



# TOUCHING LIVES

## HOW YOUR SUPPORT IS MAKING A DIFFERENCE

Improving cancer treatment for children like Evan

Developing new techniques to transform facial surgery

Making discoveries to help children with Crohn's disease

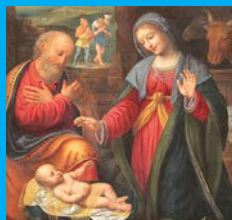
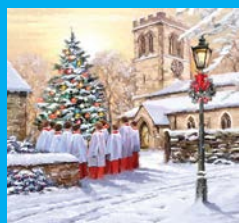
# CHARITY CHRISTMAS CARDS

Christmas will be here before you know it and it's never too early to order this year's cards.

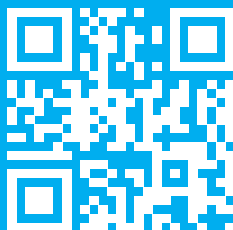
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**70%**  
from each pack will  
help fund vital  
research for  
children

**£4.95**  
a pack



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cards today



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life changed forever"**

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**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](mailto:cairey@action.org.uk)  
or Touching Lives

Action Medical Research  
5th Floor  
167-169 Great Portland Street  
London W1W 5PF

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

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Cover photo: Ben Rector

Drawing page 9 VoodooDot / photo  
page 17 Cari Griffith / Shutterstock



## WELCOME

As we head into autumn, it's a pleasure to share with you some of the exciting research and fantastic fundraising that's been happening – all made possible thanks to your support. Whether you have recently discovered Action or have been fundraising for us for many years, your support is helping to make a difference for children and their families, as you'll see in these pages.

Especially evident throughout this issue is the positive impact of our Research Training Fellowship scheme, which you can read about on page 4. This is the 50th year of the scheme, which supports talented doctors and scientists early on in their research careers. On pages 14-15 you can see how one recent Fellow has made important discoveries that are already helping children with Crohn's disease.

And looking ahead to the festive season, our charity Christmas cards and Christmas Superdraw are great opportunities to further support Action – and be in with the chance of winning some great prizes too.

Thanks for your support.



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



**13**

new research projects  
funded this year



**£300**

can fund a pioneering  
project for a day





## CELEBRATING 50 YEARS OF VITAL RESEARCH TRAINING

Launched back in 1973, our Research Training Fellowship scheme supports some of the most promising doctors and scientists early in their research careers.

Our Research Training Fellows carry out a key piece of research in their chosen area and undertake training to develop their expertise.

We've funded 186 Fellowships to date, including two new ones this year – one aims to develop new tests to help pre-school children with recurrent wheezing and the other to develop personalised treatment for children with rare inherited heart conditions, reducing the risk of sudden cardiac arrest.

Dr T'ng Chang Kwok, pictured, received his Action support in 2022 and is now carrying out research to improve care for premature babies.

You can read about the work of another current Fellow on page 7 and about discoveries made by Dr James Ashton, who recently completed his Fellowship, on page 14.

### RESEARCH UPDATE

## PREVENTING PREMATURE BIRTH

With your support, we've funded two new premature birth research projects in partnership with Borne.

Evidence suggests that bacteria passing into the womb can increase the risk of early labour. So one team of researchers is aiming to develop a therapy to boost the body's natural defences in women known to be at high risk of giving birth too soon.

Another is investigating a surgical procedure that could reduce the risk of premature birth after a previous emergency caesarean section.



### NEWS

## FIGHTING RARE DISEASES IN CHILDREN

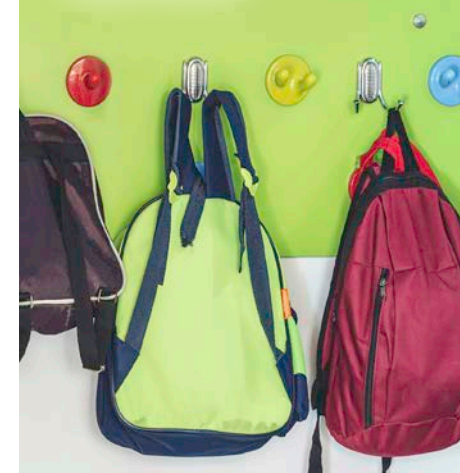
Through our rare disease research campaign, we continue to raise awareness and funds to support research into conditions that cause so much suffering for children and their families. Thanks to supporters we have now raised almost £200,000, but so much more needs to be done.

