action medical research
for children

TOUCHING LIVES

The Action Medical Research newsletter | Spring/Summer 2026

HOW YOUR SUPPORT IS MAKING A DIFFERENCE

Living with severe epilepsy – research to help children like Barnaby

New hope for children fighting drug-resistant leukaemia

Marathon magic – the runners lining up for Action this spring

Since this Touching Lives newsletter has been published we have learned that young Barnaby (featured on the front cover) has sadly passed away, following major brain surgery to try and help reduce his severe epilepsy. Our thoughts are with his family at such a difficult time.

We remain determined to help more children like Barnaby and will continue to strive to develop treatments and cures to help save children's lives.

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Action Medical Research is the leading UK-wide charity saving and changing children's lives through medical research.

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Registered charity: England and Wales no. 208701; Scotland no. SC039284

Cover photo: Ben Rector

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WELCOME

Across these pages, you'll see how your support continues to drive vital research forward for children and young people facing some of the toughest medical challenges.

Our cover story focuses on Barnaby and his family, and their daily reality of living with severe epilepsy. You can find out about the research you are helping to fund right now for children like Barnaby – and see how earlier epilepsy research has led to important breakthroughs that are already changing lives today (see pages 7 and 19).

We also share encouraging updates from recently completed research. These include work to help children fighting drug-resistant leukaemia, and research identifying treatment targets for a very rare, life-limiting condition – offering fresh hope where options for families are painfully limited.

And we celebrate some special fundraisers, from our London Marathon runners to TV's Davina McCall, who is marking an extraordinary 50 years supporting the charity.

Thank you for helping to move research forward, giving families hope for the future.

Clare, Editor
cairey@action.org.uk

50+
projects underway across the UK

£245
can fund a researcher for a day

NEWS

WATCH DIGBY'S STORY

You may remember Digby from your last *Touching Lives*. Thanks to your support, we're funding much-needed research to help boys like Digby, who has Duchenne muscular dystrophy. Our latest charity video shows why this work, which could save and change lives, is so important.

Please watch the video here
action.org.uk/Digby

RESEARCH UPDATE

NEW RESEARCH

With your support, we were able to fund 15 new medical research projects in 2025, helping babies and children affected by a range of conditions.

This new work includes developing a cot-side scanner for babies who've suffered brain injury and research to help prevent vision loss in children with learning disabilities. Other studies aim to develop new treatments to fight viral respiratory infections, childhood leukaemia and a rare life-limiting metabolic disease.

Read more: **action.org.uk/research**

DAVINA'S DOUBLE

This year marks a double anniversary in Davina McCall's relationship with Action. It will be 50 years since she first showed her support as a little girl – taking part in a sponsored walk organised by her much-loved granny, Pippy. It will also be the 20th year of her fundraising lunch, Dine with Davina Southampton. A highlight on our calendar, this event has raised more than £400,000 over the last two decades – and last year was joined by a new edition for Essex, returning this July.

Thank you Davina, for being such an amazing Action Ambassador.

“EPILEPSY HAS SUCH A HOLD OVER OUR BARNABY”

On his worst days, three-year-old Barnaby has had as many as 100 seizures. Keeping their young son safe and well is a constant challenge for parents Charlotte and Kieran.

Barnaby had seemed a happy, healthy baby, but when he was around five weeks old, his parents began to notice quick, unusual eye movements when he woke up or was sleepy. Then, when he was eight weeks old, he experienced an episode so frightening they took him straight to hospital.

That morning, just after waking, Barnaby had a series of back-to-back seizures. “They looked so severe, and he started crying out of them,” recalls mum, Charlotte.

By the time they arrived at hospital, Barnaby appeared to be fine – but his parents had video footage that told a very different story. He was diagnosed with infantile spasms, a form of epilepsy that begins in the first years of life.

Barnaby began medication straight away and it initially seemed to work. He seemed to be developing well and began to say his first words.

