action medical research for children

Spring/summer 2019

touching lives

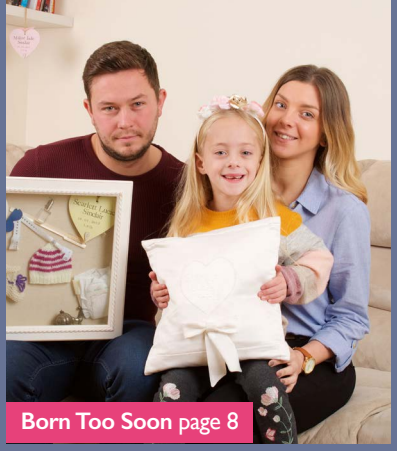
The Action Medical Research magazine

BORN TOO SOON
The toughest of starts
Read Millie's story

Plus
Research success: helping children with severe cerebral palsy

Fighting drug-resistant leukaemia

From the editor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Dear Supporter,

A warm welcome to your latest issue of *Touching Lives*. Spring is a time of new beginnings and, as you'll see, we've refreshed the design of the magazine. We hope you like the bright new look. Our weekly lottery has also been revamped, which you can read about on page 3, and we hope you might feel tempted to play! Most importantly, we have lots of fantastic new research to share with you – from a total of 16 projects funded in 2018.

Our BORN TOO SOON campaign continues and our bittersweet cover story is another reminder of why your support matters so much. At just a few weeks old, premature twins Millie and Scarlett both developed necrotising enterocolitis (NEC). Tragically only one of them survived this deadly bowel infection. New research you've helped us fund aims to protect against NEC and sepsis – two major threats to premature babies in their first weeks of life.

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 – find out more on page 11. Plus we're delighted to share the impact that a simple tool, developed with Action funding, is having for children with severe cerebral palsy and their families (see page 12).

All of this is thanks to supporters like you, so we hope you'll feel proud and inspired.

Clare Airey, Editor


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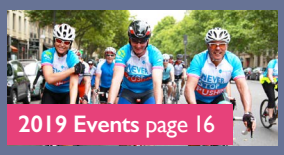
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Action Medical Research is a UK-wide charity saving and changing children's lives through medical research.

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

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Two of Dr Dawn Harper's children were born early

TV's Dr Dawn joins our fight

Launched late last year, 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."

We're also incredibly grateful to all the families who've got behind our campaign – and told us why it is so important to them. Like Lucy, mum of baby Luka, who went into labour two-and-a-half months early.

"Neonatal intensive care was a journey through hell," says Lucy. "But we are lucky enough to have our baby home and healthy now. I really want to help support vital research. Prematurity and the complications because of it are devastating to so many families."

Some very poignant stories have been shared and some fabulous fundraising efforts made, including a 10,000-feet skydive and a 12-hour fitness challenge! There are many ways you can get involved. Together we can fight back.

> *"I know only too well the fear and anxiety that comes with such an early birth"*

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

Fight for children's lives every Friday!

Since 2016, our weekly lottery has been making winners every Friday and changing lives at the same time!

Our lottery has now been revamped which we hope you agree better reflects our goals.

By playing our FIGHT BACK Friday Lottery supporters are helping us fight for answers – answers that can lead to medical breakthroughs for some of the toughest fights our children face.

Every Friday our top prize of £500 is up for grabs, as well as five runners-up prizes, and a chance to win our Rollover Jackpot of up to £5,000.

action medical research for children
FIGHT BACK FRIDAY LOTTERY

Take a look at our new-look lottery ***action.org.uk/lottery*** and help us spread the word about this fun and easy way to support our vital work.
Terms and conditions apply.

Ella spent two weeks in intensive care fighting bronchiolitis

Protecting babies from a life-threatening lung infection

Baby Ella and her family endured a terrifying experience when she developed bronchiolitis caused by the respiratory syncytial virus, also known as RSV. With Action funding, researchers aim to use the body's natural immune defences to fight this potentially lethal infection.

When baby Ella arrived six weeks prematurely with no complications, her parents Steph and Nick counted themselves extremely lucky. But at four weeks old she fell terribly ill with what initially seemed to be a simple cold.

"I had no idea of what bronchiolitis could do to premature babies," says Steph. "It will haunt Nick and I forever."

