# SHAre



Specialist support for Huntington's disease families

Summer 2025

The magazine of Scottish Huntington's Association Issue No.106



# Tipping Point

### Call to First Minister for urgent action

Over recent editions the theme of introductions to this newsletter has, unfortunately, been to highlight the "perfect storm" of rising costs and funding cuts, and what we might do to mitigate them. The storm is far from abating.

Illustrating the scale of the challenge, 240 health and social care charities have written an open letter to the First Minister calling for urgent action to address the current crisis threatening the sector. Scottish Huntington's Association was amongst the signatories.

#### The letter called for:

- An immediate and substantial cash injection in the upcoming Spending Review, including full cost recovery of the UK Government's employer National Insurance increases
- A medium-term fully funded recovery plan for the sector to address decades of underinvestment
- Multi-year funding agreements, adjusted for inflation to ensure stability for organisations
- A firm commitment to fully include the sector in planning and decision-making

Led by The Health and Social Care Alliance and The Coalition of Care and Support Providers in Scotland, the letter hit the headlines. "Apocalyptic: Scotland's entire care service faces

collapse" screamed the front page of The Herald. "Social care charities warn of sector's looming collapse" declared Third Force News. The letter to the First Minister, and the associated headlines, makes it clear that failing to act will deepen inequalities and put even more pressure on the NHS and public services — with Scotland's most vulnerable individuals and families paying the price. The sector is at a tipping point.

We will continue to apply pressure on our governments and statutory health and social care funders to defend our essential specialist services by every means possible, and have had success in reversing proposed cuts to our services that have come our way so far.

This edition of SHAre places a particular focus on work being done to raise funds for our community, and what you can do to help. If you can, please do so.

Alistair Haw,
Chief Executive



Fundraisers step up as funding crisis deepens



### "Fundraising in support of Huntington's families inspired me to fly across the Rockies"

Hugh Heath – stepfather of Trustee Dr Marie Short MBE – outdid himself with his latest fundraising challenge. A 1.2 mile long zipline through the Canadian Rockies.

The 82-year-old has taken part in many Scottish Huntington's Association challenges over the years, including our Covid lockdown Big Walk campaign. He completed 2600 kilometres over 12 months, smashing the 2000 km target and collecting more than £3000 along the way.

Then in 2023, to celebrate his 80th birthday and two metal replacement knees, Hugh announced that year's Zipslide Across the Clyde would be his final fundraiser — until the aptly named Sasquatch (aka Big Foot) came calling during his summer holiday in Canada.

The mega flying fox ride is one of the longest in the world, linking the breathtaking Whistler and Blackcomb rocky mountains and reaching top speeds of over 60 miles per hour.

"What an exhilarating experience; I would highly recommend it!" said Hugh.

"It's been a privilege to fundraise for Scottish Huntington's Association. Getting involved gives me the motivation to get up and go - but this time I really am retiring. At least until I'm 90 Iol!"

With donations continuing to come in, Hugh has raised £1300 so far, made lots of new friends inspired by his adventurous spirit, and spread the word about Huntington's disease and our work high, far and wide.

\*Hugh was going too fast for photography! We hope you like our 'recreation' of his incredible experience.\*

#### Get involved as a Trustee

Fundraising is one way to support our work, becoming a Trustee is another.

Our Board brings a wealth of experience and ability to Scottish Huntington's Association, playing a key role developing and implementing strategies that enable the charity to grow.

These roles would suit persons who have retired or are currently in a high level leadership position in the public, private or third sector organisation. We welcome applications from interested people who have worked at director level with experience of:

- · Communications/marketing
- Fundraising and income generation
- Human Resources

For an informal discussion and to find out more about the application process please email recruitment@ hdscotland.org in the first instance. Find out more about Huntington's disease and the work of Scottish Huntington's Association at hdscotland.org.

#### Parents wanted for study

Are you a parent whose partner has Huntington's disease?

Lancaster University is conducting a study to better understand the experiences of non-affected parents who are raising children while caring for a partner with Huntington's disease.

The research, led by Trainee Clinical Psychologist Elizabeth Furr, explores how caregiving and parenting roles change over time - with the goal of improving future psychological support for families.

