

SHAre



Scottish
Huntington's
Association

Specialist support for Huntington's disease families

Spring 2024

The magazine of
Scottish Huntington's Association
Issue No.102



'Life is easier because we have the right support'

Welcome from our Chief Executive



With the national and international news appearing increasingly (perhaps even unrelentingly) bleak of late, how often have you heard people say their response is to stop paying attention to the news altogether? In the face of growing international instability and funding cuts, staff shortages, recruitment issues and political turmoil at home, who can blame anyone for taking such an approach? Hopefully anyone of this persuasion can make an exception for SHAre Magazine. For this edition, like so many other before it, is like a light of good news shining in the darkness!

By working for and with the Huntington's community, and alongside our partners and funders, Scottish Huntington's Association continues to drive real change, inspiring and collaborating with other organisations, empowering people to share their experiences – and dancing!

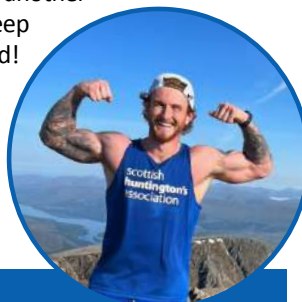
Yes Dance 100 is coming back, but with a twist. Following two successful years in Glasgow, we're taking Dance 100 on the road for the first time. First stop this September, Inverness!

You can also read about dedicated Dance 100 supporter Josh, who has Juvenile Onset Huntington's Disease. Determined to raise as much awareness as he can about the disease, he is sharing his experiences of how JoHD is changing his health and the impact that has on his mum Sharon, his full time carer. Josh's willingness to talk about how the disease has changed their lives can only help to deliver the change we are looking for – improved specialist services for every Huntington's family, regardless of where they live in Scotland.

There's also hope of a potential treatment for Huntington's disease from drug company Prilenia Therapeutics. There's good news about our Youth Service being shortlisted for a prestigious award. Good news about an international publication highlighting Scotland's advantageous position when it comes to Huntington's disease care and support. Good news about a fantastic new Board member. Good news about the Family Gathering 2024. Good news from our Board Sub-Group on Research opportunities. Good news about a new Tedx Talk on Huntington's. And good news from a whole host of fundraisers and awareness raisers across the country.

Thank you to everyone involved in making this edition of SHAre another good news publication. Keep your stories coming in, and let's keep SHAre the type of news publication people are not afraid to read!

Alistair Haw, Chief Executive



Sneak Peak at Robbie's new challenge

Good luck to Cowdenbeath captain Robbie McNab and friends who are taking on the 3 Peaks Challenge for Scottish Huntington's Association.

The team has under 24 hours to scale the UK's three highest mountains - Ben Nevis, Scafell Pike and Snowden. It follows the success of last year's challenge when Robbie ran up and down Ben Nevis in less than three hours.

"I value bringing people together in the name of fitness and challenge so this year's event is being done as a squad," said Robbie, who is facing onset of the disease.

"The snowball effect of last year's challenge was crazy – this year I'm getting more people involved to hopefully do just as good a job of fundraising and raising awareness."

Robbie has set up a Justgiving page for donations – search for Scottish Huntington's Association and his name on the site.

Sharing our expertise to train health professionals

Our HD Specialist team is rolling out its 2024 programme of Huntington's disease training for hundreds of medical, health and social care professionals across the country.

In Tayside, the session at Arbroath Infirmary was attended by 30 physiotherapists, occupational therapists and musculoskeletal staff.

It included an overview of Huntington's disease, genetics, symptoms, management and case studies. Senior Huntington's Disease Specialist Paula McFadyen also highlighted the important role of physiotherapists and occupational therapists in the management of the disease.

The response has been extremely positive, with comments from health and social care professionals including:

"The training was so interactive and educative. It added to my body of knowledge as a community physiotherapist."

"Very informative, especially with regards to cognition and processing. Gave me increased awareness and will be applied to any future input I have with patients with the condition."

CEO Alistair Haw said: "It's wonderful to see yet further evidence of the essential work of our specialist services in action.

"Congratulations to our HD Specialists on this excellent work on behalf of our community, and the hugely positive feedback it secures from those benefitting from their and our expertise."



