



## HOW YOUR SUPPORT IS MAKING A DIFFERENCE

Living with a rare disease – Finley's fight  
with Diamond-Blackfan anaemia

Developing a life-changing treatment  
for children with severe epilepsy

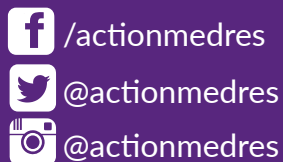
Celebrating 70 years of research

# TOUCHING LIVES

The Action Medical Research newsletter | SAVING LIVES FOR 70 YEARS | Spring/Summer 2022



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

Please send all communications to:  
The Editor, Touching Lives, Action Medical Research, Vincent House, Horsham, West Sussex RH12 2DP.

Touching Lives is also available to download at [action.org.uk](http://action.org.uk)

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Elijah's Star photo page 2  
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## WELCOME

Hello and welcome to your new-look newsletter. Action is celebrating 70 years of saving and changing lives in 2022, so it feels like the perfect time to unveil our smart new look. We really hope you like it.

As always, this issue is full of stories and information to show you how your support makes a difference, both now and over the past seven decades.

Looking back, there is so much to be proud of. Research funded by donations from people like you has resulted in some amazing medical breakthroughs that have saved and changed the lives of millions. While on pages 12-13 you can read about a more recent success that is already beginning to transform the lives of children with hard-to-treat epilepsy.

And in the spirit of celebration, our FIGHT BACK Friday Lottery also has a special 70th Anniversary Superdraw coming up. Have a look at the back cover to find out how you can join in, and help us fund even more vital research to help save and change little lives.

However you choose to support us, thank you.



Best wishes,  
**Clare**  
Editor  
[cairey@action.org.uk](mailto:cairey@action.org.uk)



**£150**

Can fund a researcher  
for a day



**50+**

Current research  
projects across the UK

## NEWS

### A SPECIAL YEAR

We're proud to celebrate 70 years of saving lives through medical research this year. Our work began in 1952, when the UK faced a deadly disease, polio, and we helped to develop the first vaccines in the UK.

Today we continue to fight disease and disability, funding some of the best research in the world. With your support, we can continue to help save and change children's lives.



## RESEARCH UPDATE



## COVID NEWS

An Action-funded study, published in the journal *Nature*, has found that children's innate immune response is better at fighting COVID-19. This helps explain why they are less likely to become seriously ill. The research team compared infection in adults and children across multiple organs. A stronger immune response in the airways of children helped to restrict viral replication early on.

## ELIJAH'S STAR TEAM TRIUMPH

Team Elijah's Star successfully completed the Talisker Whisky Atlantic Challenge after 41 days at sea. Dean, Phil, Lee and Jason rowed relentlessly throughout in two-hour shifts – and spent Christmas away from family and friends. Their incredible feat has raised over £150,000, honouring the memory of baby Elijah Halse and many other babies who were born too soon, and shining a light on the need for more research into premature birth.





# FINLEY'S FIGHT

Little Finley has Diamond-Blackfan anaemia and in his first four years of life has endured more than 100 blood transfusions, countless tests and two major operations.



"Finley is completely unique and he has taught us and his siblings so much about life," says his mum Ellie. "We didn't realise when we named him, but Finley means warrior, and that he truly is. Every single task is a battle for him but he never ever shows it. He absolutely loves life and laughs every single day."

Finley has been fighting since the day he was born. At birth, his oxygen levels were dangerously low, and tests found that he was severely anaemic. His haemoglobin level, an indicator of healthy red blood cells, should have been between 18-21 but his was just five. He needed three blood transfusions in his first 24 hours of life.

While in special care, baby Finley was also found to have a serious heart condition that would require major surgery, and a scan showed enlarged ventricles in his brain. His family were warned that this could cause developmental delay. Then at six weeks old, he was diagnosed with profound hearing loss.

**"Finley means warrior, and that he truly is. He has amazed us with all he has overcome"**

"We found ourselves on a conveyor belt of more and more poor prognosis," recalls Ellie. "We lived on a constant knife-edge, just surviving each day."

