action medical research for children

Autumn/winter 2021

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# touching Nes

The Action Medical Research magazine

Autoimmune encephalitis saw Beatrice lose the ability to walk or speak Read her story

# Plus

New research for children: Treating Duchenne, preventing asthma and continuing the fight against COVID-19

Developing a new treatment to save tiny twins

# From the editor

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### Dear Supporter,

A warm welcome to your autumn/winter issue of Touching Lives. As we enjoy the last of the summer sunshine, we look forward to sharing the latest research your support has made possible.

Real-life stories are always the best at showing the difference you can help make, and this issue's cover story is especially powerful. Out of nowhere, Beatrice lost the ability to speak, walk or control her body due to a rare type of brain inflammation. Her family endured months of uncertainty before she slowly recovered. New research aims to help families facing such a frightening illness in the future.

And as we continue to learn to live alongside COVID-19, we also have news of ongoing research in this area, as well as projects to improve care for premature babies and prevent children from developing asthma.

Plus we love to share good news, so see how our FIGHT BACK Friday Lottery brought a lovely surprise for one lucky player! If you're not already joining in, find out more on the back cover. From just f a week you can help us save lives at the same time as being in with a chance to win cash prizes.

Thank you as always for all your support. Clare Airey, Editor







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# Here for children

As a new school year begins and we head into autumn, we're delighted to have enjoyed a more normal summer of fundraising. Thank you for all your support.

Having had so many events put on hold for the last year, it really has felt very special to be able to fundraise together again this summer.

The sun shone beautifully for many of our challenge events - from our RIDE series of bike rides to our Race the Sun dawn to dusk triple challenge, which has proved especially popular. We've also been thrilled to see new volunteer and committee-led social events being adapted and springing back to life.

Thank you to everyone who's taken part or supported us in any way. In a world that's ever changing, our mission to save and change children's lives holds strong – but we cannot do it without you.

Research funded by our COVID-19 children's research appeal has now been underway for several months, trying to answer some of the questions and uncertainties that still remain around how the virus affects babies and children.

### Action Medical Research is the leading UK-wide charity saving and changing children's lives through medical research.

Touching Lives is Action Medical Research's magazine for supporters.

Editor: Clare Airey Front cover photo: Supplied by Beatrice's family Print: Propack Direct Mail Design: Paige Bowring-Martin

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### **Good luck Team Elijah's Star**

It's not long now until the crew embark on their epic journey, rowing 3,000 miles as part of The Talisker Whisky Atlantic Challenge. Shining a spotlight on premature birth, they aim to complete the crossing in 37 days to honour the memory of baby Elijah Halse, who was born too soon and lived for just 37 days. They aim to raise £100,000 for Action. Follow their progress on Facebook or Instagram at /elijahsstar

This research has implications for us all, young and old, and could help to prevent serious illness and inform public health measures now, and in any future pandemics.

We're pleased to have already raised £450,000 towards this vital research but we still need your help to continue. As the pandemic has shown, we cannot know what the future holds but with your help we continue to raise funds to support vital research for children and their families.



# **Continuing the fight** against COVID-19

While the success of vaccines has enabled the easing of restrictions, the pandemic and its potential long-term effects is far from over. Thanks to your support, research into how the virus affects babies and children is underway, and later this year we'll be funding further work to help children with long COVID.

As we enter a new phase in the pandemic, there remain many unanswered questions about how COVID-19 affects chidren. So we're pleased to share news on some of the projects funded by our COVID-19 children's research appeal, including one that addresses one of the biggest unknowns of all – why do children respond differently to the virus than adults?

With Action funding, Dr Marko Nikolić and Dr Kerstin Meyer hope to uncover vital new clues to explain this and discover why those children who do become infected are more susceptible.

They're investigating whether children generally have lower amounts of a molecule in the lining of their nose that could make it harder for the virus that causes COVID-19 to infect their cells. They will also look for differences in how the immune system responds to the virus.

