Summer 2022

Working with families to deliver better care and support for the Huntington's community

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Also inside: Joining forces to take campaign to Westminster



From engaging MPs to leaping off cliffs... together we are driving real change for all Huntington's families

As you will discover in this issue of SHAre, Huntington's Disease Awareness Month 2022 was - by common consent - the most successful in our charity's history. An enormous thank you to all families, supporters and staff who made this all happen. The only problem is, how do we top this milestone moment next year?

Dance 100 was an outstanding awareness raising and income generation success. It was everything we need to be as an organisation and as a community: ambitious, loud, proud, and unashamedly "in your face." This year's media coverage was off the scale too when compared to any previous year. And, to top it all off, we secured the backing of MPs from every political party in the UK Parliament for our call for an increase in HD Specialist Services, adding further weight to the huge level of support secured for the same outcome at the Scottish Parliament.

I have also had the great pleasure of attending the first Scottish Huntington's Association Youth Service Summer Camp since 2019. I arrived thinking I'd quickly check a few emails after a long journey before getting into the swing of things, only to be immediately presented with a



wetsuit and a helmet – and egged on into somersaulting off cliffs into a river by people roughly a quarter my age. "Thanks, but no thanks" was clearly not a legitimate response.

Once the shock of this subsided it was truly wonderful meeting the young

folks and seeing their beaming faces as they went about their various activities. It's clear that they loved camp, each other and their brilliant leaders. I left the following day, inspired by the spirit, enthusiasm and talent of our young family members. They are the future of our movement for justice, which is clearly in good hands.

Finally, I'd like to direct you to page four where you will read about Bob, a much loved grandad who is in the later stages of the disease. We were greatly moved by the words of Heather, his granddaughter, who describes how Bob's eyes lit up at seeing how she and her student friends are supporting Scottish Huntington's Association and other Huntington's families.

We hope that the many good news stories contained within this edition have a similar impact on readers throughout the country.

Alistair Haw, Chief Executive

MPs join call for expansion of specialist Huntington's services

The work of Scottish Huntington's Association to raise the profile of Huntington's disease in our parliaments and expand services throughout the country has received a further boost.

As previously reported in SHAre, a Scottish Parliamentary motion tabled by Jackie Bailie MSP calling for an expansion of specialist Huntington's services went on to become the most supported in the Parliament's history, securing 98% support from MSPs of all parties.

Further to this, Scottish Huntington's Association worked with our colleagues at the HD Associations for the rest of the UK to table a similar motion at Westminster. As the UK Parliament broke up for summer recess in July, Hilary Benn MP's motion calling for an expansion of specialist services was the most popular with 81 MP supporters. The motion has secured backing from every group/party represented in Parliament (Conservative, Labour, SNP, Lib Dem, Independent, DUP, Plaid Cymru, Alba, SDLP, Alliance,



Green). It has also been supported by 46 of Scotland's 59 MPs so far.

Having our call to expand specialist HD services so strongly supported by MSPs and MPs not only raises the profile of our charity and its cause in both parliaments but is also helping to open doors for us in areas where we need to increase services to families.

The news coincides with several positive developments, with Scottish Huntington's Association receiving funding to appoint an additional HD Specialist in Ayrshire & Arran and – for the first time - an SHA- employed HD Specialist in Dumfries & Galloway. NHS Borders has appointed joint HD Clinical Leads for the first time who are working to establish a full service, and money has been secured from various sources to fund the work of our new National HD Specialist post.

We are working with MPs and MSPs who signed the parliamentary motions to secure additional services where they are required, and are hopeful of being able to announce further positive developments in the next edition of SHAre magazine.

https://edm.parliament.uk/earlyday-motion/59775/specialisthuntingtons-disease-services



For the first time since the pandemic descended plans are in place for an in person HD family get together. The meeting will take place at the Inchyra Grange Hotel and Spa, Polmont, on Saturday, 12 November. Further details to follow – in the meantime please save the date!

Heather springs into action out of love for her grandad

"My lovely grandad Bob isn't able to walk or talk now but his eyes lit up when I showed him the photos of us fundraising for Scottish Huntington's Association. Then he lifted his arm to give everyone a wee wave of thanks."