At three months old, Finley was finally diagnosed with Diamond-Blackfan anaemia (DBA), an extremely rare condition where the bone marrow fails to produce enough red blood cells. There is currently no cure and children like Finley rely on long-term treatment, usually steroid drugs or frequent blood transfusions.

The condition is a syndrome caused by changes in certain genes. It often causes other physical problems too. For Finley, his heart condition and hearing loss are linked.

"He has amazed us with all he has overcome in his short four years," says Ellie.



## Diamond-Blackfan anaemia research

Thanks to your support, researchers at King's College London are working to better understand the underlying genetic causes of this rare disease.

**"Building knowledge about the underlying causes could lead to new treatments and improved diagnosis for children"**

Some of the genes responsible are already known but for some children there is currently no explanation.

Professor John Strouboulis and his team aim to improve understanding of the biology of the disease and identify further genes that cause it.







Finley had cochlear implants fitted at 13 months old, to allow him to perceive sound. This was followed by open heart surgery when he was three. He has also fought meningitis twice.

His current treatment regime sees Finley have monthly blood tests, followed by a four-hour blood transfusion the next day.

**“Because DBA is so rare, research funding is very limited. Without hope, we wouldn’t be where we are today”**

Finley’s mum, Ellie

The most difficult aspect of his transfusions is managing the iron overload they cause. Finley’s bone marrow cannot process this in the usual way and left untreated it causes organ failure. So he takes daily tablets to remove excess iron – but these also cause side effects. His care is a constant delicate balance.

Finley is also at greater risk of developing certain cancers, especially

leukaemias, so this too is monitored. “He has regular bone marrow and liver biopsies to see what’s happening. These are always so nerve-wrecking,” says Ellie.

But Finley never lets his challenges define him. He recently started school and has settled in well. “We don’t measure him against milestones – it’s Finley’s way and he gets there in the end,” says Ellie.

Looking to the future, Finley could need a bone marrow transplant if his current treatment stops working. His family also hope that gene therapy might one day help him.

“A cure is our dream,” says Ellie. “Because DBA is so rare, research funding is very limited. Without hope, we wouldn’t be where we are today.”

**THANK YOU!**

Together, we can support more rare disease research.

To find out more scan the QR code or visit [action.org.uk/rare](https://action.org.uk/rare)



# HELPING BABIES WITH A HEART CONDITION

**Babies born with coarctation of the aorta can need urgent treatment. But parents currently face an anxious wait of up to a week before it can be confirmed. Advanced MRI scans could change this.**

Coarctation of the aorta is a condition where the main artery, the aorta, is narrower than usual. In severe cases, restricted blood flow can cause heart failure and damage other vital organs. So babies may need major surgery.

Pregnancy scans can identify babies who are suspected to have this condition, but it cannot be confirmed until after they are born.



More than **200** babies are born with coarctation of the aorta each year in the UK

believe that advanced MRI scans could help reduce this stressful period of uncertainty and allow earlier treatment.

They are using a new state-of-the-art incubator, which can be transferred into the scanner while a baby is sleeping. This has been funded by local charity Children’s Heart Surgery Fund.

Action funding will now support detailed MRI

assessments of babies’ blood flow, to identify measurements that could help diagnose the condition earlier.

**“Our goal is to develop a new tool that can help doctors to make diagnosis much sooner after birth”**

Dr Malenka Bissell

Diagnosis usually involves daily scans and blood tests for up to a week.

Dr Malenka Bissell and her team, based at the University of Leeds,



# WHY I SUPPORT ACTION

A favourite host both on and off screen, every year Davina's support helps us raise tens of thousands of pounds.

**DAVINA MCCALL**

**Q** You've supported Action for a very long time now. Can you tell us a bit more about how you came to get involved?

**A** My wonderful granny, Pippy, ran a local fundraising group for the charity and signed me up for my first sponsored walk when I was just nine! When my TV career took off, during my *Big Brother* days, she realised that my profile could be a real asset so she brought me back to Action. And my lovely dad Andrew, who we sadly lost recently, was also always involved.