"We aim to identify biological differences that can help explain why age is a risk factor for severe disease – and why some children develop a life-threatening illness," says Dr Nikolić,

This could lead to new approaches to prevent or reduce serious illness and also help inform public health measures now and in any future pandemics.

### **Babies and COVID-19**

We're also funding research to assess the risk the virus might pose to babies - and whether it could affect the developing brain. Dr Ela Chakkarapani and his team will assess children exposed to the virus in the womb or shortly after birth, against those who were not.

"We hope to uncover vital clues to help prevent or reduce severe disease "

Dr Marko Nikolić

"This could help shape advice for pregnant women and new parents – and identify children who may need additional checks and support," he says."The results could also stimulate research into new



treatments to help reduce the long-term impact on children's lives," says Dr Chakkarapani.

### Treating children's cancer in a pandemic

Further research is looking at the wider impact COVID-19 has had on children's cancer treatment. Since the start of the pandemic, hundreds of children will have received the devastating diagnosis that they have a brain tumour – the most common cause of childhood cancer death.

Dr Ibrahim Jalloh and Professor Rachel Isba are studying whether disruptions to the health service have affected how long it took these children to receive a diagnosis and start treatment – and the likelihood of a successful outcome.

This will inform guidance for managing cancer patients and other specialist healthcare services during future periods of disruption.

# At the forefront of vaccine development

Vaccines are playing a crucial role in the fight against COVID-19. So we're very proud that Professor Sir Andrew Pollard, leader of the Oxford/AstraZeneca vaccine trial, is a former **Action Research Training Fellow.** 

As Director of the Oxford Vaccine Group, Professor Pollard has played a leading role in the development of the AstraZeneca vaccine, receiving a knighthood in recognition of his services to public health. But while his recent focus has been on a vaccine to primarily protect adults, most of his career has been spent preventing and treating diseases that threaten children, particularly meningitis.

# "My Action Fellowship was critical – it was my research training "

It is a career that Action is delighted to have supported, having funded Professor Pollard's Research Training Fellowship back in 1995. This enabled him to complete his PhD and, he says, played a key role in his development to become a leading authority in vaccinology.

"It was critical because it was my research training. It gave me a portfolio of understanding and skills

# Making vital research happen, now and in the future

We were there for children when polio was a threat in the 1950s. Almost 70 years later we're still here, helping children during the COVID-19 crisis. With your support, we can continue to help babies and children in the future too.

The last year has given a stark reminder of the huge difference medical research can make. The COVID-19 projects we're funding could lead to important answers to help now, and to



which I continue to use today. This includes both general skills around analysis but also some very specific techniques that are still used and mean I can now supervise others to work on vaccine development," he says.

With your support, our Research Training Fellowship scheme backs some of the UK's most gifted doctors and scientists early on in their careers - funding future leaders in medical research like Professor Sir Andrew Pollard. whose work has helped save millions of lives.

fight future pandemics. This research would not be possible without your support.

There are many different ways to get involved from sporting challenges, making a donation, or organising a fundraiser. You can also choose to leave a lasting legacy, a gift in your will which can help future generations of babies and children. Please help us continue to save and change children's lives.

Donate now at action.org.uk/COVID-19





Around

"Too many parents have lost children to this condition"

# Developing a new treatment for Duchenne muscular dystrophy

Boys like Tom face a relentless decline in their physical abilities, caused by this devastating life-limiting disease. New research hopes to identify new drugs to slow its progression.

Duchenne muscular dystrophy causes muscle weakness and wasting that gradually worsens over time. It almost always affects boys and sadly there is no 100 cure. Although life expectancy boys are born with is increasing, Duchenne muscular most will dystrophy each year in the UK develop heart and breathing problems that lead to life-threatening complications.

Tom's diagnosis was made when he was four but his parents had been concerned long before this. He'd been slow to reach milestones like crawling and walking, and as a toddler he fell over a lot and walked with an awkward gait.