The words of Heather Train (24), from Midlothian who with seven fellow members of the Robert Gordon University trampoline club has raised more than $\pounds 250$ for Scottish Huntington's Association.

Unable to go ahead with a sponsored bounce due to Covid-19 restrictions, members opted instead for a virtual challenge clocking up 20km by walking, running, cycling or rowing.

"In competitions we do 20 trampoline moves so we decided to do 20km for 20 moves," said Heather.

"We're a small club but still managed to raise more than £500 which was shared between Scottish Huntington's Association and another charity.

"I explained how the disease affects my grandad and our family and everyone was happy to get involved."

Bob was diagnosed more than

20 years ago and is no longer able to walk, talk or eat. He is looked after in a care home and even though he is unable to communicate, Heather knows he enjoys time with his family.

"Grandad sleeps a lot now and is fed through a tube," said Heather. "It's hard for us all to watch how much the disease has changed him. When I was young, I spent a lot of time with Grandad, he'd pick me up from school and take me to my dance class, always joking and kidding around. He'd always make me smile and we love him very much.

"Because Grandad has the disease, I know there's a chance that the gene has been passed down but for now, like my dad, I'm loving life and seizing every opportunity."

16+ bursaries extended for further year

The Scottish Huntington's Association bursary scheme is being extended for a second year to help our young people to reach their potential in education, training and employment.

During the pilot scheme in 2021/22, bursaries were given to 33 young people aged between 16 and 25 who access support from the charity's Youth Service.

Eligibility criteria for the 2022/23 Hyman Robertson Foundation-funded grants has now been widened to provide support with household bills, food and care packages. This is in response to the ongoing impact of the pandemic and the current cost of living crisis. Bursaries can help with:

- Digital and data packages including laptop and wifi costs
- PPE for site-based events and work-based learning

- Food and care packages
- Travel costs to volunteering, education or training
- Books and materials for education
- Utility bills (heating, electricity)
- Educational trips and events
- Qualification costs
- Driving lessons and tests
- Access to post-Covid sports/wellbeing related services

A maximum award of £300 is open to young people aged 16+ from Huntington's families, including those who received a Scottish Huntington's Association bursary in 2021/22.

For more information, please speak to your local Specialist Youth Advisor at <u>https://hdscotland.org/youth-service/</u>



Carolyn: "Everyone here is dancing for Huntington's families like mine"

Our Dance 100 event in Glasgow marked a real step change for the charity and the Huntington's community as we joined forces to take our message straight to the heart of Scotland's largest city.



Between Dance 100 and the accompanying matchfunding campaign, more than £21,000 was raised through sponsorship and donations, a fantastic achievement by the families and supporters who took part.

That day, you couldn't walk past George Square without seeing and hearing Dance 100. Passers-by sat down to watch. Others waved from open topped tourist buses after drivers were given a heads-up to let passengers know what was happening and why. Many threw money into collection buckets and asked for more information. Others joined in the dancing.

It was family member and Trustee Gillian McNab who first raised the possibility of Dance 100 then played a key role in driving it forward through her friends and networks, securing the support of Casualty actor George Rainsford, River City star Leah MacRae, Clyde 1 presenter Garry Spence, work colleagues, neighbours and the dance community. Feedback has been overwhelmingly positive with many family members telling us how much they appreciated the community coming together in such a positive and proactive way.

Carolyn Jenner, who took part with her husband Guy, said: "It was the most glorious day. We met so many lovely people, including a young man who is already symptomatic. We went over to say hello then we all danced together.

"There was so much passion and dedication. Everywhere I looked there were people wearing Scottish Huntington's Association T-shirts and I thought 'everybody here is dancing for us, for families like mine, and for one scottish huntington's association scottish another.' It filled huntington's my heart to see association so many people supporting families who are affected by this devastating disease."

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William: "I'll keep on singing and dancing"

Teenage musical theatre actor William Hillhouse has vowed to sing and dance his way through life – despite being at risk of developing the same incurable disease as his dad.



The super talented 16-year-old from East Kilbride has appeared in pantos with David 'The Hoff' Hasselhoff and his heroes The Krankies. He's even fulfilled a childhood ambition by joining Jimmy Krankie (pictured left) on stage to belt out the fabled Fandabidozi song.

Now William is speaking out about Huntington's disease and how it impacts individuals and families.

