

How your support
is helping save and
change children's lives

Re:action

Spring/summer 2018



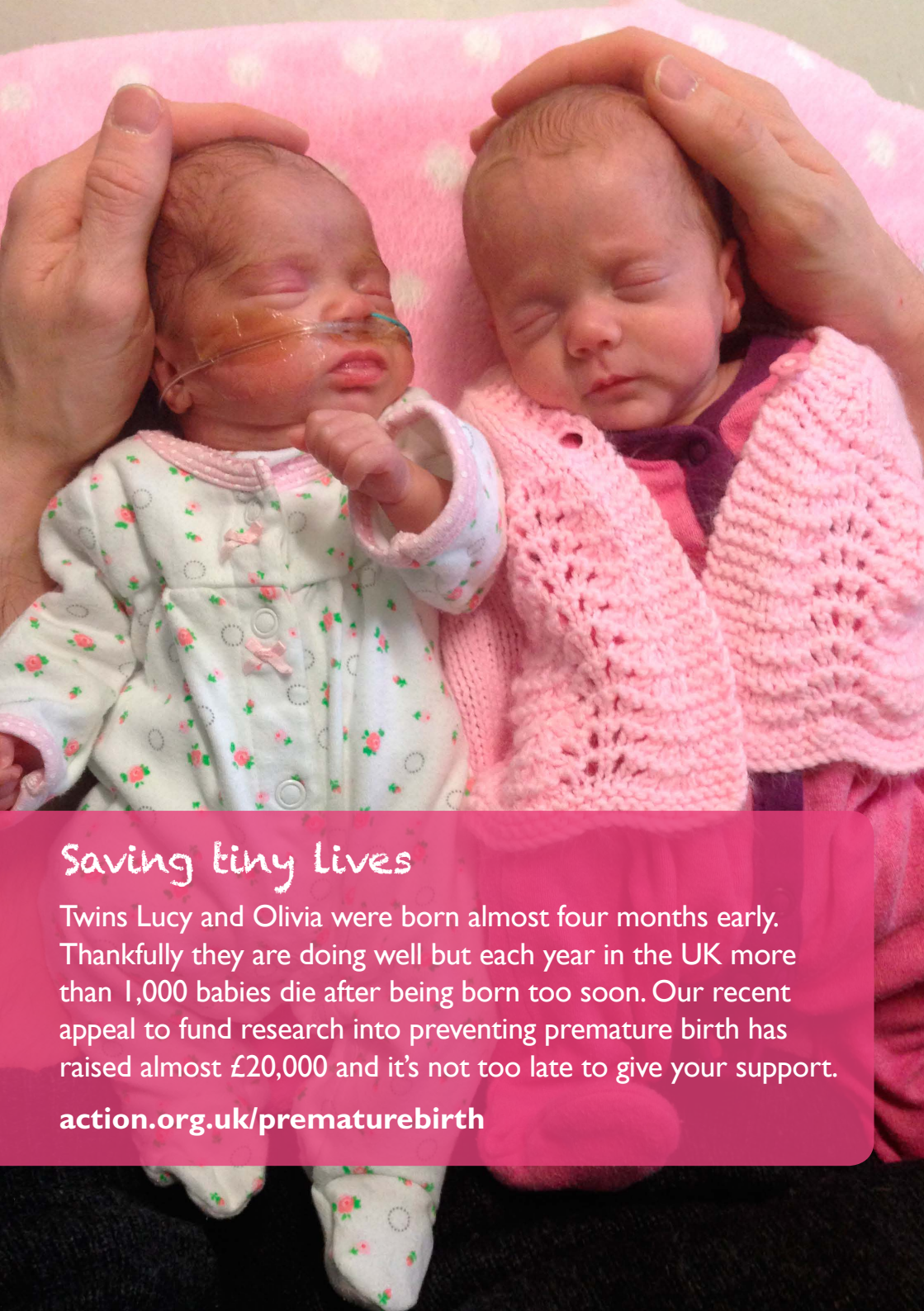
In your new *Re:action*

Fighting premature birth

Tackling neuroblastoma

Funding for the future

action medical research
for children



Saving tiny lives

Twins Lucy and Olivia were born almost four months early. Thankfully they are doing well but each year in the UK more than 1,000 babies die after being born too soon. Our recent appeal to fund research into preventing premature birth has raised almost £20,000 and it's not too late to give your support.

action.org.uk/prematurebirth

Welcome

Spring is here and it's time to enjoy your latest issue of *Re:action*. Find out more about new research we're funding with your help, as well as other ways you can get involved this year.

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Find out more!

With your support we're currently funding more than 65 groundbreaking research projects
action.org.uk/research

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BY SUPPORTING ACTION,



**HELPING TO TREAT SICK
AND VULNERABLE BABIES**



**HELPING TACKLE RARE
DISEASES IN CHILDREN**

Jack's story...

