

action medical research
for children

touching lives

The Action Medical Research magazine

Spring/summer 2020

BORN TOO SOON

Little fighter

Read Wilfred's story

Plus

**Defeating dystonia:
Edward's amazing
transformation**

**New research into rare
diseases and meningitis**



From the editor

Dear Supporter,

Welcome to your spring/summer issue of *Touching Lives*. I hope you'll enjoy reading about just some of the life-changing research you're helping to make possible – as well as maybe getting a few ideas about how you can help us even more in 2020!

This is an important year as we continue fundraising to reach our £1 million target for our BORN TOO SOON campaign, which is shining a spotlight on the impact of premature birth. Our cover story is yet another reminder of why this is so important – and it's one of several personal stories in this issue. Wilfred's mum, Imogen, went into labour more than three months early, and doctors were unable to slow it down or stop it. One of our newly-funded projects aims to develop more effective treatments that could in future safely stop premature contractions, helping babies like Wilfred.

As the families featured within these pages show, the research that your support funds can make a big difference for children facing some of the very toughest fights. For children like Sophia, who has a rare disease, it is a beacon of hope (see page 4). And for Edward, who had one of the worst cases of dystonia doctors had ever seen, it has, quite literally, transformed his life. His amazing story, on pages 12-13, is one that I'm especially delighted to share with you.

With your support, we hope to help change many more children's lives.

Clare Airey, Editor



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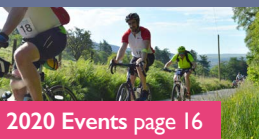
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Action Medical Research is a UK-wide charity saving and changing children's lives through medical research.

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Fighting for babies born too soon

Thanks to our amazing supporters, we have raised **£520,000** in support of our **BORN TOO SOON** campaign. Together we can reach our **£1 million** target before the end of the year!

Each year in the UK, around 60,000 babies are born prematurely, like little Wilfred, pictured on the cover, who was born at just 25 weeks.

It's for children like Wilfred that we launched our BORN TOO SOON campaign to shine a spotlight on the devastating impact of premature birth, and to raise £1 million by the end of 2020 to fund vital medical research that could benefit millions.

Parents, families and communities have been busy fighting back. In November, supporters helped us mark World Prematurity Day by going purple; organising purple bake-offs and dress down days to raise vital funds. Whilst friends and families have trekked across

mountains, organised family fun days and taken on our 60,000 Reasons event, challenging themselves to walk or run or even skip 60 miles in 60 days!

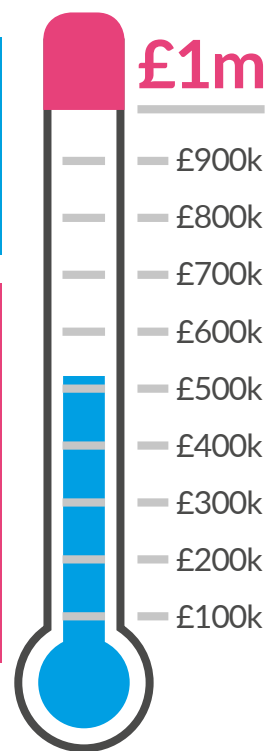
It has been amazing to see everyone coming together in support of the campaign and we're delighted that we have so far raised £520,000 towards our target, helping us to fund exciting research like Professor Taggart's that hopes to reduce the risk of early birth. Find out more on page 10.

We want to fund more potentially groundbreaking research, but we need your help. Take a look below and see how you can help us reach our £1 million target and help stop babies being born too soon.

**BORN
TOO
SOON**

**£520k
of our
target
raised
so far**

**THANK
YOU!**



Join the fight against premature birth

There are lots of fun and easy ways to get fundraising in support of BORN TOO SOON this summer.

From holding your very own bake-off, taking on a 5k run, or organising a quiz night. You can fundraise in whatever way suits you best and know that every penny raised will take us a step closer to raising £1 million

by the end of 2020 to fund vital research that could save lives.

Need some fundraising inspiration? Take a look at our top ideas, and our hints and tips on how to maximise your fundraising!

action.org.uk/GetFundraising





Sophia was not expected to live to see her second birthday

Developing a potential new treatment for spinal muscular atrophy

A week before her first birthday, Sophia was diagnosed with spinal muscular atrophy type I, a rare genetic disease that leads to the deterioration of the spinal nerves. Action-funded research hopes to add to emerging treatment strategies for this devastating condition.

Between the ages of six and nine months, Sophia's parents, Gennadiy and Vicky, noticed that she wasn't reaching the usual milestones.

Although she was happy and alert, she did not sit, did not crawl and didn't like being on her tummy. Following tests, the family was given a heart-breaking diagnosis.

Spinal Muscular Atrophy (SMA) is a progressive condition that leads to loss of movement and muscle wasting. There is currently no cure, and tragically babies born with the most severe types often die at a very young age.