"There's a 50% chance that I've inherited the disease from my dad," said William, a student at the Dance School of Scotland in Glasgow.

"We can't change that but I can do something positive by raising as much awareness about the disease as possible while pursuing my career in musical theatre.

"I've travelled all over the country and I take every chance to speak to people about Huntington's disease and its symptoms. I'm a glass-half-full person who hopes for the best because my Mum's positivity inspires me to be the same.

"I've known about the risk to me since I was young. Mum got in touch with Scottish Huntington's Association to make sure I have the right support and I've been meeting up regularly with one of the charity's youth advisors ever since. It's made a huge difference to how I live my life." William's dad – also called William – tested positive for the faulty gene that causes the disease 19 years ago, soon after he met Donna, his wife. Now 43, he has started to notice changes in his movement control and his mental health.

"He's a quieter person than the rest of us but we can see now that he's becoming more introverted and worried about people looking at him when we're out," said Donna, 40.

"We're still in the early stages and are staying positive and supporting one another with the help of an HD Specialist from Scottish Huntington's Association.

"It's important for us to talk about Huntington's and its impact on our family because there's still a stigma attached to the disease and a widespread lack of understanding amongst the wider public."

William and his family took part in the recent Dance 100 event, with William taking centre stage half way through the five-hour challenge to lead families and supporters through their moves.

"Families all over Scotland, including mine, depend on the lifeline services provided by Scottish

Huntington's Association and I was pleased to do my bit for the charity," said William.

"In the meantime, I'm living each day. I choose not to dwell on what might or might not happen – and to sing and dance instead."



Fantastic fun-filled five days!

Thirty eight young people from across Scotland joined us at our Summer Camp at Lagganlia Outdoor Education Centre, near Aviemore.

We were especially pleased to welcome nine young people who had never attended camp before and two of our volunteer Youth Ambassadors who came along to help out.



Run by our Youth Service, Summer Camp provides young people from families impacted by Huntington's disease with a break away, respite from caring responsibilities, a chance to catch up with new and existing friends and the opportunity to try new activities.

They included gorge walking, kayaking, canoeing, archery, skiing and survival skills. In the evenings, young people enjoyed games of football and rounders, drumming fun, swimming and a party on the last night.

Older attendees also took part in workshops focusing on Huntington's disease, its symptoms and the impact on families, with a focus on building coping skills. Feedback from young people has been overwhelmingly positive. "This was my first camp and it's been awesome. So good to meet people from an HD family and it's been such fun."

"I'm so pleased that you pushed me to try again to jump into the river - I was so scared but it was fun! Thanks for letting me come along to camp!"

"We don't normally get the chance to do things like this at home because my mum isn't well and my dad often looks after her. We don't really have a lot of money to do stuff. It was so good to be here and try new things."

Youth Service Lead Grant Walker said: "It was great to be back at Lagganlia for the first time since 2019, before the Covid-19 pandemic. There were smiles on every face and lots of friendships made. We could see how much our young people benefit from enjoying some time together and having the support of the charity's Specialist Youth Advisors."





Erin joins the team

Erin Armstrong has joined the Youth Service as Specialist Youth Advisor for Ayrshire and Arran, Dumfries and Galloway, Greater Glasgow and Clyde and Lanarkshire.

Erin, a former primary school teacher, who is studying for a Masters in Psychology, also has a passion for the arts, and has danced, sang and been involved in drama since she was young.



Dina gets people talking about Huntington's disease

Family member Dina De Sousa, who is facing the onset of Huntington's disease, made a dramatic style change to spark conversations and engage the media during HD Awareness Month.

> Dina (58), a retired university researcher and mum of two, coloured her hair blue and purple – the global Huntington's disease colours.

It was the latest step on behalf of the Huntington's community by Dina who has advocated for improved care and participated in research trials for many years: at a local level as former Chair of Scottish Huntington's Association Lothian Family Branch, at national level, as a Trustee of Scottish Huntington's Association, and at international level as a member of the European Huntington Association board.

"My late father was diagnosed 14 years ago, which was a big shock to us all. He was misdiagnosed for years so we had no idea about our family history," said Dina.

"I was tested soon after Dad's diagnosis and the result came back positive for the faulty gene. From that moment my outlook changed for myself and my sons who, for the first time, knew they were at risk."