You can take part if:

- You have at least one child over 16
- Your partner with Huntington's lived at home with your children (under 21) for at least 3 years while experiencing symptoms

You will be invited to one interview (60–90 minutes) via Microsoft Teams or phone. The study is recruiting until December 2025.

To find out more or register interest, email: l.furr@lancaster.ac.uk



A huge thank you to this year's Zipslide The Clyde daredevils, including Chief Executive Alistair Haw, who braved the 600ft high, 1200ft long challenge in Glasgow. Their mission was to raise awareness of Huntington's disease and generate funds so that everyone affected in Scotland can access the specialist care and support they need, when they need it, no matter where they live. The team has so raised over £5000 so far!

# Leading experts lined up for this year's Family Gathering

This year's fully booked Family Gathering will take place on Saturday 8 November at voco Grand Central, Glasgow.

We have lined up a superb programme of local, national and international speakers, and a range of interactive workshops throughout the day. There will also be plenty of free time for

you to relax and socialise with members of our community.



Our Patron Sarah
Winckless MBE will
join us and we are
looking forward to
welcoming leading
global researcher
Professor Åsa
Petersén of
the Huntington
Research Unit at
Lund University in
Sweden, who will
give a research update.
Professor Petersén has led

and collaborated on numerous

research projects worldwide and will share her unique insight and understanding of current projects and clinical trials.

There will be a choice of workshops during the day - topics will include i) Movement and Function ii) Swallowing, Talking and Reducing Choking iii) Carers' Perspective and iv) Genetic Testing.

Speakers will include Dr Sarah Gunn from the University of Leicester, Dr Dave Anderson, HD Clinical Lead for Greater Glasgow and Clyde, and Lorraine Barry, Associate Lecturer in Physiotherapy at Napier University. 'Let's Make Some Noise' is also coming back by popular demand, this time led by Gregg Muir, Choir Director from Nemo Arts Centre.

The Family Gathering will be brought to a close by the Chair of the Board of Trustees Aarran Air, however families are welcome to stay on for a 'world café' style event. This will offer opportunities in a more relaxed setting to meet

key staff from Scottish Huntington's Association and stakeholders to continue conversations and networking with family member friends, old and new.

Invitations were sent by post and email to around 1000 family members, and information and registration details were shared on our website and social media channels.





### "It's scary to think about what might happen... so I focus on the positives and get involved"

Bar worker Kerry Noble followed in her mum's footsteps at the Scottish Huntington's Association Firewalk – and she couldn't wait to face the flames!

Her biggest inspiration – mum Gillian McNab – has always been willing to step out of her comfort zone to support other families affected by Huntington's disease. In addition to giving awareness-raising talks at conferences and universities, Gillian has taken on incredible fundraising challenges including a skydive, a wingwalk, Dance 100, and organising a sold out live rock night. She also takes part in research and is a Trustee on the charity's Board.

Now Kerry (22) feels it's her moment to step up, bring people together, and do what she can to support Scottish Huntington's Association.

"I remember watching Mum doing a firewalk for the charity years ago – she loved it and from that moment I always wanted to have a go. I'm glad to finally had the opportunity this year and that two of my friends, Molly and Zoe, did it too," said Kerry.

"Mum has done so much over the years for Scottish Huntington's Association and always makes it feel very positive to be involved."

Kerry's fundraising htarted, with a soldout quiz night at Kitty O'Shea's in Glasgow's west end where she works.

"Molly and Zoe helped me to organise it and we had around 100 people there,

including folk who just walked in off the street and asked to join in," said Kerry.

"As well as asking for donations on the night and through our JustGiving page, we sold raffle tickets. That raised most of the money because we had loads of great prizes including pub vouchers, restaurant vouchers, a spa visit and lots of bottles of wine and spirits. We just asked local businesses and I was surprised by how generous they were. Nine out of 10 said yes, which I wasn't expecting. It reminds you that most people are kind and want to help.

"My sisters Emily and Gemma came along too. I'm not great at public speaking so Mum got on the stage to explain why we were raising money. She kept it pretty light-hearted but got the message across. By the end of the night we had raised £1400."

Gillian had just turned 41 when it was confirmed that she will develop Huntington's disease at some stage. It also meant that Emily, Kerry and Gemma are at 50/50 risk of the inherited condition.

"It's scary to think about what could happen but Mum has drilled it into us that there is great hope that a treatment will be found," said Kerry. "Mostly I worry for her but then I think 'what would Mum do?' and focus on the positives and what I can do to help."