» Davina's Big Day Out in 2005

He always came to my events and was a huge support. Action has a very special place in my heart – 45 years as a supporter and counting!

**Q** Your first big event for us was a sponsored walk called Davina's Day Out. Do you remember it?

**A** Yes! In Portsmouth. We did two and the second year I was seven months pregnant with my son Chester! They were such brilliant days, with so many families with their kids there to support the charity, especially around premature birth.

**Q** And you were actually a premature baby yourself...

**A** I was – my mum had pre-eclampsia when she was expecting me, so it was thanks to the medical advances of the time that I was ok. Supporting Action definitely took on new meaning for me once I became a mother myself.

**Q** So, let's talk about Dine with Davina, your annual ladies' lunch...

**A** Well, I can't believe this year is the 16th one! And I know I say it every year, but it really does get better and better. There's always such a wonderful atmosphere. Everyone comes ready for a good time and helps us raise a phenomenal amount. I genuinely look forward to it every year.

**Q** Then there's cycling. How did you come to have your own Action bike ride?

**A** Well, I got bitten by the cycling bug back in 2010 and it went from there. It's a really sociable way to keep fit. And what was important to me from the start is that it's an inclusive event. It doesn't matter if you're

a novice or a pro, it's about getting on your bike, with your mates, and enjoying a great way to help raise money. It's always a fun, friendly day out and there really is a route for everyone, whatever your current fitness level.

**Q** Can you believe we're 70 years old this year?

**A** And looking brilliant on it! It's honestly an honour to support a charity that has touched so many lives. Action does unbelievable work and I love that while it's not one of the most well-known charities, it has still helped in the discovery of some amazing medical breakthroughs – some that have benefited us all. And I'm sure there's so much more to come.



» Raring to go at her Big Sussex Bike Ride

**“** It's an honour to support a charity that has touched so many lives **”**

## FIND OUT MORE



Davina is back for her Big Sussex Bike Ride on Sunday 19 June. Scan the QR code or visit [action.org.uk/davinaride](http://action.org.uk/davinaride) to join her!



# TAKING ACTION FOR 70 YEARS

some highlights

SAVING LIVES FOR  
**70 YEARS**



## 1952

Action is set up by Duncan Guthrie to help fund research into polio and develop the first UK vaccines



## 1960s

Discovering the importance of folic acid in pregnancy



## 1970s

Helping introduce ultrasound scanning in pregnancy



## 1980s

Creating the award-winning Matrix seating system for disabled children



## 1990s

Establishing a vaccine to prevent meningitis



## 2000s

Helping to develop cooling therapy to prevent brain damage in babies



## 2010s

Developing new advice to reduce the risk of stillbirth leading to the Sleep on Side public health campaign



## 2020s

Helping to bring dedicated eyecare services to children in special schools across the UK





# EPILEPSY SUCCESS

## SEIZURE FREE FOR SEVEN YEARS

Danny (left) was diagnosed with severe epilepsy as a baby and over time various medications were no longer helping. By the age of seven, his seizures were almost constant and he couldn't live a normal life.

"Nothing was working. It just seemed to be getting worse. It was really scary and upsetting," say his parents, Jon and Jane.

As a last resort, the family agreed to brain surgery. However, when the procedure began, it became clear that Danny's epilepsy involved too large an area to safely operate.

**"If Danny had not received the stimulation treatment, he would not be the boy he is today"**

Danny was one of the first to be offered electrical stimulation – and it worked better than anyone had dared hope. For seven years his seizures stopped completely.

"We are forever grateful and pray that the treatment continues to develop, so it can go on to help as many others as possible," says Jon.

**With your support, researchers have developed a new technique that can transform the lives of children with hard-to-treat epilepsy.**

Epilepsy causes frequent seizures. These occur when there is a sudden burst of intense electrical activity in the brain and can be very unpredictable and frightening for children.

For most children, the condition can be controlled with medication, and for others brain surgery is an option. But for some, the usual treatments

don't work. This can seriously disrupt and even endanger lives.

Action funding has helped Dr Antonio Valentin and his team to develop a new way to treat focal epilepsy, which originates in localised areas of the brain. It involves suppressing the area triggering the seizures by stimulating very specific parts of the brain, using electrodes placed under the skull.