But within six months, the spasms returned with a vengeance – and he began to have atonic drop seizures. These cause a sudden loss of muscle tone, making him go limp and fall.

> **“We are still fighting so many unknowns. It can be very scary and is a huge responsibility”**
>
> Barnaby’s mum, Charlotte

He also began to regress in his skills: “he could no longer say ‘mama’ or wave and point. It vanished,” says Charlotte.

The family now know that Barnaby’s seizures cause damage to his brain, affecting his memory. MRI scans have shown he has focal cortical dysplasia in his left frontal lobe. This is an area of his brain that has not formed properly. Surgery may be the only way of ever fully gaining control of his seizures.

The location of the focal cortical dysplasia also means Barnaby has weakness on the right side of his body, affecting his balance and mobility.

Keeping Barnaby stable requires five different medicines, twice a day, plus a sedative so he can sleep at night. This has reduced his seizure activity to around 30-50 a day – but he is now on maximum doses and, in the long term, there is a risk of serious side effects.

For a toddler who wants his freedom, his seizures cause regular injuries. “He’s chipped his tooth, split his lips multiple times,” says Charlotte. “We’ve padded our home as much as possible and he sleeps in a ‘safe space bed’. He wears a protective helmet most of the day and uses a walker frame out and about. We’ve had to adapt to his way of living,” says Charlotte.

In the UK, around

64,000

babies, children and young people under 18 have epilepsy

Barnaby has taken part in research that followed babies with early-onset epilepsy – work that Action funding is now helping to continue.

“We would love to understand more about why Barnaby has the problems he has,” says Charlotte. “In an ideal world, I hope that research can get us to a point where other families never have to go through what we have. Barnaby is the happiest and most resilient little boy, but it’s not a normal life – we are so governed by his epilepsy.”

With your support, we are funding urgently-needed research to help children with epilepsy – read more overleaf.

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We remain determined to help more children like Barnaby and will continue to strive to develop treatments and cures to help save children's lives.

RESEARCH TO FIGHT EPILEPSY

With your support, we're currently funding eight different projects to improve the lives of babies, children, and young people with epilepsy.

Our previous research has helped to:

- Develop advanced scans and diagnostic tools to better understand and identify epilepsy.
- Trial a brain stimulation treatment that can reduce or stop seizures.
- Identify promising drug candidates for treating very rare forms of epilepsy.

NEW SCANS TO MAKE BRAIN SURGERY POSSIBLE

Like Barnaby, many children with severe, drug-resistant epilepsy have abnormal areas of brain tissue known as focal cortical dysplasia (FCD). Researchers at UCL Great Ormond Street Institute of Child Health are testing if an advanced new scanning technique can improve detection of FCD in children. This could offer more children the chance of potentially life-changing surgery.

Supported by a generous donation from the Garfield Weston Foundation.

HELPING CHILDREN WITH EARLY-ONSET EPILEPSY

Early-onset epilepsy is associated with neurodevelopmental differences that can significantly affect a child's learning, everyday skills, physical and mental health. At King's College London, researchers are assessing the development, behaviour and brain function of young children with epilepsy to identify early-life predictors of later outcomes.

This could pave the way for future early interventions to help improve the lives of children and their families.

Supported by a generous donation from The Baily Thomas Charitable Fund.

THANK YOU!

Together, we're giving children with epilepsy the hope of a brighter, seizure-free future.

To find out more scan the QR code or visit **action.org.uk/epilepsy**

USING AI TO BETTER PROTECT BABIES FROM PAIN

Many babies undergo surgery each year, but it can be challenging for doctors to recognise and treat their pain afterwards. Your support is helping to develop new ways to monitor babies while they recover.

Experiencing pain is distressing for both babies and their families. It may also have a negative effect on brain development. But since babies can't speak, it can be hard to know when they're in pain – and how severe it is.

Doctors and nurses use pain scores to monitor babies after surgery. These include observing behaviours, such as facial expressions, crying and activity levels, and vital signs like their heart rate. However, these checks are done intermittently, and different staff can score the same baby differently. This means there is a risk that pain is missed and left untreated.