Eventually, the family were referred to a paediatrician. Having taken a blood test 'to rule out a couple of rare conditions', he phoned the next day with terrible news. Tom had muscular dystrophy. Sadly, further tests found he had the most severe form, Duchenne,

"It was such a shock. It seemed so improbable that my gorgeous son would eventually become locked in a body he could not move

and die," says Tom's mum Rebecca.

Now 13, Tom can no longer walk. He also can't sit up from lying down and is losing strength in his arms.

This disease will most likely rob Tom of his future, which is why Action, in partnership with LifeArc, is funding muchneeded research at the University of Oxford,

Duchenne is caused by a faulty gene which means the body doesn't make enough, or any, of the protein dystrophin, which protects muscles, Professor Angela Russell and her team are investigating drugs that can boost utrophin, another protein found naturally in muscles. This could potentially act as a substitute to dystrophin and slow down disease progression.

"New treatments are desperately needed," says Professor Russell. "While gene therapy is showing exciting progress, it's not suitable for all children. A big advantage of utrophin replacement therapy is that it is potentially suitable for all patients."

Rebecca says: "Potential treatments mean everything to families like ours."





# Studying sleep cycles in premature babies

Premature babies are cared for in an environment quite unlike the womb. **Researchers believe this may interrupt** natural sleep cycles, in turn affecting brain development. They are testing this theory, with the aim of improving future care.

Advances in treatment have led to improved survival, but babies born prematurely still face an increased risk of long-term neurodevelopmental complications. There are many reasons for this, but there is evidence to suggest an important relationship between babies' sleep cycles and healthy brain development.

In the second half of pregnancy, a baby's brain undergoes rapid development, forming new connections and networks. At the same time, distinct sleep states emerge, with the baby cycling between so-called 'active' and 'quiet' sleep. For babies born too soon, these sleep cycles may be interrupted by frequent medical procedures, bright lights and loud noises.

# Predicting who will develop asthma

With Action funding, researchers aim to design a computer-based tool to to enable earlier intervention for children at risk of developing asthma.

Asthma is the most common chronic medical condition in children in the UK and has a lifelong impact on lung health. Up to half of all children aged between one and five will suffer from wheezing attacks – making a high-pitched whistling noise, mostly when breathing out. Although many outgrow this, approximately one in three develop asthma by school age.

Being able to predict which young children will develop asthma could allow early interventions to be made for those most at risk. But this is challenging as there are several potential causes for wheezing attacks, including allergies or lung infections.

Professor Sejal Saglani and her team, based at Imperial College London, are assessing



With Action funding a team, led by Professor Topun Austin at Cambridge University Hospitals NHS Foundation Trust, is investigating this further. Using a non-invasive imaging system -alightweight, flexible cap, fitted with sensors - they are studying changes in blood flow in different parts of the brain and are looking for differences between active and guiet periods of sleep, and between pre- and full-term babies.

"Ultimately, we hope to develop a new system for use in neonatal units that can help to promote sleep cycling and support healthy brain development in these vulnerable babies," says Professor Austin,

children who had severe wheezing at pre-school age and are now at school.

They will also carry out experiments to explore how lung cells, from young children who wheeze and school-age children with asthma, react to things that can trigger these attacks.

They will combine their clinical and biological data and use mathematical modelling to develop a computer-based prediction tool.



Read more about new research funded with your support at action.org.uk/latest-research

.lm

Around

children in the UK have asthma

action.org.uk touchinglives

# Beatrice's battle - fighting a rare brain disease

"I hadn't realised just how much I had missed my daughter's voice"

Beatrice's mum, Amy

# STRONG GIRLS CLUB

Aged just eight and previously healthy, Beatrice endured the terrifying effects of autoimmune encephalitis - a rare type of brain inflammation, which caused her to lose the ability to walk or speak for several months.

As the oldest of four girls, Beatrice had previously enjoyed a very happy and healthy childhood. But in May 2019, she suddenly became unwell. It's a day that her parents, Amy and David, remember all too clearly. Amy had received a concerned call from Beatrice's school – and by the time she arrived to collect her, Beatrice was suffering a prolonged seizure.

