

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

Re:action

Autumn/winter 2020

action **medical research**
for children

In your latest *Re:action*

COVID-19 children's research appeal

Fighting a devastating rare disease

Helping children in special schools

Welcome

At Action Medical Research, we fight for answers that can lead to cures, treatments and medical breakthroughs for some of the toughest fights our children face.

In this issue, find out about some of our latest research projects – plus why we want to fund important new research to understand the effects of COVID-19 on children.

Thank you, as always, for making our vital work possible.

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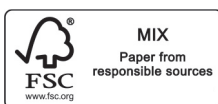
With your support we're currently funding around 60 groundbreaking research projects

action.org.uk/research

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Editor Clare Airey **Design** Paige Bowring-Martin
Print Newman and Thomson **Cover photo** Supplied by Danny's family
Registered Office Vincent House, Horsham, West Sussex RH12 2DP
T 01403 210406 **E** info@action.org.uk **W** action.org.uk
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Your support means so much

We've all had to get used to new ways of living, but one thing that hasn't changed during these difficult times is how amazing Action supporters can be.

So many of our big events have been put on hold, and we know there will be a big gap to fill this year.

To those who have donated to our Emergency Appeal, which has now raised over £90,000. To event participants who took to their back gardens or local streets to complete the ride or run distances they had intended to do for us. And those who

joined in with one of our various isolation challenges, or our online Quiz for our Nations in Isolation. However you have supported us, we are so grateful.

Our ability to fund life-changing medical research relies entirely on voluntary support. For children like Matilda, pictured above, who has the rare disease Niemann-Pick type C, this means so much.

Sign up for our new virtual event this October – find out all about Big Steps for Tiny Lives on page 14.

THANK YOU!

Thank you so much for your continued support during this difficult year. It means so much to all the children and families our research helps.

COVID-19 children's research appeal

For almost 70 years, Action has risen to the medical research challenges of the day. In 2020, a new health crisis has emerged.

The current pandemic highlights that medical research has never been more important. But there is a worrying lack of research specifically focusing on children and how the virus affects them. That's why we've launched our COVID-19 children's research appeal.

COVID-19 can and does affect children, both mentally and physically, sometimes with devastating consequences.

As children return to school, many parents are understandably fearful about its unknown effects.

Questions need tackling, like:

- Why are some children more vulnerable than others?
- How can we protect children now and in the future?
- How will the pandemic affect children's mental health?

We also need to ensure that children's care is tailored to their needs – treatments suitable for adults may not always be transferable.

And finding out why most children have been less affected by COVID-19 could also help us to better understand and fight the disease in all age groups.

Expert advice

We've brought together an expert advisory group of leading children's health researchers to help us fund research to better understand how COVID-19 affects children – but we cannot fund this research without your support.

“Children have been the quiet, forgotten bystanders in the COVID-19 pandemic”

As Dr Barney Scholefield, paediatric intensive care consultant and researcher, and a member of the Action advisory group, says: “Children have been the quiet, forgotten bystanders in the pandemic. It is essential we bring them to the forefront as they can help us all understand this disease better and we must improve the way we care for them during these uncertain times.”

Protecting children, now and always

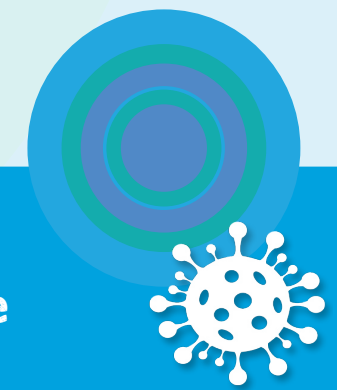
Our charity began in the 1950s in response to another virus, polio. We helped to develop the first polio vaccines in the UK, which have kept millions of children safe ever since.

Help us raise £1 million to fund vital research for children in the fight against COVID-19

Medical research can help find answers and protect children against this virus and the mental health effects of this health crisis. But we need your help to make this happen. The number of projects we're able to fund will depend entirely on how

much we raise from this appeal. We cannot fund this research without your support.

Please donate now at action.org.uk/COVID-19



Hope for boys with Hunter syndrome



“We’re going to lose our beautiful boy. For families in the future, any new hope is worth fighting for”

Danny’s family are painfully aware that time with their youngest son will be cruelly cut short by the rare disease Hunter syndrome.