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 and those who are already more vulnerable are at greatest risk. It's often caused by RSV – a virus that in older children and adults causes mild, cold-like symptoms. But for babies like Ella it can be much more serious.

When Ella initially developed a runny nose, Steph wasn't too worried. But a week later her chest started to sound crackly. Doctors suspected bronchiolitis but felt she was ok to remain at home.

More than **45,000** children are admitted to hospital with bronchiolitis each year in the UK

Then Ella suddenly stopped breathing. "She went grey, pale and limp – like all the life went out of her," recalls Steph. She was rushed to hospital where doctors struggled to stabilise her. It became clear that tiny Ella was now fighting for her life. Needing the highest level of care, she was transferred to the Evelina London Children's Hospital and spent the next eight days on a ventilator.

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.

Supported by Action and The Chief Scientist Office Scotland, the team 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. The hope is that if it could be boosted, it could help prevent RSV.

Steph says: "I support any research into this condition. We saw so many premature babies with bronchiolitis at the Evelina. We were lucky. We spent two weeks there. It could have been a lot longer and a lot, lot worse."

> *"She went grey, pale and limp. It will haunt us forever"*

Fighting drug-resistant leukaemia

Most children with T-cell acute leukaemia can be cured – but sadly some don't respond to treatment, or the cancer returns. A new approach aims to improve survival for these patients.

Leukaemia is the most common cancer affecting children and young people, affecting around 500 families in the UK each year. Up to one in five of these children will have a fast-developing form of the disease called T-cell acute lymphoblastic leukaemia, or T-ALL.

For most children, intensive chemotherapy will defeat the disease. But not for all – and in around 20 per cent the cancer eventually comes back and is then almost impossible to cure.

With Action funding, researchers at Newcastle University are investigating a new approach that combines two drugs already used to treat

leukaemia. Building on earlier work, the hope is that used together they can overcome drug-resistance and kill cancer cells. If successful, this would help children for whom currently no other treatments exist.

"If our results look promising, we aim to test this drug combination in an international trial, selecting the children with relapsed T-ALL who are most likely to benefit," says Dr Frederick van Delft, who is leading the research. "We desperately need to find effective new treatments, so we can save more young lives from being cut tragically short."

Scans to predict symptoms of autism and ADHD

Action funding is helping doctors study the role of two chemicals in the brain that could indicate which babies are at greatest risk of developing autism or ADHD.

Autism spectrum conditions (ASC) and attention deficit hyperactivity disorder (AHDH) are common – autism affects around one in every 100 UK children and ADHD up to five in every 100.

Having one or both of these conditions makes life difficult for children and their families, and can seriously affect education, employment chances and quality of life. Children with autism typically have difficulties communicating with and relating to other people. While those with ADHD tend to have short attention spans, find it hard to concentrate and are often restless and impulsive.

It is already known that these conditions can run in families. But it is not known exactly what it is that makes a baby more vulnerable to developing them.

Dr Tom Arichi and his team at King's College London believe the answer could lie in understanding the balance between two chemical messengers in the brain – known as neurotransmitters. They are using sophisticated brain scanning techniques to safely and precisely measure levels of these two chemicals to see if this could allow earlier prediction in babies known to be at risk.

This could enable families to get support sooner and help develop new treatments.

These are just some of the new research projects we're funding thanks to your support. **Read more at *action.org.uk/research***

Tailoring treatment for children with arthritis

Juvenile idiopathic arthritis causes inflammation in the joints and affected children suffer stiffness, pain and the risk of long-term disability. With Action funding, researchers are developing specialised MRI scans to help inform treatment decisions and ensure each child receives the best possible care.

Juvenile idiopathic arthritis, or JIA, is caused by a child's immune system overreacting to a perceived threat and mistakenly attacking their own joint tissues. To protect itself, the body creates inflammation or swelling. But this can have a serious impact on their quality of life and cause lasting damage.

There are a variety of treatments available to help control children's symptoms and allow them to lead active, independent lives. These include new biological drugs that can reduce inflammation and joint damage. But unfortunately they aren't effective for everyone and can have unwanted side-effects.

Around **12,000** UK children have juvenile idiopathic arthritis

At the moment it's difficult for doctors to identify who might benefit from these new drugs as it can be hard to assess inflammation in the joints, and blood tests are often unhelpful.