Beatrice was rushed to hospital, where a battery of tests ruled out a brain tumour. Doctors suspected she had epilepsy and arranged for further tests.

Over the following weeks, Beatrice was not her usual bubbly self. At times she seemed confused and disorientated. She barely slept and became withdrawn. She didn't want to talk or eat."We didn't know if this was because she was recovering from the seizure or if it was something more worrying," recalls Amy.

Concerned, her parents took her back to hospital hoping to get answers – but here her condition began to rapidly deteriorate, "I was brushing her hair when she started making nonsensical speech sounds but not saying actual words," says David. "I knew something was seriously wrong."

Beatrice was moved to the Evelina London Children's Hospital, and during that journey began hallucinating and became very agitated and distressed."By the time we

arrived, she had become non-verbal and had lost all control of her body," remembers Amy.

Beatrice was eventually diagnosed with a rare type of brain inflammation called NMDAR-antibody encephalitis. This is caused by the immune system mistakenly attacking the brain.

While awake and able to respond to stimuli, Beatrice was unable to speak, walk or control her bodily functions, and needed a feeding tube. Her parents and younger sisters were relocated to the Ronald McDonald Evelina London House so they could stay close and visit her every day.

It was an immensely difficult time, fraught with the uncertainty of not knowing when, or if, Beatrice might fully recover. She was given a number of treatments to dampen down her immune system before the family started to see improvement.

Amy recalls hearing her daughter's voice again after more than three months. She was singing one of Beatrice's favourite songs from The Greatest Showman, when suddenly Beatrice sang back. "Although I had been with her the whole time. I hadn't realised just how much I had missed my daughter's voice," says Amy.

The day after her ninth birthday, Beatrice took her first steps since losing the ability

to walk, another moment that Amy remembers vividly: "All the nurses were clapping. It felt like a huge milestone."

Shortly after this, Beatrice was discharged from hospital and at home she gradually regained her skills and ability to manage life independently again.

"But although we were so incredibly proud of Beatrice and her recovery, so little was known about what would happen next," says David. "We were very worried and uneasy. She was still severely ill and we didn't know if she was going to remain at the stage she was at or continue to progress."



"This is why research is so important to families like ours. Being able to predict outcomes for a disease where there are still many unknowns would have helped us so much during that worrying time."

Thankfully, with lots of support, Beatrice returned to school at the end of 2019. She's since passed the II+ exam and recently started grammar school.

"It's been a long journey, but she's made huge leaps in her development and returned to the fun and playful girl she is," says Amy proudly.

With your support, Action is funding research to investigate if advanced early brain scans can identify vital clues to help doctors improve treatment for NMDARantibody encephalitis.

Autoimmune encephalitis is caused by the immune system mistakenly attacking the brain, causing inflammation and a range of alarming symptoms, such as seizures, confusion, abnormal movements and loss of speech. NMDARantibody encephalitis is the most common form and mainly affects children and young people – as it did Beatrice.

Thankfully, with prompt treatment, most children survive but recovery is usually slow. Many spend weeks to months in hospital and unfortunately many children are left with lasting difficulties.

Based at King's College London, Dr Michael Eyre is investigating if advanced brain scans, taken early on in a child's illness, can identify clues that could help doctors to predict likely outcomes and personalise their treatment.



He is using cutting-edge scanning techniques to look for differences in the brains of children in early recovery from NMDAR-antibody encephalitis compared with healthy children.

"We hope our results will ultimately help doctors select the best treatment for each child, improving the chances of controlling their symptoms sooner, shortening hospital stays and reducing the long-term effects on their lives," says Dr Eyre.

This Research Training Fellowship is co-funded with the British Paediatric Neurology Association.



# Breakthrough in asthma treatment

With your support researchers have shown how prescribing medication based on a child or young person's genetic make-up could treat asthma more effectively, leading to bigger improvements in quality of life.

In the UK, asthma results in one child being admitted to hospital every 18 minutes. When the condition is managed well, children and young people can lead a full and active life but for some with severe asthma, traditional treatments are not always effective.