As schools return this month, we think of the 30% of children with a rare disease who sadly lose their lives before their fifth birthday – and of families who never get to experience the milestone of starting school.

With your help we can develop treatments and cures to tackle rare diseases. Medical research gives hope to families facing the heartbreak caused by rare diseases.

**NEVER**  
got to...

...make their first  
day at school



**With your help, we will NEVER give up**

Donate now at  
[action.org.uk/fight](https://action.org.uk/fight)

# FIGHTING BRAIN CANCER

**Six-year-old Evan was diagnosed with brain cancer when he was just over a year old. He received treatment but later relapsed. Thankfully, he now has the all clear but sadly he's living with complex complications as a result of the tumour and the treatments he had.**

Evan was just 15 months old when his mum, Lindsey, noticed that he had stopped reaching milestones. "He was having issues with his balance," she recalls. "He had been about to pull himself up comfortably, but he stopped doing that. He wasn't able to hold himself up and needed help."

Lindsey and her partner Scott spoke to doctors about their concerns and were referred to a paediatrician. Evan was assessed at their local hospital – and Lindsey hadn't even left the hospital car park when she received a call telling

her she needed to take Evan straight to another hospital for an urgent scan.

Within hours the family had received the terrifying, life-changing news that Evan had a large growth in his brain.

They were told to go home and get everything they needed as Evan needed surgery to remove a tumour.

## **"When Evan became unwell, life changed forever"**

Evan had medulloblastoma, a type of childhood brain cancer that can be very difficult to treat. Around 52 children are diagnosed with these tumours each year in the UK. They are often aggressive and spread into surrounding tissue, making it difficult

to completely remove them surgically. They are also often highly resistant to chemotherapy and radiotherapy.

Sadly, 10 months after finishing his initial treatment, Evan's cancer returned. Once again, the family had to go through the rollercoaster of scans and treatment, which had a gruelling effect on Evan, who was still just a toddler.

This time, Evan received proton beam therapy, an advanced form of radiotherapy, on his head and spine.

Three years on, Evan is doing well. He has annual scans and is thankfully tumour-free. But because he was so young when he became unwell and needed such intense treatment, he has experienced complex complications and delays in his development.



## **Developing kinder cancer treatments**

With your support, researchers are developing a new, cutting-edge immunotherapy treatment for children with medulloblastoma or high-grade glioma brain tumours. They hope this will have fewer side effects and save more lives.

Led by Professor John Anderson and his team at the UCL Great Ormond Street Institute of Child Health, this work harnesses the power of the immune system to kill cancer cells, an approach that is already proving effective at treating some other types of cancer.

*This project is co-funded with LifeArc, with support from Help Harry Help Others Cure.*

**"There is urgent need for gentler, more effective treatments that can offer hope to children and their families"**



*Evan receiving treatment in hospital*





**"If a kinder type of treatment had been around six years ago, Evan's outlook may have been different"**

*Evan's mum, Lindsey*

Evan has hearing loss, issues with mobility and learning, and a condition that affects his sight. He has recently started walking, and can cruise around furniture, but still needs support.

"We've been told that the older Evan gets, the wider the development gap will get between him and his peers," says Lindsey. "But generally, he is a very happy little boy – he loves books, playing with his toys, swimming, going out for walks and feeding the ducks."

Evan goes to a special school where he gets additional help, tailored to his needs. He takes a daily growth hormone due to his pituitary gland being affected by radiotherapy. He also has support from various specialists, including a speech and language therapist and a physiotherapist.

Speaking about the prospect of new treatments, Lindsey is hopeful: "Many of the treatments and drugs Evan received were for adults and not designed for small children. If a kinder type of treatment had been around six years ago, we'll never know if Evan's outlook may have been different," she says.

"Understanding of medulloblastoma in children has come a long way, even during Evan's lifetime. Learning about new developments is bittersweet – we know it won't be in time for our boy, but it is promising for any other family facing what we faced."

