

# SHAre



Scottish  
Huntington's  
Association

Specialist support for Huntington's disease families

Summer 2023

The magazine of  
Scottish Huntington's Association  
Issue No.100



Dancing, campaigning and joining forces for Huntington's families



# Welcome from our Chief Executive

Eagle-eyed readers will have noted that this is the 100th issue of SHAre magazine, and what a fitting edition it is. On the front cover we see Sadie and Paul who were among 200 family members and supporters to descend upon Glasgow's George Square in May to dance their hearts out and raise awareness about our charity and its cause.

In line with our plans Dance 100 was even bigger and better than the inaugural event the year before. Read on to find out more about its various celebrity endorsements and the media coverage it secured, the happiness and awareness it brought to so many – and its victory in the global “Stronger Together in the HD Community” competition. What better way to celebrate this landmark edition of SHAre than by highlighting this extra special success, which typifies where this charity is going.

On a similar note, the pages that follow are packed with positive stories from family members opening up about their determination to raise funds for Scottish Huntington's Association and increase awareness about Huntington's disease. From ballroom dancing to running marathons and taking on Iron Man challenges - or simply by sharing their story with others. For so long this condition has been blighted by stigma and secrecy, however this is in steady decline thanks to these amazing supporters and many others besides. On the opposite page you can read about this year's fantastic youth camp, where the SHA stars of the future who will continue this crusade got together for a week of education, fun, respite and friendship.

I'd also draw your attention to the article showcasing the launch of our first ever publicly available strategy, and to

thank everyone throughout our movement who has made this possible.

Publishing a strategy is one thing, implementing it between now 2028 is our next trick. A journey of a thousand miles begins with a single step and we're off and running.

Milestones, such as the 100th edition of this magazine, so often encourage us to stop and reflect upon what we have achieved and how far we have come. Talk of strategies or change can make some wary – keeping doing what we're currently doing seems like a much less anxiety provoking prospect. Rather than thinking like this let's instead draw courage from our past, for this charity's history is one of constant change – with each change taking us from strength to strength.

I'm absolutely convinced that, with your support, this too will be the outcome of the change upon which we are all now embarking as we strive to deliver the best possible outcomes for Huntington's families throughout Scotland.



**Alistair Haw,  
Chief Executive**



## Families lead from the front for Huntington's Disease Awareness Month... with a little help from our friends

May 2023 was an amazing month of collaboration and commitment as we joined forces with families and inspired actors, a chart-topping musician, a top radio presenter and MPs.

Musician Callum Beattie – who has two Scottish chart-topping albums under his belt – took time out from touring in the US to dedicate his performance of 'Wild Mountain Thyme' to the work Scottish Huntington's Association. You can watch it at <https://bit.ly/SHACallum>

We also received a video from Still Game's Winston – actor Paul Riley – encouraging people to support the charity and its work, Clyde radio presenter Garry Spence devoted a piece to Dance 100 in his Sunday Mail magazine column, and actor Tam Dean Burn joined us at Dance 100 to help spread the word (see centre pages for full story).

Of course, our real strength is the willingness of families to get involved and share their experiences, including through the media. This resulted in 35 articles in print, broadcast, TV and online, including STV television news and coverage in national/regional titles such as The Herald, The Mirror, STV Online, Daily Record online, Sunday Mail magazine. Local coverage included Dunfermline Press, East Kilbride News, Lennox Herald, Rutherglen Reformer, Wishaw Press and the Paisley Daily Express.

We thank all the family members who took part including Suzanne Armit and Claire McKechnie from Fife, Alex Wilson from Edinburgh, Stuart Oag from Aberdeen, Gillian McNab from Lanarkshire, and our Share cover stars, Sadie Clark and her son Paul from Glasgow.

**SHA Family Gathering confirmed for 4 Nov!**  
The Family Gathering will take place at the Dunblane Hydro on Saturday 4 November. Further details will be shared soon. In the meantime, please save the date.