Professor Somnath Mukhopadhyay, of Brighton's Royal Alexandra Children's Hospital and Sussex Medical School, has uncovered evidence that a commonly used asthma medicine, salmeterol, may actually offer little benefit to some patients – with genetic differences affecting how well it works.

In a landmark trial, Professor Mukhopadhyay and his team used a simple saliva test to determine differences in the genetic make-up of patients aged 12-18. They then prescribed either salmeterol or another drug, montelukast, accordingly. This approach is known as personalised treatment

# Powering research to prevent premature birth

Action funding has taken researchers a step closer to reducing the risk of early labour, by using two treatments in combination.

Around 60,000 babies are born prematurely every year in the UK and sadly more than 1,000 babies die as a result. Many others who survive a very early birth develop lifelong disabilities.

Treatment with a hormone called progesterone can reduce a woman's risk of giving birth early, but it doesn't work for everyone. So Professor Mark Johnson, of Imperial College London, has been investigating whether combining progesterone with the asthma drug aminophylline, already used to help premature babies' lungs develop, could be more effective.



and those who received it showed greater improvements to their quality of life.

This could go on to benefit many thousands of children in the UK, and many, many more around the world. The next step is to conduct a larger, clinical study, including younger children.

We are grateful to the many trusts and foundations who helped us support this project including The Henry Smith Charity.

> "I hope these results will have globally significant implications"

Professor Somnath Mukhopadhyay

- This study, with generous support from The Albert Gubay Foundation, looked at the combination
- treatment in the laboratory and in a feasibility study in pregnant women who were at high risk of early labour. It improved understanding of how the treatment would work – and, importantly, established it is safe.
- These promising results mean the treatment is now moving towards a full clinical trial. It is hoped this larger trial will start in 2022 and will help stop many babies from being born too soon.



# Developing a new treatment to save tiny twins

With your support, researchers have started trialling a new procedure that could be safer than the current treatment for twin-twin transfusion syndrome, helping to prevent serious complications and save more tiny lives.

Twin-twin transfusion syndrome (TTTS) is a serious pregnancy complication that affects around one in 10 identical twins who share a placenta. In the condition, abnormal connections develop in the shared placenta, connecting the babies' blood supplies. This causes unequal sharing of blood between them and can be life-threatening – one twin can become perilously short of fluid and the other dangerously overloaded.

Severe cases are usually treated by laser ablation surgery – a technique that has been used, and has largely not changed, for around 30 years. It involves keyhole surgery, with a small laser inserted through a cut in the womb and used to block the blood vessels, so that blood can no longer move between the babies.

The treatment carries high risks, many of them due to its invasive nature. Sometimes it can only save one twin, and sometimes neither baby survives. There is also a risk of infection, miscarriage or premature birth.

"These decisions are balanced on a knife-edge," says Professor Christoph Lees: "We have to weigh up the risks of the surgery against the risks of not intervening. There are no comfortable options."



### How Action helped

In 2012, Action awarded funding to Professor Lees and his team to investigate the safety and effectiveness of a new technology called high frequency ultrasound.

The aim was to prove this could work as a treatment and gain enough evidence to start a clinical trial in pregnant women.

Sadly, around

300

UK babies die each

year as a result

of TTTS

"As it does not involve invasive surgery, we believed it could be safer," says Professor Lees. "It could also mean babies could be treated earlier in pregnancy, hopefully improving their chances of surviving and escaping disability."

The technique uses a focused ultrasound beam, generated outside the body and aimed precisely at a treatment area inside the womb, acting only on that area. It is already used in the treatment of uterine fibroids and to kill tumours – and Professor Lees and his team have now shown that it could also potentially be safely and effectively used to block blood vessels in the placenta, without affecting the course of pregnancy.

"The results from the Action-funded work showed that our new ultrasound-based technique appears to be effective – and, importantly, has few side effects," says Professor Lees.

Guided by these encouraging results, the team secured significant further funding from the Medical Research Council. This has now resulted in a clinical trial in pregnant women, which opened this year, and is bringing this technology one step closer to becoming a new treatment option.