So with funding of almost £200,000 from Action Medical Research, Professor Margaret Hall-Craggs and her team, based at University College London, are developing new tools to help doctors make more accurate decisions.

Pictured left to right – Dr Tim Bray, Dr Naomi Sakai, Professor Margaret Hall-Craggs, Dr Alexis Jones

The team has developed specialised magnetic resonance imaging, or MRI, scans that can show when joints are inflamed. They now plan to improve their technique and create 3D pictures that are colour-coded to provide a more accurate measurement of the degree of inflammation within a joint.

"We hope that these detailed images will make it much easier for doctors to interpret complex MRI data, helping to improve clinical decision-making," says Professor Hall-Craggs. "And they will also help patients to see whether joints are improving or deteriorating over time – potentially encouraging them to keep taking an effective drug."

> *"This will help ensure each child receives the best possible treatment"*

Pioneering MRI scanning for children

MRI scans give detailed 3D pictures of the inside of the body, and unlike x-rays or CT scans do not use radiation.

Professor Margaret Hall-Craggs is internationally-recognised for her expertise in medical imaging – and it was Action funding that previously supported her in developing the use of MRI for children. In 1987 she was awarded one of our Research Training Fellowships – awards which are made to the most promising doctors and researchers early on in their careers.

"The fellowship enabled me and another worker to start the use of MRI at Great Ormond Street Hospital," she says. "We really pioneered its use in children and it subsequently became the normal practice in the hospital."

Remembering Rohan

When 10-year-old Rohan Alipour-Faridani lost his fight against a devastating rare disease his family was determined to do something positive in his memory. Through his Action Tribute Fund they have now raised more than £12,000 towards vital medical research.

Rohan was a happy little boy who loved being around people. But in his second year of school his teachers and mum Vicky became concerned about his energy levels. It was the start of a journey that would see him endure more than three years of tests, and sadly his symptoms became more worrying over time.

In March 2013 the family was finally given a diagnosis. It was heartbreaking news. Rohan had a rare mitochondrial disease.

Nobody could tell Vicky what the future might hold. She was warned that Rohan's condition was progressive and that there was currently no cure.

Mitochondria are the powerhouses of our bodies' cells, performing the essential job of generating energy. In conditions like Rohan's, the mitochondria are damaged or faulty, and this in turn means cells cannot do their jobs properly. The parts of the body most affected are usually those with the highest energy demands – the muscles and vital organs like the brain.

Later that year Rohan began to suffer stroke-like episodes. These caused him to lose his sight and mobility. Eventually his family had to take the heartbreaking decision to move to palliative care – and Rohan lost his fight in October 2014.

Remembering Rohan is hugely important to Vicky and all of Rohan's family and friends. After he died she discovered Action Medical Research, and that we were funding research into mitochondrial diseases. So she set up a Tribute Fund.

"Having the fund is a lovely way to keep Rohan's memory and his name alive. When I talk to people about Rohan I tell them about it," explains Vicky.

"As a caring, loving little boy Rohan is a massive loss to this world", she says. "We feel that raising money in any way we can to help others is what he would want us to do. Hopefully this will go towards finding a cure for some of these terrible illnesses and conditions."

Vicky hopes that in the future things will change for children with mitochondrial conditions.

"We were so pleased to hear recently that Action is funding another new study into a mitochondrial disease – it's not the exact same condition as Rohan had but there is always the potential for new information that could benefit similar conditions," she says.

"Without research, things will never change. And it's the rare conditions that won't get as much money because fewer people are experiencing it. It's so important to me – there has to be somebody supporting research into rare diseases," she stresses.

We are so grateful to Vicky for her support in Rohan's memory. It means so much to us.

You can support and find out more about Tribute Funds at ***action.org.uk/tribute-funds***

Rohan with his sister Yazmin

> *"Without research, things will never change. Raising money to help others is what Rohan would want us to do"*

BORN TOO SOON

Millie and Scarlett's story

"We are so blessed to have our Millie, but saying goodbye to Scarlett was just devastating"

The toughest of starts

Millie and her twin sister Scarlett were born three months prematurely. Both developed necrotising enterocolitis, a life-threatening bowel infection that typically strikes the smallest, most vulnerable newborn babies. Sadly, only Millie survived.

Five-year-old Millie loves school and her favourite game is pretending to be a teacher. Her parents, Emma and Dan, are incredibly proud of their little girl and how well she's doing.