Josh with mum Sharon and Senior HD Specialist Trev Law.

“I call myself one in a million!”

Josh Marshall was just 19 when his mum Sharon began noticing changes in his movement, speech and behaviour.

Only a few months earlier, after testing positive for the faulty gene that causes Huntington’s, Josh was reassuring himself that the disease would most likely develop much later in life as it had with his late father.

Instead he was faced with the onset of symptoms in his late teens and the reality that the typical life expectancy of young people with Juvenile onset Huntington’s disease is 15 years from diagnosis.

“I call myself ‘one in a million’ because Juvenile Huntington’s disease is so rare,” said Josh.

Now 25, Josh is less sure on his feet – “I fall up the stairs but not down them” - his speech isn’t as clear, and there have been struggles with mental health and behaviours. Changes in the brain have also affected his memory and cause a constant thirst.



Mum Sharon, a former solicitor, has been Josh’s full time carer for the past six years.

“We’re very close and have fun but we both know the symptoms are getting worse and that Josh has limited time. Huntington’s disease is rare; the juvenile version is extremely rare and very aggressive,” said Sharon.

“There have been times when I thought we would both end up in hospital because it was too difficult, especially when Josh’s mental health went down and his behaviour changed. Thankfully we’ve come through that and are in a much better place now.”

Around 800 people in Scotland have symptoms of Huntington’s

disease, including a very small number who were under 20 years old when symptoms emerged.

“We’d be lost without the Scottish Huntington’s Association HD Specialists Service. Josh has someone who understands what he needs and I have someone looking out for me and making sure I’m able to cope,” said Sharon.

“Josh and I are together 24 hours a day so my HD Specialist is exploring respite opportunities; even a few hours a week would make a big difference. He’s also looking at ways for Josh to get out and do things he enjoys which is just impossible right now.”

The mother and son are open with one another and candid with other people about what lies ahead. In the meantime they are keen to raise awareness and connect with others in the Huntington’s community through Scottish Huntington’s Association events such as Dance 100 and the annual Family Gathering.

Josh and Sharon also attended last year’s HDYO Congress in Glasgow where Josh met young people from across the world, many of whom he is still in touch with through HDYO, social media, and online gaming.

“I’m a bit of a celebrity because I want to inspire people,” said Josh.

“When I met Charles Sabine OBE [global Huntington’s disease activist and former war correspondent] he asked to have his picture taken with me. I also write song lyrics about my experiences and my story was included in the Huntington’s Disease Heroes book.

“I wanted to do a skydive to raise funds but it wasn’t possible so instead I go to Dance 100 each year and dance for the full five hours. I don’t stop even when people come up to speak to me. I love music, dancing and meeting people.”

Will you join Josh as this year’s Dance 100 goes on the road? Read more on P5. You can also find out more about the support provided by Scottish Huntington’s Association at hdscotland.org



Getting together at recent activity day

Vital work with young people shortlisted for national youth award

We've amazing news to share! Scottish Huntington's Association has been shortlisted for a prestigious award in recognition of our work with young people growing up in Huntington's families.

The National Youth Work Awards, hosted by YouthLink Scotland, celebrate the dedication and impact of youth workers and organisations across Scotland, highlighting their invaluable contribution to the lives of young people.

Scottish Huntington's Association is one of the top three finalists in the Health And Wellbeing Category, sponsored by Children In Need.

Our Youth Service works with 200 young people across Scotland – most are at genetic risk of having inherited the Huntington's gene and 80% are young carers for a loved one impacted by the disease.



Grant, Pete and Jenny from our Youth Service

"We're delighted for our young people and their families that this vital work has been recognised by the National Youth Work Awards committee," said Grant Walker, Scottish Huntington's Association Youth Service Lead.

"We see the difference having the right support can make, in fact most recent findings show that 91% of young people cope better with Huntington's disease because they are involved with our service.

"Together we are creating a generation of young people from Huntington's families across Scotland who, for the first time, have the knowledge, the language and the confidence to talk about the disease and share their experiences. Today's young people are more open, empowered and informed than any generation before.

"They are playing a crucial role in reducing stigma that surrounds the disease by building a wider understanding about its symptoms and the impact on families all over the country.