\*Feeling inspired? You can do your own thing by organising a fundraiser with friends, work colleagues and family. Or you might choose a 2026 fundraising challenge. Visit hdscotland.org to find out more.



# Young people gain money skills at camp

Young people from across Scotland joined together at Lagganlia near Aviemore for five days of friendship, fun and learning, led by our Specialist Youth Advisors and supported by a team of volunteers, including Youth Ambassadors.

The yearly get-away gives children and young people from Huntington's families the opportunity to meet with people their own age and the chance to try something new. Most are young carers who help to look after a loved one at home.

From gorge walking to kayaking, archery to tree climbing, there were plenty of opportunities to enjoy some time in the great outdoors, followed by a disco party night, a visit to a nearby swimming pool, baking, and games in the evenings.

This year's learning workshops included a session on managing debt, access to benefits, taking out insurance, student finance and more, delivered by our Financial Wellbeing Service Lead. It also included the relaunch of our Tip Jar information resources, which were developed by Scottish Huntington's Association in partnership with young people.

These can be found on our website at hdscotland.org.

### "Test result dashed my Royal Navy dream but now I find hope in Enroll-HD and fundraising"

Matthew Loudon had exciting plans for a career in the navy and travelling the world when he tested positive for the faulty gene that causes Huntington's.

Only a few months before he had known nothing about the disease, its symptoms, or that it was in his family.

"Grandad had Huntington's and he passed it on to my dad. My family held off telling me until I was 18," said Matthew, now 23, from Fife.

"I immediately wanted to find out what my situation was, one way or another. If I didn't have the test, I would just assume the worst so I needed the answer.

"After three months of counselling to prepare myself, I had the blood test at the Western General Hospital in Edinburgh. A few weeks later I was back to get the result with my mum and two of my friends, Josh and Tyler, for support.

"I was asked how life was going to change if the result wasn't what I was hoping for. And I said, 'well most people go travelling in their later years which won't be possible for me. So I'll just do it sooner.'

"But hearing the result was still a shock. I studied electrical engineering at college and had hoped to join the Royal Navy. In that moment, the dream was over."

In time, and with the support of family, friends, girlfriend Dailah, and his Scottish Huntington's Association HD Specialist, Matthew has accepted the life-changing news. He started working as a driver for Amazon then joined Stagecoach as a bus driver.

"I enjoy it – I'm a bit of a workaholic," said Matthew. "I've decided to live for the moment and hope to be symptom free for a long time. Grandad died a few years ago but he lived on his own until he was 80 before going into a care home. And my dad is in his 50s with no signs of the disease."

In addition to joining the Enroll-HD research study, Matthew knows how important it is for families to have the specialist services they need. So earlier this year he decided to take on his first challenge for Scottish Huntington's Association - the Glasgow Kiltwalk.

"I want to raise awareness because every time I tell someone about Huntington's they say, 'what's that?' But I was also fundraising because Scottish Huntington's Association is the only



charity specifically for families with this disease," said Matthew.

The Kiltwalk 'Mighty Stride' began at Glasgow Green where Matthew – proudly wearing his kilt and Team SHA t-shirt - joined thousands of people making their way along the 22.6 mile route to Loch Lomond. His efforts raised over £1600 – including £250 from his employers at Stagecoach and, in a gesture that was means a great deal to Matthew, a personal donation of £245 from his friend Jack.

Crucially, Matthew's efforts also helped to spark new conversations about Huntington's disease.

"Everything ached afterwards but the Kiltwalk was a great experience and I'm glad I did it," said Matthew.

"Being sad and dwelling on the disease isn't going to change anything so I just keep going. And I haven't given up on my travel dreams either – so far, I've been to Switzerland, Tunisia, Italy and Morocco."

\*Scotland's Kiltwalks are a great way to join thousands of likeminded people raising funds for good causes – if you are interested in signing up for the 2026 Glasgow, Edinburgh, Dundee or Aberdeen events in support of Scottish Huntington's Association, please contact <a href="mailto:fundraising@hdscotland.org">fundraising@hdscotland.org</a>\*

#### Make training your business

Are you in business, retail, healthcare, or any organisation that would benefit from learning about Huntington's disease?

