action medical research for children

TOUCHING LIVES

The Action Medical Research newsletter | Autumn/Winter 2026

HOW YOUR SUPPORT IS MAKING A DIFFERENCE

Diagnosing a serious heart condition before birth

Smarter scans now helping to fight brain cancer in children

A bear, breakthroughs and a bond that endures

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IN THIS ISSUE

WELCOME

Catching conditions sooner can change a child's future, and this issue is full of examples of this in action. Hattie, our cover star, was born with a serious heart condition, picked up when a routine scan took an unexpected turn. Her family's experience is a powerful reminder of why new research aiming for earlier, more accurate diagnosis matters so much (see page 4).

The same principle is at work elsewhere. You'll find a portable scanner giving doctors real-time insight into newborn brain injury, and a diagnostic breakthrough for childhood brain tumours that's already reshaping how young patients are treated (page 12) – both made possible by supporters like you.

We're also marking something rather lovely: 50 years of Paddington Bear championing Action Medical Research. Karen Jankel, daughter of his creator, shares how this special friendship began, and why it's endured (page 8).

There's plenty in our fundraising community to celebrate too. Cyclist Alan is marking 20 years of Suffolk Sunrise rides, and our new Race the Sun Chilterns event launches for 2027.

Thank you for helping research move faster, giving families the answers they need sooner.

Clare, Editor cairey@action.org.uk

12 NEW STUDIES

Funded so far this year

AROUND 200

Researchers across the UK currently supported

action medical research for children

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

Photo page 15 Crystal Light/ Shutterstock

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YOU MAKE IT HAPPEN

NEW RESEARCH MADE POSSIBLE BY YOU

Thanks to your ongoing support, we've been able to fund 12 new medical research projects so far in 2026, investing more than £2 million to help babies and children affected by a range of conditions.

Five of these studies focus on giving children the best possible start in life – including research into why babies are born too small or too soon, and new ways to diagnose serious heart and brain conditions in unborn babies earlier and more accurately.

We have also joined forces with the charity Action for A-T to help fund three new studies into ataxia telangiectasia (A-T). This life-limiting rare condition causes severe and progressive physical disability, suppressed immune function and a higher incidence of cancer.

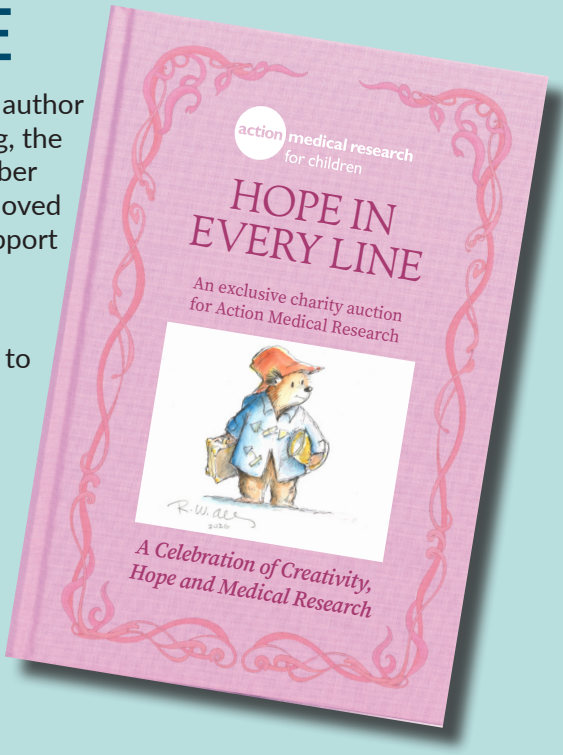
HOPE IN EVERY LINE

Inspired by Sophia Whitfield, children's author and Director of New Frontier Publishing, the Hope in Every Line campaign this October brings together some of the UK's best-loved children's authors and illustrators in support of Action Medical Research.

Sophia knows first-hand why this work matters, having lost one of her children to complications linked to cerebral palsy – an area where Action funds research.

During the National Year of Reading, contributors are donating artwork, illustrations and written pieces on hope, healing and imagination.

The collection will be exhibited at the British Library and auctioned online, helping fund research to save and change young lives.
Find out more **action.org.uk/campaign**



HATTIE'S HEART
EARLY DIAGNOSIS MATTERS

Hattie had heart surgery at just 10 days old, having been diagnosed with coarctation of the aorta while still in the womb. New research aims to improve early detection for more babies like Hattie, helping to ensure the best possible care.