With Action funding, Dr Roshni Mansfield, at the University of Oxford, aims to improve pain monitoring. She and her team are using state-of-the-art AI and machine learning methods to create a new tool that automatically generates continuous pain scores using video, audio and vital signs. They are collecting data from around 100 babies following surgery to repair a hernia, and will also assess how babies' scores change after pain relief is administered.

Dr Mansfield has received an Action Research Training Fellowship. These grants help to develop future leaders in children's research.

> **"We hope to guide more personalised pain management, helping to support babies' recovery and care"**
>
> Dr Roshni Mansfield

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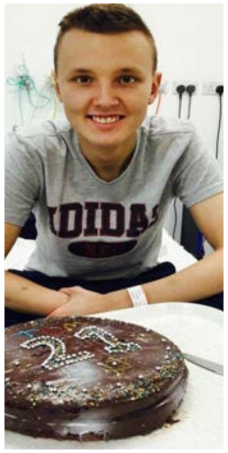
WHY I SUPPORT ACTION

During her professional cycling career, Hannah Walker won four national titles. She's now on the other side of the tracks as a commentator and presenter. She is a regular at our Champions of CycleSport Dinner, where she shared her brother Tom's story.

HANNAH WALKER

Q Can you tell us how you first got to know about Action?

A I was first invited to Action's Champions of CycleSport Dinner back in 2012, when the team I was racing for was supporting the event. It was brilliant and I've been back every year since – I never miss it! Over the years, I've had the privilege to hear some incredible success stories and some very sad family stories at the event. After my brother Tom got sick, it took on new meaning – when you have felt that loss, you know there is so much left to do.



> "Tom spent more than 900 days in hospital, including his 21st birthday"

Q Tell us a bit more about your brother, Tom

A Tom was two years younger than me and growing up we were inseparable – playing out together and, of course, competing with each other in any sport or game. Cycling became my passion, but I could never match Tom's talent. In 2014, Tom began feeling unwell. He put off having a blood test at first due to his phobia of needles. But eventually our mum made him go. That evening the hospital called. He was seriously ill and needed to go back immediately.

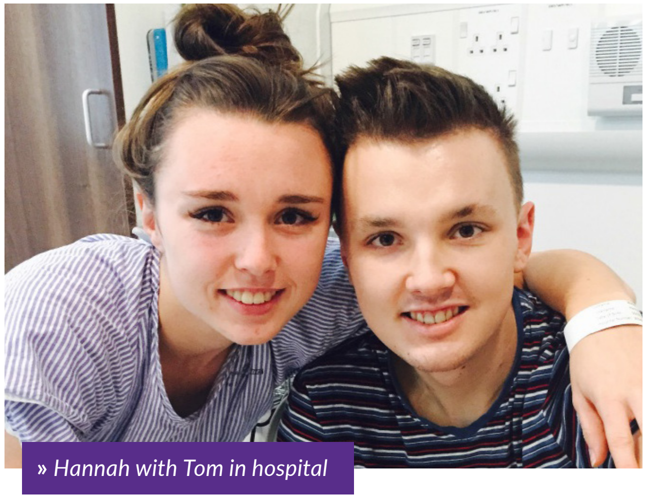
Q What was Tom's diagnosis?

A Tom had aplastic anaemia, a very rare, serious blood disorder. It's also called bone marrow failure. He was later also diagnosed with acute myeloid leukaemia. Over four years, he endured three bone marrow transplants, relentless infections, long periods in isolation and over 900 days in hospital before he tragically passed away at just 23.

Q Remembering Tom, what does Action mean to you now?

A Tom's courage was extraordinary. He faced every setback with positivity and an unwavering belief that life was still worth fighting for.

Around 100-150 people a year are diagnosed with aplastic anaemia in the UK – two people in a million. We need to fund the work Action do, especially to care for young people with ultra rare diseases. Supporting Action means giving families hope for earlier diagnoses, better treatments and the chance of a different outcome.