## Laser quest, climbing, abseiling, kayaking and catching up with our very own Olympic hero

### What an wonderful week it was at Summer Camp!

This year we were joined at Lagganlia Outdoor Centre near Aviemore by 45 young people from across Scotland, our Patron Sarah Winckless MBE, Chair of Trustees Cat Martin and Chief Executive Officer, Alistair Haw.

Our Youth Service team went all out to make sure the five days away were jam packed with First Aid training, swimming, laser quest, abseiling, archery, tree climbing, kayaking, gorge walking and canoeing. The fun didn't stop there – evening activities included a games night, an awards ceremony, a disco, HDs Got Talent and a visit from the Ice Cream Cart company!



Youth Service Lead Grant Walker added: "Nearly 50% of the young people were joining us for the first time, and for many it was their first time away from home. The success of this year's camp is a huge credit to dedicated staff and volunteers, and the hard work by people across the organisation to support our young people and their families."

Watch our summer camp video on our Facebook page at <https://bit.ly/SHAcampFB>



Young people aged 13 to 17 took part in an HD gene discussion while the 18+ group was invited to a workshop about the HD-YAS study led by Sarah and Cat. The two groups then came together to hear about Sarah's experience of Huntington's disease and the importance of SHED (Sleep, Hydration, Exercise and Diet) for physical health. This was followed by a session looking at coping strategies led by Cat - APPLES: Advocacy, Peers, Positive attitude, Love, Education, Support network).

For our Patron the benefits of camp combined with the work of the Youth Service and the wider organisation are increasingly evident.

"We now see young people who are able to talk about Huntington's disease; they can share what is going with them and their families because they have a good understanding, the knowledge and the language they need," said Sarah.



### Thank you to our funding partners

We are hugely grateful to our funding partners for making the 2023 Summer Camp possible.



**"Coming to camp means I can get a break from Huntington's disease in my house, forget about my problems at home and have a lot of fun"**



# New strategy sets out roadmap to improved specialist services for all

Scottish Huntington's Association has taken a major step forward with the launch of **Standing Tall: A Strategy For Growth 2023 - 2028** – the first publicly available strategy in the charity's history.

Developed following extensive consultation with the Huntington's community, trustees, staff and other stakeholders, it provides a clear roadmap towards growth and expanded specialist services while ensuring that families remain at the very heart of all we do.

Trustee Professor Lorna Milne, of the University of St Andrews, said:

"Since its foundation, Scottish Huntington's Association has made a real and increasing difference to Huntington's families, but we know there is still more we can do.

"I am confident this ambitious, realistic and persuasive strategy will have the right effect out there in the wide world while maintaining the Scottish Huntington's Association ethos of blending a warm personal touch with high-quality professional expertise."

The key aims of Standing Tall: A Strategy For Growth 2023 – 2028 are:

1. To increase awareness of Scottish Huntington's Association
2. To enhance knowledge of Huntington's disease
3. To grow our charity to meet the needs of the future
4. To expand access to specialist care and support
5. To ensure strong participation within global research activities

Refreshing our branding - including introducing a new logo and the distinctive blue/white SHA t-shirts worn by so many of our families and supporters - is helping to raise our profile locally, nationally and globally.

That was a very visual first step in what is a comprehensive and targeted approach towards the day when every family has the personalised care and support they need, regardless of where in Scotland they live.

Chief Executive Alistair Haw said:

"This strategy is our commitment to families that we will ensure the continued expansion, resilience and impact of Scottish Huntington's Association. It demonstrates our ambition, confidence and professionalism to partners and funders. And it highlights the expertise, dedication and tenacity of our staff, trustees and supporters to fight for our cause.

"I want to pay tribute to everyone for getting us to this stage – Huntington's families, staff and trustees alike.

"In advance I also want to thank everyone for the work they will do to deliver upon this strategy. This is an exciting time as we begin a five-year process that will involve and engage every member of our movement. So it couldn't be in better hands."

View the full Standing Tall: A Strategy For Growth 2023 – 28 document on our website at [hdscotland.org](https://hdscotland.org)



## Huntington's on the agenda at UK Parliament

The UK Parliament rose for recess earlier this summer, with a motion tabled on behalf of SHA, HDA (England & Wales) and HDA Northern Ireland calling for an increase in specialist support remaining amongst the most supported of the 22/23 session.

