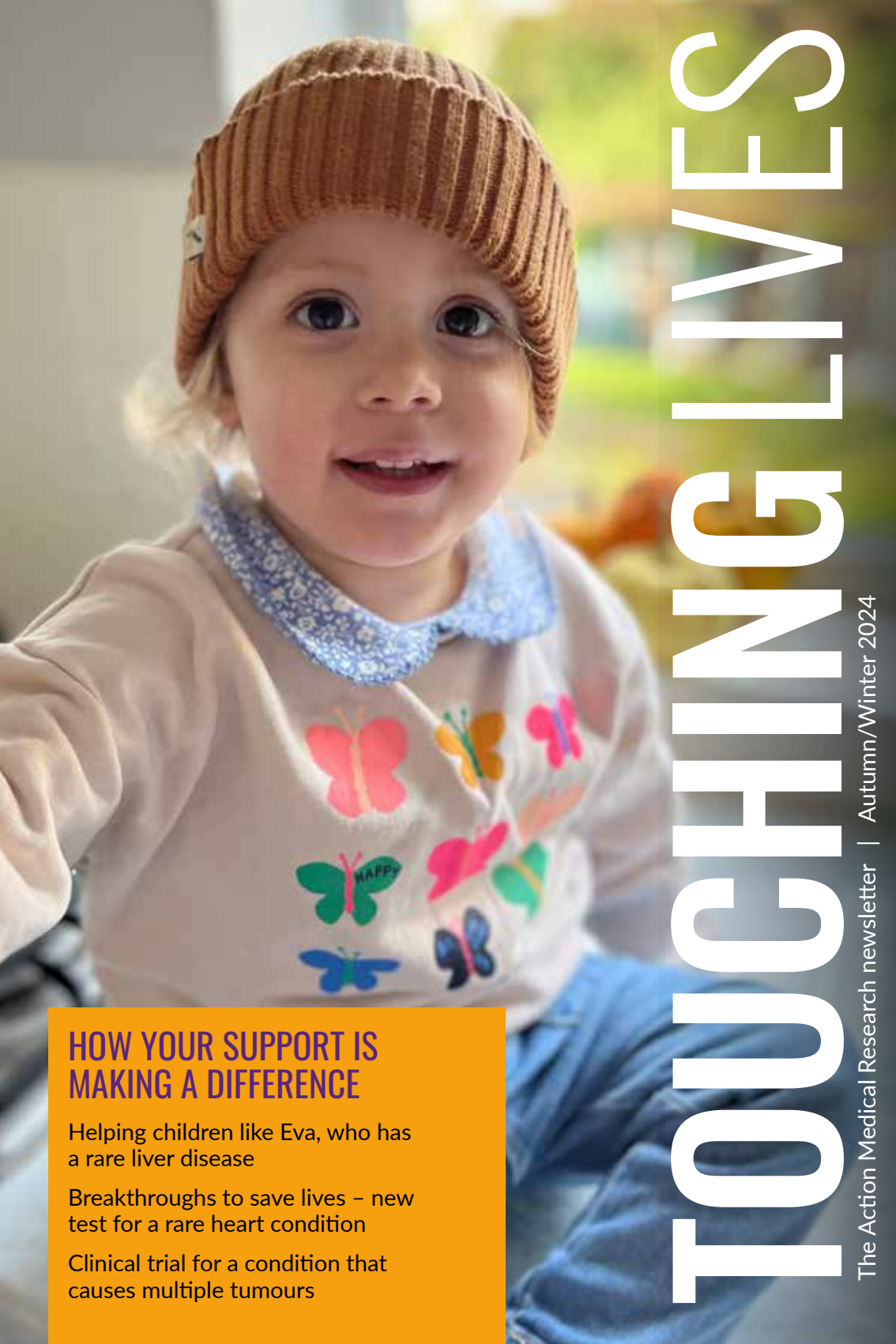

TOUCHING LIVES

The Action Medical Research newsletter | Autumn/Winter 2024

HOW YOUR SUPPORT IS MAKING A DIFFERENCE

Helping children like Eva, who has a rare liver disease

Breakthroughs to save lives – new test for a rare heart condition

Clinical trial for a condition that causes multiple tumours

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IN THIS ISSUE

action medical research for children

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

Please send all communications to:
cairey@action.org.uk
or Touching Lives
Action Medical Research
5th Floor
167-169 Great Portland Street
London W1W 5PF

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WELCOME

In these pages you'll find stories of children who show strength and resilience beyond their years, whose families live in hope of medical breakthroughs that could transform their lives. You are playing a crucial part in driving vital research forward – and we are delighted to share with you the progress that is being made, thanks to your support.

Among the successes you can read about is a simple blood test that could save lives of children at risk of sudden heart failure (page 5). While a clinical trial is bringing a much-needed new treatment option ever closer for children like Oscar, who has the rare disease neurofibromatosis type 2 (see pages 14-15).

We also have new research to share. On page 4 you can read about some of these projects, which aim to improve care for babies born too soon. With around 55,000 babies born prematurely each year in the UK, research in this area remains crucial.

