty gene has been passed on to her, the disease having already claimed one of her aunts.

Having a part-time job elsewhere, Jade felt given her circumstances, her new role as a Wellbeing Volunteer would be a good way to learn more about the impact HD can have on people's lives.



“The more knowledge I can gather about this condition, the easier it will be to cope in the future whatever direction my life takes. I think there is so little knowledge out there about HD. It's important that people like me, who are affected directly, try and increase people's understanding of how it affects people and the wider impact it can have on families.”

As a Wellbeing Volunteer, Jade has already been through a careful selection process before going through initial structured training that will help her to support people living with HD, as well as help her develop her own personal goals.

Jade also benefits from an ongoing tailor-made training and development programme so that she can keep up to date with future developments in HD and ensure her support for HD family members is the very best she can provide.

Sam McBride, West Dunbartonshire

Sam understands only too well the experience of and pressure on carers, having been a full-time carer for his late wife for a number of years.

He contacted us through an article in his local newspaper and brings with him many useful skills and abilities being qualified in First Aid and Medical Administration amongst other things.



“I want to volunteer and help other people so that what I went through won't be wasted. I'd also like at some point to get a part-time job whilst continuing as a Wellbeing Volunteer so the training and experience I receive will hopefully make a real difference to my chances.”

Sam is a really keen music fan and concert goer with diverse tastes from Mozart and Bach to Leonard Cohen, Pink Floyd and is pictured here with Pink Floyd's most famous album "Dark Side of the Moon".

Well, we're "over the moon" that Sam, Jade and their other compatriots have decided to join the SHA family as Wellbeing Volunteers and look forward to meeting more of them soon!



Family Branch/Support Group update

Isobel Darroch - Branch/Support Development Officer



Branch and support groups have had a very busy year and some take the opportunity to have a well-deserved break over the summer period and are now starting up again for their Autumn/Winter meetings.

Support Groups

Ayrshire: held a client carer day in August at the People's Palace which was enjoyed by all.

East Dunbartonshire: the East Dunbartonshire Support Group held an HD awareness information event on 14 June at the Regent Shopping Centre, Kirkintilloch. MSP Fiona McLeod, pictured



East Dunbartonshire Support Group with MSP Fiona McLeod

second right with family members, came along to meet and have a chat with them about Huntington's disease. The group were delighted with the response from the public and wish to thank Fiona for taking the time to come along to support them.

Highland: group are enjoying meeting up quarterly in Inverness. They are busy planning the raffle for this year's family conference. All donations welcome.

Lanarkshire Carers: continuing on last Monday of the month at their new venue in East Kilbride. All welcome.

Renfrewshire and Surrounding Area: are planning another fundraising walk on Saturday 12 September around Erskine by the River Clyde. Please come along and support them. Contact Isobel on 0141 848 0308 for more details.

Fife: are currently re-evaluating their support groups and hope to have new dates shortly. Contact Fife directly on 01592 647 993.

Tayside: support groups continuing on a regular basis.

East End: A new support group for the East of Glasgow has been set up. The first meeting is being held on Wednesday 28 August 6.30 - 8.30 pm at Milnbank Housing Association, 53 Ballindalloch Drive, Glasgow. All welcome to a much needed group for families living with HD.

Family Branches



Millport in May!

with HD t/shirts certainly achieved that. Please see also the Fife branch fundraiser at the Culross Fayre, bottom of page 7.

Fife: this very busy branch welcomes all family members to their monthly meetings. They had another very successful outing at Millport in May. Their June excursion to the famous Anstruther Fish & Chip shop also co-incided with HD Awareness week and a photo opportunity

Forth Valley Family & Friends: along with John Eden, have been campaigning for an HD Specialist Nurse in Forth Valley. Malcolm Macleod, Professor of Neurology & Translational Neuroscience, who works for NHS Forth Valley Health Board



Forth Valley group at their monthly meetings

met with family members, John and other professionals who are currently involved in the care of families in Forth Valley living with Huntington's disease. An action plan and a follow-up meeting is planned for the Autumn.

Glasgow: are looking forward to catching up with everyone at the Family Conference in October and can be seen here studying plans for their summer 2014 trip to the Knowe self catering holiday house situated at Portpatrick Harbour.



The Glasgow Support Group

Lothian: are looking forward to their weekend trip on 20-22 September to Low Port centre. Please contact Carrie Ho, Lothian HD Specialist on 0131 537 1057 for more details.

Tayside: David Husband is settling into his role as chairperson, and this long established branch would like to extend a welcome to family members in Tayside.

