

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

Re:action

Autumn/winter 2019

action medical research
for children

In your new *Re:action*

Helping children with cerebral palsy

Hope for tiny heart patients

Fundraisers fight premature birth



Welcome

One year on, we're delighted that our BORN TOO SOON campaign has raised an amazing £400,000. Find out how you can help us hit the £1 million mark – join in our 60,000 Reasons challenge. Or, for something less sporty, Go Purple this November! Thank you for all your support and we hope you enjoy this issue of *Re:action*.


In this edition...

- 3** Action update – BORN TOO SOON latest
- 4** Taking Action – Alice's story
- 6** Latest Action news
- 8** Action update – Fighting NEC appeal
- 10** Heroes in Action – Hope for the tiniest heart patients
- 12** New research – Helping critically ill children
- 14** Supporters in Action – Fighting premature birth
- 16** Action events – Fundraise for Action in 2020

Find out more!

With your support we're currently funding more than 60 groundbreaking research projects
action.org.uk/research

Follow us

 /actionmedres
 @actionmedres
 @actionmedres

Editor Clare Airey **Design** Action design team
Print Gemini Print **Cover photo** Ben Rector
Registered Office Vincent House, Horsham, West Sussex RH12 2DP
T 01403 210406 **E** info@action.org.uk **W** action.org.uk
© Action Medical Research 2019 Action Medical Research is a registered charity:
England and Wales no. 208701; Scotland no. SC039284



Fighting back against premature birth

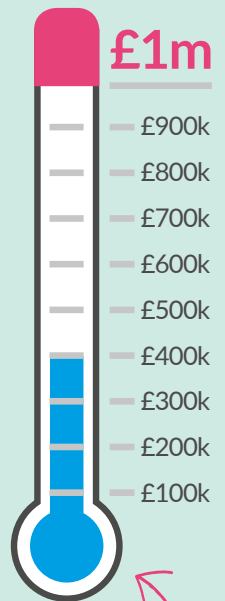
Last September we launched our BORN TOO SOON campaign, shining a spotlight on the devastation caused by premature birth. With around 60,000 babies born too soon each year in the UK, sadly premature birth is still taking lives.

Over the last year parents, families and communities have been fighting back. We're all working together to raise £1 million by the end of 2020 to fund vital medical research that could benefit millions.

We're pleased to say that already more than £400,000 has been raised as a result of the campaign!

There are so many different ways you can help us reach our target.

- Be inspired by some of our amazing fundraisers on pages 14-15.
- Join the fight and take part in our new 60,000 Reasons challenge, running from now until the end of November.
- Why not Go Purple for World Prematurity Day this November? See page 7.



Join the fight – See how you can help
action.org.uk/borntoosoon

£400k of our target raised so far!

BY SUPPORTING ACTION, YOU ARE...



**HELPING CHILDREN
AFFECTED BY DISABILITY**



**HELPING TO TREAT SICK
AND VULNERABLE BABIES**



**HELPING TACKLE RARE
DISEASES IN CHILDREN**



**HELPING TO PREVENT
CHILDHOOD INFECTIONS**

Alice's story...

When Alice was born two months prematurely, an early scan showed no signs of brain damage. But at her six-week check-up her parents, Jenny and Matthew, were given devastating news. Alice had cystic masses on her brain, a sign of severe and irreversible damage.

Alice was diagnosed with a condition called periventricular leukomalacia. Cerebral palsy is the most common symptom and sadly Alice's body, arms and legs are severely affected.

Cerebral palsy is the most common serious physical disability in children, affecting around 2,000 babies born in the UK every year. The specific cause is often unknown but babies born prematurely, or with a low birth weight, are known to be at increased risk.

"Alice is a bright and happy child but she gets so frustrated because she cannot walk, crawl or even sit up without help," says Jenny. "Anything that gives us more ways to help our children is really important."



With your support...

Action is funding a number of different research teams, all developing treatments and therapies to give children with cerebral palsy the best possible quality of life. These include a team developing a wrist-worn device and smartphone app to help children with hemiplegic cerebral palsy, affecting one side of the body. This aims to improve strength and movement in their affected hand and arm.

Another team is conducting a UK-wide study to ensure children with bilateral cerebral palsy, affecting both legs, receive the best possible treatment to correct muscle and bone deformities and help them walk.

Find out more [action.org.uk/cerebralpalsy](https://www.action.org.uk/cerebralpalsy)

Supporting premature children at school

We're delighted to have funded the development of new resources for teachers, to help them better understand and support children who were born too soon.

Children born early are at higher risk of experiencing learning difficulties or special educational needs as they grow up. But research had shown that many teachers are not aware of the issues these particular pupils may face – even though, on average, a typical school class is likely to have two or three children who were born too soon.

With Action funding Professor Samantha Johnson and colleagues from five universities have developed an interactive e-learning resource. It explains the impact preterm birth can have on a child's development and learning, and includes practical strategies that teachers can use to support them.

It is available now, free of charge, to schools and teachers across the world.

action.org.uk/e-learningresources



Make your celebration one to remember

Donating to charity in lieu of birthday or celebration gifts is becoming an increasingly popular way to support a favourite cause – after all, you can't beat the feeling of giving and how many boxes of chocolates do we all really need?