Hattie recently turned eight years old and is a very creative and active little girl. She enjoys arts and crafts, goes to Brownies and theatre school classes and loves swimming. You would never guess that she had been born with a congenital heart condition, says her proud mum, Marie.

Her pregnancy with Hattie had been going completely smoothly, until the 20-week scan, explains Marie.

"Everything changed when the sonographer asked us to go away and walk around for a bit"

Hattie's mum, Marie

"We went looking forward to seeing a bit more of the baby," she recalls. "But everything changed when the sonographer asked us to go away and walk around for a bit, then come back to see if the position of the baby had changed for a better look."

When Marie and husband Sam returned, there was a second, more senior, sonographer in the room. "We soon realised there was more to the 'walk'. They said they could only see one main vessel in the heart and one of the chambers looked really small."

As a former paediatric intensive care nurse, Marie was acutely aware of different heart conditions and feared the worst. “I’d done everything by the book. But you immediately think what have we done wrong?” she says.

The couple were referred to the Evelina Children’s Hospital in London, where it was confirmed that their baby had severe coarctation of the aorta (CoA). This is a condition in which part of the main artery – the aorta – is narrower than usual, forcing the heart to work harder to pump blood around the body.

CoA affects more than 200 babies born in the UK each year and often requires surgery or other procedures shortly after birth. The condition is not always detected in the womb, putting babies at greater risk of life-threatening complications.

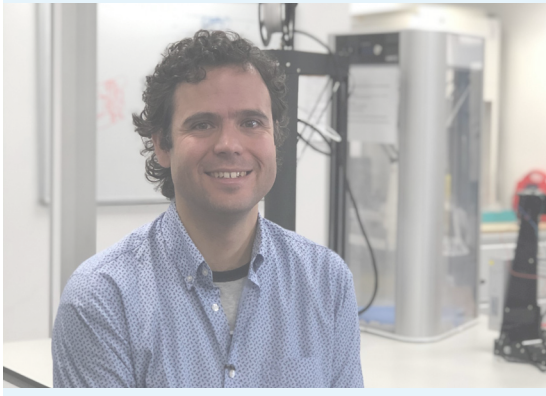
Improving diagnosis before birth

Professor Pablo Lamata and his team at King’s College London are developing a tool to reconstruct the 3D shape of a baby’s aorta from routine ultrasound scans.

They’ve previously shown that 3D reconstructions from fetal MRI scans greatly improve diagnosis of coarctation of the aorta before birth. But MRI is only available at a few specialist UK centres.

“We want to adapt this approach so that similar 3D reconstructions can be generated from widely available, 2D ultrasound scans, as early as the 20-week scan,” explains Professor Lamata.

“This could enable improved early detection – reducing uncertainty for families and improving outcomes for babies”



Marie was closely monitored and was reassured by more detailed scans she received. “But it was still a very long and worrying pregnancy,” she says.

“Sadly, some families don’t find out there’s a problem until they find themselves facing an emergency in their baby’s first days of life”

Knowing Hattie had CoA meant that doctors could prepare carefully for her birth, and Marie was induced at 38 weeks. “I got a quick cuddle and then she was taken off to neonatal intensive care with a red hat on,” she recalls.

At 10 days old, Hattie had a successful four-hour operation to repair her heart. “Nothing prepares you enough for seeing your baby attached to a machine, with a breathing tube from their nose, wires and drains and a large red dressing on their chest,” says Marie. “But she was soundly sleeping and the medical team were happy.”

Today, Hattie only needs check-ups every two years. “Her start in life was different to what we expected, but we now see it as a positive. She is an absolute fighter and is fully aware of that time and how special she is.”

Reflecting on her family’s experience, Marie says: “Although it was scary at the time, I felt our care was as smooth as it could be. Sadly, some families don’t find out there’s a problem until they find themselves facing an emergency in their baby’s first days of life. It would be amazing for more detailed scans to be available and for more babies like Hattie to be picked up before birth.”

THANK YOU!

Together, we are making vital research possible.

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

A COT-SIDE SCANNER TO HELP BABIES AT RISK OF BRAIN INJURY

Around 3,700 babies experience brain injury at or around birth each year in the UK. With your support, researchers are testing an innovative scanning device that can provide an unprecedented window into how a baby's brain is working.

Brain injury can occur during or soon after birth, often due to premature birth or complications that interrupt oxygen and blood supply to a baby's brain. Advances in neonatal care mean more babies are now surviving these difficult starts – but many remain at risk of long-term disabilities.