"And they know we will be here to support them over the years as their parent's health deteriorates and to cope with their own their own genetic risk."

The winners of all 14 categories will be announced during the awards ceremony in Glasgow on 12 June

New research reveals gaps in UK services

A study, believed to be the first to undertake a comprehensive review of specialist services for Huntington's disease in the UK, has been published in the Journal of Huntington's disease.

An Overview of Specialist Services for Huntington's Disease in the United Kingdom highlights the variation in organisation and capacity within individual HD specialist services as well as resourcing and gaps in access that influence this capacity.

The article highlights Scotland's favourable position in comparison to the rest of the UK stating: "The authors...note that other neurodegenerative diseases such as Parkinson's disease have had clinical specialist nurses (who acted as care coordinators) in place for many years. Indeed, some HD services in the UK do have this role. In Scotland, the Scottish Government backed National Care Framework for HD specifies that "care co-ordination should be provided by a single named specialist.

"HD Specialists (individuals who co-ordinate HD care) employed by the SHA and funded by NHS Boards and Health and Social Care Partnerships are found in 8 of 10 HD services in Scotland. However, many services in England and Wales do not have such an individual and there is no policy or mandate for this role in the context of HD throughout the whole of the UK."

Authors include our Chief Executive Alistair Haw; HDA England and Wales Chief Executive Cath Stanley; Cardiff University's Prof Anne Rosser and Wendy Kane and Rachel Blair (Roche). Fees paid to Alistair Haw for his contribution have been donated to Scottish Huntington's Association.

Read the full report at <https://bit.ly/HDresearchreport>



Dance 100 hits the road to Inverness

Join our live 100-song DJ set in the Capital of the Highlands

Two left feet? It doesn't matter! Round up your friends, family and colleagues and strut your stuff at Dance 100, Scottish Huntington's Association unique dance challenge event.

Now in its third year, Dance 100 is taking to the road after two wonderful years in Glasgow. For the first time, and by popular demand, we'll be taking over Falcon Square in Inverness on Saturday 7 September with the support of local families and volunteers.

For people of all abilities and ages, we promise an unforgettable experience filled with hope, fun and the best music! Show off your best moves to our 100-song live DJ set while raising funds and awareness to provide vital specialist support for people impacted by Huntington's disease in Scotland.

The £10 registration fee includes entry and a free Scottish Huntington's Association t-shirt to wear on the day. We ask that you aim to raise a minimum of £50 sponsorship in aid of Scottish Huntington's Association to help fund the lifeline services relied upon by Huntington's families across Scotland.

Your regional fundraising advisor will be in touch after you to support you with fundraising ideas and plans, and you'll find loads of suggestions and tips in your handy downloadable Dance 100 Welcome Pack to help spread awareness and encourage even more people to join in.

We're looking forward to welcoming participants old and new to our all new Dance 100 roadshow! Scan the QR code to find out more and register or email fundraising@hdscotland.org



Open for business: sponsor options tailored to suit you

Would you like to increase your visibility and promote your business and brand? If you do then we have a number of sponsorship opportunities available.

What better way is there to show your customers you care than by sponsoring a high-profile event for a good cause? Whether you choose to be a headline sponsor or a song sponsor, Dance 100 in Inverness can be a strategic and rewarding investment if your company is looking to expand its reach. Increase awareness of your business by linking with a local charity.

- Take advantage of this fun and engaging PR and social media opportunity.
- Reach a diverse and enthusiastic audience in the heart of the city.
- Help fulfil your Corporate Social Responsibility objectives.
- Increase engagement with your clients, customers and suppliers.



Scan to find out more:

Taking it global

Dance 100 has inspired European Huntington Association (EHA) to launch a global online dance challenge for this year's Huntington's Disease Awareness Month!

The project is the brainchild of EHA President Astri Arnesen who hailed Dance 100 as "a great example to all of us" adding: "This shows how you fight stigma and shame and have fun together in public."

Groups and families around the world will perform a choreographed dance to the Katy Perry track Firework, which was chosen for its message of empowerment.

"They will then share short videos of their dancing on social media using the **#HuntingtonDance** hashtag.