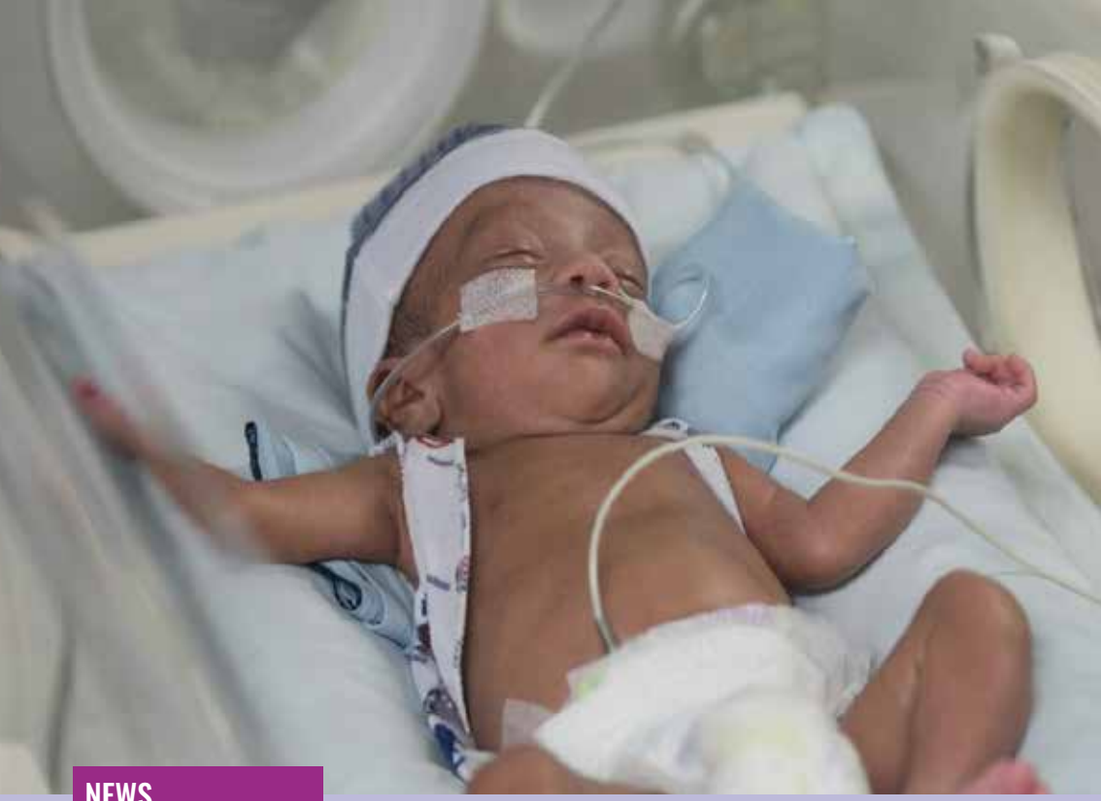
And as we head towards the festive season, our charity cards and Christmas Superdraw offer an extra opportunity to support Action – plus, you could win some fantastic prizes in the Superdraw!

Thank you for helping to make a difference for babies and children.

Clare, Editor
cairey@action.org.uk

45 PROJECTS
underway
across the UK

£300
can fund a pioneering research project for a day



NEWS

RESEARCH TO HELP PREMATURE BABIES AND CHILDREN WITH RARE DISEASES

Thanks to your support, we've recently funded three new Research Training Fellowships, investing almost £825,000.

Our Research Training Fellowship scheme supports doctors and scientists early in their research careers, developing future leaders in children's medical research.

Two of our new Fellows will undertake work that aims to improve care and long-term health for premature babies. The other to improve treatment for children with rare inherited conditions that affect the immune system.

Based at the University of Nottingham, Dr Shin Tan aims to reduce the risk of breathing tubes causing life-threatening infections in preterm babies. She is testing a new antimicrobial polymer coating.

Dr Heather Kitt at the University of Oxford is studying the immediate and long-term benefits of giving skin-to-skin care during painful procedures that preterm infants experience.

And Dr Tom Altmann, at Newcastle University, is developing a computer model to personalise the best doses of chemotherapy drugs for children with rare conditions who need a stem cell transplant.

NEWS

SHARE YOUR STORY

Our ongoing rare diseases research campaign has now raised more than £600,000 for research to fight conditions that can cause so much suffering for families.

As we continue to shine a spotlight on this area, we have launched a new rare diseases story sharing gallery. If you or your family have a story you'd like to share, please visit **action.org.uk/RareStories**

Together we can fight rare diseases and show others they are not alone.