When Jack was born more than three months prematurely, his parents were told he had a fifty-fifty chance of surviving. His early arrival was a terrible shock. He was delivered by emergency caesarean section, weighing just 11lb 15oz.

Jack needed oxygen, help with his breathing and feeding tubes to survive. He suffered a collapsed lung and brain bleeds, and contracted the potentially deadly bowel infection necrotising enterocolitis (NEC).

Now four, Jack is doing well but has experienced some developmental delay. He has chronic lung disease, due to the oxygen needed in his early months, and there are concerns about his eyes. He may also have epilepsy.

His mum Jenny says: "Anything that helps identify why women go into labour too soon is vital. Without research, we wouldn't have medical advances, and Jack probably wouldn't be here today."

YOU ARE...



**HELPING CHILDREN
AFFECTED BY DISABILITY**



**HELPING TO PREVENT
CHILDHOOD INFECTIONS**

With your support...

Professor Donald Peebles and his team are looking at the role infection can play in causing premature birth. Evidence suggests that bacteria can sometimes pass into the womb and trigger inflammation. This can cause early labour and also damage the baby's developing brain. The researchers are developing and testing a new treatment that is designed to boost the body's natural defences against such infections.

Join our fight to stop premature birth
action.org.uk/fightback





Our film featuring a family affected by juvenile Batten disease was shortlisted for the 2018 Charity Film Awards. More than 40,000 people voted for films entered in the awards, which recognise the role charity films play in raising awareness and fundraising.

Our five-minute film showed the devastating impact of juvenile Batten disease on twins Corey and Toby, and little sister Izzy. Tragically, all three children have this rare condition, which causes a range of distressing symptoms. As the fatal disease progresses children lose their sight and become severely disabled. The film also highlights research Action is funding which hopes to develop the first ever treatment for the disease.

Our newest charity film features Lily who has BPAN, another devastating and life-shortening rare disease for which there is currently no cure. Lily and her family are an inspiration to us all and right now your support is funding potentially groundbreaking research that could in the future help children like Lily.

You can watch both films at
action.org.uk/videos



Lily with her dad

How your support has helped

Dr Joanna Cook has made important steps towards developing a blood test that could be used to identify women at high risk of giving birth too soon.

With Action funding, Dr Cook investigated the role of naturally occurring substances involved in controlling when labour starts. These can be detected in the blood and, importantly, their levels were found to be different in women who go on to develop cervical weakness – a known cause of premature birth.

If diagnosed early enough, cervical weakness can be treated and pregnancy prolonged. So a blood test used in early pregnancy would allow doctors to identify and help women who are at risk.

The results are now being tested further and, if successful, a blood test could be ready in around five years.



Dr Joanna Cook is one of our former Research Training Fellows.

Find out more about these special people on page 10.



Action Weekly Lottery

Congratulations to Petronella Keeling, founder member of our Spalding Committee of fundraisers, who won £500 in our Weekly Lottery.

She said: "After 50 years of supporting Action, I believe more than ever that the conditions the researchers aim to address are really worth fundraising for. Playing the lottery is a great way to help fund this vital research and win big prizes. I was delighted to learn of my win!"

Our Weekly Lottery is a fun and easy way to support us.

Enter at action.org.uk/weeklylottery



Fighting for children like Felix

Felix was four years old when he was diagnosed with neuroblastoma – a cancer that starts in the nerve cells and can spread rapidly. He endured two years of aggressive treatment but tragically lost his fight, aged just six. “Research is really important to help children like Felix fight this devastating disease in the future,” says his dad, Matthew.

With your support, we’re funding research to try and give children the best possible chance against neuroblastoma. Find out more [**action.org/cancer**](https://www.action.org/cancer)





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HEROES
DEDICATED TO SAVING CHILDREN'S LIVES

**MEET OUR RESEARCH
TRAINING FELLOWS...**

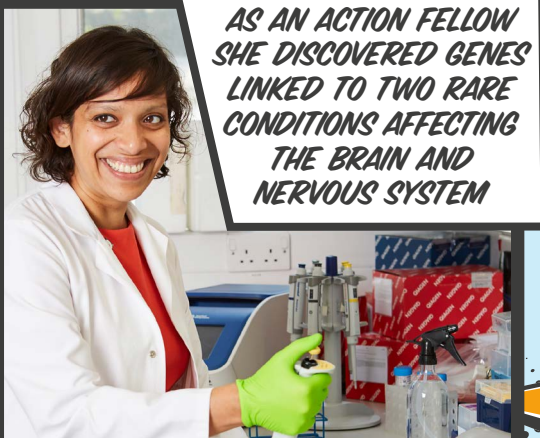


**THIS YEAR WE CELEBRATE 45 YEARS OF OUR RESEARCH
TRAINING FELLOWSHIP SCHEME. THIS SUPPORTS THE
MOST PROMISING DOCTORS AND RESEARCHERS.**