The motion, tabled by UK Parliament Huntington's disease champion Hilary Benn, was the most supported by Scottish MPs. Of the 1523 motions tabled during the session it was one of only three to secure over 100 supporters. View the motion at <https://edm.parliament.uk/early-day-motion/59775>

As we approached the end of the session Mr Benn raised the issue of Huntington's disease at Prime Minister's Question Time, which can be viewed at <https://twitter.com/ScottishHD/status/1677322662475956224>

These recent developments bolster our work in the Scottish Parliament, which saw a call to increase specialist HD services by Jackie Baillie MP become the most supported motion in Scottish Parliament history. View the motion at <https://www.parliament.scot/chamber-and-committees/votes-and-motions/votes-and-motions-search/S6M-00923>.

We continue to use these outcomes to lobby for additional services, in line with our Vision and Mission.

## Big thank you to Grant Thornton

**We are grateful to Grant Thornton for two years of charity partnership that has raised money, increased awareness and opened doors for our young people.**

Staff at the accountancy firm have collected over £7500, organised a series of fun fundraising events, and inspired colleagues and others to learn about Huntington's disease and its impact on families.

From turning Glasgow city centre into a giant game of Monopoly to taking part in Dance 100, Grant Thornton employees have shown amazing creativity and commitment in their efforts in support of the Huntington's community.

Keen to provide support beyond fundraising, the firm also invited our young people to a World of Work Day to boost employability skills and take part in group sessions and mock interviews.

\*Could your business or employer be our next charity partner? Contact [gemma.powell@hdscotland.org](mailto:gemma.powell@hdscotland.org)\*

# "We never hid Huntington's from Sadie and she knows her situation is different"

A married couple who first met at a Scottish Huntington's Association summer camp have opened up about their lives after finding out they are both facing the disease.

Support worker Martin and Rachel Philip tied the knot in 2010. Martin (36) found out earlier this year that he has inherited the faulty gene that causes Huntington's from his late father George, while Rachel tested positive more than a decade ago.

The couple from Culbokie near Inverness have an eight-year-old daughter Sadie, who was born after Martin and Rachel became one of the first couples in Scotland to undergo pre-implantation genetic diagnosis (PGD). The pioneering treatment meant that Sadie was born without inheriting the gene from either of her parents.

"Martin and I met when I was 12 and he'd just turned 14," said Rachel (35), who is studying for a degree in psychology.

"We began going out a year later even though we lived hundreds of miles apart. I was in the Black Isle and Martin is from Ayrshire so there was a lot of travelling up and down. We also met up at summer camps and other Scottish Huntington's Association Youth Service activities. After I left school, I moved to live with Martin and his dad George, who by then was starting to develop symptoms.



"George was a real character who did his best to enjoy life and have fun and I was used to being around people with Huntington's, including my late auntie. Martin and I moved back up north in 2008 because we love it here.

"Sadly, George passed away in 2012 and my mum's symptoms began to progress a few years ago. We cared for her at home



but as her health changed it went from not being able to lift the kettle safely to falling over. We couldn't leave her in the house alone and she began to fixate on things, especially money which wasn't like Mum at all. We had carers but she needed more than we could give. Mum went to a care home nearby in 2020 and is settled there now."

Martin and Rachel credit Scottish Huntington's Association and the strength of their families for helping them to cope.

"Huntington's disease was never something to be hidden away when we were growing up," said Martin. "We've been the same with Sadie who has a very good understanding about how it affects people, including her gran, Sarah. Sadie is a real granny's girl.

"Rachel, Sarah and I have an HD Specialist and SHA's Financial Wellbeing Service has been a Godsend, especially when Sarah wanted to retire. Over the years, Rachel and I have both volunteered at Youth Service summer camps and we took Sadie when she was a baby.

"When we were young, summer camp gave us time away to meet other young people in a similar situation and to learn more about Huntington's and what to expect. Now Sadie is supported by her own Specialist Youth Advisor and this summer she went to camp by herself for the first time.