» *Hannah with Tom in hospital*

> "Tom's journey showed our family how desperately research is needed for rare diseases affecting children and young people"

AN EVENING OF CHAMPIONS

Our latest Champions of CycleSport Dinner saw cycling stars raise over £300,000 to power life-changing research for children.

We're hugely grateful to Garmin, BDO and ERDINGER Alkoholfrei for their ongoing support of this event, as well as Vires Velo and Rouleur.

We're already looking forward to the 2026 edition in November!

Find out more at **action.org.uk/champs**

VICI SYNDROME

UNLOCKING TARGETS FOR TREATMENT

With your support, researchers have made important progress to better understand this rare disease – opening up promising new pathways towards future treatments.

Vici syndrome is a very rare and severe genetic condition that affects many different parts of the body. There is currently no cure and sadly the condition is life-limiting.

With support from Action, researchers at University College London have recently made significant discoveries about how Vici syndrome affects cells – and how this contributes to its many serious symptoms.

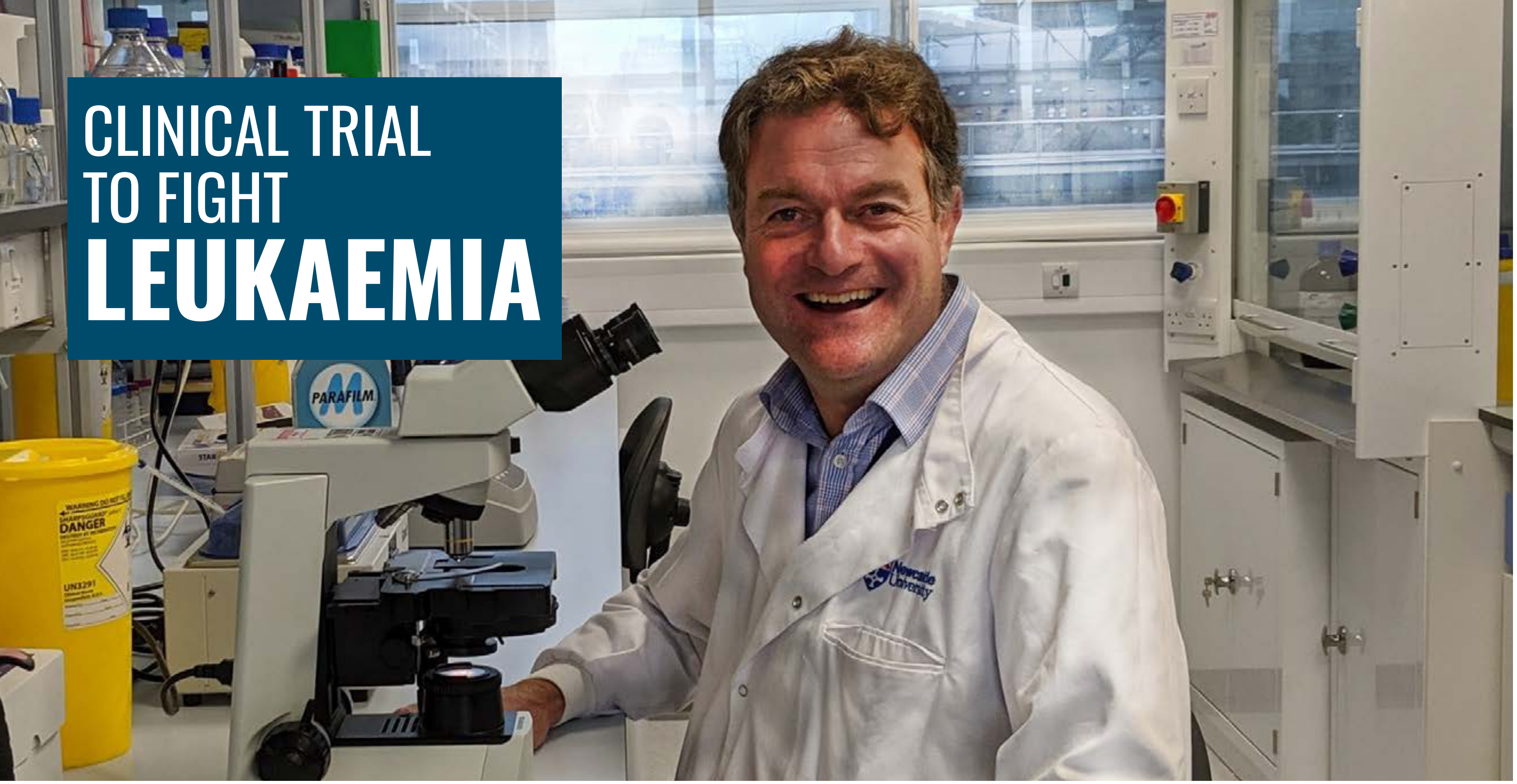
Crucially, the researchers have identified multiple biological pathways that could be targeted with drugs. Early laboratory studies have found that drugs aimed at these pathways could restore cell function. This has revealed exciting new possibilities for treatment, opening the door to future clinical trials.