This has been shown to reduce children's seizures and can result in longer, completely seizure-free periods for some.

**"Without Action funding, we couldn't have got this far. We have patients waiting who could benefit from these treatments"**

# 1 IN 3

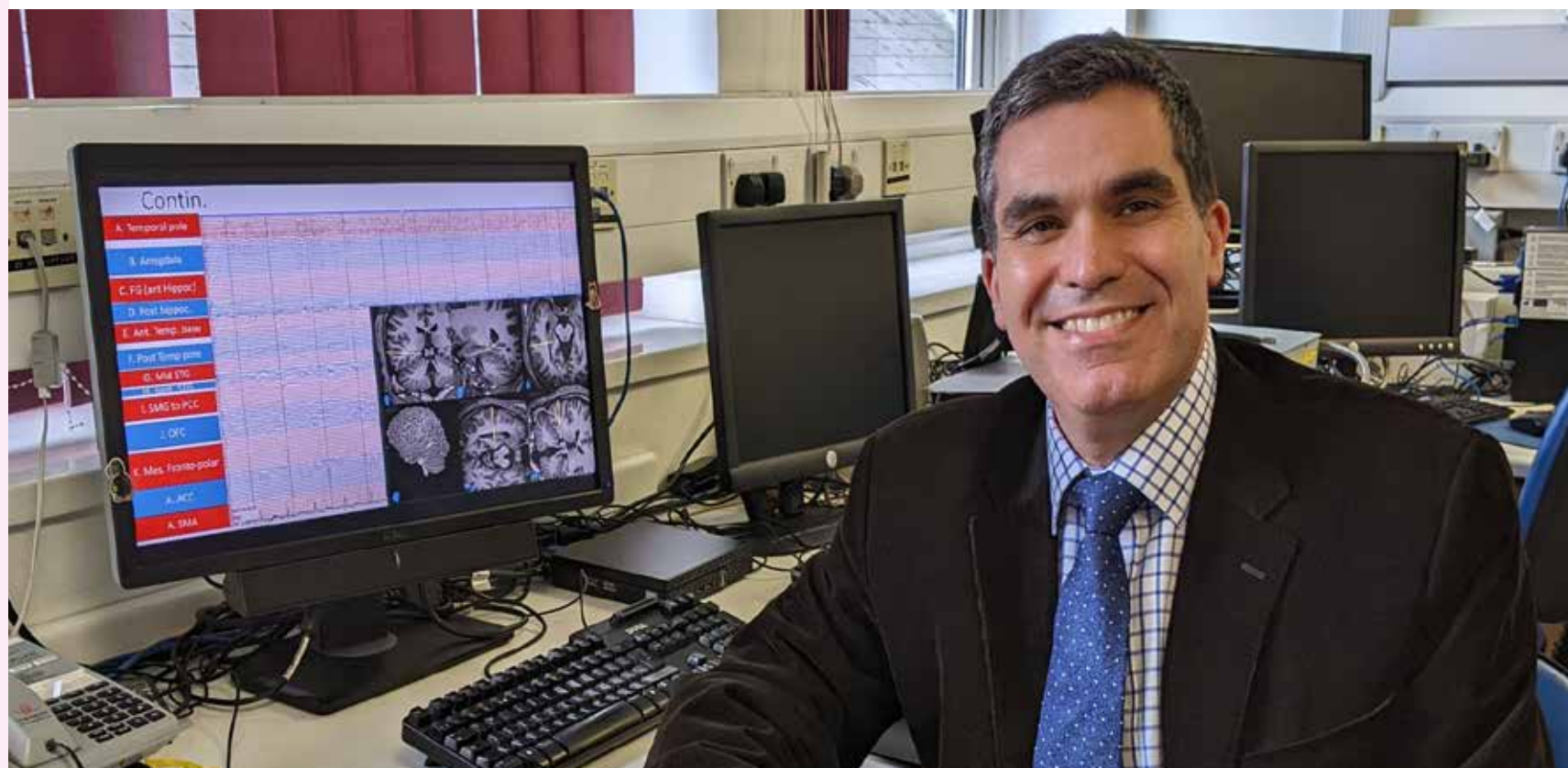


children with epilepsy find their condition cannot be controlled with drugs

The technique, called sub-acute cortical stimulation, is less invasive than surgical treatments, meaning it is safer and may also be used in situations where surgery is not possible.