"You face watching your beautiful child lose their abilities to move, eat and breathe," says Gennadiy.

Sophia was not expected to survive beyond the next 12 months. "We were told to take her home, love her, but don't get used to her," says Gennadiy.

Now four-and-a-half, Sophia defied these desperate odds.

A new drug – the first, and currently only approved treatment available – has significantly slowed the disease's progression and vastly improved her quality of life. But it's a treatment that the family, and others like them, had to fight for.

Prior to this, Sophia's health had been deteriorating dangerously. She'd lost head control, the ability to move her arms and would frequently choke on food. Having been almost paralysed, she has now regained strength in her hands and arms, and gained new abilities – she sits, plays and drives a little power wheelchair.

Sophia still needs a great deal of support with all the physical aspects of daily life. And, due to her muscle weakness, her respiratory system doesn't work well, so a simple cold can easily become a serious infection. "Everything is influenced by SMA," says her dad.

Sophia's parents are in no doubt that she is alive today because of

the new drug, called nusinersen. But it is not a cure – and nobody knows its long-term effectiveness. The future remains uncertain, and new treatments are still very much needed.

Together with SMA UK, Action is funding research led by Dr Melissa Bowerman at Keele University. This work is investigating if another drug, already used for other conditions, could help boost the effectiveness of new gene therapy treatments which are beginning to be used to treat SMA.

Medical research is a vital lifeline that Sophia's dad likens to a beacon of hope.

"Medical research is a glimmer of hope that families look to in their darkest hour of need"

Tackling new and emerging causes of meningitis

Most cases of pneumococcal meningitis are now caused by strains of bacteria not covered by existing vaccines. Action is supporting a nationwide study to improve understanding and treatment of these non-vaccine strains.

Pneumococcal meningitis is a potentially deadly illness caused by certain strains of pneumococcus bacteria. It most often affects babies and toddlers, and can have devastating consequences.

Sadly, up to one in seven lose their lives and a quarter are left with severe after-effects – including sight or hearing loss, seizures and learning disabilities.

Thankfully, vaccines now protect against the most common strains of pneumococcus bacteria. Part of the national immunisation programmes in the UK and Ireland, these have led to a rapid decrease in severe infections, including those which cause meningitis.

Led by Dr Godwin Oligbu, researchers at Public



Pneumococci bacteria can cause meningitis

Health England now want to find out more about cases caused by non-vaccine strains of bacteria.

They are analysing data from children diagnosed with pneumococcal meningitis across the UK and Ireland, and from laboratory analyses of biological samples to identify the bacteria involved. They are also studying symptoms and treatment received.

The aim is to identify opportunities for improving diagnosis and treatment, and develop new guidelines that reflect the changing nature of meningitis.

“Our results will enable us to make recommendations for future studies and interventions that can save lives and reduce complications,” says Dr Oligbu.



Pioneering ear reconstruction surgery

3D bio-printing could revolutionise ear reconstruction for children born with a missing or underdeveloped ear, offering a safer and less-invasive treatment option.

Microtia means being born with a small or missing ear and affects around one in 6,000 babies in the UK. As well as affecting their hearing, looking different can have a negative impact on a child's confidence and self-esteem as they grow up.

Existing reconstruction procedures involve removing cartilage from the ribs to create a new ear, and may be complex and painful. Mr Tom Jovic, a plastic surgery trainee at the Welsh Centre for Burns and Plastic Surgery and Clinical Lecturer at Swansea University, aims to develop an alternative.

The research group at Swansea University is currently using innovative 3D-printing technologies to create an exact replica of a child's missing ear – made from a

plant-based biomaterial loaded with the patient's own cartilage-producing stem cells.

Mr Jovic now plans to grow stem cells from human nose tissue in the laboratory, to work out the best way to encourage them to produce cartilage. He will also refine the biomaterial to ensure it has the best qualities for successful treatment and surgical implantation.

This Research Training Fellowship is supported by Action and the VTCT Foundation.



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

Helping children with serious head injuries

Traumatic brain injury is sadly common in children and is a leading cause of disability. A team of London researchers is building a better understanding of the long-term effects such damage has on brain development.

Usually caused by road accidents, sports injuries or falls, serious head injuries can cause lasting brain damage and have life-changing consequences. Some children will lose their lives, and some will be left with long-term difficulties such as learning disabilities or emotional or behavioural problems, such as aggression.

Unfortunately, it is currently difficult for doctors to predict the future effects of a moderate or severe injury on a child's brain development.

In previous Action-funded work, researchers studied a group of children with traumatic brain injuries. Using advanced MRI scans and detailed neuropsychological assessments, they identified specific types of injury that were linked with marked impairments in memory, concentration and behaviour in affected children.

Around
35,000

UK children are admitted to hospital each year with a traumatic brain injury



Now the team, based at Imperial College London, is assessing the same children again, along with a group of uninjured children.