Professor Michael Duchen says: “Our findings have been very exciting. This work could ultimately lead to new treatments to help reduce the impact of Vici syndrome, and other related devastating diseases.”

» *Emmy, pictured, was diagnosed with Vici syndrome at 18 months old. She is blind, tube-fed and unable to walk or talk.*

> “We are grateful for the research teams investigating Vici syndrome and other rare conditions.”
>
> Emmy’s mum, Ellie.

CLINICAL TRIAL TO FIGHT LEUKAEMIA



Thanks to your support, researchers have moved a vital step closer to a new treatment for T-cell acute lymphoblastic leukaemia (T-ALL). This will now be tested as part of a new international clinical trial in patients, starting this year.

Leukaemia is the most common cancer affecting children and young people, impacting around 700 families in the UK each year. Nearly 100 of these children are diagnosed with T-ALL, an aggressive form of the disease that can stop responding to treatment.

While most children with T-ALL will be cured, some don't respond to treatment or find the cancer returns.

Sadly, there are very limited options for those with drug-resistant or relapsed T-ALL, and these children often lose their lives.

In 2018, Action awarded funding of more than £200,000 to Dr Frederik van Delft and his team, based in Newcastle and Glasgow.

> **"The Action-funded work confirmed that our drug combination looked very promising. A new clinical trial will now test how well it works in patients"**
>
> Dr Frederik van Delft

Their early laboratory studies had suggested that combining two existing drugs could overcome treatment resistance and successfully kill T-ALL cancer cells.

With Action funding, the team carried out further tests to confirm their findings. This showed that the drug combination was more effective than using either drug on its own.

This research, alongside work by other groups in the field, has now led to the new combination being included in an international trial of different drugs to treat children with resistant or relapsed T-ALL.

Five hospitals across the UK will take part in delivering this trial.

IN NUMBERS

ALMOST 100 CHILDREN are diagnosed with T-ALL leukaemia each year in the UK

As part of the project, the team also developed a new laboratory system to test how different drug combinations affect leukaemia cells taken from patients.

This allows researchers to try multiple drug combinations and select only the most promising ones for further development and clinical testing. Teams can focus more quickly where there is the greatest potential for new treatments, helping to speed up progress towards better outcomes for children.

We are grateful to the Team Lewis Trust and other charitable trusts who so generously supported this research.

THANK YOU!

> **"We know this research has already found translation into clinical management, resulting in potential immediate impact. We remain eternally grateful for your support"**
>
> **Dr Frederik van Delft**

TOWARDS A NEW TEST TO DETECT CMV IN BABIES

Helped by your support, researchers have developed a low-cost biosensor for detecting cytomegalovirus (CMV). This could enable newborn screening for a common but often hidden virus that can cause serious harm.