Our HD Specialists provide tailored sessions to help recognise the challenges people with Huntington's disease face and how to offer appropriate support.

We provide training on:

- Understanding Huntington's disease and its symptoms
- Supporting individuals and families
- Effective communication
- Raising awareness within your team or organisation

We can help to ensure more organisations across Scotland have the knowledge and understanding they need to make a real difference in the lives of those affected by Huntington's disease. Contact <a href="mailto:sha-admin@hdscotland.org">sha-admin@hdscotland.org</a> to learn more.

#### Mapping your care journey

Everyone's journey with Huntington's disease is unique - and care should reflect that.

That's why the National Care Framework for Huntington's Disease was created - to ensure individuals and families get the right health and social care support.

Funded by the Scottish Government and backed by all major parties, the National Care Framework provides a clear structure that promotes specialist, multi-disciplinary, and holistic care at every stage of the Huntington's disease journey.

- Tailored care plans no "one-size-fits-all" approach
- Multi-disciplinary support teams to meet complex needs
- Specialist training and education for healthcare professionals

Learn more about the framework at hdscotland.org



## "When mum was diagnosed we all wanted to do what we could to help other families"

From 'tattie shed' dances to abseils; Santa tractor runs to a ladies' day, Fiona Gray and her family have raised nearly £50,000 for Scottish Huntington's Association.

Bringing their community together in support of the Huntington's community has become a big part of their lives over the past 12 years as a thank you for support from the Scottish Huntington's Association HD Specialist Service and Specialist Youth Advisors.

This year alone Fiona's husband Kevin has raised over £2200 by taking part in the Falkirk Wheel Abseil and donations continue to come in from the collection can at their local petrol station. Fiona's nephew Blair Scott took part in the Aberdeen Kiltwalk in June and the family also took on the Dundee Kiltwalk on 17 August, on what would have been Fiona's mum Marion Scott's 83rd birthday.

"When Mum was diagnosed it was a big learning curve for all of us. She had mobility issues and over time was no longer able to walk or speak. The support we had from Scottish Huntington's Association made a real difference," said Fiona, who lives in Turriff, Aberdeenshire.

"Dad was able to look after her at home, which is what Mum wanted, with carers coming just to help get her up and ready in the mornings."

The family's fundraising began amongst family and friends – but over the years has grown to involve the town's wider community.

"We started with coffee days at my brother Gordon's house and we just invited people we knew," said Fiona.

"As well home baking, we had a raffle and, as my husband is farmer, we also sold small bags of potatoes and carrots. The coffee days usually made around £2000. My nephew Lachlan, who was a keen baker as a child, collected recipes from family and friends and created a small recipe book, which we also sold. His brother Blair made a calendar to sell too.

"Then at the beginning of 2014, we decided to go bigger by organising our first Tattie Shed Dance in one of the sheds on our farm. Sadly Mum died in the February that year, just a few months before it took place.



"People we invited brought their own drink and a friend did the disco. We borrowed tables and chairs, sold raffle tickets, lucky squares and a lucky key game. A local caterer supplied food and there was an ice cream bike. We raised over £4000 and everyone was desperate for another one so In 2018 we brought it back.

"My daughter Abbie was keen to get involved too, and she did the Falkirk Wheel abseil and collected sponsorship and donations when she was 14. It was a fantastic day and she enjoyed doing something she'd never done before. This year it was her dad Kevin's turn, and we all went along to cheer him on too."

The Covid pandemic forced a pause but the family got into the swing again in 2021 when a team of seven took on the virtual Kiltwalk, trekking the full 26.4 miles around their hometown.

Then, as restrictions began to lift, new opportunities came along – including the chance to involve the whole town.

"Kevin was President of the Turriff Show in 2023 and traditionally the President's wife – me – along with the Ladies Day committee organises the Ladies Day, which is a very popular event. It raises money for different charities each year and the committee agreed to include Scottish Huntington's Association that year. We had an HD Specialist joining us as a guest on our table, and there was entertainment, an auction, raffles and games. It raised over £20,000, shared between Scottish Huntington's Association and the two other charities," said Fiona.

Another huge success was the annual Turra Christmas tractor run in 2023, involving 116 decorated tractors parading through Turriff and neighbouring towns. Hundreds of people turned out to watch and wave to the drivers, and it raised nearly £5000 for Scottish Huntington's Association.