Some go on to develop conditions such as cerebral palsy or epilepsy, or experience learning and behavioural difficulties. These challenges affect children's health and quality of life, while placing emotional and practical strain on families.

Early diagnosis allows doctors to provide more targeted support. But while current brain imaging is good at detecting injury, it is less effective at predicting long-term outcomes.

Professor Topun Austin and his team at the University of Cambridge are working to change this. They are testing a new, non-invasive, portable brain scanning device designed specifically for newborn babies. It combines two advanced imaging technologies to give real-time information about how a baby's brain is functioning.

This tool could transform diagnosis and treatment of brain injuries, improving outcomes for sick and preterm babies across the world.

"This system could help transform neonatal care by enabling early diagnosis and more targeted treatment for brain injuries"

Professor Topun Austin

WHY PADDINGTON™ SUPPORTS ACTION

From a conversation back in 1976, to a lasting legacy that now spans five decades. Karen Jankel, daughter of Paddington Bear's creator and author, Michael Bond, shares how Action Medical Research became Paddington Bear's favourite UK charity.

» *Karen on an Action trek in Peru*

Q **Paddington has been helping Action for an amazing 50 years! How did he first get involved?**

A My father met Action's founder Duncan Guthrie in 1976, as Paddington's profile was soaring. The charity's appeal was clear for my father. This was not about sticking a plaster over a problem. It was about finding solutions, using science. He also liked the fact that it supports research into a range of different conditions. It was like several charities all rolled into one and, as we know, Paddington is a bear who likes a bargain!

"The charity's appeal was clear for my father. It was about finding solutions, using science"

I remember proudly displaying a charity sticker that he brought home after that meeting.

Q **There was also a more personal connection...**

A Yes, as a child I spent a lot of time in hospital due to a congenital hip condition. On the wards, we saw many children dealing with the effects of polio. Duncan Guthrie had founded the charity after his own daughter had polio. His mission helped fund research to develop the first polio vaccines in the UK. So this especially resonated with my father.

Q Paddington's been involved in so many different ways over the years...

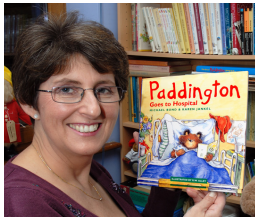
A He's played a big part in helping to bring the charity's work to life – appearing at events, inspiring fundraising initiatives, and capturing the imagination of supporters of all ages. From early activities like the 'Make It Grow Club' for children, to school fundraising and countless other events.

Q And you've been very closely involved yourself with Action...

A As Paddington's business side took off, I joined to help my father and became managing director in 1985. This brought regular contact with Action through meetings, events, and stewardship of Paddington as charity mascot. In 1992 I became a Trustee, a role I cherished for the next 20 years. My first meeting was just after my daughter India's birth, when ultrasound, a technique Action championed, confirmed she didn't share my hip condition. But her birth brought its own complications: I had pre-eclampsia and she was born prematurely.

» *Michael Bond, Paddington and a young Bonnie Langford at a Make It Grow Club event*

> **"Action is a perfect fit for Paddington, as a bear who always wants to help others"**



» *The book Paddington Goes to Hospital was written by Karen and her father, with all UK royalties donated to Action*

Q A personal milestone was taking part in a Peru trek for Action...

A Yes, in 2010 I became the first in my family to visit Peru. A hip replacement two years earlier, made possible by research the charity had pioneered decades before, meant I could finally make that trip. Trekking with my daughter Robyn, in Paddington's homeland, for a charity that had touched my life in so many ways, was an incredible, proud moment.

Q 50 years on, how does it feel to see the relationship endure?

A I feel extremely proud that he has continued his association with the charity for so long. It's a perfect fit for Paddington, as a bear who always wants to help others.

SMALL BEGINNINGS BIG IMPACT

Action-funded work has helped to spark global research to develop digital and physical exercise programmes for young people with cerebral palsy and a range of other conditions and disabilities.

A pilot study co-funded by Action has become the launchpad for a much larger programme of work now set to help improve the lives of children with disabilities in the UK and beyond.

In 2017, Professor Helen Dawes and her team began investigating classroom-based exercise programmes for children with cerebral palsy. This was an important first step, proving that breaks in the school day for physical activity had wide-ranging benefits – improving children's academic performance, strength, mobility and overall wellbeing.

Following this initial study, the team has gone on to develop exercise interventions adapted for children and young people with autism spectrum disorder, attention deficit hyperactivity disorder (ADHD) and developmental coordination disorder (DCD).