Around two to three babies born every day in the UK will develop lifelong health issues, such as hearing loss, as a result of congenital CMV. But symptoms often appear only months or years after birth, when sadly interventions are much less effective.

At Swansea University, Professor Vincent Teng and his team have developed a low-cost printed biosensor that can quickly detect CMV in urine or saliva.

With Action funding, the team refined both the manufacturing and performance of the biosensor, which they've shown can outperform current, more complex, tests.

This is a step towards the possibility of routine newborn screening for CMV, giving babies the chance for early treatment and healthier futures. The test could also be adapted for other diseases in the future.

> “The support from Action Medical Research has been absolutely vital for our progress”
>
> Professor Vincent Teng

RESEARCH UPDATES

DEVELOPING NEW TREATMENTS FOR NF1

Neurofibromatosis type 1 (NF1) is a rare condition that causes tumours to grow along nerves. These can cause distressing symptoms – and in some cases become cancerous. There is currently only one approved drug treatment, but it can cause serious side effects and doesn't always work. With Action funding, researchers at the University of Exeter hope to develop a new treatment option to help children like Tora, pictured.

This project is co-funded with LifeArc and is generously supported by The VTCT Foundation.

HELPING TEENS WITH PCOS

Polycystic ovary syndrome (PCOS) affects around one in 10 women in the UK and can begin in teenage years. Symptoms, such as irregular periods, acne, excess body hair and weight gain, can affect both physical and mental wellbeing. A pilot study at Birmingham Women's and Children's Hospital is exploring whether a food supplement called myo-inositol could help. The results will guide a larger clinical trial and could lead to a safe and accessible new treatment.

Kindly supported by The Waterloo Foundation.

Read more about research funded with your support at action.org.uk/research

FIGHTING HEART RISK IN LUPUS

Childhood-onset lupus sees the immune system attack healthy tissues, causing serious symptoms and damage to vital organs. It affects around 10,000 children and young people in the UK and can sadly shorten lives.
At University College London, Professor Coziana Ciurtin is developing a simple blood test to identify those at high risk of early heart disease. This could make assessment easier and enable more targeted, life-saving treatment.

This project is co-funded with LifeArc.

RUNNING FOR LITTLE LIVES

As this issue lands, our Team Action runners are about to take on the TCS London Marathon.

Among them is Olympic [redacted] partner Ian Arnold.

Also running is Lee Collier, in tribute to his daughter Phoebe, who was sadly stillborn in 2005. Lee, pictured, ran his first marathon for Action in 2008, beginning a fundraising journey that has lasted nearly two decades and raised more than £26,000.

Midwife Abby Rivers will run in memory of the babies she has "had the privilege of meeting who have not been able to stay", and in support of her brother, who has a rare chromosome disorder.

Thank you and good luck to all our amazing runners. To find out more about running for Action in the 2027 London Marathon visit **action.org.uk/run**

IT'S TIME TO RIDE!

Our summer cycling season starts next month, so why not join us for a great day in the saddle while helping to raise vital funds for life-changing research?

We start with RIDE Castle in Kent (10 May), followed by RIDE Suffolk Sunrise, which is celebrating its 20th anniversary (17 May).

Then we have a new addition to our roster, the RIDE Tommy Godwin Challenge (28 June). Named in honour of 1948 Olympic cycling medallist Tommy Godwin, this event reflects his passion for getting more people out on bikes. It takes in some of the best of the Warwickshire and Worcestershire countryside, with two routes on offer.

Find out more about our cycling events at **action.org.uk/ride**

YOUR CHANCE TO SHINE

From sunrise to sunset, Race the Sun is a chance to take on an unforgettable team adventure – while helping to change children's lives through medical research.

It's not too late to join our Lake District edition. Across one epic day (Saturday 5 September), teams of four, or two, will bike, hike and paddle their way through some of the UK's most breath-taking scenery, racing against the setting sun.

It's tough, thrilling and it's packed with feel-good moments you'll be talking about for years!