"Millie knows about Scarlett," says Emma. "She is very sweet towards her and blows her kisses when we go to visit her grave."

Scarlett and Millie were delivered by caesarean section 28 weeks into a very difficult pregnancy. The twins had been affected by a condition called intrauterine growth restriction, also known as fetal growth restriction. It meant they were growing too slowly, putting their health at serious risk. Babies with this condition often need to be delivered early, so it is also a cause of premature birth.

Scarlett arrived first, weighing just 1lb 6oz, followed by Millie weighing a tiny 1lb 4oz. To Emma and Dan's immense relief, both girls cried as soon as they were born. But both were incredibly vulnerable.

The girls needed help to breathe and were not yet ready for milk, so were given fluids by tube into their tiny veins. They were too small and fragile to be held, but Emma and Dan could place their hands on their daughters' heads.

"Scarlett was so poorly that they didn't want to move her at all, but Millie seemed to come on in leaps and bounds, even though she was smaller," says Emma.

Emma expressed milk for her babies which the hospital staff froze and stored. But while Millie was soon able to take tiny amounts, given by syringe down a tube, sadly Scarlett couldn't respond. Scarlett also continued to need a great deal of support with her breathing.

Then, at three weeks old, Scarlett's health deteriorated more rapidly. She developed necrotising enterocolitis (NEC), a potentially deadly infection of the bowel. It can strike shockingly quickly and babies born prematurely, or who are already poorly, are sadly the most susceptible.

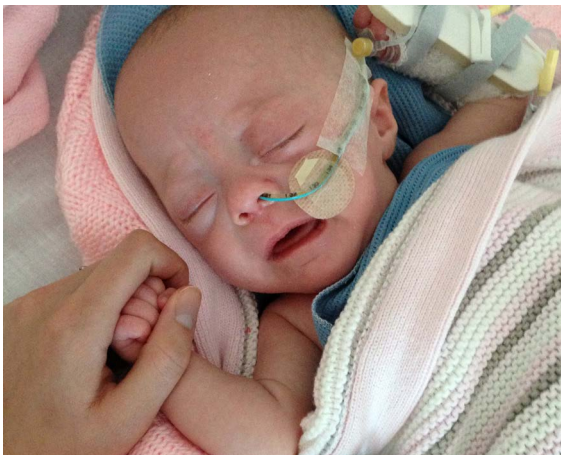
It became clear that Scarlett could not survive and Emma and Dan faced the heartbreaking loss of their tiny daughter. "They told us we could hold her until they switched off life support," says Emma quietly. "We held her in our arms, on a cushion as she was so fragile."

Sadly more heartache was in store, as Millie also became very ill with NEC. A top paediatric surgeon decided to operate on her immediately, on the ward, rather than waiting to take her down to theatre. "It was the worst wait ever," recalls Dan. "We sat in a side room and the eventual knock on the door was so scary."

But thankfully medics were positive, explaining that they had removed a small amount of Millie's bowel, repaired it, and given her a stoma bag to manage her body's waste.

After three and a half months in hospital, Millie was well enough to go home, and her stoma was later reversed.

The family are now passionate about medical research to help babies like Millie and Scarlett, and Dan has thrown himself into fundraising. Joined by his friends and colleagues from Cross Street Garage in Swindon, he completed four charity challenge events last year and raised more than £15,000.



Millie became very ill with NEC

"If research wasn't done, doctors wouldn't have the knowledge that they do now, and the ability to treat tiny babies who are born prematurely or get conditions like NEC," he says. "We are so blessed to have our Millie, but having to say goodbye to Scarlett was just devastating."

New research to help babies like Millie and Scarlett

With your support, Action is funding a team who are looking for new ways to protect babies from deadly infections – including necrotising enterocolitis, the disease which killed Scarlett.

Every year in the UK around 10,000 babies are born before 32 weeks of pregnancy. Up to 4,000 of them develop either necrotising enterocolitis (NEC), the serious bowel disease that Millie and Scarlett had, or sepsis, a life-threatening blood infection.

After the first week of life, these two conditions are the biggest threats to the lives of very premature babies. NEC is also the most common reason for emergency surgery in newborn babies.

With your support, Action is funding a team, based at the University of Northumbria in Newcastle, looking for new ways to protect babies from these deadly infections.