Already 16 children have benefited from the new technique, reducing their seizures and improving their quality of life.

This research was jointly funded with Great Ormond Street Hospital Children's Charity.







## PROGRESS MADE FOR CHILDREN BORN TOO SOON

**Babies born extremely prematurely may be more susceptible to anxiety in later life. With your support, researchers have used brain scans to better understand which babies are most at risk.**

Babies born before 32 weeks of pregnancy are thought to be nearly twice as likely to have

problems with anxiety during their teenage years.

With funding from Action and Dangoor Education, Professor Chiara Nosarti and her team at King's College London have been working to develop a way to identify which children are most likely to be affected.

Their findings showed that early changes in babies' brains can be used to predict how they may regulate their emotions later in life.

This could allow the most vulnerable to be identified and to receive targeted therapies or treatments to protect their mental health as they grow up.

## OUR LATEST RESEARCH



### INFECTION

#### HELPING CHILDREN WITH LONG COVID

Some children experience ongoing symptoms long after an initial COVID-19 infection. These can include breathlessness, anxiety or low mood, tiredness, headache and finding it hard to concentrate.

Two new projects aim to improve understanding of long COVID in children and develop ways to help.

One is using brain scans to see if affected children have, or may have had, mild inflammation in the brain. Another is developing a new, online treatment programme to address breathing and mental health difficulties.



### CHRONIC DISEASES

#### TREATING COLITIS AND CROHN'S

Inflammatory bowel disease, like Crohn's and ulcerative colitis, causes debilitating symptoms, including pain, diarrhoea and tiredness.

With Action funding, researchers aim to develop a simple new blood test that can improve diagnosis and help doctors select the best treatment for each child. The goal is to help deliver precision medicine, improving long-term outcomes and quality of life.



### RARE CONDITIONS

#### FIGHTING A RARE TYPE OF EPILEPSY

Your support is also helping a research team who are striving to identify chemical compounds that could form the basis of urgently needed new treatments for children with *KCNT1*-related epilepsies.

A new drug to control seizures and prevent brain damage could transform the lives of children with these very severe conditions.



**Read more about research funded with your support at [action.org.uk/research](https://action.org.uk/research)**





# A SPECIAL REASON TO RACE THE SUN

**Each summer, intrepid teams bike, hike and canoe in our triple challenge events. For Chloe Reeves, taking part was a way to help others after the tragic loss of her daughter.**

When Chloe first saw an advert for Race the Sun, she wasn't aware of what Action did. "But as I read more, it brought back memories of the life we'd had with Ysella," she says. "That's what really

spurred me on to do it. To help families going through similar things."

Ysella was just six years old when she died, having suffered a rare condition that was never diagnosed.

"We lived in constant hope but after so many tests, and seeing so many different doctors, still nobody could tell us what was wrong. That was really hard," explains Chloe.

"By the age of four, her bedroom was like a hospital. But she was the most amazing girl with a very infectious smile. She knew her mind and could tell us what she wanted with her eyes."

As Team Ysella's Robins, Chloe and her sisters Jane, Hetty and Charlotte took part in our Race the Sun Coniston event, set in the Lake District.

"The challenge was incredible and beautiful," says Chloe. "We enjoyed every moment. Having Ysella in our minds pushed us all the way. We were exhausted at the end but felt so proud and fulfilled. It was the best experience."



**Scan the QR code to find out more about our Race The Sun events or visit [action.org.uk/coniston](https://action.org.uk/coniston)**

## FUNDRAISING NEWS



## GET ON YOUR BIKE

Our RIDE series has something for everyone, from new cyclists to seasoned sportive riders. Routes range from 21 to 124 miles, both on-road and off-road, across six different events all set in stunning locations.