"Sadie knows her situation is different because it's unusual for both parents to have the faulty gene and, unlike most

of the young people who were with her, she's not at risk of developing the disease."

Despite the challenges they face, the family is determined not to let Huntington's disease define their lives.

"We focus on making sure Sadie has a happy childhood and looking after one another. Martin is dedicated to his job and I enjoy my university studies," said Rachel.

"For a long time we had hope that neither of us had the faulty gene. But when we began to think about having children, I spoke to my Specialist Youth Advisor then had counselling before being tested.



"There were tears when the result came back but we were able to look at our options to have a family, which led us to PGD treatment.

"It was three long years of travelling up and down for appointments and hormone injections. Our families put us up while we went for hospital appointments and, along with our friends, were a great support throughout. It was all worth it to have Sadie and to know that she will never have the disease.

"Being tested is a personal choice and Martin was never under any pressure. He changed his mind so he can take part in research studies and clinical trials which could help him and other families like ours in the future. I'm very proud of him for wanting to do that."



# Dance 100: A day of hope, joy and solidarity



**“What a day! Absolutely amazing! Well done everyone for making it so special.”**

Gillian McNab, family member and Scottish Huntington's Association Trustee



**“My late husband had Huntington's disease and three of my five children have inherited the condition. It**

**was great to see so many families at Dance 100 and to catch up with people that we haven't seen for some time. There needs to be more awareness about Huntington's disease and Dance 100 was a great way for us all to help make that happen.”**

Sadie Clark, with her son Paul, from Glasgow



**“The most joyous occasion. Huge thanks to Scottish Huntington's Association for hosting a brilliant event -**

**coming together in such a fun and wholesome way is an experience I will never forget.”**

Sharon Brack, family member

**Here's what others had to say:**

**“Fantastic day and can't wait until next year, it was great seeing everyone come together to support a great cause.”**

**“This just goes to show what our combined strength, care, compassion and sheer determination can equate to.”**



**We set out to make this year's Dance 100 bigger and better than ever – and it certainly was! Dancers turned out in their droves, including a busload from Fife, family members from Aberdeen, a team from Ayrshire and even more from Glasgow and Edinburgh.**

Nearly 250 family members, staff, trustees and supporters inspired and moved members of the public to donate, dance with us in Glasgow's city centre, ask questions and learn more about Huntington's disease.

Senior Fundraising Officer Gemma Powell said: “It was brilliant to see everyone in the iconic setting of George Square, highlighting the determination of the

Huntington's community to dance and engage members of the public to build understanding about the challenges being faced by families. We are a force to be reckoned with!

“We're so grateful for everyone's incredible efforts which raised over £17,000 and reached many thousands of people on the day and afterwards in newspapers, online coverage and the STV news that evening.”

The event has also inspired celebrated stage and screen actor Tam Dean Burn to get involved with our work.

The man who terrorised Shieldinch as gangster Thomas McCabe in BBC's River City hit the George Square dancefloor

and talked to families about the impact of Huntington's disease. After chatting to as many people as possible, Tam pledged to do whatever he can to help.

“I was aware of Huntington's disease and had vague notions about the symptoms, but I didn't know about the hereditary aspect. That's so tough for families, it's brutal,” he said.

“There were so many lovely people at Dance 100 and I had a great time. It was good to see how Scottish Huntington's Association and Huntington's families are working together to drive change and increase awareness, and I'm keen to do whatever I can to help.”

We thank everyone who took part, the

Dance 100 organising committee, our friends in business and sponsors, people who donated and helped out on the day, and staff and trustees, for making it such a huge success.

We're already planning for next year – which will be even bigger and better again – and who knows, maybe Dance 100 will one day go global!

After seeing photos of the event, President of European Huntington Association Astri Arnesen hailed the event as a “great example for all of us”.

“Many families living with Huntington's disease tend to isolate themselves. This shows how you fight stigma and shame and have fun together in public,” said Astri.



