

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

# Re:action

Spring/summer 2019

**action** medical research  
for children



*In your latest Re:action*

Fighting life-threatening infections

Hope for rare diseases

**BORN TOO SOON** update

# Welcome

In this issue, find out about two of our newest research projects – from a total of 16 funded in 2018. There's also exciting news of progress made in research that has now finished, including a big breakthrough for children with a devastating rare disease. All thanks to supporters like you.

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## Find out more!

With your support we're currently funding more than 60 groundbreaking research projects

[action.org.uk/research](http://action.org.uk/research)

## Follow us

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**BORN  
TOO  
SOON**



**Our BORN TOO SOON campaign has been gathering momentum – with a new celebrity ambassador and supporters from across the UK sharing personal stories, raising awareness and doing some fantastic fundraising.**

Best known for co-presenting the Channel 4 series *Embarrassing Bodies*, we're delighted to have Dr Dawn Harper's backing. Two of Dawn's children were born prematurely and spent weeks in special care.

She says: "I know only too well the fear and anxiety that comes with such an early birth. My children are now grown up but it is so frightening that premature birth is still the biggest killer of babies in the UK, and that 61,000 babies are born too soon each year. Medical research is so important if we are to change this and that's why I'm supporting this campaign."

- **Together we will find the answers.**
- **Together we will help STOP babies being born too soon.**



**Join the fight – See how you can help**  
[action.org.uk/borntoosoon](http://action.org.uk/borntoosoon)



# BY SUPPORTING ACTION, YOU ARE...



**HELPING TO TREAT SICK AND VULNERABLE BABIES**



**HELPING CHILDREN AFFECTED BY DISABILITY**



**HELPING TACKLE RARE DISEASES IN CHILDREN**



**HELPING TO PREVENT CHILDHOOD INFECTIONS**

## Millie and Scarlett's story...

Millie and her twin sister Scarlett were born three months prematurely. At three weeks old, Scarlett developed necrotising enterocolitis (NEC), a life-threatening infection of the bowel.

**Sadly it became clear that Scarlett could not survive and parents Emma and Dan faced the heartbreaking loss of one of their tiny daughters.**

Then Millie too became very ill with NEC, needing life-saving surgery.

Doctors removed a small amount of her bowel and gave her a stoma bag to manage her body's waste. Thankfully, Millie recovered and her stoma was later reversed.

The girls' dad Dan says: "NEC comes so quick, it's a shock. We hope research will find a way to stop it or catch it sooner. We're so blessed to have our Millie, but saying goodbye to Scarlett was devastating."



## With your support...

Dr Darren Smith and his team are studying immune-boosting factors in breast milk. These are believed to reduce the risks of both NEC and sepsis, a potentially deadly blood infection, in very premature babies. Each year in the UK, these two conditions affect up to 4,000 babies born before 32 weeks. NEC is also the most common reason for emergency surgery in newborn babies. This research could lead to new ways to prevent or treat these illnesses. It could also affect handling and storage of breast milk in special care baby units.

**Find out more**  
[action.org.uk/borntoosoon](http://action.org.uk/borntoosoon)

## Promising early findings

We have some exciting early findings to share from one of the research projects you've helped support. This is looking at how an existing asthma medicine could be used to help prevent premature labour.

Women who previously suffered miscarriages went on to deliver babies after 34 weeks of pregnancy after combining treatment with progesterone and the asthma drug aminophylline, which is already used to help premature babies' lungs develop.

Although this study is small scale, the drug's use to help prevent premature labour has been hailed as a breakthrough. It is hoped that a larger trial will follow.

**A great reminder of why research is so important!**



## Cream Teas coming soon!

Join us for our easiest, tastiest fundraising event on 27 June.

Our Action Cream Teas boxes are filled with everything you need for the perfect summer tea break treat, delivered direct to your door. All you need to do is get a group of friends or work colleagues together and place your order online.

**Every scone savoured helps us fight for little lives, so please join in!**

Order at [action.org.uk/tea](https://action.org.uk/tea)



## Become a social champion

Are you passionate about what we're doing? Then why not become a social champion and help us spread the word?

Right now we're looking for social champions to get behind our BORN TOO SOON campaign. Premature birth is the biggest killer of babies in the UK. So we're fighting back!

Share the fight with your family and friends by simply following us on Twitter, Facebook and Instagram and sharing our posts with your followers. Or why not vlog or blog about our fight and why you're getting involved?

Find out how you can get involved [action.org.uk/socialchampion](https://action.org.uk/socialchampion)

## Premature birth progress

Steps have been made towards developing a new test to identify women most at risk of early labour.

Thanks to previous Action funding, it had already been discovered that women who lack white blood cells at the cervix, the opening to the womb, were more likely to give birth prematurely. These cells are a key part of the body's immune defences, killing bacteria.

Further Action funding allowed Professor Nigel Klein and his team to continue this work. They aimed to simplify the way of detecting cells so that it could be developed into a test for use in early pregnancy. They have now identified four biomarkers that when absent or reduced in cervical fluid greatly increase the chances of preterm delivery if left untreated. They next plan to see how well this biomarker test performs on samples taken from 400 women.

Thank you to Dangoor Education for generous support of this project.



# Hope for children Like Rohan

Rohan was diagnosed with a rare mitochondrial disease when he was nine years old. This devastating, progressive condition would cause him to suffer stroke-like episodes. He lost his sight, mobility and eventually his life.