**THANK YOU!**

**Together, we can fight rare diseases.**

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



# TRANSFORMING FACIAL SURGERY FOR CHILDREN

Living with a facial disfigurement can be especially difficult for children as they grow up. Action Research Training Fellow Mrs Cynthia de Courcey is working on an approach that aims to transform reconstructive surgery in the future.

Children can be affected by facial disfigurements if they are born with missing or malformed features, or because they have suffered injury, burns or cancer. Sadly, they often experience long-term emotional and/or physical problems as a result.



*Cynthia de Courcey*

## IN NUMBERS

**OVER HALF A MILLION** people in the UK are living with a facial disfigurement



While surgery is an option, it often involves taking tissue from other parts of the body. This can be painful and carries high risks of infection or rejection.

Mrs Cynthia de Courcey, pictured, is a plastic surgery trainee and a recipient of one of our Research Training Fellowship grants.

These awards help young doctors and scientists to develop their careers in research.

At Swansea University, she is part of a team developing 3D-bio-printing technology.

This would allow surgeons to create precise, patient-specific implants, loaded with a child's own cells. This would help overcome many of the challenges that are associated with current procedures.

Mrs de Courcey's work aims to establish if the

biomaterial is likely to be well-accepted by the body, and to refine its properties to maximise the chance of success.

**"This would revolutionise surgery for children"**

"There is a need for safer, better alternatives for corrective surgery for children who are affected by facial differences," she says.

*This Research Training Fellowship is supported by the VTCT Foundation.*

# WHY I SUPPORT ACTION

Since 1983, Jane has supported Action as a volunteer fundraiser with the East Coker Committee in Somerset



JANE DONNELLY

**Q** You've supported Action for an amazing 40 years. Can you tell us how you first got involved?

**A** It was by accident really! A group of mums from a local toddler group had set up a fundraising group for Action. This was before I even had my own children! Their first event was a coffee morning, and I was asked if I could help. It went from there. I helped out a few more times and was asked to join the committee. By 1986 I'd become the chair and then a regional chair. I had no idea I'd still be fundraising 40 years later!

**“** I had no idea I'd still be fundraising 40 years later **”**

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

**A** There can't be too many things we haven't done! We used to do sponsored walks, coffee mornings, barn dances, a lot of balls, then craft fairs. We've kept scrapbooks of all the things we've done over the years, so we're able to look back. We've learnt what works and what doesn't, and we've always been able to adapt. The main focus now is our summer Cream Teas and autumn Diva Lunch events.

**Q** Your committee was one of the first to do Action Cream Teas deliveries, which have gone on to be very popular. Can you tell us a bit more about that?

**A** We did our first event in 2005. It just seemed a good idea and it took off straight away. We thought we'd take 100 orders that year but had to stop at 300! People say it's so nice to support a charity and get something back. They look forward to it each summer. This June we delivered 740 teas – we have it down to a fine art now! Over the years, we've raised around £85,000 through cream teas alone.

**Q** You've experienced some of the conditions Action has funded research into. Can you tell us a bit about this?

**A** Both of my sons had to be delivered early due to pre-eclampsia – and with Joe, my eldest, I was dangerously ill. I was in intensive care for a week and very lucky to survive. Then my second son, James, had bronchiolitis when he was a baby. He was six months old and became very, very poorly. It was a really nasty infection, and he spent a week in



» The East Coker Committee's first Cream Teas back in 2005

**“** When our grandson George was born with a very rare heart condition, I thought I can't stop fundraising now **”**



» Baby George



hospital. And now our grandson George has spent almost the whole of the first year of his life in hospital due to a very rare heart condition. He's had four open heart surgeries and only recently came home. It does bring it home to you, why we're fundraising and so much research only happens because of charities.

**Q** What does supporting Action mean to you now?

**A** When I got to 40 years supporting the charity, I started to think maybe it was time to retire. But then George was born and was so unwell and I thought, no I can't stop now. The doctors and nurses caring for him have been amazing. If he'd been born 10 years ago, he wouldn't have made it.



# CYSTIC FIBROSIS INFECTION BREAKTHROUGH

With your support, researchers have made a significant breakthrough that could pave the way for new treatments to fight infections caused by the bacterium *Pseudomonas aeruginosa*. This is a major threat to children with cystic fibrosis.