**Thank you so much to our incredible charity partners who helped make Dance 100 such an amazing success.**

They include headline sponsor Benson Wood + Co whose staff also came along on the day and raised a further £800! Not content to stop there, the Lanarkshire firm's CEO John Moffat is already taking on a new challenge for Huntington's families – Walk 100! John is trekking 15,000 steps a day for 100 days then tackling the Speyside Walk in his last week – which is over 100km on its own!

Benson Wood + Co hopes to raise £10,000 to help Huntington's families, and a totaliser stand now has pride of place in the head office in Bellshill to encourage everyone to get involved.

A massive thanks to everyone who supported us on the day and beforehand - including song sponsors KeyStore, DP Joinery, Dakota Hotels and the Broomgate in Lanarkshire; Lucozade and Ribena for the generous donation of refreshments; DJ extraordinaire Steve McKenna; our Dance 100 organising committee members; Maureen Hascoet; Sue Man; singer-songwriter Callum Beattie for dedicating a special song to our work; Fife Family Branch; SHA staff and trustees; actors Tam Dean Burn and Paul Riley; Zumba Scotland; and the fantastic students from New College Lanarkshire.





# Support for families granted government standard of approval

The high standard of support for families provided by our Financial Wellbeing Service has been recognised with re-accreditation on behalf of the Scottish Government.

Endorsement by the Scottish National Standards for Information and Advice Providers (SNSIAP) commends our work in welfare, benefits and money advice and our commitment to continuous improvement in the delivery of the service.

Having undergone rigorous assessment, an extensive audit of procedures and processes and peer review of casework, it also demonstrates to the wider public and funders that the Financial Wellbeing Service is well managed and provides good quality advice.

“It’s thanks to the team’s hard work that we have achieved re-accreditation and we look forward to redoubling our efforts to support families as we head towards another winter,” said Jo Baldock, Financial Wellbeing Service Lead.

Since the service was established in 2015 it has secured more than £6 million in financial gain for individuals and families in the Huntington’s community. Our free and confidential support can help with:

- Access to benefits and products
- Household budgeting
- Planning for the future
- Organising power of attorney
- Managing debt
- Regular financial health checks
- Completing complex applications and forms
- Appeals and tribunals
- Advocacy on your behalf
- Managing household energy bills and increasing efficiency

Specialist advice from Scottish Huntington’s Association is completely impartial and we never promote specific products such as bank accounts, mortgages, pensions or insurance products/ providers.

The nationwide network of officers covering the whole of Scotland is:

Financial Wellbeing Service Lead Jo Baldock works with families in Lothian and Borders. Contact [joanne.baldock@hdscotland.org](mailto:joanne.baldock@hdscotland.org)

Financial Wellbeing Officer Mel Higgins covers South West Scotland, [melissa.higgins@hdscotland.org](mailto:melissa.higgins@hdscotland.org)

Financial Wellbeing Officer Ben Peter covers Tayside, Fife & Forth Valley. Contact [ben.peter@hdscotland.org](mailto:ben.peter@hdscotland.org)

Financial Wellbeing Officer Emma Pollard covers the north including Grampian, Highland and the Isles.

Contact [emma.pollard@hdscotland.org](mailto:emma.pollard@hdscotland.org).

You can also visit our website at [hdscotland.org](http://hdscotland.org)



## Patrishia’s Strictly fundraising triumph

Ballroom beginner Patrishia Adams from Easterhouse entered a prestigious dance competition – then waltzed to first place and raised more than £1000 for Scottish Huntington’s Association.

The 42-year-old anaesthetics nurse hadn’t danced since her ballet and tap days 30 years ago. But her determination and 10 weeks of rigorous training paid off when she and partner, former Scottish ballroom champion James Shields, wowed the judges on the big night.

“The Step Up For Charity challenge was just like Strictly – all the non-dancers were paired up with a professional partner and we trained three or four times a week. As the competition got closer, we were practising every day and I loved it,” said Trishia, who is married with two children.

“On the night the dancers were all backstage so we couldn’t see what was going on. I was nervous but my friends and family were there, and Linda from Scottish Huntington’s Association came along to cheer me on too. The atmosphere was brilliant.