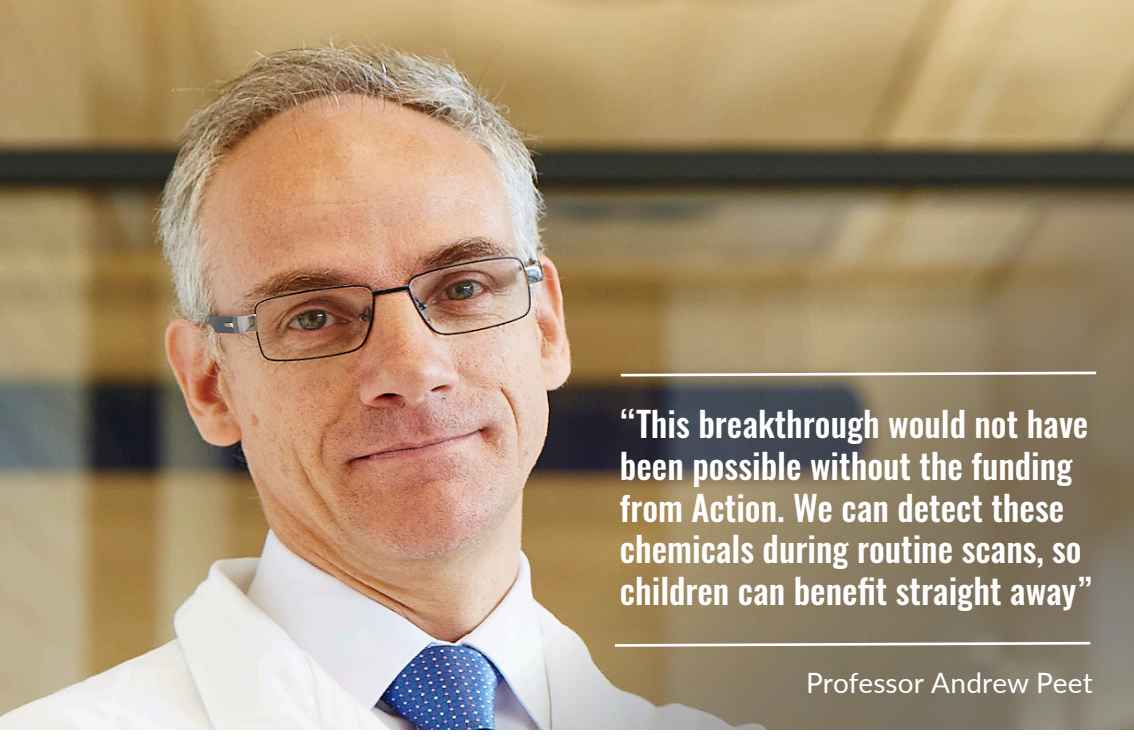
A key focus now is 'exergaming' – gamified exercise delivered through virtual reality, designed to make it more enjoyable and motivating for neurodiverse children. Further work aims to help children with Duchenne muscular dystrophy and ataxia.

Over the next five years, the team plans to develop AI-driven, personalised exercise programmes for the NHS, with an ambition to eventually reach wheelchair users worldwide.

This research was co-funded with the Chartered Society of Physiotherapy Charitable Trust.

"This study has now led to changes in practice and the development of novel inventions to improve the lives of thousands of children across the world"

Professor Helen Dawes



SMARTER SCANS THAT ARE NOW FIGHTING BRAIN TUMOURS

With Action funding, researchers have developed a new way to diagnose brain tumours in children. It looks at the chemical makeup of each tumour to assess how aggressive it is, helping doctors tailor treatment – and it's now shaping how children with brain tumours are cared for.

Brain cancers are the most common solid tumours in children, and they remain the most deadly type of childhood cancer. Sadly, one in four children diagnosed with a brain tumour loses their life within five years of diagnosis. Treatment is usually prolonged and gruelling – and while it can be lifesaving, it can also have very serious side effects and leave children with life-long disabilities.

In 2013, Action Medical Research and The Brain Tumour Charity awarded nearly £200,000 to Professor Andrew Peet and his team at the University of Birmingham, to find new ways to assess and diagnose childhood brain cancers.

The project looked at the chemical makeup of brain tumours, to see whether this held clues about the tumour type and how aggressive it was likely to be. This could then help guide treatment decisions.