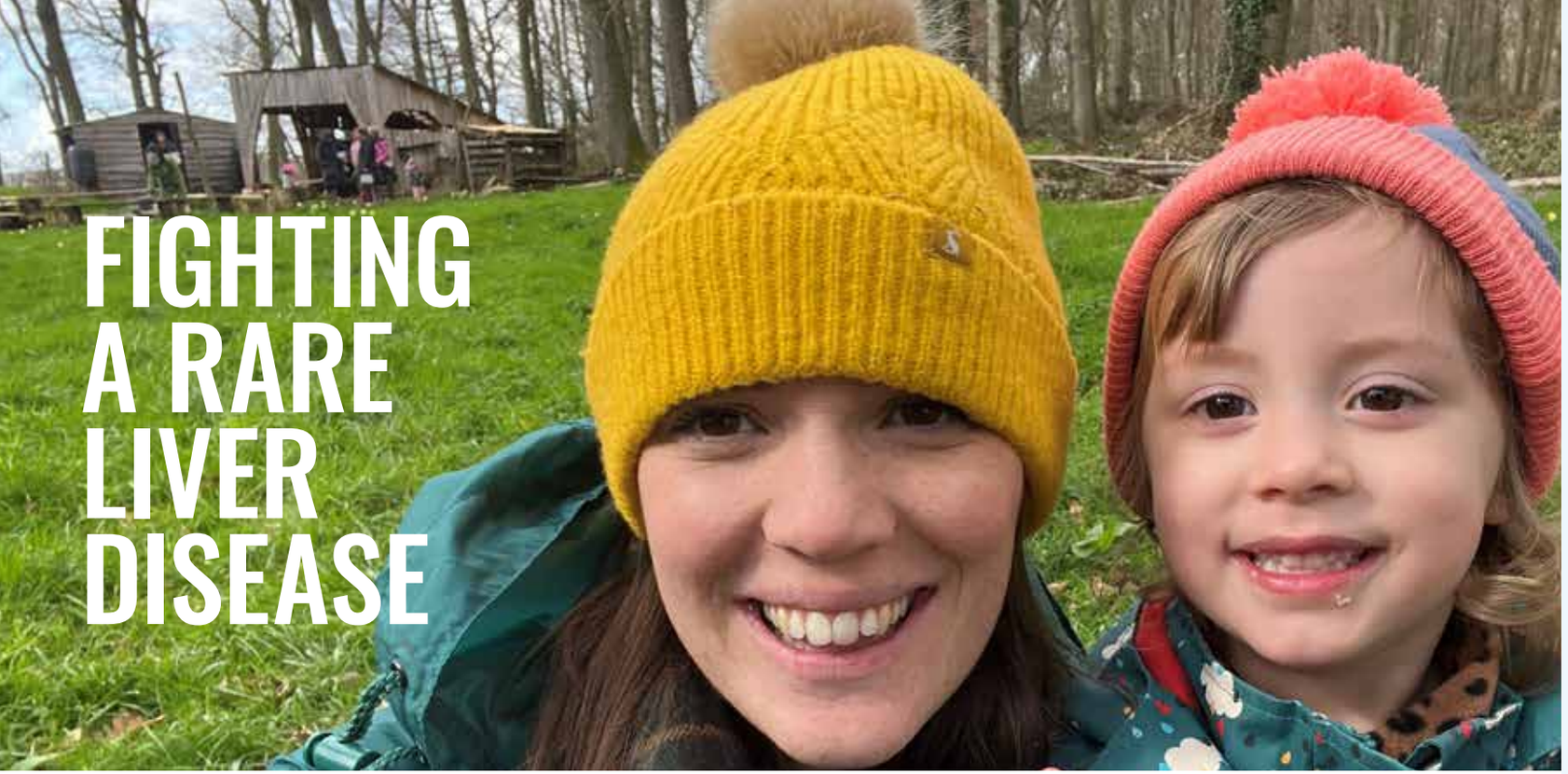
RESEARCH UPDATE

HEART DISEASE TEST BREAKTHROUGH

Your support has helped to develop a new blood test that could help prevent sudden child deaths caused by a rare heart condition. Hypertrophic cardiomyopathy causes thickening of the heart muscle and affects around 1,000 UK children, including Henry whose story has previously featured in *Touching Lives*.

With funding from Action and LifeArc, Professor Juan Kaski and his team, based at University College London and Great Ormond Street Hospital, have now shown that their test can successfully detect proteins in the blood that are a marker for this disease. It can also help to identify those who are at highest risk.

This research featured on *Channel 4 News* recently, along with Henry and his family.



FIGHTING A RARE LIVER DISEASE

Three-year-old Eva has a very rare liver disease that causes severe and progressive damage. Treatment options are extremely limited, with affected children eventually needing a life-saving liver transplant.

Eva is a very chatty little girl, who loves the outdoors and going to forest school. "She's a real bright spark," says her mum, Sophie. "She goes to nursery and is a happy little thing."

When she was nine months old, Eva was diagnosed with progressive familial intrahepatic cholestasis type three or PFIC3. This is caused by faults in a gene which provides instructions to make a protein that is essential for healthy liver function. Sadly the condition causes damage and scarring which eventually leads to liver failure.

After a very tough start in life, Eva has more recently had a period of better health, something her parents are incredibly grateful for. "But we know there will come a time when her health degrades significantly again," explains Sophie.

> **"It feels like a ticking time bomb. At the moment, Eva is well enough to live relatively normally"**

As a baby Eva was extremely thin, struggled to feed or sleep and had very elevated liver enzymes. She'd been re-admitted to hospital, following a seizure, when she was 10 days old and spent most of the first months of her life there.

"Because the disease is so rare, it was really difficult to get a diagnosis and to understand why she was so poorly," says Sophie.

Eva was initially classed as failing to thrive. She suffered from constant sickness and diarrhoea, and remained in tiny or premature baby clothes for a long time.

In the end it was Sophie, a biologist by background, who asked for Eva to be tested for PFIC. "I did loads of online research and have been told that we probably wouldn't have had a diagnosis when we did if I hadn't been pushing for it," she says.

Once Eva had a diagnosis and started taking a liver medication, she began to improve. But the future remains very uncertain.

Developing a new gene therapy

Your support is helping researchers to develop a gene therapy. This could offer a safer and better treatment option for children like Eva.

Led by Professor Paul Gissen at the UCL Great Ormond Street Institute of Child Health, the aim is to use a harmless virus to deliver a working copy of the faulty gene that causes PFIC3 into liver cells.

> **"This could transform children's lives, sparing them from long waits and complications often associated with liver transplants"**
>
> Professor Paul Gissen

This work could also pave the way for the development of similar gene therapies for children with other severe liver diseases in the future.

Eva receiving treatment in hospital

For the last two years, Eva has been generally well, but she already has scarring to her liver. Recent tests have also shown that her liver enzyme levels are starting to rise again. She is also developing nutrient deficiencies such as anaemia. This means she can get quite tired and is not as active as other children.