"Our children Abbie, Kyle and Logan, and my nephews Lachlan and Blair were always a big help with the fundraising," said Fiona. "They served coffees, sold tickets, drew raffles, helped set up seats and tables and were very enthusiastic to help make our efforts a success.

"Also friends and everyone we asked to our events have been keen to do what they can to help, which makes things easier to organise and helps them to be so successful."



## "The charity understands Huntington's – unlike shop staff who called the police"

When Paul Clark (49) was accused of being 'highly intoxicated' and asked to leave an amusement arcade he was furious - and disappointed.

He and wife Kirsty tried to tell the manager that staff were seeing the symptoms of Huntington's disease – not alcohol – but the explanation fell on deaf ears. Their young daughter witnessed the row, adding to Paul and Kirsty's distress over the incident which took place on the first day of their summer holiday.

"It wasn't the first time people have made that mistake – I've had police at my door after supermarket workers reported me for drink driving," said Paul. "They said they had photographic evidence of me in the carpark and I ended up doing a breathalyser test to prove I was sober."

"It's annoying and frustrating for all of us but getting down doesn't do me any good. We've also had people telling us we should have our children tested, without any understanding about Huntington's disease, what testing involves, or how it impacts us as a family."

Having been in such upsetting situations, Paul and Kirsty are keen to raise awareness about the disease to reduce the misunderstandings that they – and many others – have experienced.

"My late dad had Huntington's disease so I grew up with it," said Paul. "Kirsty worries a lot and it's very hard on her but we've been together for nearly 30 years and we have a good life."

Enjoying time together as a family is a priority, including time away with their daughter at a caravan park during the summer holidays, made possible by a grant from the Scottish Huntington's Association Short Break Fund.

Paul and Kirsty are also supported by a Huntington's Disease Specialist from the Greater Glasgow and Clyde service, and the Financial Wellbeing Team stepped in to help with benefit applications when Paul was no longer able to continue working. The couple attend the charity's annual Family Gatherings and their daughter is visited regularly by a Specialist Youth Advisor. This year she went along to the charity's Summer Camp for the first time.

"I don't know where we'd be without Scottish Huntington's Association," said Paul. "Its services are essential and should be properly funded. I'd also like to thank all the volunteer fundraisers who do so much to help make sure families like ours have the support we need."

Paul's onset began with extreme mood swings – his behaviour changes were dramatic and unpredictable, impacting the whole family. Now, with the help of medication, the anger issues have improved and Paul feels more like his usual upbeat self. Physically, he has the beginnings of involuntary movements associated with Huntington's

disease and these are also affecting his mobility and balance.

"I don't think Paul notices how much he moves so it doesn't bother him too much," said Kirsty.

"I was devastated when Paul was diagnosed and I still am, but we can't change his test result. All we can do is look after each other and our family. We've been to

our family. We've been together since we were teenagers and have had

our ups and downs – but he's still making me laugh after all these years," said Kirsty.



Thank you to everyone who took part in our recent client survey. The responses, which were collated and verified by a third party consultant, are now being shared with funding partners to highlight the need for - and impact of - the specialist Huntington's disease services we provide.



Scottish **Huntington's Association is** the ONLY organisation in Scotland providing the specialist Huntington's services families need

Medical, health and social care workers trained by our specialist staff



Families accessing our **HD Specialists, Youth Service and Financial Wellbeing Officers** 







**83%** are better able to manage symptoms with support from our services





**96%** have more understanding about the disease

**85%** say their

mental health

and wellbeing

is improved



**87%** know more about their rights



and benefits



89% say life is better with our support 🎾



88%

have more resilience



89% feel less

isolated and lonely

\*Client survey 2025



friendship for **Huntington's** families

Volunteer-led **Branches that** provide vital

fundraising,

support, and

### "I cried at the start, as I ran and at the end; 13 miles of emotion"

Every step of her first half-marathon, and knowing it was in support of Scottish Huntington's Association, was loaded with mixed feelings for mum Tammy Sinclair.

Fuelled by a determination to spread awareness and raise as much money as possible, the 35-year-old from Burntisland in Fife completed the 13.5 mile run as part of the Edinburgh Marathon Festival earlier.

And she admits to being in tears when her 18-year-old daughter Aleece hugged her at the finish line.