“Danny lives in the moment and enjoys whatever he has,” says his mum Sally. “He wins hearts wherever he goes.”

His ‘in the moment’ outlook is one that Sally tries hard to adopt. Time with Danny, aged eight, is incredibly precious.

Hunter syndrome almost exclusively affects boys. It’s caused by a faulty gene that leads to the lack of an enzyme that’s vital for breaking down sugars in the body. Without this, waste sugar molecules build up in all the major organs, tissues and joints.

Danny’s diagnosis, at three years old, followed a history of developmental delay. Sadly, he has the most severe form of the disease, causing progressive damage to his brain.

In his younger years, Danny’s behaviour could be extremely

unpredictable and challenging. But life has got calmer lately – for the saddest reason. Danny is losing skills he previously had. He now no longer speaks and will become more reliant on his wheelchair:

“I’d love to have my little trouble back in full force, because I know what this calm after the storm is leading to,” says Sally.

Enzyme replacement therapy can help relieve some symptoms. But it cannot reduce the damage the disease is causing to Danny’s brain.

Sally knows that new research will come too late for them, but says: “Each new development brings real hope. That is worth fighting for, so that families in the future don’t have to feel that the bottom is dropping out of their world.”



With your support...

Professor Brian Bigger and his team at the University of Manchester are testing a new way of overcoming the problem of getting much-needed treatment into the brain.

Being able to reduce the neurological damage caused by this devastating disease could transform the outlook for boys like Danny.

This research has been jointly funded as part of our partnership with LifeArc to develop treatments for children with rare diseases.



You’re helping make this research happen. Thank you. Find out more action.org.uk/danny

A young boy with short brown hair and red-rimmed glasses is smiling broadly while playing a dark wood piano. He is wearing a white t-shirt and a blue patterned tie. The piano has sheet music on the stand. The background is slightly blurred, showing a guitar on the left and a window on the right.

Kinder treatment for brain tumours

Your support has enabled researchers to develop a new, non-invasive technique to more accurately assess brain tumours. This approach especially benefits children with tumours in high-risk areas who may not be able to undergo a biopsy. It allows doctors to better predict how aggressive a cancer might be and tailor treatment accordingly, making it only as toxic as it needs to be.

Joey was diagnosed with a brain tumour when he was just four. Thankfully, his treatment worked and he now hopes to become a doctor. His dad Darren says:

“We are so delighted that this progress has been made that will help make treatment even better in the future”

Find out more: action.org.uk/braintumours

Bringing eyecare to special schools

With your support, researchers have successfully shown the benefits of offering comprehensive eyecare services in the familiar setting of a child's school.

Children with learning disabilities are 28 times more likely to have a serious sight problem than other children, but nearly 40 per cent have never had an eye test or any eyecare.

Access to eyecare can be very challenging for children with developmental disabilities and their families. These children may also be less able to express, or even recognise, that they have sight problems – and adults may assume that their behaviour is just part of their disability.

So sight problems often remain undiagnosed, and therefore untreated, preventing children from reaching their full potential.



How research helped

In 2016, Action awarded almost £190,000 to a team led by Professor Kathryn Saunders at Ulster University. Called the Special Education Eyecare project, or SEE for short, two hundred children and young people from Northern Ireland's biggest special school took part.

“The support from Action was pivotal”

Nearly two thirds of the children involved were found to have at least one significant eye or vision problem. Nearly half also had at least one unmet visual need, like no glasses or needed large print learning materials.

The research proved that providing full eyecare in the familiar school setting – with glasses dispensed on-site and written information and advice shared with teachers and parents – had a positive impact.



“Our study demonstrates, for the first time, measurable benefits to children and young people. These were apparent in both children's vision and behaviour,” says Professor Saunders.

“The modern NHS requires evidence of benefit when developing and funding services. So the support from Action was pivotal in providing this,” she says.

The findings have already begun to influence provision of in-school vision services for children in England, with plans to inform provision more widely across the UK in the near future – meaning this research is set to benefit many thousands of children and young people.

Around
130,000
children attend
special schools
across the UK

Matthew's story

Matthew has autism and took part in the research. His mum Julie says: “It was invaluable. Although we knew Matthew had vision problems from an early age, it wasn't until the SEE project that we got a really accurate prescription and he started to wear his glasses regularly.”