As Chair of Scottish Huntington's Association Lothian Family Branch since 2015, Dina brought families together to share experiences and support one another.

Earlier this summer, she made the difficult decision to step down as Chair, feeling it was time for a change and also to focus on her health.

"Over the years, the Lothian Family Branch welcomed many family members including couples, carers who had lost loved ones and single people who were at risk or had tested positive for the faulty gene," said Dina

"Our activities included book reading, Christmas carols, game nights, weekends away, boat trips, an annual meal out and Tai Chi on Fridays. We fundraised to help to pay for trips out and provide muchneeded welfare grants for our area.

"We gained great friendships and support and I am proud and thankful for what we achieved for one another and for the wider Huntington's community."

Alistair Haw, Chief Executive of Scottish Huntington's Association, paid tribute to Dina for her service to families across Lothian and beyond.

"Dina is an outstanding advocate and supporter of the Huntington's community who will be very much missed as Chair of the Lothian Family Branch," said Alistair.

"She will however continue to give her invaluable support by sharing her expertise and insights as a Trustee of Scottish Huntington's Association and through her involvement with the European Huntington Association. We are so fortunate and grateful to have Dina as part of our team."

Short break funding is open for applications

Do you know that we provide funding for families to go on a short break?

If you would like to be considered for the upcoming round of funding, please make sure we receive your application before the deadline later this month -Tuesday, 20 September.

The funding of up to £500 can be used for a short stay in the UK or put towards the cost of going abroad.

It gives family members who are impacted by Huntington's disease – including carers in need of respite - the opportunity to have some much-needed time away.

So far this year we have given out grants to 12 family members, totalling £4800.

One applicant is visiting family abroad for the first time since the pandemic. Another is keen to enjoy new experiences away from the care home where they now live.

The fund is for families who find it difficult to get away because they have limited household savings.

To find out more about our Short Breaks Fund and eligibility, please speak to your HD Specialist, Youth Advisor or Financial Wellbeing Officer in the first instance – but be quick as applications must be received by Tuesday, 20 September.

"I struggled to cope with losing my Mum but SHA has always been there for me"





Sarah Mitchell, from Perthshire, is speaking out about Huntington's disease to help other young people after losing her much-loved mum.

Natalie passed away 18 months ago, aged just 55. Coming to terms with her loss was made even more difficult for 18-year-old Sarah because pandemic restrictions meant that for a long time she hadn't been able to visit the care home where Natalie lived.

"I was only seven when Mum went to live in a care home so I can't really remember a time when she was well. I know that, from what everyone tells me, Mum was great fun and had lots of friends. She was funny and would laugh a lot. Even when she was really ill, my dad could always make her laugh," said Sarah.

"We received a call during lockdown to say that her health was getting worse. I struggled to cope because I couldn't see her so my Dad got in touch with Scottish Huntington's Association to tell them what was happening. I've been supported by the charity's Youth Service for a long time and my Specialist Youth Advisor kept in touch with me every couple of days.

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"It made a huge difference having someone to speak to. We would talk about Mum, ways to look after my mental wellbeing, how I was getting on at school, anything that was worrying me.

"My Specialist Youth Advisor was also there for me when Mum died and now that some time has passed, I think I'm doing OK. I'm working part time and in my second year at college.

"I'm ready to share my experiences with other young people growing up in Huntington's families. It's an opportunity to give back to Scottish Huntington's Association - and if I'm able to help somebody at the same time, even just a little bit, that will be really good."

Moray families celebrate funding boost

Families in Moray have secured a major award of £4000 towards our work supporting young people from families impacted by Huntington's disease.

Members of Scottish Huntington's Association Moray Family Branch applied to the Money for Moray scheme for funding for our Specialist Youth Service.

Jock Anderson, Chair of the branch, said: "Huntington's disease has a devastating impact on the life of the person who has the disease and their whole family.

"Young people are especially in need of the specialised and tailored support that only Scottish Huntington's Association can provide. Each child of a person with Huntington's disease is at 50/50 risk of also having inherited the faulty gene. This means they watch their parent's health decline as complex physical, mental and cognitive symptoms develop while knowing that they too might develop the condition.

"There are 25 families in Moray that we know of who are living with this condition, however there are more people out there who have not come forward for help or support."