HD Support Groups & Family branches extends a warm welcome to old and new family members, who enjoy a tea / coffee and a chat to people living with Huntington's disease. For venue dates and times call Isobel on 0141 848 0308.

2 Minute Interview...

Aidan McCallum

Family member and avid fundraiser

Where and when were you born?

I was born in Forth Park, Kirkcaldy on 20 March 2002.

How did you get involved with the SHA?

When I found out that my dad had Huntington's disease, I wanted to do some fundraising and try out some of the trips.

Who or what is your biggest inspiration in life?

Andy Murray. I love tennis and would like to be as famous as him. My mum is also my inspiration.

What are your favourite things?

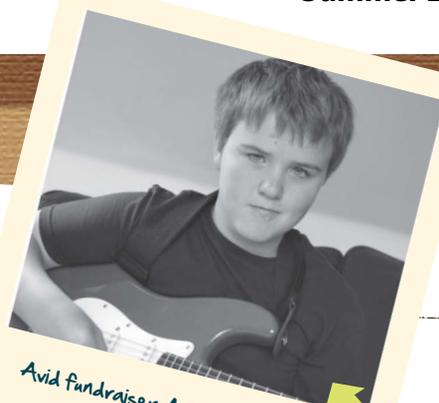
The Simpsons, Coldplay, singing, playing the guitar, art work, reading, a wide variety of other music interests, and most of all fundraising.

What don't you like?

One Direction, wasps, midges, spiders and being too hot!!

What has been your biggest achievement to date?

Winning the 'Show Racism the Red Card' poster competition. Entries were submitted from children across Scotland.



Avid fundraiser Aidan McCallum

How come you managed to become involved with St Andrews University recently?

I was chosen to take part in the six week Space School programme because I am good at Maths and Science. The programme focused on chemistry, biology, astronomy, geo-science, computer science, mathematics and psychology. I really enjoyed meeting the astronauts and getting my certificate at the end of the course.

What career path would you like to take?

I would like to be an artist or science teacher.

What would your friends say about you?

I think that they would say that I am funny, smart, kind, thoughtful, sensitive and sporty.

And finally.....What is your motto in life?

Keep calm and carry on.
Be kind, be helpful.

Culross Fayre

On Sunday 30 June, SHA held their second stall at Culross Fayre following on from last year's success.

Braving the extremely windy weather, which caused several gazebo problems, the three tabled stall boasted tombola, home baking and 'name the dog' competition. 'Bat the Rat' was introduced. Challenging contestants to hit a target, coming from a downpipe, before it fell into the bucket.

Nicola, Susan and Sue began planning the event in March and were overwhelmed by the generous donations given. An initial £50 pledge was donated from MGM Timber in order to organise a separate raffle before the event. This raised £174 and was a fantastic start to the day.

Susan, Tina, Shelley, Ronnie and Aidan all worked hard to raise another £526 on the day, totalling £700!! Thank you so much to all who contributed in making this another successful year at Culross. You will all be needed again next year!!



The Culross Fayre team



Family Conference

Macdonald Aviemore Resort, 25 & 26 October

SHA want to celebrate the enormous worldwide effort to provide support to people living with Huntington's disease and find a treatment. We are privileged this year to be joined by Dr Ed Wild and Professor Bernhard Landwehrmeyer, CEO of European Huntington's disease Network (EHDN) both of whom will share the latest progress in the research for a treatment for HD.

We are also pleased to have Bea Deschepper, President of the European Huntington's Disease Association and our own Patron Sarah Winckless is

This year we will learn a little more about how young people across the world are joining together under the auspices of the Huntington's Disease Youth Organisation (HDYO) to change the support that is available to everyone growing up in a family living with HD. Matt Ellison from HDYO, Carina Hvalstedt and our own Catherine Martin will be sharing the international work being done in this area.

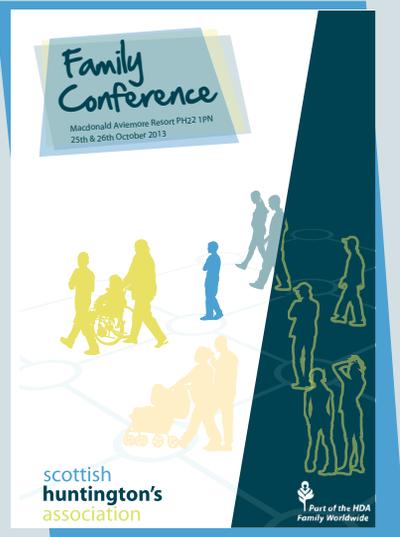
In our afternoon session you will have the opportunity to put your questions to our guest speakers as they join you at your table to chat about the issues that interest you.