"The drug Eva takes is not a cure. It just slows things down and buys us time, which is the best we can hope for at the moment"

Eva's mum, Sophie

"We're very concerned about the long-term impact of these deficiencies," says Sophie. "Although this is a liver disease, it can affect the whole body, including the brain, eyesight and growth. We constantly have to monitor her."

For Eva and her family, research like the work Action is funding is hugely important. "Because it's a rare disease, so much is unknown," says Sophie. "Different people can have different severities. They think Eva has a moderate form, but we still don't really know how it will be for her."

"There are so few treatment options. Really, it's just the medication she's on now or a liver transplant. The longer Eva remains well, the better in terms of her development and growth. But also, the more time there is for research and for new treatments to become available."

THANK YOU!

Together, we can fight rare diseases.

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

DEVELOPING NEW TREATMENTS FOR A RARE SKIN DISEASE

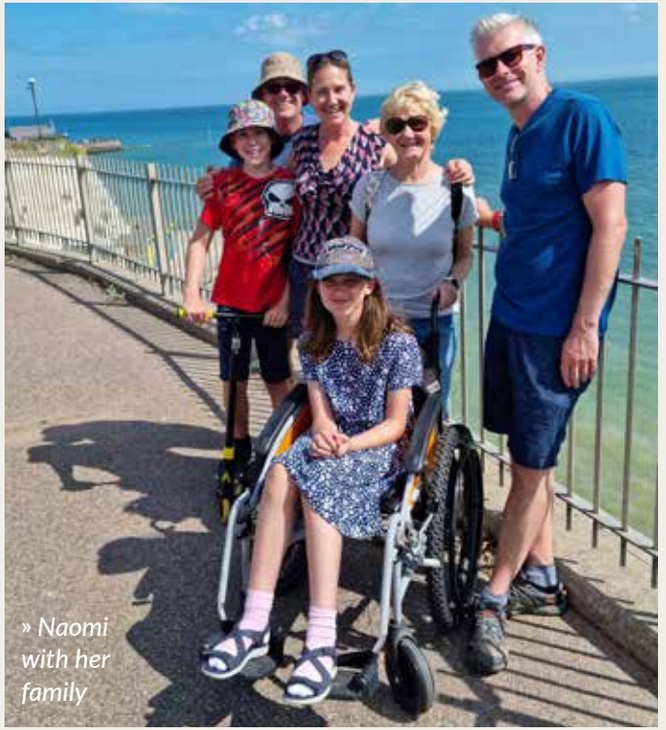
Children with epidermolysis bullosa simplex have fragile skin that blisters very easily. New research hopes to find drugs that can help improve symptoms for children like Naomi, pictured.

Naomi was diagnosed with epidermolysis bullosa simplex (EBS) as a baby. When she had started crawling, she'd developed blisters on her fingers that wouldn't go away.

Sadly, there is no cure for this debilitating genetic condition. Affected children usually develop painful blisters on their hands and feet. Some also suffer more widespread blistering. In the most severe cases, a child can develop up to 200 blisters in a single day.

With joint funding from Action and DEBRA UK, Professor John Connelly and his team aim to better understand the biology of EBS – and to identify potential new drug treatments that could help to alleviate symptoms.

Based at Queen Mary University of London, the researchers are creating a 3D laboratory model of human skin using cells from patients with EBS.



» Naomi with her family

They will use this to test a panel of existing drugs with the potential to reduce disease severity.

"We hope this will ultimately lead to a new drug treatment that can help to transform the quality of life for affected children," says Professor Connelly.

"If we could reduce or stop the blisters coming it really could transform Naomi's life and the lives of thousands of other children"

Naomi's mum, Carly

WHY WE SUPPORT ACTION

Since 1996 the Peterborough Committee, led by Angela Hyde, has run some of our biggest community fundraising events – from celebrity golf days, to a lunch club, an annual quiz and the Las Vegas Cabaret Night! They are celebrating the amazing milestone of raising £1 million for Action.

» *Longest-serving committee members Ronnie Palmer, Angela Hyde and Margaret Cripps*

Q You've supported Action for almost 30 years. How did you first get involved?

A A lady called Jane Moon, who worked for Action at the time, was wanting to start a committee in Peterborough and asked me if I would help. I hadn't heard of Action Medical Research at that time, but once she explained what the charity did, I wanted to help. I feel blessed with the life I've had and that my children and grandchildren were all born healthy. It breaks my heart to hear of others not so fortunate. I love children and when you hear what a difference the charity has made, I just want it to carry on and to keep funding those amazing researchers.

> **"We just want to keep funding those amazing researchers"**

Q Tell us a bit about some of the early events...

A Our first event was a Magic Ball. Just over 100 people came and we were so excited to make £1,000 for the charity. We also did It's a Knockout at the Peterborough United football ground, with two of the stars from TV's *Gladiators*. Then we did a Mad March Ball and had some photos from the event feature in *Tatler* magazine!

Q You've been involved in so many different fundraising activities over the years...

A Yes, and we think it is important to do different events. The PB Lunch Club, which started in 2006, is one of our favourites. It's a dining club that meets four times a year, with lunch and a guest speaker. Paddington Bear ™ is the charity mascot and we are so proud to have Karen Jankel, Michael Bond's daughter, as the Patron. Karen supports us whenever she can, and makes the most marvellous marmalade which we sell!

Q You've been great at bringing celebrities on board. Is there a secret?

A In the beginning it was very hard! Really I started the golf days as I knew some celebrities loved their golf. Once a few came they then helped with getting others, so it had a good knock-on effect. Some have been so supportive, especially Tony Hadley. The star of our golf day now is the lovely Ricky Groves, who was in *Eastenders*, and Tony will still try and come too. Then we have our quiz master Shaun Wallace from *The Chase*.