"Too many lives are being lost because of these serious complications, and babies who do survive often grow up with life-changing disabilities," says Dr Darren Smith, who is leading the research.

Breast milk is known to reduce the risk of NEC and sepsis in premature babies. This is believed to be due to its immune-boosting factors rather than its nutritional qualities. So these researchers are analysing breast milk samples to better understand which components provide these protective effects and how they work.

This could shed new light on how to prevent and treat these illnesses. It could also have implications for the handling and storage of breast milk in special care baby units.

THANK YOU!

At Action Medical Research we fight for medical breakthroughs for some of the toughest fights our children face. We fight for babies like Millie and Scarlett. ***Thank you for joining us and making this vital research happen.***

"NEC comes so quick, it's a shock. We just hope research will find a way to stop it or catch it sooner"

Millie and Scarlett's dad, Dan

Batten disease breakthrough

Thanks to your support, researchers have made a significant discovery, revealing vital new information that could quickly open up new ways of fighting this devastating rare disease.

Children with juvenile Batten disease seem healthy and develop typically in their early years but then things take a dramatic turn for the worse. They experience increasingly distressing symptoms which progress over time, including sight loss and epilepsy.

There is currently no cure and no way to stop or slow down this neurodegenerative disease – other than to try and alleviate symptoms. Tragically, children become severely disabled before losing their lives.

For the Penn family, research into juvenile Batten disease means absolutely everything. Three of their four children were diagnosed with it in 2015. Twins Toby and Corey were 11 and daughter Izzy (pictured with Corey) was just six.

The faulty gene that causes the disease was only discovered 20 years ago. It gives the body's cells instructions on how to make a protein called CLN3 but, until now, nobody knew what this protein did.

With Action funding awarded in 2015, Dr Emyr Lloyd-Evans and his team at Cardiff University aimed to unravel this mystery. Their findings are, says Dr Lloyd-Evans, 'truly remarkable'.

"We have made a breakthrough in finding what the CLN3 protein does and in that case what the first thing that goes wrong in this disease is," he explains. "Secondly, we have identified two potential treatment strategies."

Having discovered what CLN3 does, the researchers identified that certain epilepsy drugs that affected children may already be taking could be more beneficial than anyone had realised – and explain why some have better outcomes than others. This finding could rapidly help patients.

They also tested another existing drug, approved for other diseases, with promising early results. This could now lead to a clinical trial in patients in the near future.

Progress made in predicting risk of premature birth

Researchers have taken exciting steps towards developing a test to identify women most at risk of going into labour too soon.

Thanks to previous Action funding, researchers had already 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.

In 2016, Action secured further funding so that Professor Nigel Klein and his team, based at University College London's Institute of Child Health, could continue this work. They aimed to simplify the method of detecting cells so that it could be developed into a test for use during early pregnancy.

The team has now identified four biomarkers that when absent or reduced in cervical fluid greatly increase the chances of delivery before 34 weeks of pregnancy, if left untreated.

Worldwide 15 million babies are born prematurely every year

They now plan to see how well this 4-biomarker test performs on early-pregnancy samples taken from 400 women.

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

Helping severely disabled children to communicate

Communication is incredibly difficult for children with severe cerebral palsy but for some their eyes can be their voice. Tested with Action funding, a new eye-pointing scale is now helping medical professionals and families to better understand how well children can use their eyes to engage with the world.

If you couldn't speak, couldn't reach and couldn't point, how would you communicate? How would you ask someone to give you something you wanted or were interested in?

Cerebral palsy is a lifelong condition caused by a problem with the brain usually before, during or just after birth. It affects movement and coordination, and severely affected children are often unable to speak, nor can they point, reach or press buttons.

But some children can use their eyes to communicate. They might look at an object they want, then at another person, then look back to the object to indicate they want it – this is called eye pointing. However, in the absence of clear guidance on how to describe this behaviour, doctors and other professionals often struggle to tell how well a child is able to use it.

How we helped

In 2016 Action Medical Research and Great Ormond Street Hospital Children's Charity jointly funded Dr Michael Clarke and his team so they could test, with patients, a new eye-pointing classification scale for children with severe cerebral palsy.

"Being able to understand how a child is using their eyes is absolutely critical in helping parents and professionals provide the right kind of support," explains Dr Clarke, who is based at University College London.