# Katie's story

In 2018, Katie and husband Fred were overjoyed to discover they were expecting identical twins. But by 19 weeks the babies had developed twin-twin transfusion syndrome and were at imminent risk.

"With immediate effect, we needed to make a life-or-death decision which could compromise both of our babies," recalls Katie.

Within hours, Katie underwent laser ablation surgery – an experience she describes as terrifying. "You're having something pushed into your pregnant stomach. It's so naturally something you'd protect against, but you do it because there's a chance you might save your babies."

Initially, the procedure seemed to have gone well. But sadly, three weeks later, a scan showed that the smallest twin, who Katie and Fred named Faith, had severe brain damage. It was likely that she'd been unable to cope with the effects of the surgery and suffered a stroke.

After fretful deliberation, Katie and Fred had to make the heart-wrenching decision to terminate Faith's life to give her sister, Constance, the best chance of survival.

The rest of the pregnancy was filled with fear and uncertainty, before Katie's waters broke at 28 weeks.

Constance was delivered weighing just 2lb and was rushed to neonatal care. Thankfully she made good progress, but having already endured such a traumatic pregnancy, Katie found the intensity of caring for such a tiny, vulnerable baby almost overwhelming.

"When we lost Faith, someone said if we could get through that and Constance survived, we'd never have anything harder to deal with," says Katie. "I would beg to differ – the neonatal journey was way, way harder." Katie says: "If there's anything that can be done to help families going through these sorts of pregnancies then it's of critical importance."

For Katie, the non-invasive nature of the potential new treatment is key."It would be so beneficial for the psychology of the patient," she says. "And while laser treatment maybe did save Constance, she was still delivered at 28 weeks, most likely due to the previous procedures – so preventing this would make a huge difference in the future."

> "We received incredible care and have a healthy child – but we still lost one too"

Katie, mum of Faith and Constance



You've helped drive forward

the development of a vital new treatment that could save babies' lives.

Find out more about other research successes **action.org.uk/successes** 

# Davina delights!

### Davina McCall has been supporting Action since she was a little girl of nine and over the last year has continued to be the most incredible ambassador.

As our outdoor events were able to get going again, Davina got on her bike to join us for her Big Sussex Bike Ride in June. And having taken her Dine With Davina ladies' lunch online during last November's lockdown, she's looking forward to meeting guests in person again at this year's event next month.

Davina is also now helping to promote the charity via her online fitness platform, Own Your Goals, helping us attract support from the popular site's wider audience.

## Thank you Davina for all you do for Action.

# A Rapturous ride

The charity's inaugural insurance industry bike ride, Raptör, was a huge success this summer. Riders had been due to cycle from London to Paris in 2020 and then this year too, but due to the pandemic they instead completed a 340-mile ride taking in vineyards of the South East. Event sponsor and founding partner, Brit Insurance generously donated and triple matched their riders' efforts meaning over £200,000 was raised. An incredible first year which we hope to build on for 2022's London to Paris.



# New partnership with Satchel

### We're delighted to have teamed up with award-winning schools learning platform Satchel as their first official charity partner.

Satchel is used in a third of all UK secondary schools and the partnership is set to deliver significant income for Action. We have already delivered a joint webinar looking at the impact of COVID-19 on children. Satchel CEO, Naimish Gohil said: "After getting to know the charity, everyone here is inspired and motivated to support the critical medical research that is required. This is the start of a long-term partnership and I'm excited about the journey ahead."