**DEVELOPING AND TRAINING
FUTURE LEADERS IN
CHILDREN'S RESEARCH...**



**...LIKE DR MANJU KURIAN,
A CONSULTANT PAEDIATRIC
NEUROLOGIST.**



**AS AN ACTION FELLOW
SHE DISCOVERED GENES
LINKED TO TWO RARE
CONDITIONS AFFECTING
THE BRAIN AND
NERVOUS SYSTEM**

**SHE NOW LEADS HER OWN RESEARCH
TEAM, INVESTIGATING MORE
DEVASTATING CHILDHOOD CONDITIONS.**

*TODAY, WITH YOUR SUPPORT,
MORE YOUNG RESEARCHERS
ARE HARD AT WORK...*

AND DR EMILIE SAUVAGE...



*...LIKE DR JAMES ASHTON,
WHO'S INVESTIGATING THE
CAUSES OF CROHN'S DISEASE...*



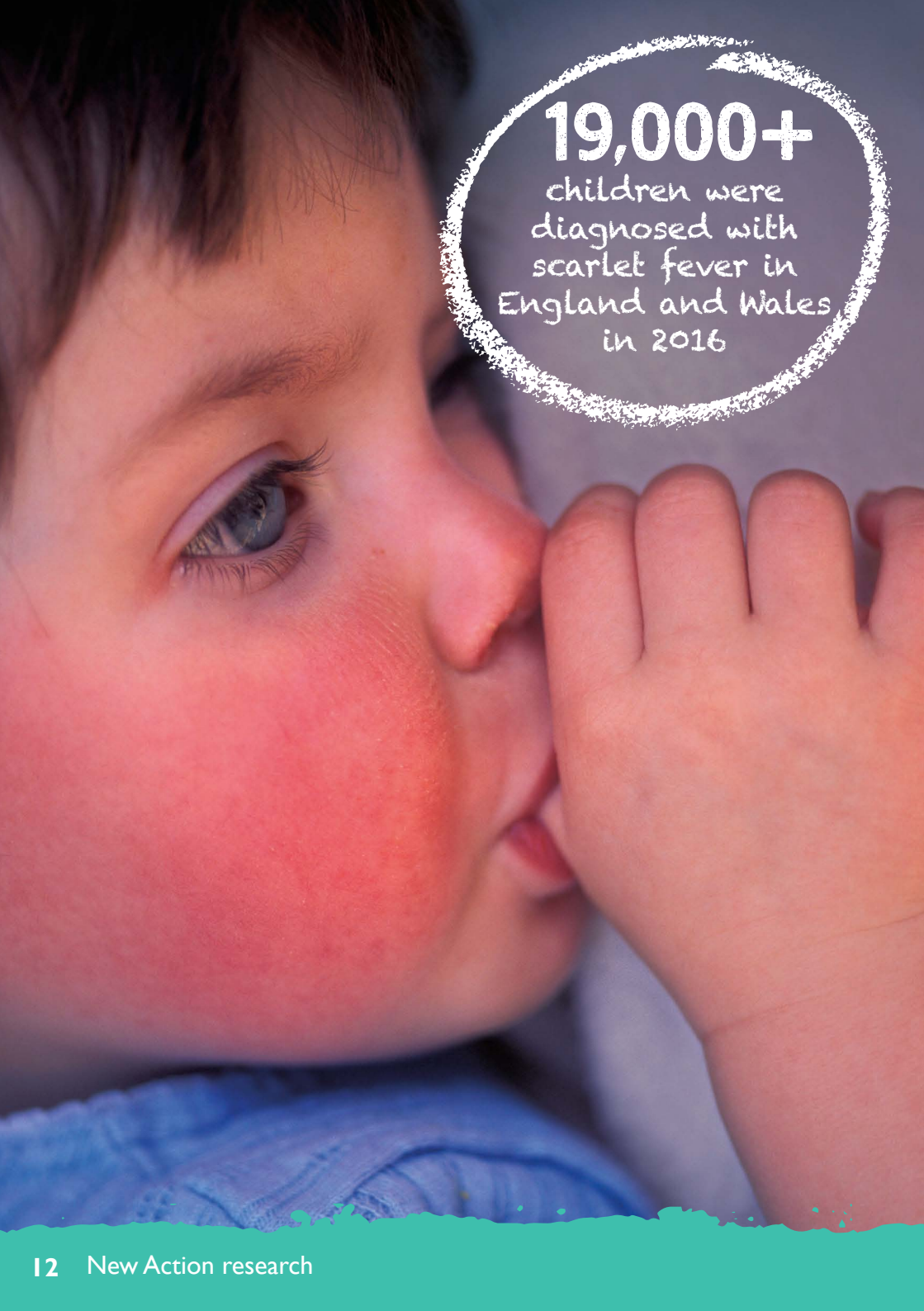
*...WHO'S DEDICATED TO
HELPING BABIES BORN WITH
SERIOUS HEART PROBLEMS.*

*WE'RE INCREDIBLY PROUD OF OUR FELLOWS. RIGHT NOW THEY
ARE SEARCHING FOR NEW TREATMENTS, IMPROVING CARE AND
WORKING FOR A BRIGHTER FUTURE FOR FAMILIES ACROSS THE UK.*



*THANK YOU
FOR SUPPORTING
FUTURE STARS OF
RESEARCH*

READ MORE AT [ACTION.ORG.UK/RESEARCH-TRAINING-FELLOWS](https://action.org.uk/research-training-fellows)

A close-up photograph of a young child's face, showing a prominent red, inflamed rash on the cheek and around the eye. The child has dark hair and is looking slightly to the side. Their hand is visible near their mouth. The background is a soft, out-of-focus grey.

19,000+
children were
diagnosed with
scarlet fever in
England and Wales
in 2016

Stopping scarlet fever

Scarlet fever has made a worrying comeback and the bacteria that cause the infection can sometimes trigger more dangerous illnesses. New research aims to reduce its spread.

After decades of decline, scarlet fever infections hit a 50-year high in England in 2016. Thanks to modern antibiotics, it's usually not serious – with symptoms, including a blotchy rash, sore throat and high temperature, usually clearing up within a week. But the strep A bacteria that cause it can have a darker side. In rare cases they can trigger life-threatening illnesses such as pneumonia, meningitis, toxic shock or sepsis.

Professor Shiranee Srisakandan, of Imperial College London, is leading research that will guide future public health strategy on scarlet fever. This includes finding out which antibiotics are most effective and whether current hygiene and treatment guidelines for schools and nurseries are enough to limit the spread.