"To close the campaign, a single video will be created that will reflect the success of participation and reinforce the idea that we are not alone, that we are a global community," said Astri.

HD Specialist service scores highly with our families

Thank you to family members who took part in our most recent client satisfaction survey.

Feedback for our HD Specialist Services across Scotland has been overwhelmingly positive. Headline findings from the 172 people who took part include:

- An average satisfaction rate of 4.8 out of 5
- 99% view their HD Specialist as friendly and approachable
- 98% feel the HD Staff treat them with dignity and respect
- 89% feel involved in decisions about their care

These excellent results are a result of the dedication and expertise of our HD Specialist teams. They also reinforce why having the right support is so important for families.



HD research opportunity

Are you interested in taking part in a university research project

A study at Reading University is looking for people who have experience of psychological therapy (whether successful or unsuccessful) to increase understanding about what might be helpful or unhelpful in order to help others impacted by Huntington's disease.

To find out more, contact g.r.adams@reading.ac.uk

Forth Valley HD Clinical Lead joins Board



We are delighted to welcome Dr Tim Soane to our Board of voluntary Trustees.

Dr Soane has worked as a consultant Neurologist in Forth Valley since 2019, having trained in Nottingham, Newcastle, Dundee and Edinburgh. He is the Clinical Lead for Huntington's Disease in Forth Valley and runs a joint neurogenetics clinic in Edinburgh in addition to his other clinical roles.

Before studying medicine Tim studied as a scientist and he has a degree in biochemistry and a PhD in molecular biology investigating models of neurodegeneration.

"I became interested in Huntington's with the advent of genetic therapies on the horizon and whilst to date there have been many disappointments, I remain hopeful that we are close to meaningful treatments," said Tim.

"I came across Scottish Huntington's Association in my role as HD Clinical Lead in Forth Valley and am impressed by its dedication to all of those affected by the condition, including wider family members and carers. It is an honour to serve on the Board, and I look forward to our future together."

Dr Soane joins us as the charity embarks upon a new recruitment drive for additional volunteer Trustees to help ensure the highest standard of governance and diversity of skills and experience across the Board. We are especially interested in hearing from professionals from the following backgrounds:

- Law
- Communications/Marketing
- Income Generation
- Contracts/Procurement
- Human Resources

If you or someone you know is interested in joining the Board of Trustees please get in touch by emailing sha-admin@hdscotland to find out more.

Taylor's gigs and gags just keep coming

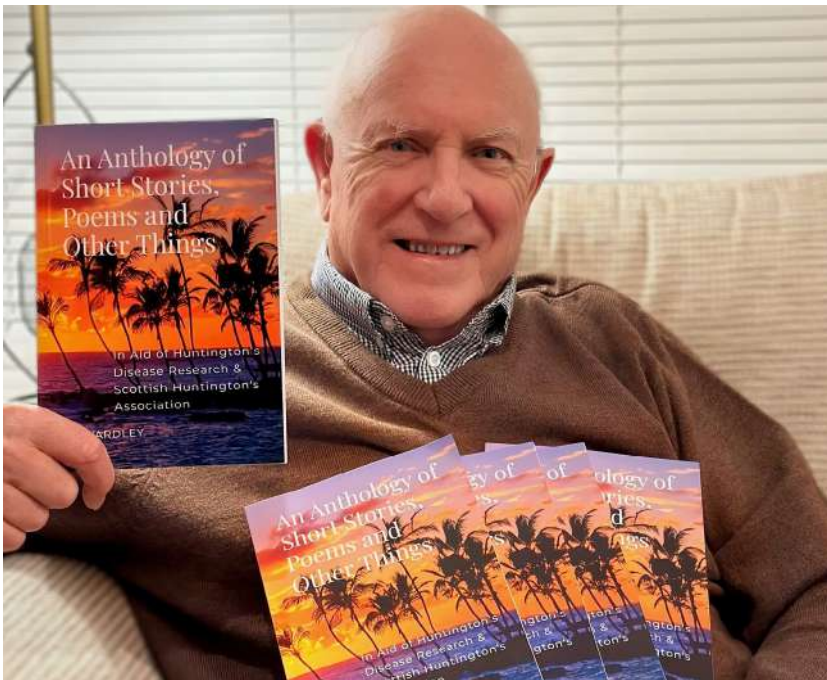


Family member and stand-up comedian Taylor Graham followed up his two-night run at the Edinburgh Fringe with double hitter at the Glasgow International Comedy Festival.