The Money for Moray award includes funding for local young people to attend the Scottish Huntington's Association annual summer camp where they can make new friends, share experiences and develop the resilience they need.

"A break away from the family home gives everyone a chance to get some kind of normality back into their lives, even for a short time. Knowing they are not alone gives a child confidence growing into adulthood and we are particularly pleased to be able to support that through this funding," added Jock.

Families consider setting up new support groups

Families joined Scottish Huntington's Association staff at a special get together in Westhill, on the outskirts of Aberdeen, to explore next steps towards creating peer-led support family and carer groups.

Organised by Paula Hepburn, Admin/ Resource worker for Grampian, colleagues who attended included Sam Buckley, Senior HD Specialist; Eve Graham, Specialist Youth Advisor; and Nathan Charles, Fundraising Officer.

They were joined by, from the University of Aberdeen, Stella Sihlabela, Specialist HD Research Nurse; Resifina Seyara, Proof HD Study Site Co-ordinator; and Professor Zosia Miedzybrodzka, Clinical Director of Genetics for NHS Grampian and HD Clinical Lead for North of Scotland.

"Family members are keen to set up new groups and were very interested to hear about the latest research from Professor Zosia. Now we're looking at how best to overcome the logistical challenges resulting from some of our families living in more remote locations," said Sam.

New factsheets are ready to view on SHA webiste

A suite of updated factsheets – You, Your family and Huntington's Disease – is now available on our website at <u>https://hdscotland.org/</u> you-your-family-and-huntingtonsdisease/.

Developed by colleagues across the organisation, the factsheets aim to provide families with information covering a range of Huntington's disease-related topics, including choosing a care home, managing behaviours, driving, mortgages and life insurance.



Join us as we hear from global HD activist Charles Sabine OBE

As part of the Huntington's Disease Alliance, we are delighted to welcome Charles Sabine OBE as the next speaker in our 'Family Voices' series.

Charles, a former Emmy-winning news journalist for NBC, is a tireless global campaigner for the Huntington's community.

Coming from a Huntington's family himself, Charles discovered in 2006 that he also carries the expanded gene.

"My neurologist said, 'There is nothing you can do about this disease, just live your life as well as you can," remembers Charles.

However, in the following months, Charles realised the neurologist was completely wrong.

"There is everything I can do about this disease. The problem is finding the time to do it all," he says.

Since then, Charles has travelled the world advocating for Huntington's families. In 2017 he co-organised an event where the Pope met Huntington's families, documented by the film 'Dancing at the Vatican'.



In what is sure to be an inspiring webinar, Charles will ask the question: 'Where have we come in the 15 years since I left NBC to become an advocate for the Huntington's disease community in 2007?'

The answer, he will tell us, is a very long way indeed - especially in scientific understanding of the disease and the use of communications to create a well-informed global community collaborating in research.

There is however, still one area Charles wants to see improve.

"Most families, knowing that they have the disease in their blood, feel the need to hide that reality. Imagine what we could do if we engaged all of them, too? '

In Conversation with Charles Sabine OBE takes place on Monday, 3 October at 7pm. You can register via the events section of the Huntington's Disease Association England and Wales website at <u>https://www.hda.org.uk/events/family-voices-in-</u> <u>conversation-with-charles-sabine</u>.

SHA celebrates most successful HD Awareness Month to date!

Thanks to the endeavours of families, supporters and staff Huntington's Disease Awareness Month 2022 proved to be the highest profile yet.

By working together we reached tens of thousands of people during May through print and online articles across Scotland, with coverage of our Awareness Month activities continuing into the weeks that followed. This included stories in the Sunday Mail, The Courier, Glasgow Evening Times, Daily Record, Press and Journal, Glasgow Live, The Scotsman and Edinburgh Evening News. We also featured on STV, Clyde 1 and global sites MSN and Yahoo!

In total there were over 50 articles featuring family members. We also shared their stories on social media and worked with high profile advocates such as SHA Patron Sarah Winckless and Casualty actor and HDA England and Wales Patron George Rainsford.

Having joined forces with our HD Alliance partners to carry out a UK and Ireland wide YouGov survey we now have up-to-date insight into the level of awareness about Huntington's disease. The findings confirm that too many members of the public still don't know about Huntington's or don't understand the symptoms and impact on families.