"Aleece fundraised at her school in the past, she invited her Specialist Youth Advisor to give a talk to pupils, and she is a Youth Ambassador for Scottish Huntington's Association," said Tammy.

"Watching how she has grown up not knowing whether or not she will develop Huntington's in the future, and seeing how close she is to her gran who has the disease, Aleece is my biggest inspiration.

"I cried at the start of the run, I cried during it and I cried at the end. I felt joy, sadness, empathy, and pride that I was doing it as Aleece's mum. It was time for me to step up and do my part, and it was an honour to raise over £400 for Scottish Huntington's Association.

"We were running down Portobello beach and 'Perfect Day' was playing, the song that was on when Aleece was born. It felt so fitting that I stopped for a few moments to take it in."

Having discovered recently that her dad has tested negative for the gene that causes Huntington's, Aleece now knows that she won't develop the disease. But with family members who have the disease and others who are at risk of having inherited the faulty gene, Tammy



and Aleece are determined to continue doing that they can.

"We want to spread awareness – when I was fundraising, I realised that most people don't know about Huntington's disease or that it is passed down through the generations. I came from a family that doesn't have any inherited conditions so before Aleece was born it was all new to me too," said Tammy.

"Aleece's dad and I aren't together but we're on very good terms – he thought I was crazy for signing up for the half marathon, especially as I hadn't done any training, but he is very proud of us both.

"Scottish Huntington's Association has been incredible for Aleece. Its Youth Service is a huge part of her

life and has always been there to answer the questions that I can't, and to give Aleece the space she needs to talk. To have that support in her life is invaluable."

# Dates for your diary: Support group meetings

In-person Greater Glasgow and Clyde support groups will be held on Wednesday 10 December, from 2pm to 4pm, at Pollok Community Centre, 134 Langton Road, Glasgow, G53 5DP.

The venue is fully accessible and car parking is available.

There will also be an online support groups (via Microsoft Teams) on Thursday 6 November, from 7pm to 8.30pm.

You will need to have Teams installed on your computer or other device to access the online meetings.

To find out more, contact your Greater Glasgow HD Specialist or email

sha-admin@hdscotland.org

# Looking to inspire your employees and help families?

Want to bring your team together while making a real impact?

Get your workplace involved in helping families across Scotland affected by Huntington's disease.

From our unique £50 workplace challenge, bake sale sponsored challenges, dress-down days to corporate donations, there are so many ways to get involved and make a difference.

Plus, it's a great way to boost team spirit and show your company's

commitment to social responsibility!

Get in touch today to start your workplace fundraiser at fundraising@hdscotland.org or visit https://hdscotland.org/get-involved/corporate-and-workplace/ for more information.

### Find the ideal event for you



Whether you are a seasoned event participant or taking on your first challenge, there's an event for everyone!

You can walk, run, jump or even fly to help ensure people impacted by Huntington's disease feel less isolated and better connected to the specialist support they need.



Every pound we receive from your fundraising stays in Scotland to help people across the country and of all ages whose lives are impacted by Huntington's disease.

Our work would not be possible without the dedication of our supporters, donors and corporate partners.

Registered with and regulated by the Office of the Scottish Charity Regulator No: SC010985, Scottish Huntington's Association is a wholly Scottish charity and is registered in Scotland as a company No: 121496

Check out our full events calendar below and scan the QR code to find out more and sign up.

Alternatively, you can call us on <u>0141 848 0308</u> or email events@hdscotland.org



### 2026 EVENTS CALENDAR

Supernova (Falkirk) Friday 14/Saturday 15 March 2026

Edinburgh Marathon Festival Saturday 23/Sunday 24 May 2026

Tough Mudder (Queensferry) Saturday 6 June 2026

Women's 10k (Glasgow) Sunday 21 June 2026

Men's 10k (Glasgow) Sunday 21 June 2026

Falkirk Wheel Abseil Sunday 22 March 2026

Glasgow Kiltwalk Sunday 26 April 2026

**Aberdeen Kiltwalk Date TBC** 

**Dundee Kiltwalk Sunday 16 August 2026** 

Edinburgh Kiltwalk Sunday 13 September 2026

If you can't find an event that appeals to you, why not organise your own and invite friends, family and colleagues to join the fun!









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