The funds you raise by asking for donations to Action will help provide a very special gift for thousands of children across the UK.

And as a present from us, we'll send you a pack of Action thank you cards!

Find out more action.org.uk/CelebrationGiving



£5,000 lottery winner

In July, for the first time, our FIGHT BACK Friday Lottery Rollover Jackpot reached £5,000!

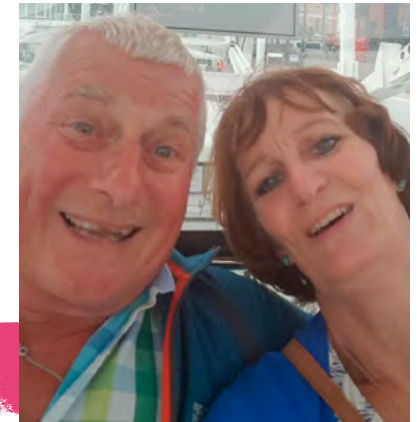
The lucky winner was Mr B from Poole, who has been playing two lines for just over a year.

Delighted with his win, Mr B explained:

"We signed up to the Action lottery as our two great-grandchildren had recently been born. Thankfully they're both fit and well but we know many others aren't so lucky. It is a fantastic cause to support."

If you're not already playing, it costs just £1 to play our FIGHT BACK Friday Lottery. There's a £500 winner every week and you could win up to £5,000 in our Rollover Jackpot!

Sign up today action.org.uk/lottery



This November, we're going purple!

Purple is the official colour of World Prematurity Day, a special day to raise awareness of premature birth on 17 November each year.

So throughout November we're asking you to Go Purple, raise money and help stop babies being born too soon.

You could hold a purple bake sale, put on a purple pamper party or a big purple quiz! We have lots of fun ideas for you to choose from, fundraising with friends or colleagues. Take a look at the link below for inspiration and help raise vital funds that could really save lives.

action.org.uk/GoPurple



Fighting NEC appeal

Gorgeous Luka was born at just 30 weeks and had major life-saving surgery on his bowel after he developed necrotising enterocolitis (NEC).

“ I knew it was serious. His tummy was extended and the doctors felt they must operate straight away ”

recalls his mum Lucy.

Our NEC appeal has so far raised £13,000 towards the vital research we're funding into NEC at the University of Northumbria. Thank you!

Find out more action.org.uk/fightNEC

**BORN
TOO
SOON**



Now aged one, Luka is thriving

Photo: Jamie Williamson

action **HEROES**
DEDICATED TO SAVING CHILDREN'S LIVES

HOW YOU'RE HELPING TINY HEART PATIENTS...



BABIES BORN WITH HYPOPLASTIC LEFT HEART SYNDROME NEED A SERIES OF URGENT LIFE-SAVING OPERATIONS – THE FIRST WHEN THEY ARE LESS THAN TWO WEEKS OLD

THESE OPERATIONS ARE VERY COMPLEX AND IT CAN BE HARD TO KNOW WHICH APPROACH IS BEST FOR EACH CHILD



DR PABLO LAMATA AND HIS TEAM ARE USING ADVANCED COMPUTER TECHNIQUES TO HELP SURGEONS...



THEY CAN NOW CREATE 3D MODELS OF INDIVIDUAL BABIES' HEARTS

THESE MODELS CAN EVEN BE PRINTED IN 3D...

AND THEY HAVE REVEALED THINGS THAT COULDN'T BE SEEN BEFORE

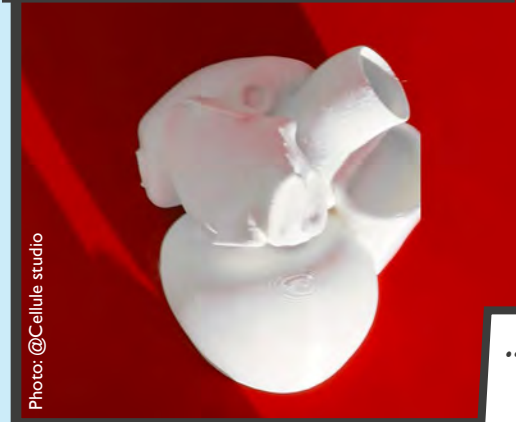
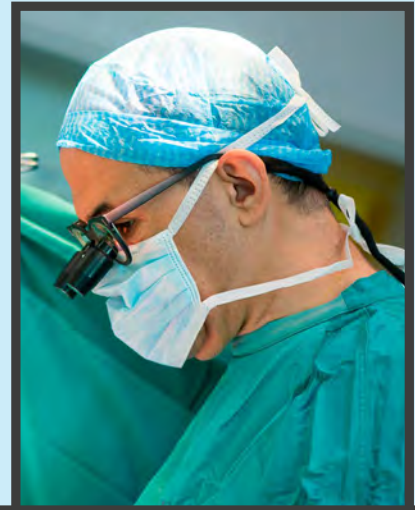