“Given the current magnitude of scarlet fever outbreaks, it’s really important that we find out how we can control it better. We aim to build our understanding of how scarlet fever infects children and spreads so we can identify the best ways to slow down transmission in future outbreaks,” she says.



Photo: Thomas Angus, Imperial College London



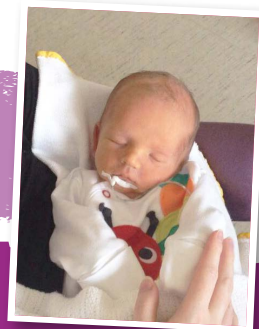
Fintan's Fund

The Heading family have raised almost £10,000 in memory of their baby son. Last year they set their sights high – persuading family and friends to join them on a 175-foot high zip wire over Belfast's River Lagan.

It was a huge shock for Annie and Paul Heading when their newborn son was whisked off to neonatal intensive care. Fintan was born in April 2015 – four weeks early but weighing a healthy 6lb 5oz. But sadly he wasn't very well. Doctors believed he had a rare genetic condition. Then things took a tragic turn for the worse. He developed necrotising enterocolitis. This devastating bowel infection typically strikes the most vulnerable babies – those who have been born very prematurely or, like Fintan, who are already poorly.

Determined to do something positive, Annie and Paul set up an Action Tribute Fund. "It means Fintan's memory can continue to light up the lives of people in the future, especially babies and children who are affected by sickness and illnesses around the UK," says Annie.

You can find out more about Tribute Funds at
action.org.uk/tribute-funds



Challenge events 2018



Running

Vitality London 10,000 28 May

Mud Monsters Run West Sussex, 3 June

Cycling Ride 100 series

Castle Ride 100 Kent, 13 May

Suffolk Sunrise 100 20 May

Davina's Big Sussex Bike Ride 10 June

Trossachs Ton Scotland, 17 June

York 100 19 August

Essex 100 2 September

Prudential RideLondon-Surrey 100 29 July

Team Challenges

Trek the Night Cotswold Way 9 to 10 June

Trek the Night South Downs 14 to 15 July

Race the Sun – canoe, climb and cycle:

– **Brecon Beacons** 23 June

– **Isle of Wight** 30 June

– **Lake District** 1 September

Mountain Challenges

Snowdon 9 June

Yorkshire 3 Peaks 17 June

Ben Nevis 8 September



Sign up today action.org.uk/events

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Weekly Lottery

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up to
£5,000

Rollover
Jackpot!

£500

winner every
week

only **£1**
a week to
play

Start playing today
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