» *Committee members with the late Jane Moon (second l) and snooker player Willie Thorne at a PB Lunch Club event in 2007*

> **"We know that every penny counts and whatever event we do, we are all inspired to make that difference for children"**

Q How do you feel about having raised such a fantastic amount?

A We are all delighted but we need to say a BIG thank you to all our long-time supporters and sponsors who have helped us make so much money – especially Quai-digital and Boongate Kia.

Q What inspires you today to continue supporting Action?

A When I watch the charity videos we show at events, I cannot help but shed a few tears. Action has to carry on finding cures for the rare diseases that some children have. We know that every penny counts and whatever event we do, we are all inspired to make that difference for children.

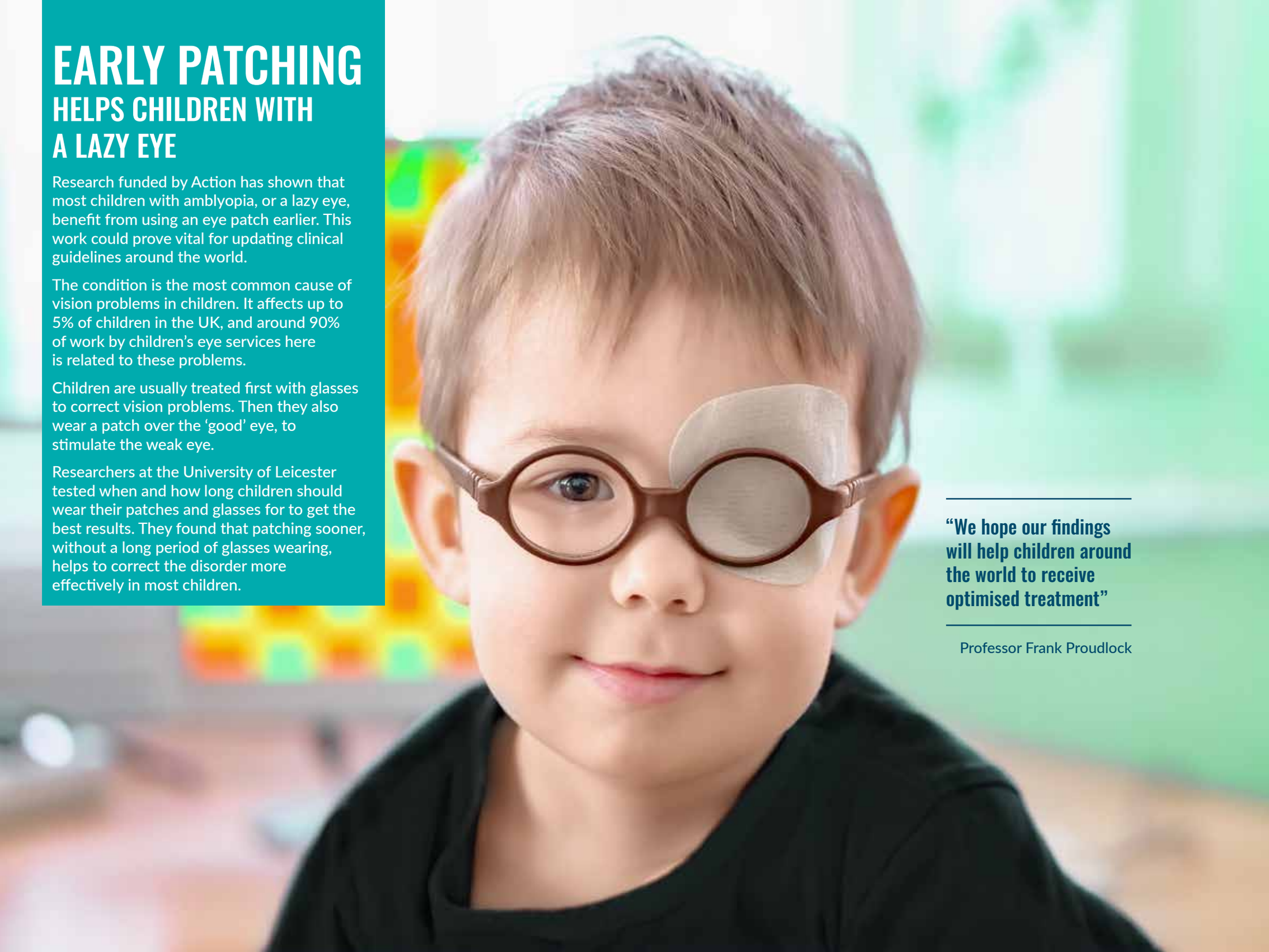
EARLY PATCHING
HELPS CHILDREN WITH A LAZY EYE

Research funded by Action has shown that most children with amblyopia, or a lazy eye, benefit from using an eye patch earlier. This work could prove vital for updating clinical guidelines around the world.

The condition is the most common cause of vision problems in children. It affects up to 5% of children in the UK, and around 90% of work by children's eye services here is related to these problems.