Every paddle stroke and every step helps to fund vital research for sick and disabled babies and children. Join us and enjoy 50% off team registration when using the code RTSTL.

RACE THE SUN
NEVER STOP PUSHING

Sign up now!
Scan the QR code
or visit
action.org.uk/RTSTL

BRILLIANT BGC DAY

Davina McCall and some special families represented Action at the **BGC Charity Day** in London and did an amazing job. The event sees city traders, plus celebrity guests, raising money for good causes to commemorate those killed in the Twin Towers attack of 2001. We were hugely grateful to be a part of the day and to receive more than £53,000 to fund vital research.

A HIGH-OCTANE EVENING

The return of the **Celebration of Motorsport** event in Belfast saw more than £65,000 net income raised for Action. Guests included Jonathan Rea, six-time World Superbike Champion, and Bernie Collins, former chief strategist for McLaren and now Formula 1 pundit. We look forward to another edition this December.

TAM PEDAL POWER

We were delighted to receive more than £40,000 from the 2025 TAM Charity Ride, run by **TAM Asset Management**. The ride saw 100 cyclists from the asset and wealth management sectors pedal from Brussels to Paris. It is spearheaded and run by James Penny from TAM, with Action again set to benefit in 2026!

SUPPORTER STORY

TEAM FINLEY SHINES

Inspired by his son Finley and research Action has funded, Joe Hall and his partner Chelsea MacColl formed a team to take on Race the Sun Cheddar Gorge.

Finley was born with almost complete hearing loss in one ear due to congenital CMV. This was only discovered after he failed his initial hearing test. Luckily, at the hospital where Finley was born, a consultant was trialling screening for CMV. Thanks to this, he was diagnosed quickly and treated straight away, helping to limit the impact of the virus. But this kind of screening isn't routine in the UK.

Read more about our research to help change this on page 14 – and thank you to Team Finley for raising more than £2,000 to support this work.

To find out more about Race the Sun visit **action.org.uk/sun**

LOOKING BACK TO 2016 WITH SOPHIE

A recent social media trend has seen people looking back and sharing what life looked like for them 10 years ago.

For Sophie Lennox, pictured, things couldn't be more different. Back then, aged 15, she was recovering from life-changing brain surgery for severe epilepsy. She was simply relieved to be alive, and finally seizure-free.

Sophie's operation used a technique that was new at the time and was developed with support from Action.

Sophie says: "As I've watched people sharing their memories, I've reflected on my own with gratitude for the life and opportunities I've been given since."

"Ten years ago, the surgery I had was part of a medical trial that fewer than 100 people had undergone. Today, it is common practice – thanks to the work of organisations like Action Medical Research."

WORD SEARCH

Complete the word search and let us know which word is missing.
Send us your answer for a chance to win a £15 National Book Token.

E	L	R	G	L	I	A	K	I	O	S	A	Y	D	Y	A	S
P	L	N	N	M	I	D	L	N	S	A	P	M	N	N	C	Y
I	R	L	I	B	I	R	B	B	Y	E	E	A	O	L	I	N
L	E	U	K	A	E	M	I	A	L	B	I	H	H	B	U	D
E	A	P	L	A	P	U	W	I	A	N	A	B	T	J	M	R
P	A	U	A	L	U	N	W	L	R	F	E	N	A	E	F	O
S	I	S	W	N	U	S	E	H	T	E	C	A	R	B	P	M
Y	R	U	J	N	I	N	I	A	R	B	R	Y	A	A	Y	E
F	U	N	D	R	A	I	S	I	N	G	S	E	M	H	B	U

1. Barnaby
2. Epilepsy
3. Pain
4. Babies
5. Syndrome
6. Leukaemia
7. Clinical trial
8. Lupus
9. Brain injury
10. Marathon
11. Fundraising
12. Race the Sun

Please send your answer to **editor@action.org.uk.** Entrants must be 16 years or over. Terms and conditions apply, for details visit **action.org.uk/wordsearch**

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Freya

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Feb 2026

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