Led by Dr Tanmay Bharat, the team has made important discoveries about how this bacterium is able to create a biological 'suit of armour', preventing antibiotics from killing it. This could lead to future drugs which target and defeat this protective shield.

New treatments would help children like five-year-old Sophia (pictured). She takes a daily cocktail of drugs, in addition to daily physiotherapy to loosen the mucus from her lungs, where the bacteria harbour.

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**“This could open the door for new treatments, helping children with cystic fibrosis overcome serious and potentially fatal infections”**

---

Dr Tanmay Bharat

*This research was jointly funded with the Cystic Fibrosis Trust.*





# HELPING CHILDREN WITH CROHN'S DISEASE



**Crohn's disease is the most common form of inflammatory bowel disease in children. With your support, Action Research Training Fellow Dr James Ashton has made new discoveries which are helping improve diagnosis and care for children.**

Crohn's disease causes debilitating bouts of abdominal pain, diarrhoea, and tiredness. It can have a serious impact on children's lives – affecting their growth, self-esteem, school work and social lives.

Around one in four people with Crohn's are diagnosed before the age of 18 and the numbers of young people, between the ages of 10 and 16, are increasing significantly.

While the condition is common, more research was urgently needed to better understand the triggers of the disease, especially in children.

In 2017, we awarded a Research Training Fellowship to Dr James Ashton, based at the University of Southampton and Southampton General Hospital.

Dr Ashton analysed how young patients' genes, immune system and gut bacteria all interacted together.

**“We are now building a clinical tool to predict children's risks of serious complications”**

Dr James Ashton

Using the latest gene sequencing techniques, Dr Ashton and his team identified specific genetic changes in some children. Most importantly, some of these changes were linked to an increased risk of more severe illness or serious complications.

One gene was shown to be linked to a higher risk of 'strictures', where parts of the intestines become narrowed. As a result, the team are now developing a test to identify children at risk who may need surgery.

Dr Ashton also found a specific pattern of gene activity that is linked to a higher risk of flare-ups. This could be used to identify children who need to be given more aggressive treatment, sooner.

## IN NUMBERS

MORE THAN

**500,000**

people in the UK have IBD\*



*\*Inflammatory bowel disease (the most common type in children is Crohn's disease).*

Last year, a new clinic was set up where doctors are using this new genetic information to benefit patients. Currently around 100 children a year are benefiting from the new testing. This is likely to increase as it is more widely adopted across the UK.

“Our findings are helping in the diagnosis and treatment of more children with Crohn's disease and will enable doctors to use genetic information to personalise care for each patient,” says Dr Ashton.

*With thanks to Liberty Specialty Markets and others for their support of this work.*

## THANK YOU!

**“Huge thanks to people who donate. Without you, it would not have been possible to have done this”**

**Dr James Ashton**

*pictured above*





**“This could help to optimise treatment for young people with a chronic, lifelong condition”**

Professor  
Margaret Hall-Craggs

## NEW SCANS TO HELP CHILDREN WITH ARTHRITIS

**Children and young people with juvenile idiopathic arthritis are set to benefit from improvements in their treatments and quality of life, thanks to successful research.**

Juvenile idiopathic arthritis causes inflammation in the joints, leading to pain, joint deformity and disability. The latest drug treatments can help but they are expensive and can also have serious side effects.

Supported by Action funding, Professor Margaret Hall-Craggs and her team at University College London have developed new techniques, using MRI scans, to precisely measure how much inflammation is present in young patients' joints. Treatments can then be adjusted, so that just the right amount is given.

The team has completed the largest ever study of whole-body imaging in young patients and shown that these scans

could alter treatment and management decisions in up to a third of cases.

They're now developing colour-coded pictures, which can be used to show whether a child's inflammation is getting better or worse.

Professor Hall-Craggs says: “This could optimise treatment and improve quality of life for young people with a chronic, lifelong condition.”