Find out more and sign up at [action.org.uk/RIDE](https://action.org.uk/RIDE)



## SHOP AND SUPPORT

One of the easiest ways to support us is through online shopping schemes, AmazonSmile and Give As You Live. Both make donations to Action when you shop, at no extra cost to you.

Find out how to sign up at [action.org.uk/shopping](https://action.org.uk/shopping)





## CYCLESPORT DINNER RAISES £230,000

Some of the biggest names on two wheels joined us for the return of our Champions of CycleSport gala dinner. Sponsored by Garmin and supported by BDO, guests included Yanto Barker, Alex Dowsett and Dani Rowe MBE (pictured). This year's date is 24 Nov. See [action.org.uk/champs](http://action.org.uk/champs)

## LENLEASE DONATION

We were delighted to be a beneficiary of The Guvnor's Ball, held in December. The prestigious event is run by property and construction company Lendlease. They kindly added £10,000 to the Elijah's Star team's fundraising.

## BUSINESS ON BIKES

Corporate bike rides are a key part of our cycling calendar. These include Raptör, our insurance industry event, sponsored by BRIT. Plus Ziggurat for the construction industry, which is now in its fifth year and raised more than £140,000 in 2021.

### SUPPORTER STORY

## RUN FOR BABIES BORN TOO SOON

Born three months prematurely, twins Winnie and Teddi spent 67 days in neonatal care. As their babies fought multiple complications, parents Megan and Dan feared the worst many times.

Thankfully Winnie and Teddi overcame the many challenges they faced, and to celebrate their first birthdays, Megan and Dan took on a 67-day challenge and raised more than £2,600 for Action. The couple ran 6.7km every day, for 67 days, in the countdown to the twins' special day.

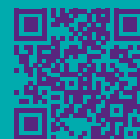
"It took our babies 67 days to come home – we want to help prevent this from happening to other families in the future," says Megan.



## EXCITING NEW PRIZES!

Our FIGHT BACK Friday Lottery has had a prize makeover. There are now more chances to win a prize each week, with a **top prize of £500 and 30 runner-up prizes of £5 up for grabs.**

And that's not all – our Rollover prize will now increase by £150 each week that it hasn't been won until it reaches an incredible £10,000!



There's never been a better time to play!  
Scan the QR code or visit [action.org.uk/lottery](http://action.org.uk/lottery)



### WORD SEARCH

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

X	I	S	J	Y	A	V	K	Z	B	G	E	I	Y	Z	X
F	G	B	N	N	A	V	F	F	P	X	J	D	Z	R	J
E	J	U	S	H	P	Q	H	U	P	Q	S	R	N	G	A
G	S	E	Q	P	O	M	X	Z	K	W	A	Z	N	Z	C
N	O	Y	G	E	P	R	Y	S	P	E	L	I	P	E	K
E	M	D	E	N	H	H	C	R	A	E	S	E	R	U	P
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- Seventy
- Polio
- Rare
- Finley
- Heart
- Davina
- Breakthroughs
- Research
- Epilepsy
- Premature
- Crohns
- Cycling
- Fundraising
- Lottery
- Challenge
- Jackpot

Please send your answer to [editor@action.org.uk](mailto:editor@action.org.uk). Entrants must be 16 years or over. Terms and conditions apply, for details visit [action.org.uk/wordsearch](http://action.org.uk/wordsearch)



# 70th Anniversary Superdraw!



17 June 2022

**WIN £500 and a luxury hamper to celebrate 70 years of amazing research**



Only  
**£1**  
a chance!

**Other prizes include:**

- ★ 70 runner up prizes of £5
- ★ Up to £6,000 in our Rollover Jackpot\*



**Win big and help save little lives – Play today!**  
**[action.org.uk/superdraw](http://action.org.uk/superdraw)**



**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.

Terms & Conditions apply please see [action.org.uk/superdraw](http://action.org.uk/superdraw) for details.

**Quick reply draw!**

Hurry! Reply within 14 days for a chance to win a SMEG hand blender worth £149.99.



\*In our Rollover Jackpot you have the chance of winning a maximum of £6,100 and minimum £150