Being seen at school was, says Julie, crucial. “It was fantastic for an autistic child, as Matthew can be very fearful. We had previously found eye tests very stressful,” she says.

Matthew had also been very reluctant to wear his glasses. He would cry when his teachers asked him to. But following the detailed advice provided by the SEE project, school staff worked as a team to encourage him and now he enjoys wearing them.

THANK
YOU!

You've helped pave the way for dedicated eyecare services to be delivered in special schools across the UK.



Around
60,000
babies are born
prematurely each
year in the UK

Protecting premature babies from infection

Bacterial infections are especially dangerous for premature babies. It's hoped new research will lead to life-saving new tests and better treatment for those who have been born too soon.

More than 1,000 UK babies die each year as a result of being born prematurely. Many of these babies lose their lives due to a severe bacterial infection, and those who do survive repeated infections can be left with life-changing disabilities, like cerebral palsy.

Dr Deena Gibbons and her team at King's College London aim to improve understanding of how the immune systems of such tiny babies react to infections, and find new ways to prevent and treat them more effectively.

The research team will study blood samples taken from premature babies, hoping to identify specific features that could be used to aid diagnosis and treatment.

“We hope this will lead to new tests that can help identify babies who may be at higher risk of developing a severe infection so that steps can be taken to help protect them in the critical, first few weeks of life,” says Dr Gibbons.



Lockdown legends

With so many of our usual events postponed or cancelled, we are hugely grateful to all those supporters who refused to let lockdown get in their way – you are all amazing!

Our new Vyking Ride was one of our first event casualties back in April. But that didn't stop Euan Campbell, who took to his static turbo trainer to pedal the 101-mile route distance in the safety of his back garden!

Euan was determined to complete the challenge as his son Wilfred, a former *Re:action* cover star, was born extremely prematurely. Now a happy three-year-old, Wilfred was on hand to cheer his dad on, along



with little sister Edith. Euan raised a fantastic £1,570.

A huge thank you to all those event participants who, like Euan, have carried on fundraising during this difficult time.

Get active for Action this autumn

This October we challenge you to join our fight for tiny lives by running or walking 20, 40 or 60 miles. It's free and easy to take part. Just choose your distance and fundraise at least £20, £40 or £60 depending on your distance chosen. If you'd like to push yourself further, that's fine by us!



Cover your distance wherever you like and at your own pace between 1-31 October and log your progress on your own fundraising web page.

Every step counts, so why not get all the family involved?
Sign up now at bigsteps.action.org.uk

BORN TOO SOON

Our BORN TOO SOON campaign was launched two years ago to shine a spotlight on premature birth – and before COVID-19 hit, supporters had raised more than £520,000 towards our target of raising £1 million by the end of 2020.

With fundraising activities affected by the pandemic, our ability to reach this target has been delayed. There is also now the urgent need to fundraise for research that could give vital insights into the effects of COVID-19 on children.

So, whilst we continue to fund vital research into premature birth – like that on page 13 – we are extending our BORN TOO SOON fundraising campaign.

We look forward to continuing our fight for babies born too soon.



action.org.uk/borntoosoon

Lockdown lottery win!

Congratulations to the aptly named Victory who won an amazing £4,000 in our Rollover Jackpot!

The mum of three and one of the nation's keyworkers, working in her local supermarket, was happily surprised. "It made my day! I joined the lottery because the research Action funds helps to give vulnerable and sick children a fighting chance," she says.

Enter our FIGHT BACK Friday Lottery from just £1 a week. Support our vital work and be in with a chance of winning cash prizes every Friday. Terms and conditions apply. Find out more at fightbackfridaylottery.org.uk



£4,000
Rollover Jackpot
WINNER!



Join the peloton to Paris 14 to 18 July 2021

© Graham Watson



If you thought you'd missed the chance to ride alongside a former Tour de France yellow jersey holder, your luck is in!

Former pro rider Sean Yates has confirmed that he will join cyclists on our London to Paris bike ride next year – just as he'd planned to this year. Sean will ride with us for the final stretch into the French capital.

We're offering *Re:action* readers 50% discount on the registration fee (usually £145) until 31 October, using the code REACTION

Register today with confidence – we don't want anything to hold you back from signing up to your next Action event! If we cannot go ahead with the ride in 2021 due to COVID-19, we will offer you a money back guarantee.

Sign up now at action.org.uk/L2PTL



For latest details on all Action events visit action.org.uk/events