

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

# Re:action

Autumn/winter 2018

**action** medical research  
for children



## In your new *Re:action*

Fighting for babies  
born too soon

Helping children with  
heart conditions

Events for 2019

# Welcome

We hope you'll feel inspired by your latest issue of *Re:action*. Read more about research we've funded with your support and how it's already helping families. Plus find out how we can all join together to fight premature birth – the biggest killer of babies in the UK.

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## Find out more!

With your support we're currently funding more than 65 groundbreaking research projects

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

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**BORN  
TOO  
SOON**

# FIGHTING TO STOP PREMATURE BIRTH

At Action Medical Research we fight for medical breakthroughs for some of the toughest fights our children face.

61,000 babies are born prematurely each year in the UK, and tragically more than 1,000 lose their little lives as a result – making premature birth the biggest killer of babies in the UK. It's too many. Far too many.

We know through medical research we can stop the devastation. That's why we've launched our BORN TOO SOON campaign.

We're fighting back – parents, children, families and the research community. We're working together to raise £1 million by 2020 to fund groundbreaking medical research that could go on to benefit millions worldwide.

- Together we can find the answers.
- Together we are unstoppable.



**Join the fight.**

See how you can help  
[action.org.uk/borntoosoon](http://action.org.uk/borntoosoon)

## PREMATURE BIRTH TAKES LIVES. TOGETHER WE CAN FIGHT BACK.

Over the last few months, families have been sharing their experiences of premature birth with us online. They are stories of heartbreak and fear but also courage and hope.

### Isla was born more than three months too soon

“My twin granddaughters were so tiny and fragile, one dark, one blonde. Those little girls fought their way through their first weeks of life until tragedy struck – Paige became ill and lost her battle for life. Isla fought on. She gave us all the courage, love and hope to carry on.”

Isla and Paige’s grandmother, Marcya

### Grace was born at 28 weeks

“The NICU was a terrifying place, babies in little plastic boxes all around, machines beeping, wires everywhere, but the minute I saw my daughter she was utterly perfect. You never know true determination and strength until you witness it coming from someone so small.”

Grace’s mum, Shanice

Read more stories or share your own  
[action.org.uk/borntoosoon](http://action.org.uk/borntoosoon)



Together we are unstoppable.

Parents. Children. Families. Communities. We’re all working together to **raise £1 million by 2020** to fund groundbreaking medical research that could go on to benefit millions.

We all have a part to play. Act now.



Isla



Grace

"This really is a cause close to my heart. My mum developed pre-eclampsia when she was expecting me, and I was born prematurely - I could so easily have not been here today if it wasn't for medical advances. It's still the biggest killer of babies in the UK. So join me, and fight back."

♥ Davina xx

BORNTOO SOON  
Ambassador Davina McCall

## Join the fight.

- Pledge your support
- Raise money
- Give your time
- Spread the word

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

# BORN TOO SOON

## Fighting neuroblastoma

At just four years old Felix was diagnosed with neuroblastoma. After two years of intensive treatment, he sadly lost his fight.

Our amazing Action supporters have now donated more than £15,000 to help fund research to develop a new treatment for children with high-risk neuroblastoma.

You're playing a vital part in fighting this rare and devastating disease.

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



Felix (on the right) with his brother and sister

## Raise money while you shop!

Do you shop on Amazon? Then you could raise money for Action whenever you buy something and it won't cost you a penny. Sign up now (ready for Christmas shopping!) and whenever you order selected items 0.5 per cent of the money spent will be donated to us.

You just need to remember to always start your shopping at [smile.amazon.co.uk](http://smile.amazon.co.uk). From there, your Amazon shopping experience is exactly the same.

**amazon**smile

Find out more at  
[action.org.uk/shopping](http://action.org.uk/shopping)

# Reducing the risk of stillbirth

With your support, we're proud to have helped fund an important study that has led to practical new advice for pregnant women and a public health campaign aimed at saving babies' lives.



Stillbirth is devastating, with long-lasting effects on bereaved families. Tragically, around 9 babies are stillborn every day in the UK.

Action, along with research partners Cure Kids and Sands, funded a three-year study looking at mothers' sleep positions in late pregnancy in relation to the risk of stillbirth. This confirmed that in the third trimester, after 28 weeks of pregnancy, women who go to sleep on their back are more likely to have a stillbirth.

Supported by NHS England, a 'Sleep on Side' awareness campaign has now been launched. It's estimated that if all pregnant women in the UK follow this advice it could save around 130 babies a year – and internationally up to 100,000 babies a year.

## Festive greetings...

Our exclusive selection of Christmas cards is back, with packs ready to order now – and every penny raised from their sale comes straight to Action. This is thanks to generous sponsorship of every part of their production.

Cards cost £3.50 for a pack of five. See all designs and order online [action.org.uk/xmas](http://action.org.uk/xmas)





Freya was born three months early

# Our fight for babies like Freya

“Many of the women I met in hospital had gone into labour too soon and nobody could say why. We know so little about it and, as mums, we have a huge sense of guilt. It’s so important to raise awareness of prematurity as it happens to so many people.”  
Freya’s mum, Steph.

Together, we can help STOP babies being BORN TOO SOON.

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

Picture courtesy of Freya’s family

**BORN  
TOO  
SOON**

**action**

# HEROES

DEDICATED TO SAVING CHILDREN'S LIVES

HOW YOU'RE  
HELPING CHILDREN  
LIKE ALFIE...