“It was an amazing experience and I couldn’t believe it when I came out top. I’m even more delighted to have raised funds Scottish Huntington’s Association through my Justgiving page plus a share of what was raised by the Step Up For Charity event.”



# “We knew what was coming with Dad and I just wanted to know what I was facing”

With a family history of Huntington’s disease, Suzanne Armit had convinced herself that she would develop the condition too.

So after testing negative for the faulty gene she was left struggling to believe the result.

“I was in shock and actually didn’t take it well at first, but my mum and dad were over the moon and I accepted it in time,” said Suzanne (30) from Rosyth.



“We knew what was coming with Dad and I just wanted to know about me. I was 18 when I was tested; looking ahead I wanted to get married and have children but I didn’t know if I would be able to have all of that.”

In addition to reassessing her own life plans, Suzanne began to concentrate even more energy on her dad. Thomas

had tested positive in 2004, a year after his mum – Suzanne’s grandmother – found out she had Huntington’s disease.

“Nobody had any idea that Huntington’s was in the family, or what it was, until my nan was diagnosed,” said Suzanne, who has a partner Andy and stepdaughter Annabella.

“When we discovered it was hereditary my dad decided to get tested. Unfortunately, his result came back positive but he did remain symptom free for a long time.

“Things began changing when he was 48-49 years old. We noticed his movements first – sitting in his chair he would suddenly give a little kick every so often, a minimal twitch. But it happened enough for us to suspect what was happening.”

The family began seeing other things too. For example, routine suddenly became very important for Thomas.

“Dad liked to have a Red Bull every morning and it had to be on a particular shelf in the fridge. If it wasn’t on that shelf or in the fridge, it would become a disaster,” explained Suzanne.

“Time was also a massive thing – if anything suddenly changed, Dad became very agitated and frustrated.”

Over time, Thomas developed difficulties with swallowing food and he lost the

ability to speak and communicate. He went into a care home around eight years ago and was there until he went into hospital in 2021. He was 61 when he passed away in February last year.

Still grieving her family’s loss, Suzanne remains determined to help raise awareness and understanding about the disease and has also taken part in many fundraising events.

“Scottish Huntington’s Association has been in my life since I was 12 years old.

My Specialist Youth Advisor helped me through the testing process, before and after, and I’m still in touch with Pete who works with young people in Fife and Lothian.

He’s been my rock over the years and supported me last year when I was struggling with Dad’s death.

“I went to camps, conferences and days out, and have shared my experiences one-on-one with people about the testing process. The charity has been a constant in our lives and I hope for it to continue that way.”



## Family branch shop takes message to local community

Fife families joined forces to hold another ‘pop-up’ shop to raise funds and increase awareness about Huntington’s disease in the local community.

Open for one week during the summer, the shop in Wellesley Road, Methil, raised more than £1600 by selling a wide range of donated items including bric-a-brac, toiletries and household goods. It was staffed by members of the Scottish Huntington’s Association Fife Family Branch and other volunteers.

The branch meets regularly to provide support and social activities for local Huntington’s families and to fundraise. It also put on a bus so as many local people as possible could take part in Dance 100 in Glasgow.

Volunteer co-chair of the Scottish Huntington’s Association Fife Family Branch, Claire McKechnie (38), from Rosyth, said: “Dance 100 was the Fife branch’s first official outing since the pandemic and it really lifted the spirits of our families, carers and everyone who took part. For me, it shows how we come together as a charity and as a community.”

Claire and her sister Heather took over as voluntary co-chairs following the death of their dad Brian who ran the group for more than 17 years. His late mother had Huntington’s, and this fuelled a determination to do what he could to help other families impacted by the incurable condition.

“Heather and I were honoured to be asked to continue in his place. We feel blessed not to be at risk of developing the disease but are grateful to be a part of the Huntington’s community. It’s important to both of us that we continue Dad’s legacy by supporting local families,” added Claire.





# Liam's family pulls together to get him over the famous finishing line



**When civil servant Liam Anderson signed up for the London Marathon in support of the Huntington's community, he had no idea how much it would inspire his own family.**

The 31-year-old tried unsuccessfully for 10 years to win a ballot place in the world-famous run - then Scottish Huntington's Association stepped in with the offer of a charity spot.