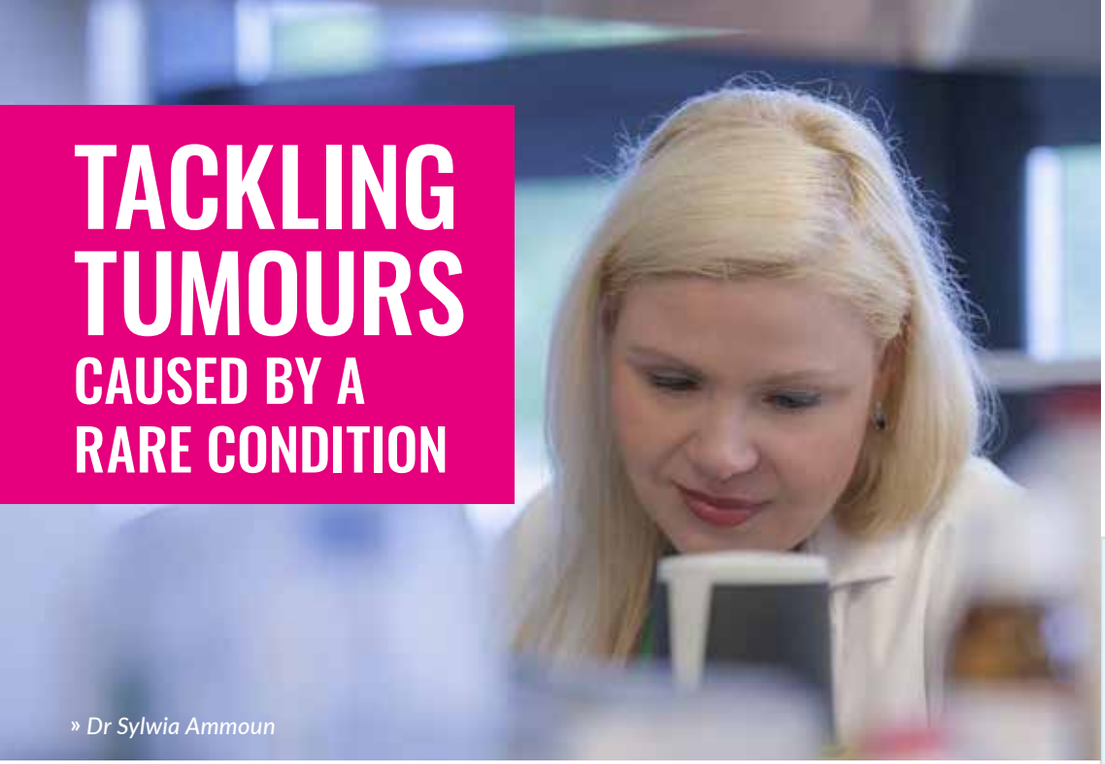
Children are usually treated first with glasses to correct vision problems. Then they also wear a patch over the 'good' eye, to stimulate the weak eye.

Researchers at the University of Leicester tested when and how long children should wear their patches and glasses for to get the best results. They found that patching sooner, without a long period of glasses wearing, helps to correct the disorder more effectively in most children.



"We hope our findings will help children around the world to receive optimised treatment"

Professor Frank Proudlock



TACKLING TUMOURS CAUSED BY A RARE CONDITION

» *Dr Sylwia Ammoun*

Neurofibromatosis type 2 causes multiple tumours, typically on nerves, the spine and around the brain. Action funding supported work to test drugs that could help treat the condition. This has now led to an exciting clinical trial in patients which started this year.

Neurofibromatosis type 2 (NF2), more recently known as NF2-related schwannomatosis, causes slow-growing tumours in different parts of the nervous system. While these are not cancerous, their locations – often on crucial nerves, the spine and around the brain – can cause significant symptoms and make them very difficult to treat.

NF2 is a genetic condition and is usually diagnosed in childhood or as a young adult. It can cause hearing loss, problems with balance and mobility, pain and paralysis. Symptoms tend to worsen over time and life-threatening complications can develop.

There is currently no cure and treatments such as surgery, where it's possible, or radiotherapy are often only partially effective – and tumours can recur.

In 2016, Action awarded funding to Dr Sylwia Ammoun at the University of Plymouth. This was to continue work to explore the role certain virus proteins in the body played in the development of tumours linked to NF2, and to test if antiviral drugs could offer a new treatment option.

The team showed that viral proteins do contribute to the growth of NF2 tumours and, excitingly, that existing drugs, already used to treat HIV, could reduce and slow the growth of NF2 tumours in the laboratory.

"These promising results have now helped lead to a clinical trial to test if these drugs can be repurposed to treat NF2-related tumours," says Dr Ammoun.

This first trial involves patients over the age of 18, but if the treatment works as expected, then children and young people would be involved in future tests. "NF2 develops in childhood, so it will be of great importance to test these drugs in children," adds Dr Ammoun.

THANK YOU!

"The grant from Action made all the difference... it allowed us to continue the research which we believe has great potential for developing new effective treatments for NF2 patients and also for patients suffering from other types of brain tumours"

Dr Sylwia Ammoun

HOPE FOR CHILDREN LIKE OSCAR

Oscar recently turned 13 and was diagnosed with NF2 when he was six years old. A new drug treatment could be life-changing for children like him, says his mum Jo.

Oscar is a determined and resilient young man, whose biggest passion is football. But while Oscar loves to be active, this has become more difficult due to the impact of NF2.

Currently, Oscar has 10 different tumours. These include two growing on the hearing nerves on both sides. This is causing low level hearing loss.

He also has a frontal lobe meningioma in his brain and left and right trigeminal schwannomas at the base of the skull.

But it is the spinal tumours he has that have caused the most damage, resulting in severe problems in his left leg and foot. Oscar needed major surgery to correct this, meaning he couldn't play football for almost a year.

Oscar's current treatment includes a monthly intravenous infusion of a drug called Avastin. This is also used to treat some kinds of cancer and can help to stabilise tumours – but it can have serious side effects.

"These new drugs could be a game-changer for families, allowing them to better manage the condition and to live a more normal life. Our kids deserve that," says Jo.