Photo: @Cellule studio



...AND IDENTIFIED A NEW 'WEAK LINK' IN THE AORTA THAT REMAINS AFTER SURGERY FOR THESE BABIES

THE NEW TECHNIQUES ARE ALSO AN ADVANCE TOWARDS SAFER, NON-INVASIVE ASSESSMENTS FOR CHILDREN LIVING WITH CONGENITAL HEART CONDITIONS



THIS VITAL RESEARCH WILL IN FUTURE HELP SURGEONS MAKE THE VERY BEST TREATMENT DECISIONS FOR EACH CHILD

ACTION JOINTLY FUNDED THIS RESEARCH WITH GREAT ORMOND STREET HOSPITAL CHILDREN'S CHARITY



Around
20,000
children are
admitted to intensive
care units in the UK
each year

Preventing infections in critically ill children

Children in intensive care often receive life-saving antibiotics but heavy use of these medicines is a growing concern. With Action funding, researchers are studying a new infection control treatment.

Most critically ill children will be given antibiotics to treat suspected infections that are either a cause or complication of their illness, and this undoubtedly saves lives. But high exposure to these drugs can also increase the risk of developing antibiotic-resistant infections. This can have very serious consequences. A new preventative treatment could reduce the need for strong antibiotics in these very vulnerable young patients.

Dr Nazima Pathan is leading a pilot study involving children in six intensive care units across the UK. This research is comparing standard treatment with a new infection control treatment, called selective decontamination of the digestive tract. This already appears to benefit adults, reducing infections and improving survival.

Most infections that occur when a child is receiving intensive care arise from bacteria growing in the gut. The new treatment uses non-absorbable antibiotics to stop this.

“Some critically ill children have long-term or complex health problems and infection by antibiotic-resistant bacteria could make them much sicker and reduce their chances of survival,” says Dr Nazima Pathan.





**BORN
TOO
SOON**

Fundraisers fight back

Pedalling to Paris – Alex and Ashley’s story

Twins Alex and Ashley took on our London to Paris cycle challenge, riding in memory of their mum, Jayne, who sadly died shortly after their early birth.

Jayne had developed pre-eclampsia during her pregnancy and, when her condition dangerously deteriorated, the girls had to be delivered under controlled conditions. They were born weighing just 2lb and spent several months in hospital.

“Pregnancy complications and premature births happen daily and it breaks our hearts – the thought of others having to go through such a difficult time,” says Ashley.

“The expert care we received as babies might not have been possible without the help of charities like Action”



First-time mum turned fundraiser – Lucy’s story

Lucy shared her story with us when the campaign launched. Baby Luka arrived suddenly, 10 weeks too soon, in May last year. With his traumatic start thankfully behind them, Lucy’s thoughts turned to helping others. She’s been playing our weekly lottery and as a social media champion has encouraged friends and family to support us via Facebook and Instagram. Luka’s helped too as the face of our recent NEC appeal! And as this magazine went to press, Lucy was about to hold her first fundraising event.

Running for tiny lives – Marcy’s story

Driven by the loss of one of her tiny granddaughters, Marcy took on the challenge of running the Vitality London 10,000, with support from son Keith. Together they raised more than £500.

“I would climb a mountain today to bring Paige back. I can’t do that, but I can help raise funds for Action”

Twins Isla and Paige were born at just 26 weeks. “The girls were perfect – tiny and fragile – but beautiful,” says Marcy. “For four weeks they went from strength to strength. Then Paige became ill. She developed necrotising enterocolitis (NEC), a truly devastating illness, and despite an operation and a battle for life she died in her mummy and daddy’s arms.”



**60,000
reasons**



Join our new event

This autumn sees the launch of our new BORN TOO SOON event, 60,000 Reasons. We challenge you to run, walk, plod or even skip 60 miles in 60 days to raise £60 or more to help babies born too soon. Around 60,000 babies are born prematurely each year in the UK. Tragically more than 1,000 lose their lives due to premature birth.

We’re fighting back. Will you join us? Cover 60 miles, wherever you like and at your own pace, between 1 October and 29 November 2019.

However you choose to complete the challenge, the money you raise will help fund vital research.

Sign up today and take your first step!
60kreasons.action.org.uk

Challenge events 2020



Running

The Vitality Big Half | March

London Landmarks Half Marathon 29 March

Schneider Electric Paris Marathon 5 April

ASICS Greater Manchester Marathon 5 April

Virgin Money London Marathon 26 April

Vitality London 10,000 25 May

Cycling

Castle Ride 100 3 May

Suffolk Sunrise 100 17 May

Davina's Big Sussex Bike Ride June

Land's End to John O'Groats 9-21 June

Action London to Paris 15-19 July

Prudential RideLondon-Surrey 100

16 August 2020

Treks

Snowdon by Night 13-14 June

Yorkshire 3 Peaks Weekend 28-30 August

Saharan Mini Adventure 15-19 October

Inca Trail to Machu Picchu 17-26 October

Team challenges

Race the Sun Wales TBC

Race the Sun Lake District TBC



Plus more... sign up today
[action.org.uk/events](https://www.action.org.uk/events)