The team found that levels of fats (called lipids) and a molecule called glutamine are very good predictors of a tumour's aggressiveness. This can help doctors choose the best treatment for

each child – ensuring that fast-growing tumours get intensive treatment quickly, while slower-growing ones avoid unnecessary treatment and its harmful side effects.

Excitingly, the team showed these clues could be detected using a specially adapted MRI scan, without the need for invasive tests or surgery.

This non-invasive approach is now being used in clinics treating young patients, giving doctors a clearer picture of how best to treat each tumour.

EACH YEAR IN THE UK

MORE THAN 400 CHILDREN AND YOUNG PEOPLE

are diagnosed with brain tumours

The work Action funded has also inspired research teams worldwide, who are building on these findings to better understand childhood brain tumours and explore new treatment options.

THANK YOU!

Thanks to supporters like you, research backed by Action is helping to improve the diagnosis and treatment of childhood brain tumours.

HELPING CHILDREN LIKE EVAN

Diagnosed with a brain tumour at just 15 months old, Evan is thankfully now cancer-free, but his long-term health and development have suffered due to the tumour and intensive treatment.

Evan had a type of brain cancer called medulloblastoma. These tumours are often aggressive, and he endured two gruelling rounds of treatment, involving chemotherapy, radiotherapy and, after suffering a relapse, proton beam therapy.

"Evan has a lot of ongoing health issues due to the treatments he received. These saved his life but have also altered his life," explains his mum, Lindsey.

He has had to cope with mobility and learning issues and needs a daily growth hormone due to his pituitary gland being affected by radiotherapy. He also uses hearing aids, due to the effects of chemotherapy.

"Being able to tailor treatment more specifically will hopefully mean fewer children have to endure the harshest treatments"

Evan's mum, Lindsey

George, pictured, was diagnosed with lung surfactant deficiency as a small baby

NEW HOPE FOR BABIES BORN WITH RARE LUNG CONDITION

With your support, researchers have made important progress towards a gene therapy that could transform the outlook for babies born with a devastating lung condition.

Some babies are born with a condition that prevents their lungs from working properly. Caused by a faulty gene called ABCA3, it stops the lungs from producing surfactant – a substance that's essential for breathing. Affected babies need immediate mechanical ventilation at birth and, sadly, their treatment options are limited.

Without a lung transplant, fewer than one in five children will live to celebrate their fifth birthday.

Funded by Action and LifeArc, researchers have been working to develop a gene therapy that could deliver a working copy of the ABCA3 gene directly into babies' lungs. Led by Professor Deborah Gill at the University of Oxford, they have now successfully created a method to do this and tested it in human cell models of the disease. Their goal now is to move into clinical trials with patients.

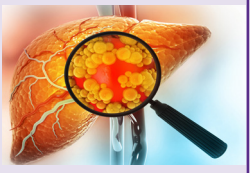
"When George was diagnosed, we were told to prepare for the worst. It is such a relief to hear that a treatment could be on the horizon"

George's mum, Rame

RESEARCH UPDATES

TACKLING A RISING LIVER DISEASE THREAT

Metabolic dysfunction-associated steatotic liver disease, previously known as 'fatty liver disease', is the most common liver condition that affects children. Over time, it can cause serious damage – and cases are rising, particularly among children with obesity. Dr Jake Mann at the University of Birmingham aims to improve understanding of how this condition develops and progresses in children. This could lead to new tests and improved treatments – helping children live longer, healthier lives.



FIGHTING PREGNANCY COMPLICATIONS

The placenta supplies vital oxygen and nutrients to babies in the womb, and problems with it can cause serious complications. Dr Viki Male of Imperial College London is studying a specialised immune cell's role in placental development, aiming to create tests that spot at-risk pregnancies earlier. This could help to improve outcomes for babies and families.

This project is jointly funded with Borne.

Read more about research action.org.uk/research

HELPING CHILDREN WEAR THEIR GLASSES

Children with learning disabilities are much more likely to have vision problems and often need glasses to see clearly. Wearing their glasses consistently is important to support the development of healthy vision and prevent permanent sight loss. But for many children, this can be difficult.

A research team at Queen's University Belfast and Belfast Health and Social Care Trust is developing a package of practical strategies to support children with learning disabilities to wear their glasses more successfully. This aims to support learning, confidence and long-term eye health.

Kindly supported by a donation from The Hospital Saturday Fund.

RACE THE SUN 2027: FOUR EVENTS, ONE EPIC CHALLE

Our award-winning triathlon-style series pits teams against the setting sun as they race to bike, hike and paddle around some of the UK's most beautiful locations. It's an adventure race like no other!