The 25 year old, who is supported by Specialist Youth Advisor Pete Carruthers, is donating all proceeds to Scottish Huntington's Association. He'll add funds raised to the money collected each month from his regular comedy slot at Edinburgh's Bar 13.

"I get a real buzz out of helping families who are impacted by this terrible disease and enjoy making people laugh and having a fun night out," said Taylor, who is a full time carer for his dad Sean.

"I put leaflets on the tables about Scottish Huntington's Association and Huntington's disease then collect donations at the end. One night we had a table of medical students who had never heard of Huntington's disease. They were really interested in learning more and said they would ask about it at university. That was a great moment for me."



Peter begins fundraising chapter in life inspired by his family's experiences...

We are hugely grateful to Peter Yardley who is raising money in support of Huntington's families with his new book through the sales of his book 'An Anthology of Short Stories, Poems and Other Things.'

Peter's late sister Myra had Huntington's disease and his niece Gillian McNab – a Scottish Huntington's Association trustee, family member and volunteer fundraiser and speaker – is also facing onset of the disease.

"As a family we don't know if our Mum had the condition, but presume she did, as she died from a heart attack at the age of 42, well before it would have been diagnosed," said Peter.

Peter is visiting book fairs to promote the anthology and raise awareness about the disease at the same time. If you would like to help raise as much possible, please contact him at peter@yardley.me.uk

The price of the book is £12.50 which includes post and packaging. Peter can take payments by PayPal or cheque so please let him know which you prefer with your contact details including your postal address.

Money raised will be shared between Scottish Huntington's Association and our friends at Huntington's Disease Association.



...While niece Gillian gets ready to rock

Meanwhile, Gillian held a live music event to boost her fundraising even further.

SHA Rocks at St Nicholas Church Hall, Lanark, featured four top local bands - Mixed Signals, The Screaming Divas, Sniper Alley and Bueller?

They have been inspired by Gillian's mission to raise awareness about Huntington's disease and her successful fundraising which so far tops £20,000.

"I'm a big live music fan and have friends and contacts who are in bands and are happy to get involved. SHA Rocks tickets sold out very quickly and I hope it's the first of many similar events here in Lanark and potentially expanding to bigger venues in Glasgow," said Gillian.

"I am so grateful to the bands for giving their time and their talent to support Scottish Huntington's Association."

HDYO release community survey series

Our friends at HDYO are running a series of surveys to understand the best communication methods and resources for the Huntington's community, the challenges of taking part in research, and how best to support families.

The first survey asks about what resources and communication tactics are most useful for the community, and the second one focuses on emotional and educational barriers of research. The third survey will compare Huntington's milestones to life milestones to analyse how to improve support the many stages of the disease, not just the point of symptoms.

"We'd love to get the Scottish community to share their thoughts. All results will be shared with the community as a whole for our benefits in developing programmes," said HDYO Chief Executive Jenna Heilman.

Drug company to begin bid for EU market authorisation

Drug company Prilenia has begun the process to seek market authorisation from the European Medicines Agency (EMA) for the drug Pridopidine for the treatment of Huntington's disease.

Marketing authorisation is the process of reviewing and assessing the evidence to support a medicinal product in relation to its marketing, finalised by granting of a licence to be sold if approved.

This is the first time that a drug developed to treat Huntington's disease has reached this stage. Whilst a notable milestone, the Huntington's community should remain mindful that this is the beginning of a potentially lengthy process with no guarantee of a positive outcome.

Pridopidine was the drug used as part of the PROOF-HD trial, which included a research site in Aberdeen (<https://www.abdn.ac.uk/news/14828/>).

In April 2023 Prilenia announced the findings from the PROOF-HD study, which unfortunately did not meet its primary or secondary endpoints. Nevertheless the manufacturer remains hopeful that the treatment can still potentially provide benefit to patients.