The Action-funded work successfully proved that the scale was easy to use in real-life clinical settings, by different people, and gave consistent, reliable results. The scale has since been named eyePoint and made available to download for free. It has already been downloaded more than 600 times, mostly by people in the UK but also in more than 35 countries around the world. It is now available in five languages, plus an App version was launched earlier this year.

The eyePoint scale has already been downloaded in 35 different countries

"We are delighted that the scale has been so well received and is making an immediate and direct impact on support for children and their families," says Dr Clarke. "We aim to build on this and establish its use as standard clinical practice in the UK and overseas."

The research team has also received positive feedback from doctors who have used the scale with children who have other complex disorders, such as Rett syndrome, as well as adults with learning disabilities. This shows it has the potential to benefit very many people with conditions that make speaking difficult or impossible.

The eyePoint scale can be downloaded at ***ucl.ac.uk/gaze***

> *"We are delighted that the scale is making an immediate and direct impact on support for children and their families"*
>
> **Dr Michael Clarke**

Alfie's story

Alfie, who is now 13, suffered devastating brain damage at birth and has severe cerebral palsy as a result. He is profoundly affected in terms of physical movement and cannot speak – but he can see and hear.

"Alfie's stuck in a body that doesn't work. But his eyes do work, and he can understand everything – he just needs a way of telling us," explains his mum, Sam. "He is a bright, funny boy. He understands us, but it can be hard for us to understand him."

As a baby Alfie received specialist support and was taught to look left for no and right for yes. Then, as he got older, Sam realised he was actively eye pointing.

"I felt relieved for the immediate future," says Sam. "We knew Alfie would need a lot of outside help but just being able to get the answers to everyday parenting questions – like are you in pain? Are you hungry? – was a big relief."

Fast forwarding to today, Alfie can now join in a family board game.

"As long as the trivia questions have multiple choice answers, you can have an answer to eye point to on your left hand, head and right hand," Sam explains.

"He can communicate his needs, questions and frustrations using his low-tech symbol communication book, which is very thick and continues to get thicker the more he learns."

For Sam, giving more children the chance to communicate through eye-pointing is, she says, 'awesome'.

"It's giving children like Alfie hope for the future – independence and the chance to be part of their communities, to be part of the world," she states.

THANK YOU!

With your support, we're currently funding five studies which aim to help babies and children with cerebral palsy in various ways. Find out more action.org.uk/cerebral-palsy

Gearing up for the 10th CycleSport Dinner

Sir Chris Hoy, whose son Callum was born 11 weeks prematurely, joined a host of sports stars to support our ninth Champions of CycleSport dinner, which raised £180,000 in November.

Held in London, and supported by Garmin and Frog Bikes, the 2018 event saw guests mingle with elite cyclists, including Dani Rowe MBE a World, Olympic and European champion. There was also the chance to bid for some fantastic auction prizes, which this year included a chance to ride with Grand Tour stage winner Nico Roche.

Our 10th Champions of CycleSport Dinner will be held on Thursday 21 November. For details visit ***action.org.uk/champions***

Our cycling season starts again in May! See back cover for dates and sign up at ***action.org.uk/cycling***

Business supporters in action

From brand new partnerships, to long-term fundraisers, we're incredibly grateful for the efforts of all our corporate supporters.

We're delighted to have been chosen by the **Bioindustry Association (BIA)** as their Charity of the Year for 2019. The partnership kicked off in January when we were beneficiaries of the annual BIA Gala Dinner. Action supporters Simon and Sam Harriss (pictured), parents of Lily who has the rare disease BPAN, spoke movingly about what our work means to families like theirs.

We're also thrilled to be one of **Alliance Healthcare's** charities of the year. Members of staff will be running for us in this year's Virgin Money London Marathon. They're also set to play a major role in our new Race the Sun Offas's Dyke event, with seven teams taking part.

Back for a second year, our construction industry bike ride, **Ziggurat,** raised £130,000 in 2018. Supported by Brett, Glider Technology and the Grafton Group, the latest challenge saw 55 cyclists take on a 300-mile journey from London to Brussels.

The Paddington™ Shop at Paddington Station has celebrated a fantastic fundraising milestone – raising more than £50,000 for Action from special Paddington pin badges. The store's retail director Jackie Tyson (pictured) was delighted to receive a framed certificate to mark the occasion.