*The Albert Gubay Charitable Foundation helped to support this research.*

## OUR LATEST RESEARCH



### INFECTION

#### DEVELOPING A TEST TO PROTECT BABIES

Cytomegalovirus, or CMV, is a common and usually harmless virus. But it can cause lifelong problems for babies whose mothers pass it on to them during pregnancy, including sight or hearing loss.

Early detection and prompt treatment helps to improve outcomes. But there is currently no routine screening for newborn babies in the UK – partly because of the lack of a suitable diagnostic device.

With your support, Professor Vincent Teng and his team at Swansea University want to change this. They are developing a new, low-cost, highly-sensitive device that could give rapid results, enabling timely treatment to help more babies.



### DISABLING CONDITIONS

#### SCANS TO HELP TREAT SEVERE EPILEPSY

Many children who have severe drug-resistant epilepsy have abnormal areas of brain tissue known as focal cortical dysplasia.

Surgery can offer a cure but only if the affected tissue can be detected. Researchers are testing a new type of advanced brain scan which could give the possibility of life-changing treatment to more children.



### RARE DISEASES

#### IMPROVING DIAGNOSIS

Thousands of babies are diagnosed with rare developmental disorders each year in the UK, often caused by changes in their genes.

Your support is funding research that could help doctors to interpret genetic tests more accurately. This work is initially focusing on three disorders but could ultimately lead to earlier diagnosis and improved treatment for children with a wide range of genetic conditions.

*This research is jointly funded with LifeArc.*



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

# JOIN US TO RACE THE SUN IN 2024



"We had the best time ever.  
Not only was it for an amazing  
cause, but we had lots of fun  
doing it"

2022 Race the Sun finisher

**Our triathlon-style Race the Sun challenges pit teams against each other to bike, hike and paddle around some of the UK's most beautiful National Parks – while raising vital funds for life-changing research.**

Our Race the Sun events have gone from strength to strength in recent years, proving so popular that we're adding new dates for 2024.

There will be six events to choose from next year, including the return of those in Bannau Brycheiniog (Brecon Beacons) and the Lake District. Plus two brand new locations – on the Jurassic Coast in Dorset and Yr Wyddfa (Snowdon) in Wales.

Race the Sun Jurassic Coast will feature exciting off-road, mixed-terrain cycling,

past the iconic white chalk stacks of Old Harry Rocks, whilst the canoe section sees paddlers take to the open sea.

The Yr Wyddfa (Snowdon) event features a stunning circular road ride from Llanberis to the coast, as well as summiting Wales's highest mountain, standing at 1,085m, via the Llanberis path.

Also new for 2024 is the inclusion of two-person teams, successfully introduced this summer. So you can take part either as a four or a duo.

Whether you want the challenge of setting a fast time, or just an exhilarating adventure for a great cause, Race the Sun is a fundraising challenge not to be missed!



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

## EVENTS DIARY 2024

### RUNNING

**21 April** TCS London Marathon

### CYCLING

**14 April** RIDE Wessex Downs

**5 May** RIDE Castle, Kent

**19 May** RIDE Suffolk Sunrise

**26 May** RideLondon-Essex 100

**2 June** Davina's Big Sussex Bike RIDE

**13 to 16 June** London - Paris

**16 June** London to Brighton

**30 June** Maratona dles Dolomites

**Date tbc** RIDE Vyking

### RACE THE SUN

**27 April** Yr Wyddfa (Snowdon)

**15 June** Bannau Brycheiniog  
(Brecon Beacons)

**29 June** Jurassic Coast Off-Road

**12 July** Lake District Coniston  
Off-Road

**7 Sept** Lake District Keswick

**8 Sept** Lake District Keswick  
Off-Road

We have events to suit all and  
would love you to join us!  
Visit [action.org.uk/events](https://action.org.uk/events)





## BRILLIANT BGC DAY

For the past seven years, we've been a beneficiary of the BGC Charity Day, held annually to remember those who were tragically killed in the Twin Towers attack of September 11, 2001. This has raised close to £300,000 for Action, including £40,000 raised at last year's event, attended by our celebrity ambassador Davina McCall and the Mitchell family (pictured).

### SUPPORTER STORY

## RUNNING FOR RARE DISEASES

A huge thank you to the 46 runners who joined Team Action for the mighty TCS London Marathon this year.