ALFIE HAS CEREBRAL PALSY. HE CAN SEE AND HEAR, BUT HIS PHYSICAL MOVEMENT IS PROFOUNDLY AFFECTED – AND HE CANNOT SPEAK

COMMUNICATION IS  
INCREDIBLY DIFFICULT FOR  
CHILDREN LIKE ALFIE

...BY EYE-POINTING HE CAN INDICATE  
WHAT HE WANTS OR NEEDS



HE RELIES ON HIS EYES TO  
ENGAGE WITH THE WORLD...

BUT IT CAN BE HARD TO KNOW FOR  
SURE HOW WELL A CHILD IS USING  
THEIR EYES TO COMMUNICATE...

*...SO WITH ACTION FUNDING\*  
DR MICHAEL CLARKE HAS TESTED A  
NEW CLASSIFICATION SCALE TO ASSESS  
CHILDREN'S EYE-POINTING ABILITY*



*THE SCALE HAS NOW BEEN  
LAUNCHED AND CAN BE  
DOWNLOADED FREE OF CHARGE*

*IT HAS ALREADY BEEN USED IN  
25 COUNTRIES, AND TRANSLATED  
INTO OTHER LANGUAGES*

*AROUND 2,000 BABIES A YEAR ARE DIAGNOSED  
WITH CEREBRAL PALSY IN THE UK. LIKE ALFIE,  
20 TO 30 PER CENT HAVE LITTLE OR NO SPEECH*



**THANK  
YOU**

*THIS NEW TOOL IS HELPING PARENTS  
AND PROFESSIONALS TO BETTER  
UNDERSTAND CHILDREN, AND ENSURE  
THEY GET THE RIGHT KIND OF SUPPORT*

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

A close-up photograph of a newborn baby lying in a hospital bed. The baby's chest is visible, with several medical sensors attached. One sensor is on the hand, and another is on the chest. A green tube is connected to the hand sensor. The baby's face is partially visible on the right side of the frame. The background is softly blurred, showing the white fabric of the hospital bed.

Congenital  
heart defects  
are common,  
affecting almost

**1 in 100**

babies born in the  
UK each year

# Helping children born with heart defects

**Up to half of all children born with a heart condition also experience neurodevelopmental issues. Action is funding new research to try and discover why.**

Thanks to major medical advances over the last 50 years, the majority of children born with a heart condition now survive. But researchers have found that they tend to do worse at school, with many experiencing problems with movement, coordination, memory, hyperactivity, attention or speech and language skills. These difficulties can have a major impact on their life chances as adults.

Professor Serena Counsell and her team at King's College London want to find out what causes these children to struggle in other areas of their development. They have already collected detailed MRI brain scans of 80 newborn babies before they underwent heart surgery. They will now repeat these scans on the children, aged around two years old, and compare these images with those taken from a group of healthy children. They will also carry out tests to assess movement, learning and language skills.

**“Our aim is to reduce the long-term effects of congenital heart disease on brain development, helping children to achieve their full potential,” says Professor Counsell (pictured with her team).**





## Riding to Paris for Peter

Our London to Paris bike ride holds a special place in many cyclists' hearts. Riders often return to complete the challenge again and relive special memories made. This year saw one team unite to ride in memory of Peter Nelson, who pedalled to Paris with us twice in the past.

Peter 'Pedro' Nelson was, says his daughter Charlotte, an amazing man who was never happier than when he was on his bike. Sadly Peter passed away suddenly last September, and when thinking of a fitting tribute to her father, Charlotte decided to sign up for our London to Paris 2018 event.

"He had done this ride twice in the past and would no doubt be doing it this year if he could, so I wanted to do it for him," she says. "The event is particularly special to me. The last time my dad did it, in 2016, I had not seen him for almost two years as I'd been away travelling. I flew to Paris for the end and, when he came to the finish line in front of the Eiffel Tower, I was there to meet him."

Charlotte was joined by her partner Matt Evans and three of her dad's cycling friends – Jason Lucas, William Butler and Chris Bex – who rode alongside Peter on previous Action London to Paris events.

Peter's family and friends joined this year's London to Paris bike ride for Action and raised more than £10,600 in his memory.

Find out more about the London to Paris ride  
[action.org.uk/action-london-paris](http://action.org.uk/action-london-paris)



# Challenge events 2019



## Running

**The Vitality Big Half** 10 March

**London Landmarks Half Marathon** 24 March

**Virgin Money London Marathon** 28 April

**Vitality London 10,000** Date TBC

## Cycling

**RIDE100 Series** Various UK dates  
May to September

**Maratona dles Dolomites** 7 July

**Prudential RideLondon-Surrey 100** 4 August

**Action London to Paris**

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

## Team challenges

**Trek the Night Cotswold Way**

**Race the Sun Brecon Beacons**

**Race the Sun Isle of Wight**

**Race the Sun Lake District** Dates TBC

## Mountain series one day challenges

**Snowdon, Yorkshire 3 Peaks  
and Ben Nevis** Dates TBC



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

# Action London to Paris

20th Anniversary Tour – 24 to 28 July 2019

Our Action London to Paris bike ride is a classic and ever popular challenge suitable for any cycling enthusiast.

Join us for our 20th anniversary ride through the beautiful, rolling countryside of Southern England and Northern France before arriving in Paris for one of the most exciting sporting weekends in the calendar – the spectacular finale of the 2019 Tour de France.



London to Paris  
20 Years



Solo and  
Team Entry  
available

[action.org.uk/action-london-paris](http://action.org.uk/action-london-paris)