This year's conference will take place at The Macdonald Aviemore Resort www.MacdonaldHotels.co.uk/Aviemore. Please see the booking form (attached to your flier) for more information on room choices and dietary requirements.

Youth Activities

Our Youth team will provide a day programme of, cinema, bowling, crazy golf and activities in Aviemore for young people who want to attend the conference with their parents.

You should have received your invitation to this year's two day conference event, if not, please contact Christine on 01463 729958



looking forward to seeing familiar and new faces. A long-time friend of the SHA, Jim Pollard, is making the trip across the pond to share his wisdom about supporting people living with HD.

Paddy Ryan

Community and Corporate Fundraiser (North and East)



Paddy has always been involved with charities. From working with Barnardos at age 15 to founding and directing his own charity, Young Explorers Scotland, Paddy

has always enjoyed helping where he could. During 16 years in the military he continued this theme by instructing cadets whilst in the UK or volunteering with organisations such as Médecins Sans Frontières whilst abroad. He even spent some time as a volunteer nurse.

Since 1999 Paddy has run a number of his own businesses, where a wealth of "Real time" business and life lessons have been absorbed, making him a well-rounded and pragmatic business man.

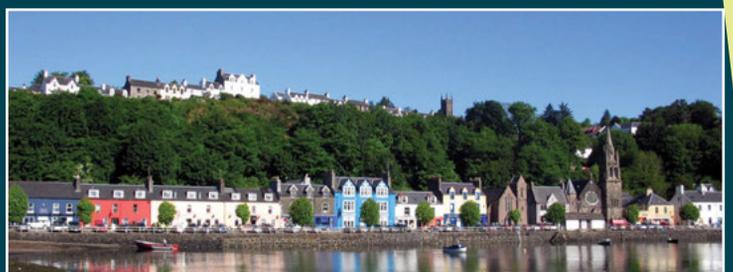
Earlier this year he took the decision to leave business to concentrate his efforts where they could make a direct impact on people who needed it. Looking for an organisation where he thought he could achieve this Paddy applied for the role as fundraiser for north and east Scotland.

Paddy says,

“ My induction training was fascinating and I really enjoyed meeting the rest of the SHA team and some of the clients. I'm really happy with my new role and am confident I will make a significant difference to income and awareness for the organisation. ”

Short Break Fund

The Fund makes up to £500 available to families living with HD in Scotland to help them get away for a few days. The Short Breaks Fund Grants Committee met for the first time in June to consider applications and awarded £1,900 towards individual and family holidays. If you would like to apply for this grant please contact your local HD Specialist, or call Head Office on 0141 848 0308.



SUMMER
CAMP

Fun and Festivities

Kirsten Walker, Senior Specialist Youth Advisor, Reports

49 young people from Scotland and Northern Ireland joined forces to take on the mighty Benmore Centre for Outdoor Education in Dunoon from 15 -19 July 2013 and rose triumphant!

During the day the young people participated in a range of activities which certainly weren't for the faint hearted. These activities varied for each age group, but included: kayaking, sailing, gorge walking, abseiling, caving and mountain biking, plus many, many more. The young people excelled at these incredibly challenging activities and as one young person stated;

“ This is the most fun I have EVER had, why does it have to end! ”

To keep everyone entertained each evening a full programme of fun activities was developed to allow the young people a chance to have fun with their new friends whilst relaxing. The activities included fruit kebab scrumptiousness, arts and crafts craziness, table tennis and pool play-offs, swimming fun, inflatable excitement and the inaugural Festival Party Night which culminated in an exciting Bonfire display. Each night the young people ended their fun-filled day with a Chi breathing workshop which was designed to help them relax and clear their mind from any stressors.



Enjoying the break at the Benmore Centre in Dunoon

For those aged first year and above the annual Young Persons Festival was based on 'Coping Well In HD' and gave the young people the opportunity to learn more about HD in a protected and semi-formal environment on Thursday 18 July. The groups partook in seminars around coping with anger and understanding their

emotions, the triad of HD symptoms, the five stages of HD, how the brain works and how HD affects the brain. The Festival was well received and one young person stated;

“ it's put my dad's illness in perspective for me - I thought he was much worse than he was, but now I realise that he's doing better than I thought and that makes me feel better ”



Taking a cycling break

Thank you very much to the Short Breaks Fund for kindly granting us the money to make the camp a success. Without their generosity this much needed respite opportunity would be incredibly difficult to fund.