We are thrilled that our Race the Sun series featured for the first time this year in the Massive Top 25 report. This recognises the UK's top 25 largest fundraising events. So why not check it out in 2027?

With four fantastic events to choose from, Race the Sun is perfect for family, friends, groups, and work colleagues seeking an exhilarating day while raising money to help sick and vulnerable babies and children.

Races can be found on the South Downs (featuring a revamped off-road cycle route), the Jurassic Coast, the Lake District and, new for 2027, the Chilterns.

Be among the first to take on our latest Race the Sun challenge, with the majestic Chiltern Hills as your backdrop in this area of outstanding natural beauty.

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

Find out more and sign up! Scan the QR code or visit

action.org.uk/RTSTL

Race the Sun has had amazing support from Cencora Alliance Healthcare over the last four years. Six teams tackled the Lake District edition in September, which the company also sponsored as a gold partner. Since teaming up with Action, staff have raised £150,000. **Thank you for going the extra mile for children who need it most.**

EVENTS 2027

RUNNING

24 & 25 April TCS London Marathon

We also have places in other events, including Royal Parks Half Marathon, Hackney Half, London Landmarks Half Marathon. Check our website for more details.

CYCLING

24 April Dirty Reiver (off road)

9 May RIDE Castle (Kent)

May tbc Garmin Ride Out

16 May RIDE Suffolk Sunrise

June tbc RIDE Tommy Godwin Challenge

4 July Maratona dles Dolomites

11 July RIDE Wessex Downs

August tbc RIDE Essex

RACE THE SUN

15 May South Downs Way

26 June Jurassic Coast

10 July Chilterns **NEW**

4 September Lake District

We have events to suit all and would love you to join us! Visit **action.org.uk/events**

Event dates correct at time of press, please check website for the latest details.

ON SONG FOR ACTION

The Fingest Great Barn Opera returns this September, hosted by Charles and Sylvia Crowther at their beautiful Buckinghamshire barn. Renowned touring company Diva Opera perform over two nights, with profits shared between Action and other charities. Our sincere thanks to Charles and Sylvia for all their support, and to Sheila Davis and the Chiltern Committee who help to run the event.

100 RIDERS, ONE GOAL

September also sees the **TAM Charity Ride**, which aims to raise an amazing £100,000 for Action. The three-day event involves 100 riders from the asset and wealth management sectors. They will cover 320km, cycling from Vienna to Budapest, following the River Danube.

CHAMPIONS RETURN

We're gearing up for another unmissable **Champions of CycleSport Dinner** in November! Last year's raised £300,000, and we can't wait to build on that with cycling stars, stories and celebration. Our thanks to sponsors Garmin, Saffery and Erdinger Alkoholfrei, plus Win Your Dream Bike and Vires Velo. **action.org.uk/champs**

SUPPORTER STORY

ALAN'S AMAZING RIDE ACHIEVEMENT

Alan Regan first rode for Action in 2001 and has barely missed a year since. In 2007 he took part in the inaugural RIDE Suffolk Sunrise. The ride celebrated its 20th anniversary this year and Alan has been there for every single event!

Alan says the ride has evolved over the years, but what hasn't changed is the warm welcome, superb organisation and the marvellous Suffolk countryside.

He always tackles the Classic Route, at just over 100 miles, and at 71 has no plans to stop. "I see no reason to," he says, "I hope to be enjoying the ride for a good number of years yet. What hasn't changed over all this time is the importance to the charity of the funds we raise."

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

OUR FESTIVE THANK YOU TO FIGHT BACK FRIDAY LOTTERY PLAYERS

As a thank you for supporting Action through our FIGHT BACK Friday Lottery, every active player will be automatically entered into our Christmas Superdraw on 11 December.

In addition to our usual cash prizes, players will have the chance to win a festive hamper, perfect for Christmas celebrations.*

Not playing yet? Join the FIGHT BACK Friday Lottery by 20 November and you'll also be entered into the Christmas Superdraw, while helping fund life-changing medical research for babies and children.

Find out more and sign up:
action.org.uk/lottery

*Contents may vary. Players must be aged 18 or over. Terms and conditions apply.

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

1. Hattie
2. Aorta
3. Cot-side scanner
4. Paddington
5. Brain tumour
6. Diagnose
7. Lung disease
8. Placenta
9. Sight
10. Race the Sun
11. Cycling
12. Festive hamper

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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action medical research for children