Key points to keep in mind:

- Pridopidine is NOT intended to be a "cure" for Huntington's disease. The manufacturer believes that the treatment shows potential for a slowing of disease progression.
- The review of the application to be licenced by the EMA takes time, potentially up to a year from application. EMA can reject the application.
- EMA authorisation covers the EU, Norway, Iceland and Lichtenstein only. If the EMA agrees to licence the treatment it will still take time before the medicine is potentially available across these jurisdictions. Prilenia will need to go to the relevant authorities in each country and negotiate market access and pricing. One of the key questions at that stage would be affordability compared to patient benefit.
- Prilenia will need additional permission from authorities in the UK to market the drug here, which it would presumably seek to do if EMA approval is secured.
- You can read the Prilenia news release and community letter on our website at <https://hdscotland.org/news/>

"Whilst we of course welcome news that a drug developed to treat Huntington's disease has reached this stage for the first time, and the hope that this provides for the Huntington's community, we remain mindful of the significant hurdles that lie ahead before patients could potentially benefit from this treatment."



Alistair Haw
Chief Executive
Scottish Huntington's Association



Great to see our friends and supporters in Lanarkshire continuing to go from strength to strength.

Their most recent event, held just before Christmas, was packed with stalls and fun activities for all the family. Together they raised more than £3,000.

We thank everyone for the months of hard work they put in to make it such an amazing success, including involving members of the local business community to support with donations and prizes.

Our friend Charles Sabine OBE is raising incredible levels of awareness while challenging perceptions around Huntington's disease. His TEDx Bath talk is now on the TEDx Talks YouTube channel, which has over 40million subscribers. This inspiring presentation describes how Charles decided to go all in to 'mess Huntington's disease up' and why he believes taking personal responsibility for even the most hopeless destiny can prove there is never an occasion when nothing can be done. Watch the full TEDx Talk at <https://www.hiddenmore.com/>



Strengthening our research networks while supporting families to take part

Our work to support research and ensure families are kept up to date with studies and clinical trials has taken a major step forward with the introduction of a Research sub-committee of trustees.

In addition to strengthening relationships with researchers, the sub-committee will provide support, create opportunities and share its expertise to:

- Develop national and international networks within the research community to ensure Scottish Huntington's Association is represented in relevant forums.
- Ensure that relevant current research activities and breakthroughs are communicated effectively by Scottish Huntington's Association.
- Assure the board that Scottish Huntington's Association, through a research focused webpage, is providing information and guidance for families who want to get involved in research; sharing experiences of family members and staff who have been involved research and sharing examples of past and current research projects where Scottish Huntington's Association has been involved.
- Make recommendations to the board on how sub-group budget will be spent and assure the board that robust processes are in place for the awarding of funds to external organisations and individuals.

"This is an important step for Scottish Huntington's Association and the families we support to reinforce our national and international networks within the research community and make sure we are represented and recognised for our commitment and expertise," said Research sub-committee Chair Professor Louise McCabe.

"In addition to ensuring that relevant research activities and breakthroughs are communicated effectively, the sub-committee will provide information and guidance for families who want to get involved in research, help them to share their experiences, and actively engage with researchers to provide insight and, in some cases, impact grants to support promotion of findings."

Research sub-committee members



Chair

Professor Louise McCabe
Trustee and Professor of
Dementia Studies at
University of Stirling



Professor Lorna Milne
Trustee and
former Deputy Principal
University of St Andrews



Gillian McNab
Trustee and
Palliative Care
Specialist Nurse



Dr Marie Short MBE
Trustee and member
of the EHDN Scientific
and Bioethics Advisory
Committee (SBAC)

Visit to top safari park rounds off youth service trip

Our Youth Service held its spring residential break for young people from Tuesday 2 to Thursday 4 April at Carronvale House, Larbert.

The trip included group activities on the first day followed by a visit to Blair Drummond Safari Park the next day.

Reaching the health experts of tomorrow

Greater Glasgow and Clyde HD Specialist Helen Maginnis delivered a presentation about the causes, symptoms and impact of Huntington's disease at the National RAREAware Conference in the Advanced Research Centre at the University of Glasgow.

The event, aimed at medical and life sciences students, was organised by RAREAware, a society dedicated to raising awareness about rare diseases, the impacts which they can have on both patients and carers, and what medical students can do to drive change.