"It made total sense to do it for Scottish Huntington's Association because Huntington's disease has been part of our lives for so many years," said Liam (31), who lives in Edinburgh with his partner, Eilidh.

"My mum told me it was in our family when I was 18; until then I'd no idea and didn't know anything about Huntington's disease. Since then I've never hidden it from my friends and my immediate family is quite open, however it's been more of a taboo subject amongst some of our wider family."

But things were to change when Liam announced he was running the London Marathon for Scottish Huntington's Association.

"That definitely helped to cast light on something that had not really been talked about in the family," he said.

"Everyone got on board, we are a close family and if one of us needs something, everyone shows up. This was the first time we had done something for Huntington's though."

It was only after Liam's gran passed away in the early 1990s that a post-mortem examination revealed that she had undiagnosed Huntington's disease. It meant that Liam and his mum are also at risk of having inherited the condition.



"My grandma was in hospital for many years and died the year after I was born. She was taken into hospital when my mum and her siblings were very young, and they didn't really see her after that. It was too hard and too sad," said Liam.

"My grandma was loved and she was lost to her family because of Huntington's disease. Later on her brother was also diagnosed with the disease and ultimately passed away with this too. Fundraising for Scottish Huntington's Association gave us a shared purpose, a way to honour our grandma's memory, and the opportunity to raise awareness about the disease and its impact."

The family set about organising a fundraising event to get Liam started towards his initial £2000 target.

"It was pretty daunting so my Auntie Fi came up with the idea of holding a race night" he said.

"Running the London Marathon was my dream so I was training hard while everyone was making sure it was going to be a great event that raised as much as possible. My younger sister Kathryn was our fundraising manager, she did a great PR job on social media - we were hoping for 50 people and ended up with 140.

"We shared a lot of stories and information about the disease on social media and when we spoke about Huntington's disease and why we were fundraising, people were happy to donate and buy tickets."



The race night raised more than £2000 and with the support of his family, friends and work colleagues Liam has now pushed his total to over £4500. He completed the London Marathon in a personal best time of 3 hours 30 minutes and then, just a few weeks later, travelled to Yosemite in the US for a half-marathon with friends he met while travelling through Asia in 2015.

"Running both marathons and raising so much money has been an incredible experience, however what stays with me most is having the support of my family and the way everyone helped. They're the ones who got me over the line," said Liam.

# Meet some more London Marathon superstars!



## Brilliant Beinn goes bigger and better

**Beinn Burroughs, from Ayrshire, has smashed a super-tough triple challenge in support of families impacted by Huntington's – while knowing that he too is facing onset of the disease.**

After a year of training, the 22-year-old physiotherapist completed the London Marathon in April, the Stafford Half Ironman in June, then the Bolton Ironman in July. His efforts have raised nearly £4000 towards providing the specialist services families need.

Beinn, who has been supported by the charity's Youth Service since he was 10, tested positive for the faulty gene that causes Huntington's disease when he was 18 and in his first year at university.

"It helps that I've always had a Specialist Youth Advisor at Scottish Huntington's Association to speak to, but it was still difficult to talk about," said Beinn.

"I became much more aware of my mortality and during my first year at university I cracked on but kept myself to myself. In fact, until last year only five people outside my family knew."

At the London Marathon, Beinn achieved a personal best of 3 hours, 21 minutes. A few weeks later he conquered the 70-mile Half Ironman, swimming for 1.2 miles, cycling for 56 miles and finishing off with a 13.1-mile run. Then he took on the big one - the 140-mile Bolton Ironman, completing the 2.4-mile swim, 112-mile cycle and a 26.2-mile marathon in an impressive 14 hours, 20 minutes.

"My friends have been very generous with donations and the months of training have all been worth it to support such a good cause," said Beinn.



## Mario and Luigi bring the fun for spectators

**Semi-retired surveyor Alex Wilson and his daughter Kate (29) from Edinburgh ran their first London Marathon together – and it was an experience they'll never forget.**

The 59-year-old watched his father's physical and mental health deteriorate at a time when there was little support for families trying to cope with the devastating impact of Huntington's disease.