The five days absolutely flew by. Camp was a resounding success and already many of the young people are asking what the plans are for 2014. All I can say at the moment is;

'plans are already starting to take SHAYP, so watch this space!'



Jump to it!

Fundraising



West Highland Way

Friends **Sandy McDonald, David Stewart and Chris Hartley** (pictured here l-r) had a great time walking the West Highland Way and raised a fabulous £1,655 for SHA. Thanks, guys.

SHA's Skydive Challenge in June was a huge success, raising over €5,000

A fabulous fundraising event and a huge thank you to everyone who took part in this amazing event - same time next year, everyone....?!



Well done to our daredevils Angus Ruthven and Cally Mackenzie



Stewart Robertson, Beth Christie, Jennifer Hall, Judith Barber & Gemma Barclay pictured here before their skydive.

A HUGE Thankyou

Lyndsay Davis, family member from Glasgow, organised an information stall and tombola at the Glasgow East Parks Festival, Alexandra Park, Dennistoun on Saturday 27 July. **Lyndsay is pictured here on the left with Councillor Elaine McDougall, SHA Staff Isobel Darroch, Wellbeing Volunteer, Jade Gemmill and Family Member, Jane Williams** at the event. Over £109



was raised. Lyndsay said 'A huge thank you to Councillor McDougall who is a huge support and to Milnbank Housing Association who kindly gave us a stall free of charge.'

Gareth Wade says of his London to Paris challenge



'after booking my flight to Gatwick for the wrong day and only realising the night before! It wasn't the perfect start.... after a drive to Edinburgh to collect a hire car I drove from 10pm through the night to Crystal Palace arriving at 5.30am ready to register at 6am. I've never had a close call like it! However, it made the first day more of a challenge! Days 2,3 and 4 were a breeze, apart from a 30 mile detour on one of the days when the route arrows were pointing in the wrong direction! Minor confusion! But glad to say I arrived in Paris with no further problems and was lucky to escape any punctures. I really enjoyed the challenge and raised £1,162 for SHA.'

Aidan McCallum is the most extraordinary boy

Ever since he found out that his dad had Huntington's disease he has been working tirelessly to raise funds for SHA. To date he has raised hundreds of pounds for the association and continues to look for innovative ways of raising even more money to support HD families.



In June, Aidan, along with other children from Star Youth Club, walked up the West Lomond. This walk proved tough for the smaller children who, once at the top, rolled most of the way back down! This was great fun for them! Thanks goes to Aidan, Ross and Kay for organising the event and to the parents who joined in. It was a great night and raised the magnificent sum of £314.

Our Comedy Club event at The Stand Glasgow raised over €500.



A great night of fun and laughter was enjoyed by over 70 people. Thanks to family and friends who came along to support us on the night.

Linda Byars is pictured here with compere Raymond Mearns, Linda Lucas, HD Specialist and Scott Andrew, headliner for the evening.

We have challenged our supporters to send in pictures of themselves wearing their SHA t-shirt in interesting places. Here are some of our enthusiasts. Keep sending them in!



Spot the SHA t-Shirt...

Christmas Cards...

It may only be August but Christmas is on it's way! For those of you who are starting to get organised we have a great selection of Christmas cards for you to choose from... some for the grown-ups and some for the kids. Our cards are the same lovely designs as last year, but with an extra special price tag of £2.50 per pack of 10. Please complete the form below and return to us with payment and we'll help get Christmas underway!



1 Wreath



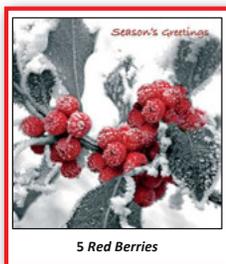
2 Snowman



3 Santa Claus



4 Rudolph - designed by Keira Amy Russell, age 11



5 Red Berries



6 Christmas Morning



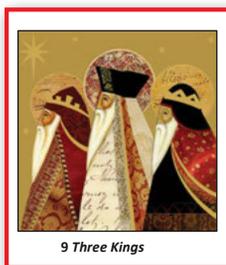
7 Festive Characters



11 Variety Pack



8 Dove of Peace



9 Three Kings



10 Colourful Trees

Choose Your Design...