"Children with NF2 deserve a better future. One without fear of where the next tumour will pop up and which nerve or sense it will take"

Oscar's mum, Jo

HEADING TOWARDS A GENE THERAPY FIRST

Thanks to your support, researchers have made vital progress towards developing a cure for a rare disease that attacks the blood vessels.

Deficiency of adenosine deaminase 2, or DADA2, is a rare inherited type of vasculitis, caused by faults in a particular gene. In affected children the immune system mistakenly attacks their blood vessels, causing them to swell and narrow. This results in continuous inflammation, which damages tissues and organs – and can lead to serious complications such as repeated strokes, heart attacks and severe skin ulceration.

Professor Despina Eleftheriou and her team at UCL Great Ormond Street Institute of Child Health aim to develop a new gene therapy that would offer patients a life-changing cure.

With Action funding, awarded in 2021, the team investigated the best way of getting a replacement gene into patient blood stem cells and evaluated its effects in the laboratory.

These positive results have now enabled them to secure significant further funding to complete the next stage of work – ahead of a first clinical trial in patients, expected within the next five years.

Professor Eleftheriou says: "We now have a unique opportunity to make strides towards a complete cure of DADA2 and to help children worldwide break free, once and for all, from the lifelong burden of this genetic disease."
She adds: "We are the first to develop gene therapy for a rare inflammatory disorder. This could also pave the way for similar treatments for other rare genetic diseases."

"We have a unique opportunity to help children break free from the lifelong impact of this genetic disease"

RESEARCH UPDATES

NEW FACE MASKS FOR BREATHING SUPPORT

More than 2,000 UK children currently need non-invasive ventilation to support their breathing at home – and for most, this will be a lifelong need. But 'off the shelf' face masks are often a poor fit for children, especially those with facial differences. This can cause them to need to use more invasive ventilation instead, which is more challenging for families to manage.

Dr Connor Myant, of Imperial College London, aims to deliver a fully automated process to design and produce customised masks. He hopes this will lead to well-fitting masks becoming more readily available, reducing hospital stays for children and giving them a better quality of life at home with their families.

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

FINDING NEW DRUGS TO TREAT KIDNEY DISEASE

Nephrotic syndrome is a rare kidney condition, which mainly affects children. While most respond well to existing medications, those with steroid-resistant nephrotic syndrome do not – and usually experience total kidney failure within a few years. These children will need dialysis or a kidney transplant. This has a huge impact on their quality of life and can also reduce their life expectancy.

With funding from Action and LifeArc, University of Bristol researchers are screening thousands of potential drug compounds to identify possible new treatments. "We hope this will ultimately transform the outlook for many of the children who don't respond well to existing medications," says Professor Moin Saleem.

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

PEDAL FOR A PURPOSE LONDON TO PARIS 2025

This summer has seen Paris in the spotlight, with the Olympic Games and some epic sporting achievements. Next year could see you basking in the glow of your own cycling triumph!

Our London to Paris bike ride is back for 2025 and registration is open now. This ever-popular event sees participants cycle 300 miles, over four memorable days, arriving in time to soak up the atmosphere of the final stage of the Tour de France. It's an incredible journey, filled with scenic routes, camaraderie and unforgettable memories.

So much so, that many riders return to do it all again! Like Gary Sheehan, who has taken part three times now, motivated by his daughter Megan who was born more than 13 weeks early.

Gary says: "Thanks to years of research around premature birth, Megan survived. Action provides funding for this – and I wanted to help, so that research can continue to save babies in the future. Each ride has been organised with perfection and I've met friends for life. I can't wait to ride and raise more money for a charity so close to my heart. I will certainly do it again!"

Setting out on Wednesday 23 July, the ride passes through Kent before crossing the Channel. It then continues through small French villages and medieval market towns, finishing with a flourish along the famous cobblestone Champs-Élysées to reach the iconic Eiffel Tower.

To find out more and sign up, scan the QR code or visit **action.org.uk/L2P25**

EVENTS DIARY 2025

RUNNING

27 April TCS London Marathon

CYCLING

30 March RIDE Wessex Downs
25 April Dirty Reiver
11 May RIDE Castle, Kent
18 May RIDE Suffolk Sunrise
1 June RIDE The Dales
8 June RIDE Ultra
6 July Maratona dles Dolomites
23-27 July London to Paris
7 Sept RIDE Essex

RACE THE SUN

17 May Lake District Coniston Off-Road
14 June Jurassic Coast Off-Road
21 June Bannau Brycheiniog (Brecon Beacons)
12 July Cheddar Gorge **NEW**
6 Sept Lake District Keswick
13 Sept Yr Wyddfa (Snowdon)
27 Sept Jurassic Coast Road **NEW**

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

TRADING FOR CHARITY

We're proud to again be taking part in the BGC Charity Day in London. This special event remembers those killed in the Twin Towers attack of September 11, 2001, with city traders raising money for good causes. Our celebrity ambassador Davina McCall and nine-year-old Sophia (pictured) attended last year when almost £40,000 was raised for Action.

GOLF FOR GOOD

We're delighted to be this year's charity for the **Cambridge Business Golf Society**, chosen by current captain, Steve Gray. The Society runs golf days throughout the year and a fundraising dinner. This month also sees Action on the green for the Ricky Groves Celebrity Golf Day in Peterborough, plus a brand new Manchester Golf Day.

STAFF SUPPORT

We're very grateful to **EMW Law** for their ongoing support. For the last few years, the company has kindly hosted the charity free of charge for many of our staff meetings, held at their offices in West Sussex, allowing us to save precious charity funds.