Among them was Amy Durbin, pictured, who was inspired by our research to help children with rare diseases. Amy sadly lost her younger brother to spinal muscular atrophy. Action has funded research to develop enhanced treatments for children with this rare muscle-wasting disease.

Amy said: "Running the marathon for Action was one of the best things I have ever done! I've never felt a sense of achievement like it."

To find out more about running for Action visit [action.org.uk/running](http://action.org.uk/running)

## ACTIVE FOR ACTION

**Airport Parking & Hotels** continue to do amazing things for Action and are again encouraging staff to get involved in their Strava Challenge. For every mile of physical activity recorded on the fitness app, the company donates £1. This has already generated £6,000 so far this year, bringing their total raised since 2018 to over £85,000!

## NEXT LEVEL SUPPORT

We're very grateful to **Next** for their ongoing support. For the past 15 years, the company has donated between £10,000 and £15,000 annually. Their support is often centred around our social events so they also provide wonderful gifts for us to use at these.



### FUNDRAISING NEWS

## PETERBOROUGH PLAY FOR ACTION

Brilliant at spotting opportunities, our Peterborough Committee of fundraisers nominated Action to benefit from a Selebrity Soccer match held at Peterborough United's home ground in May. Musician and *X-Factor* winner James Arthur, TV's *Danny Dyer* and former *Eastenders* actor Ricky Groves were among the famous faces who played. Always busy, as we went to press the Committee were getting ready to



tee off for their Tony Hadley Golf Classic for the charity.



## A CYCLING CELEBRATION

Our last Champions of CycleSport Dinner raised £267,000 to help save and change children's lives. So we can't wait to do it all again this November! We'll be joined again by a host of cycling superstars and are supported by fantastic sponsors Garmin, BDO and Rouleur, with new partner Lifeplus. Find out more at [action.org.uk/champs](http://action.org.uk/champs)

## ULSTER WARRIOR

Adventurer and endurance athlete, Linda Blakely is embarking on a record-breaking attempt to row solo across the Atlantic Ocean and raise vital funds and awareness for our children's rare disease research.

Linda, who is from Northern Ireland, sets sail in January in the aptly named *Ulster Warrior*. She has been inspired by three-year-old Piper, the daughter of one of her employees, who has a rare form of epilepsy.



## SUPERDRAW WINNER

Steve from Cornwall was our lucky Spring Superdraw winner of £500 and a luxury hamper worth £100.

Already playing the lottery, Steve purchased extra chances for the Superdraw and it certainly paid off!

"I support Action in the hope that children all over the world get the chance to have any treatment they would need. I'm over the moon with my winnings!"



There's another chance to WIN £500 and a luxury hamper in our Christmas Superdraw, which takes place 10 November, just in time for Christmas. Buy your chances now [action.org.uk/superdraw](http://action.org.uk/superdraw)



## 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.

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

1. Evan
2. Treatment
3. Surgery
4. Transform
5. Cystic fibrosis
6. Arthritis
7. Infection
8. Genetic
9. Cure
10. Race the Sun
11. Marathon
12. Prize

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)

# Christmas Superdraw

Draw date: 10 November 2023

Only  
**£1**  
a chance!



Hamper worth  
**£100**

WIN  
up to  
**£10,000**  
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](http://action.org.uk/superdraw)



**Hurry! WIN a bottle of Bollinger and luxury chocolates worth £80**

Reply before 6 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.

**BeGambleAware.org**



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\*Information correct 23/08/23, for latest rollover amount visit [fightbackfridaylottery.org.uk/results](http://fightbackfridaylottery.org.uk/results).



# Write your will for free and change children's lives forever



Order your free guide today – scan this code with your phone camera or visit [action.org.uk/willguide](https://action.org.uk/willguide)

## Your legacy could be the next medical breakthrough for children

Paddy has KCNT-1 related epilepsy, a very rare and severe neurological condition. We are funding research to identify chemical compounds that could form the basis of much-needed new medicines to treat children.

**action** medical research  
for children

We are the leading  
UK children's medical  
research charity.

**FR** Registered with  
FUNDRAISING  
REGULATOR

A member of the:  
**amrc**  
ASSOCIATION OF MEDICAL RESEARCH CHARITIES