Over the years he has taken on many physical challenges to raise funds – and this time around he joined forces with Kate who suggested dressing up as the Nintendo legends.

"The London Marathon was amazing – it was Kate's idea and without her I don't think I would ever have done it," said Alex. "We loved the atmosphere and the music, and the crowds went wild when they saw our outfits. We got lots of high fives as we ran."

"Kate went above and beyond with her fundraising. We raised more than £4000 and most of that was by Kate. I'm extremely proud of her for doing so much and for training so hard."

"I hadn't run a marathon for more than 30 years and it was my first time in London so it was a real adventure. We were both very emotional crossing the line with a time of just over five hours."



## Stuart runs to his second London triumph

**Aberdeen accountant Stuart Oag who dedicates his marathon runs to his late father has raised more than £17,000 in support of families impacted by Huntington's disease.**

His dedication has inspired an overwhelming swell of kindness from friends, family and work colleagues who kept Stuart going with generous donations and messages of support. He completed this year's London Marathon in an impressive 3 hours, 48 minutes, 35 seconds, cheered on by loved ones including mum Hazel, his wife Glenda, their children Kirsty and Campbell, and his sister Julie and her daughter Ailsa.

"My dad Les was funny, fun-loving, generous, wise, loving and loved and we all miss him," said Stuart, 50.

"His symptoms started quite late in life, but things went downhill quickly in his last two years when he began to have trouble swallowing and with his walking. At 65 he was fit, active and loved to socialise but he was an old and frail 72-year-old when he died.

"I never heard Dad complain but it was hard, especially on those occasions when the disease affected his personality. Mum did an amazing job as Dad's primary carer, and it was only towards the very end that he had to go into a psychiatric ward and then to a home."

Les and Hazel were supported by an HD Specialist and a Financial Wellbeing Officer.

"I've seen the difference that donations make for families," said Stuart. "We wouldn't have known where to start but thanks to Scottish Huntington's Association we had the help we needed."

Stuart, who has previously completed the New York Marathon, ran his first London Marathon in October 2022 for the charity – and loved it so much that he immediately requested a 2023 charity place.

"It's been overwhelming to see so many friends and colleagues donating and leaving messages of support. I've heard from people I'd lost touch with and it's been great to reconnect," added Stuart.



## SHA's Fundraising Calendar of Events 2023/24

### Running events

#### Great Scottish Run – Glasgow

Sunday 1 October 2023

Secured your own Great Scottish Run place? Why not run in aid of Scottish Huntington's Association?

#### Edinburgh Marathon Festival

Saturday 25 and Sunday 26 May 2024

- › Edinburgh Marathon
- › Edinburgh Half Marathon
- › EMF Hairy Haggis Team Relay
- › EMF 10K
- › EMF 5K
- › EMF Junior 2K
- › EMF Junior 1.5K
- › EMF Kids Kilometre



For more information and to secure your running place email [fundraising@hdscotland.org](mailto:fundraising@hdscotland.org) or call **0141 848 0308**.



### Your preferences

You can update your preferences or choose not to receive post from us at any time, just let our team know on **0141 848 0308** or at [sha-admin@hdscotland.org](mailto: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](http://hdscotland.org)

### Walking events

#### Walk the Famous West Highland Way

Various dates available

#### Three Peaks Challenge

Various dates available

Email: [fundraising@hdscotland.org](mailto:fundraising@hdscotland.org)

or call **0141 848 0308** to find out more

#### Edinburgh Kiltwalk

17 September 2023

Secure your individual or team place at [www.thekiltwalk.co.uk/events/edinburgh](http://www.thekiltwalk.co.uk/events/edinburgh)



### Do Your Own Thing

Planning your own event or looking for some inspiration?

We are here to help and support you in any way we can.

Contact the SHA Fundraising Team by email [fundraising@hdscotland.org](mailto:fundraising@hdscotland.org) or call **0141 848 0308**.



No matter how you choose to support Scottish Huntington's Association you will be doing something amazing for the Huntington's community. Thank you.