18 awards given for Short Breaks

The Short Break Fund Committee has granted 18 awards for 2024/25, totalling £8051.34. The average award was £447.30 and applications included requests relating to carer respite and family breaks.

The Short Break Fund will reopen for applications for 2025/26 later in the year following a full review of the new process and feedback from families and staff.



A massive thank you to the Sounds International Choir!

Its concert at Netherlee and Stamperland Church, Glasgow, raised more than £4000 for Scottish Huntington's Association.

The event was attended by SHA Chief Executive Alistair Haw, pictured left, and Fundraising Officer Linda Winters.

Moray families pass First Aid training course

Six people have completed a First Aid course in Elgin, funded and organised by Moray Family Branch in response to concerns from family members and carers about how to respond in an emergency situation.

"The feedback to the course has been positive and I'm pleased to say that everyone who took part passed the course and received a certificate," said Moray Family Branch Chair Jock Anderson.

"Well done to everyone involved, especially Jackie Lewis our secretary for organising."

Jock was re-elected as Chair during the Branch AGM meeting in February; Jackie was elected to continue as Secretary and Anne-Marie Wright was also re-elected as Treasurer.

The Branch's fundraising continues to go well with members organising a coffee morning and craft fayre which will be held at Hopeman Memorial Hall on Saturday 4 May. It follows a generous donation of £500 from the crew on the Shell Nelson Platform in the North Sea.

"A massive thanks to Paul Wood and all the guys there for their continued support," added Jock.



Learning to use first aid equipment



Practising the recovery position

Service confirms 2024 Support Group dates

The Greater Glasgow and Clyde HD Specialist Service has confirmed its calendar of family member support groups, which take place in Pollok Community Centre, 134 Langton Road, Glasgow.

Thursday 6 June | Thursday 1 August | Thursday 3 October | Thursday 12 December
Contact your Greater Glasgow and Clyde HD Specialist for more information.

2024/5 Find your fundraising event challenge



April

Glasgow Kiltwalk 28 April 2024

London Marathon 21 April 2024

May

Edinburgh Marathon Festival 25 and 26 May 2024

June

Aberdeen Kiltwalk 2 June 2024

Tough Mudder 15 June 2024, (Drumlanrig)

Men's 10K (Glasgow) 16 June 2024

Women's 10K (Glasgow) 16 June 2024

#TeamSHA Skydive Challenge

29 June 2024, (Glenrothes)

August

Dundee Kiltwalk 11 August 2024

Scottish Half Marathon (Edinburgh) 18 August 2024

Scottish 10K

18 August 2024, Edinburgh

September

Dance 100 (Inverness)

7 September 2024

Ziplide Across the Clyde (Glasgow)

15 September 2024

Kiltwalk (Edinburgh) 15 September 2024

Men's 10K (Edinburgh) 22 September 2024

Women's 10K (Edinburgh) 22 September 2024

Loch Ness & Festival of Events

29 September 2024

October

Great Scottish Run 10K & Half Marathon (Glasgow)

6 October 2024

Three Peaks Challenge Ben Nevis, Scotland; Scafell Pike, England; and Snowdon, Wales

Various Dates

November

Firewalk (West of Scotland) Date TBC

Firewalk (East of Scotland) Date TBC

SuperNova 5K (Forth Road Bridge) 2 November 2024

March 2025

SuperNova Kelpies 5K (Falkirk)

14 March 2025

Falkirk Wheel Abseil

16 March 2025



No matter how you choose to support Scottish Huntington's Association we are here to help you in any way we can to do something amazing for the Huntington's Community. Get in touch with your ideas at fundraising@hdscotland.org or call 0141 848 0308 to speak to a member of the team.



DANCE 100

Inverness

Saturday 7 September



- Dance to our 100-song live DJ set
- Bring your friends, family and colleagues
- Raise vital funds and awareness
- Register to take part by scanning the
- QR code and claim your free t-shirt too!



Your communication preferences: You can update your communication preferences at any time, just let our team know on 0141 848 0308 or at sha-admin@hdscotland.org. We will not pass on your details to any other organisations. Your data will be treated in accordance with our Privacy Policy which you can view at hdscotland.org