With your support we're funding a cutting-edge research project that could help produce a cure for mitochondrial disease, giving hope to families like Rohan's that, in the future, lives could be saved.

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

“ We feel his loss every single day. As a caring, loving little boy he is a massive loss to this world. Without research, things will never change. ”

Mum Vicky, pictured with Rohan and his sister Yazmin





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



Photo: Adrian Sherratt

**SIBLINGS TOBY, COREY AND IZZY ALL HAVE JUVENILE BATTEN DISEASE – A RARE GENETIC CONDITION. THERE IS CURRENTLY NO CURE OR WAY TO SLOW DOWN THIS CRUEL, LIFE-LIMITING DISEASE.**



**THE BOYS ARE NOW BLIND AND HAVE MANY OTHER DIFFICULTIES...**



**IZZY IS ALSO LOSING HER SIGHT. SHE HAS SHORT-TERM MEMORY LOSS AND HER BEHAVIOUR CAN BE CHALLENGING.**

**THE DISEASE IS CAUSED BY A FAULTY GENE. BUT NOBODY KNEW EXACTLY WHAT IT DID IN THE BODY.**



**DR EMYR LLOYD-EVANS AND HIS TEAM WANTED TO UNRAVEL THIS MYSTERY.**



**THEY'VE NOW MADE A BREAKTHROUGH DISCOVERY...**

**...AND BY FINDING OUT WHAT THE GENE DOES, THEY'VE NOW IDENTIFIED TWO PROMISING POTENTIAL TREATMENT STRATEGIES.**

**DR LLOYD-EVANS SAYS: "WE FEEL WE HAVE MADE HUGE STRIDES FORWARD FOR THIS DISEASE."**



Photo: Ben Rector

**YOUR SUPPORT HAS HELPED FUND THIS VITAL RESEARCH, WHICH COULD RAPIDLY HELP CHILDREN WITH THIS DEVASTATING DISEASE.**

**THANK YOU**





Baby Ella developed bronchiolitis when she was a month old and spent two weeks in intensive care

Worldwide,  
more than  
**100,000**  
children under five  
lose their lives to  
RSV each year

## Preventing life-threatening lung infections

**Bronchiolitis can make vulnerable babies struggle to breathe. Action funding is helping researchers fight the virus that often causes it.**

Bronchiolitis is a type of chest infection which can cause congestion in the lungs, making breathing difficult. It's very common in children under one but very young babies, premature babies and those who are already more vulnerable are at greatest risk. It's usually caused by the respiratory syncytial virus, also known as RSV, but little is known about why some children develop potentially lethal infections while others have milder symptoms.

Led by Dr Donald Davidson, researchers at the University of Edinburgh have discovered a naturally-produced substance in the body that they think protects against RSV. But it's thought that very young babies, especially those born early, don't yet have enough of this substance, called cathelicidin, in their noses.



© Douglas Robertson courtesy of the MRC

Supported by Action and The Chief Scientist Office Scotland, they want to find out when babies begin to make cathelicidin, track its levels as they grow and see how it influences the risk of severe RSV infection. If it could be boosted, it could help prevent RSV.

**“Understanding why some children are more susceptible to severe RSV infections could lead to new ways to protect babies from serious illness,” says Dr Davidson.**

# BORN TOO SOON



## Albie's mum takes action

Inspired by our BORN TO SOON campaign, Melissa Taylor took on a 12-hour fitness challenge. She wanted to raise funds and awareness after her son Albie was born two months prematurely.

Gym manager Melissa challenged herself to complete back-to-back fitness classes, from 10am in the morning until 10pm at night, to raise money for Action. Her 12 hours of exercise included Spin, HIIT, Circuits and Yoga at PureGym's Bristol Union Gate branch where she works.

Melissa wanted to help because Albie, now three, was born eight weeks early.

"Initially he couldn't breathe on his own so he was immediately put on a respirator," she says. "He was so small, weighing just 4lbs 3oz. The doctors needed to help him grow and so he was put in an incubator for a while and then a 'hot cot' to help regulate his temperature. It was 30 days before we could take Albie home. We're so fortunate that he's now a happy, healthy toddler."

Melissa's BORN TOO SOON fundraiser raised more than £550 for Action. Thank you Melissa. For ideas about how you can support BORN TOO SOON visit [action.org/borntoosoon](http://action.org/borntoosoon)



## Challenge events 2019

### Running

**Vitality London 10,000** 27 May

**Mud Monsters Run** West Sussex, 9 June

**Bournemouth Marathon** 6 October

### Cycling

**Castle Ride 100** Kent, 12 May

**Suffolk Sunrise 100** 19 May

**Davina's Big Sussex Bike Ride** 16 June

**Maratona dles Dolomites – Enel** 7 July

**Action London to Paris**

**20th Anniversary Ride** 24-28 July

**Prudential RideLondon-Surrey 100** 4 August

**York Ride 100** 18 August

**Essex Ride 100** 1 September

### Team Challenges

**Trek the Night Cotswold Way** 1 to 2 June

**Race the Sun – canoe, climb and cycle:**

– **NEW Offa's Dyke** 15 June

– **Isle of Wight** 6 July

– **Lake District** 31 August

Plus more...



Sign up today [action.org.uk/events](http://action.org.uk/events)





action medical research  
for children

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