However change is happening - and for family members Mike and Jennifer Paton from Kirriemuir that makes all the difference. Their story has been featured in their local paper several times and friends have raised funds for Scottish Huntington's Association and helped spread the word.

"There is much more awareness in Kirriemuir now, I think nearly everyone here knows about Huntington's disease. People come up for a chat or to ask questions, which is fantastic," said Jennifer.

"When Mike's outside on our porch, walkers stop to give him a wave and he gets lots of big hugs in the pub. It can be emotional because Mike's a humble person but we're all pleased that people have a better understanding about his illness now."

If you are interesting in sharing your experiences, please get in touch with our Communications Lead <u>Roisin.Eadie@hdscotland.org</u>



Rhona takes to the skies again in support of families with Huntington's disease

Just over ten years after braving a skydive in support of Scottish Huntington's Association, Rhona Beaton decided it was time to take her fundraising to new heights.

So the 38 year old took to the skies again, this time strapped to a 1940s Boeing Stearman biplane as it carried out daredevil manoeuvres including bobbing and weaving, a nosedive from 500 feet and a zoom climb.

Her daredevil wing-walk inspired work colleagues, friends and family who rallied round to raise more than £3000 for the charity.

Rhona, who works as an office administrator in Glasgow, grew up on the Isle of Skye. Her mum May was diagnosed with Huntington's disease when Rhona was in her early 20s.

"Everyone close to me knows about Huntington's and its devastating impact on my family but before Mum was diagnosed it wasn't something I was aware of," said Rhona.

"Mum's father, my grandpa, had the disease and my late uncle was diagnosed a couple of years after Mum.

"We were supported by Scottish Huntington's Association throughout Mum's illness. When our HD Specialist Gordon came to visit, Mum was always especially interested to hear about research into a treatment or cure. She knew it would come too late for her but she was thinking about the people she loved and other families.

"Mum was a very sociable person who enjoying seeing people but as the disease progressed her movements became more and more jerky. Then towards the end her speaking and eating was increasingly affected and she passed away in 2014.

"The skydive in 2009 was a thank you to Scottish Huntington's Association for all of its support. I still feel that way today so I looked at the charity's events calendar and signed up for the wing-walk challenge. I was finally able to go ahead this year after a couple of delays because of the pandemic and bad weather. It was a fantastic experience, made even better by the kindness of my family and friends with their generous donations."

*Scottish Huntington's Association is offering a range of fundraising events, from wing-walks to marathons and Kiltwalks. Visit <u>https://hdscotland.org/events/ to find your challenge!</u>"

scottish huntington's association

To sign up for any of these events or view our full Events Calendar, please visit <u>www.hdscotland.org/events</u> Alternatively, you can contact us on 0141 848 0308 or email <u>fundraising@hdscotland.org</u>

SHA's Fundraising Calendar of Events 2022/23

Running Events

Great Scottish Run Sunday, 2 October 2022

London Virgin Marathon Sunday, 2 October 2022

Edinburgh Christmas 5k, 10k & Santa Toddle Sunday, 4 December 2022

London Marathon Sunday, 23 April 2023

Edinburgh Marathon Festival 27-28 May 2023

Set your own challenge date

Skydive St Andrews

Wingwalk Yorkshire

Sharkdive Queensferry









Walking events

SHA's Big Walk 1 January to 31 December 2022

Edinburgh Kiltwalk Sunday 18 September 2022

Edinburgh 7 Summits Challenge Saturday, 5 November 2022

Winter Ben Nevis Weekend 11 March – 13 March 2023

West Highland Way Challenge 6 May – 14 May 2023

Three Peaks Challenge Multiple dates

Overseas Trek

Fancy challenging yourself by taking on one of the world's greatest treks while helping families right here at home in your own community? From Machu Picchu to Kilimanjaro we can help make your dreams come true!







HD MOVES: Your challenge, your place, your pace

Get moving this October and sign up for HD Moves. You can walk, run, cycle, jump - anytime and anywhere throughout the month. This year we want to bring together the biggest **#TeamSHA** ever with everyone wearing SHA T-shirts in communities all over Scotland. Anyone can be part of HD Moves – just choose your challenge, invite family and friends to join you and start fundraising as an individual or team. Visit our website to find out more!



Your preferences

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