A big thank you to all the businesses that support us and make our vital research happen. To find out more about how your business can support us visit action.org.uk/support-us



NEVES

PUZHING

**Royal Patron** 

Remembering our

It was with great sadness that we

marked the passing of HRH The

Duke of Edinburgh in April, Patron

of our charity since 1955. He was a

fantastic supporter of our work for

over 60 years, generously hosting a

and taking great interest in the

shone through, and we are

for our life-saving work.

research we fund. His passion for

and commitment. We were very

science and helping children always

immensely grateful for his enthusiasm

fortunate to have had his support for

so many years to help generate funds

number of receptions for the charity

STOP

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# Taking BIG steps for Tiny Lives

### We're so proud of nine-year-old Hannah, who's raised more than £700 by taking part in our Big Steps for Tiny Lives virtual event – inspired by her big brother Joey who had successful treatment for a brain tumour.

loey was just four years old when his family faced the terrifying news that he had a brain tumour. He endured a 10-hour operation then, with the tumour found to be cancerous, underwent radiotherapy, chemotherapy and further surgery. Thankfully his treatment was a success, and loey is now a healthy fifteen-year-old.



loey was treated under the

Peet, whose work to improve

brain tumours has been helped

by Action. So when his younger

sister Hannah decided she'd like

to raise money for charity, we

loined by family and friends,

including loey and oldest

were a natural choice.

treatment for children with

care of Professor Andrew

brother Ben, plus Bessie the Springer Spaniel, Hannah clocked up 35 miles over three weeks. She raised £763, an amazing effort which makes her our second biggest fundraiser ever in Big Steps for Tiny Lives!

Mum Kathryn says: "It was lovely to see how much support Hannah received, which far surpassed her original target. Action's research can lead to treatments and medical breakthroughs for some of the toughest fights children face. As a family we know too well how hard that fight is, We're blessed that we are a complete family and truly hope that our contribution will in the future help more families like ours to stay complete."

Big Steps for Tiny Lives continues this October, with a special focus on Baby Loss Awareness Week, You can take part in your own time and at your own pace. Sign up now at bigsteps.action.org.uk

touchinglives Autumn/winter 2021

"We hope to help more families like ours to stay complete"



# Researcher on the run

Also going the extra mile this summer was Action-funded researcher Dr Adam Shortland, who ran in the Vitality London 10,000.

Research led by Dr Shortland's team has developed a new 3D ultrasound scanning technique to improve screening for hip problems in children with cerebral palsy. Completing the run in an impressive 54 minutes and raising nearly £300, Dr Shortland said:"I was delighted to take part. Action have been supportive in helping fund my research and continue to do amazing work for families affected by cerebral palsy, who live with uncertainty about their child's future."

Find out more about running for Action at action.org.uk/running



Our RIDE Series of one-day cycling sportives returned this summer and we've exciting plans for next year. Some of our long-established and ever-popular events will be expanding, with new routes – including off-road gravel options. Plus there'll be some brand new rides added to the series. **action.org.uk/RIDE** 



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**FRIDAY LOTTERY** 

With cycling, running, trekking and team challenges, we've events to suit all. See our website for dates and details, or scan the QR code with your phone camera. **action.org.uk/events** 

# Race the Sun

After a phenomenal year in 2021, with two extra events added to the schedule due to high demand, Race the Sun will return in 2022. Teams of four compete against each other, racing the setting sun, to be crowned champions in a dawn to dusk triple challenge – cycling, hiking and canoeing or kayaking around courses in the beautiful Brecon Beacons and Lake District National Parks. Find out more **action.org.uk/race-sun** 



£5,000 Rollover Jackpot WINNER!

# Next time, it could be you!

In June our FIGHT BACK Friday Lottery rollover prize reached £5,000 which meant it had to be won!

The lucky winner was David from Lincoln, who now plans to treat his wife, a keyworker throughout the pandemic, to an extra special holiday. David says: "I was very surprised. I support Action because I can see that

their work really does change people's lives, more importantly those of children. It never fails to amaze me about the amount of research, breakthroughs and medical care delivered by charities in this country, with so much of it unseen. I am proud that my monthly contribution is helping to enable that."

It's easy to enter our FIGHT BACK Friday Lottery. From just  $\pounds I$  a week, you can help us save lives and be in with a chance of winning  $\pounds 500$  every Friday and up to  $\pounds 5,000$ in our rollover jackpot.

Find out more at fightbackfridaylottery.org.uk or scan the QR code.