Throughout 2018, **Airport Parking & Hotels (APH)** challenged staff across the UK to collectively run, walk or cycle 25,000 miles. For every mile they logged, APH donated £1 to Action. Massive thanks to all involved and congratulations for hitting the £25,000 target!

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***

THANK YOU!

Romeo's reason for pedalling to Paris

The difficult birth of his baby son has inspired Romeo Nazareth to join his work colleagues from Price Bailey on our 20th anniversary London to Paris bike ride this summer.

When accountancy firm Price Bailey chose Action as their charity of the year for 2018/19, our cause especially struck a chord with new dad Romeo Nazareth, who works in their London office. The previous year, his partner Emily had endured a very long and daunting labour when their son Ezra was born.

"Ezra was getting very tired and the doctors were concerned about his wellbeing," explains Romeo. "They suggested using a brand new machine to monitor his vital signs more closely through a wire attached to his skull. This was much more accurate than traditional monitors."

After the delivery Emily suffered from postpartum sepsis and was very ill. Ezra too was at risk from the infection and given intravenous antibiotics as a precaution.

"To think that the work Action does can have an impact in helping the most vulnerable babies means I am instantly passionate about the charity," says Romeo.

Mother and son recovered well and Ezra is now 'a cheeky one-year-old who's growing and developing at a great pace'.

"I'm not the fittest of people but I love cycling and I'm now committed to this cause, so I thought taking part in the ride was a great way to raise some money," says Romeo.

Romeo is one of a team of eight Price Bailey riders taking part in the London to Paris bike ride. So far the company has raised more than £45,000 for Action through various other staff events.

"It's so important to help the most vulnerable babies and give them a fighting chance"

Recycle and raise funds

Recycling your empty inkjet cartridges is a free and simple way to support us. Working with The Recycling Factory, over the last decade we've raised £58,000 – all from items that may otherwise have gone to waste. Find out more at *action.org.uk/recycling*

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 online at: *action.org.uk/tea*

Best of British Action Cream Teas IN A BOX

2019 Challenge Events

RUNNING

28 April Virgin Money London Marathon
27 May Vitality London 10,000
9 June Mud Monsters Run, West Sussex
6 October Bournemouth Marathon

CYCLING

12 May Castle Ride 100, Kent
19 May Suffolk Sunrise 100
16 June Davina's Big Sussex Bike Ride
7 July Maratona dles Dolomites – Enel
24 to 28 July Action London to Paris 20th anniversary ride
4 August Prudential RideLondon-Surrey
18 August York Ride 100
1 September Essex Ride 100

TREKKING

6 July Trekfest Brecons
20 September Peak District Challenge

TEAM CHALLENGES

1-2 June Trek the Night Cotswold Way

Race the Sun Series:
15 June Offa's Dyke
6 July Isle of Wight
31 August Lake District

For more details and to book visit
action.org.uk/events
or call: 01403 327444
or email: events@action.org

NEW Race the Sun Offa's Dyke

After 15 amazingly successful years of Race the Sun, we're taking our popular team challenge to another beautiful part of the UK, Offa's Dyke along the England/Wales border. Setting out at dawn, teams will tackle a 22km cycle along the Gospel Pass, the highest road in Wales. Swapping bikes for hiking boots, they will then trek a 22.2km stretch along the Haterall Ridge of the Black Mountains – with breathtaking views of the peaks, the Wye Valley and the Brecon Beacons beyond. Then it's a 3.4km canoe journey down the River Wye to reach the finish line. Join us for this brand new event on 15 June.

Find out more and register at
action.org.uk/race-sun-offas-dyke

Join us for RideLondon

There's still time to join Team Action for the Prudential RideLondon-Surrey 100 this August. Cycling on closed roads, the Olympic Legacy route sets out from the Queen Elizabeth Olympic Park. You'll whizz through the streets of London and out into the beautiful Surrey Hills to tackle climbs including the infamous Box Hill. Then head back to the capital for a hero's welcome on The Mall – all to help fight for little lives.

The ride also forms part of the London Classics sporting challenge, with those who complete the 100-mile ride, along with a London Marathon and the two-mile Swim Serpentine event being eligible for a special London Classics medal.

Find out more and sign up at ***action.org.uk/prudential-ridelondon-surrey-100***