Order Form

Name:		Address:		
Telephone:		Postcode:		
Ref	Card Name	Cost Per Pack (10)	Number of Packs	Total
1	WREATH	£2.50		£
2	SNOWMAN	£2.50		£
3	SANTA CLAUS	£2.50		£
4	RUDOLPH*	£2.50		£
5	RED BERRIES	£2.50		£
6	CHRISTMAS MORNING	£2.50		£
7	FESTIVE CHARACTERS	£2.50		£
8	DOVE OF PEACE	£2.50		£
9	THREE KINGS	£2.50		£
10	COLOURFUL TREES	£2.50		£
11	VARIETY PACK	£2.50		£
SUBTOTAL				£
POSTAGE				£2.50
DONATION				£
TOTAL				£

Please complete and return to us at SHA, St James Business Centre, Linwood Road, Paisley, PA3 3AT

HD Research



Some of the world's top researchers in Europe, the United States and Australia aim to set a new standard in the field of rare genetic disease diagnostics and treatment. Their joint research under a five-year project has been granted €12 million in EU funding.

Work has already begun on a major project titled NEUROMICS ('Integrated European project on omics research of rare neuromuscular and neurodegenerative diseases'), which is headed by Professor Olaf Riess from the University of Tübingen's Department of Medical Genetics and Institute of Human Genetics. The focus will be on certain groups of rare neurodegenerative and neuromuscular diseases. Approximately half a million people are affected by such diseases in Europe alone.

A rare disease, also referred to as an orphan disease, is any disease that affects a small percentage of the population. Although rare diseases affect few people (1 in 2,000 or less than 1 in 2,000), there are thousands of such diseases (around 7,000 currently described) and this number is increasing every year.

For 80% of rare diseases, the origin is genetic, which means it is present in a person's genes their entire life, even if symptoms do not immediately appear.

The Global Genes Project estimates there are 350 million people worldwide affected with a rare disease, while the European Organization for Rare Diseases (EURORDIS) estimates that as many as 5,000 to 7,000 rare diseases exist, affecting 6% to 8% of the population of the European Union.

The **NEUROMICS** consortium, comprising leading academic institutions as well as businesses, will be utilising the latest technologies to revolutionise diagnostics and to develop new treatments based on the mechanisms of each disease. The focus

will be on 10 rare diseases, including ataxia, spastic paraplegia, Huntington's disease, muscular dystrophy and spinal muscular atrophy. The results will then help hospitals to apply directly, giving patients immediate benefits.

Professor Riess says;

"The focus of our work is the especially rare neurological diseases. So we are very glad that we were able to convince the reviewers of the value of our project. The next five years will offer an unrivalled opportunity to establish diagnostics for most of these rare neurodegenerative and neuromuscular diseases and to develop treatments for some of them."

State-of-the art sequencing technology will provide the opportunity to analyse many genes or gene sequences simultaneously. Both the finding of recognised genetic alterations and the discovery of new ones is now easier, faster and cheaper. For rare neurodegenerative and neuromuscular diseases, diagnosis is no longer like searching for a needle in a haystack. **NEUROMICS** makes it possible to examine every straw in the haystack individually.

Already, progress has been made in the diagnosis and treatment of the ataxia group of diseases and spastic spinal paraplegias. Diagnostic panels have been developed for both, enabling the analysis of more than 50 genes in parallel for disease-causing genetic alterations. This has been devised by Professor Olaf Riess and his fellow colleague Professor Peter Bauer, alongside Professor Ludger Schöls from the University of Tübingen's Center for Neurology.

Professor Olaf Riess explains what diagnosis means for some patients: 'Establishing the disease's genetic bases can have implications for treatment -and for all patients, it at least means they know the cause of their illness, which can have important implications for other family members.

500+ Club Winners

Month	1st prize £100	2nd prize £50	3rd prize £25	4th prize £25
2012				
April	Midlothian	Aberdeenshire	N Lanarkshire	Fife
May	Aberdeenshire	Ross-shire	Perthshire	Edinburgh
June	Banffshire	Aberdeenshire	East Lothian	Angus
July	Highland	Tayside	Banffshire	Aberdeenshire
Aug	Caithness	Aberdeenshire	Angus	Lanarkshire
Sep	Ross-shire	Lanarkshire	Edinburgh	Glasgow
Oct	Tayside	West Lothian	Lothian	Aberdeenshire
Nov	Tayside	Ayrshire	Fife	Ayrshire
Dec	Ayrshire	West Lothian	Tayside	Highland
2013				
Jan	Midlothian	Lanarkshire	East Lothian	Tayside
Feb	Lanarkshire	Aberdeenshire	Fife	Lanarkshire
Mar	Inverness-shire	Morayshire	Inverclyde	Perth & Kinross

For a regular payment of £5 per month, you could have the chance of winning one of the prizes. **Please contact Ann Carruthers if you wish to join our 500+ Club.**