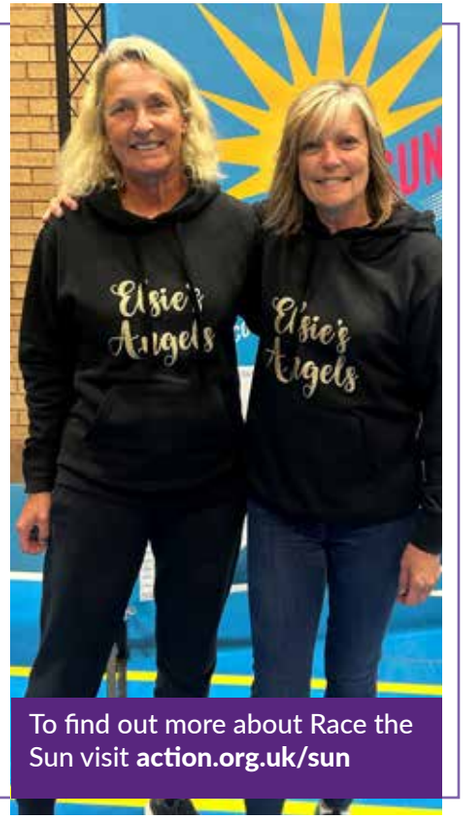
SUPPORTER STORY

ELSIE'S ANGELS

A huge thank you to all the amazing teams who've biked, hiked and kayaked their way through our Race the Sun events!

Among them were team Elsie's Angels, who are Sandra Wescott and Ricci Lennon, pictured. The duo braved all the British weather could possibly throw at them at the Brecon Beacons event, inspired by the battles faced by Sandra's granddaughter Elsie, who was born extremely prematurely in May 2022.

"Elsie is a little warrior, who brings us so much joy," says Sandra. "I wanted to do something a bit different, a physical challenge to mark my 60th birthday this year and also to raise money for a charity that helps babies like Elsie. This fitted the bill perfectly."



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

FUNDRAISING NEWS

CYCLING CHAMPS

Hot off the back of the Olympic Games comes our Champions of CycleSport Dinner in November. This year sees the fifteenth edition of this event, one of our biggest annual fundraisers.

We'll be joined by a host of cycling stars including Team GB's Pfeiffer Georgi and Lizzie Deignan. As always, we are hugely grateful for the support of sponsors Garmin, BDO, Lifeplus, as well as ERDINGER Alkoholfrei and Rouleur our media partner.

» *Olympic cyclist Pfeiffer Georgi*

AMBERLEY IN BLOOM

The residents of Amberley once again welcomed visitors to their open gardens event this summer. This beautiful biennial fundraiser has been running for more than 30 years, hosted in the pretty village that was the home of our charity's late founder, Duncan Guthrie. A record 28 properties opened their gardens to more than 1,000 visitors, who also enjoyed home-made refreshments and ever popular plant stalls. Nearly £15,000 was raised - an amazing result!

AN EASY NEW WAY TO SUPPORT US

We've partnered with GiveShop to turn your everyday spending into fundraising pounds! GiveShop is a shopping gateway that serves as a fundraising and sponsorship platform for charities and businesses.

Simply download the GiveShop app, create an account, link your card, add us as your favourite charity and start shopping to start giving!

A percentage of each purchase made with your linked card goes to Action Medical Research.

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

GiveShop

PLAYING OUR LOTTERY IS A WIN WIN!

By playing our FIGHT BACK Friday lottery you're in with a chance of winning up to **£10,000** in our Rollover Jackpot and a guaranteed weekly prize of **£500.**

You're also helping to fund vital medical research like the amazing projects detailed in this newsletter. If you're not already playing, then sign up today for just £5 a month. You'll also be automatically entered into our Christmas Superdraw.

fightbackfridaylottery.org.uk

Already playing the lottery?

Thank you. If you'd like to increase your chances and help fund even more research, add an extra chance today for just £5 a month.

fightbackfridaylottery.org.uk/extrachance

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.

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

1. Eva
2. Liver disease
3. Cardiomyopathy
4. Care
5. Treatment
6. Amblyopia
7. Breakthrough
8. Kidney failure
9. Cycling
10. Champions
11. Golf
12. Jackpot

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**

Christmas Superdraw

Draw date: 8 November 2024

Only £1 a chance!

Hamper worth £150

WIN up to £3,000 in our rollover!*

Free Gift Draw!

WIN £500 cash and a luxury Christmas hamper!

Plus... for every 12 entries you purchase we'll give you an extra chance of winning a box of festive treats in our Free Gift Draw!

Play now!
action.org.uk/superdraw

Hurry! WIN a bottle of Bollinger and luxury chocolates worth £85

Reply before 4 October and you'll also be entered into our Quick Reply Draw!

Already playing the lottery?

You'll be automatically entered into the Superdraw. Increase your chances of winning by buying extra entries for just £1 per chance.

action medical research for children
FIGHT BACK FRIDAY LOTTERY

Change children's lives forever with a gift in your will

"We feel proud to know that the gift we leave behind will help fund breakthroughs, like the one that made a real difference to our son Paul."

Anne and Stuart's son Paul was born with spina bifida and paralysed from the waist down. He was the youngest person in the UK to benefit from a revolutionary walking device developed with Action funding. This made a huge difference to his physical and mental wellbeing. He attended his local school, along with his friends, and enjoyed trips to support his beloved Manchester United. Paul lived a happy and fulfilled life but tragically died when he was 14. Anne and Stuart have kindly decided to leave a gift in their will to change the lives of other children like Paul.

Could you leave a gift in your will like Anne and Stuart?
Find out more and request your free guide at **action.org.uk/wills**