They will see if the children's brains follow expected growth patterns over time, and assess how any changes affect behavioural development – and whether the location of a brain injury can predict the type of issues they go on to develop.

Professor David Sharp, who is leading the research says: "We hope to distinguish the early and later effects of their injuries on brain development – and identify specific changes that can help predict who will have long-term complications."

This project is being generously supported by Garfield Weston Foundation.



Help us fight a rare and incurable disease

Matilda was just five years old when she was diagnosed with Niemann-Pick type C (NPC), a life-limiting neurodegenerative disease. It was shattering news that left the family overwhelmed with anger and fear.

Over time, children with NPC develop major problems with their coordination and movement. Their vision can be impaired, and their intellectual abilities decline. Treatments are very limited and sadly many do not survive into adulthood.

Action is supporting an important two-year study to test the effectiveness of

a potential new drug treatment for NPC. This is an exciting collaboration, with Action Medical Research, the Niemann-Pick Research Foundation and Niemann-Pick UK funding this study, together with NPSuisse and Niemann-Pick de Fuenlabrada.

"This disease will try and take away abilities that Matilda has," says her mum, Georgina. "But we won't just sit back and let it happen. We need to fight against it."

Help support this research
action.org.uk/NPC



Elijah's special fund

When their premature baby son Elijah tragically died, Jenny and James Halse set out to raise £37,000 – £1,000 for every day of his life.



Baby Elijah was born extremely prematurely, at just 25 weeks and three days, in March 2013. Sadly, although his initial prognosis had been promising, he became desperately ill with necrotising enterocolitis (NEC), a devastating bowel disease.

His heartbroken parents, Jenny and James, decided to channel some of their emotion and grief into raising money in memory of their baby boy – setting themselves a target of raising £1,000 for every day of Elijah's life.

"The fund was a place to collect everyone's energy to make a difference," explains Jenny. "Elijah led a very traumatic little life. We hoped that through fundraising for Action Medical Research we could make a small difference in the care of other babies in a similar situation in the future."

Together with friends, family and members of their close-knit

Sheffield community, Jenny and James signed up to take part in their local Percy Pud 10K – an event that starts and finishes close to where Elijah is buried.

More than 50 people joined them to run in that first event. Some have returned every year since, running as Team Lightning – the nickname given to Elijah by one of his two older brothers because he'd been born so quickly.

Reaching, and now exceeding, their target understandably brings mixed emotions for the family. "It feels both wonderful and complex," says Jenny. "It's a link to those early dark days. But also gives us an easier way to talk about him. All parents want to talk about their children, it's no different when one has died.

"But what it really represents is love," Jenny reflects. "Nearly seven years of active, loving support

from countless people who have stood beside us. People who believe in the opportunity to change outcomes, who have run with us, run on behalf of us, or sponsored us every year," she says.

"We always say that as soon as he was born, Elijah was a team effort – and so it is with his fund. It's a huge team effort that saw us push through the target to more than £38,000."

You can find out more about in memory giving at action.org.uk/Remember

"If we can help make a small difference, it'll be another way to remember our beautiful baby boy"

Team Lightning has raised more than £38,000



“It was awful – first we thought he would die at birth, then he was well, and then he got NEC. We felt so helpless”



**BORN
TOO
SOON**

Tiny but tenacious

Born extremely prematurely, Wilfred was so very delicate his parents were unable to hold or even touch him for his first three weeks of life.

Wilfred is now a very busy toddler who's always on the go. For his mum Imogen and dad Euan, their little boy's sunny nature and enjoyment of life is especially precious because, born more than three months too soon, they feared they would lose him.

Imogen's pregnancy was progressing smoothly and all had seemed well, until labour pains started one night without warning.

Realising the pains were following a pattern, Imogen and Euan went straight to their local hospital. At just 25 weeks and four days into her pregnancy, Imogen thought she'd be monitored and then come home.

But it soon became clear that baby Wilfred was on his way – despite medics' desperate attempts to try and slow her labour.

"I was in denial more than anything," Imogen recalls. "I kept thinking he can't come, he can't come. But your body knows and in the end it was all very quick."

Wilfred was born weighing a tiny 2lb 6oz and within hours was transferred to another hospital where staff were more able to care for babies born before 28 weeks. Many weeks of anxiety were to follow for new parents Imogen and Euan.

Wilfred was tube fed and needed a ventilator to help him breathe. But despite this, he was initially considered to be doing well – something Imogen describes as a 'honeymoon period'.

However, tests soon found that sadly Wilfred had suffered a bleed into his brain around the time of his birth. Doctors warned that this brain damage could cause him to have cerebral palsy, and no prognosis could be given about how this might affect him.

At the same time, other concerns were mounting, as it was feared Wilfred had also developed the life-threatening bowel disease necrotising enterocolitis (NEC).

Premature babies are particularly vulnerable to this dangerous condition and swift treatment is vital. Aged just six days, Wilfred endured surgery to remove 25cm of his bowel and fit a stoma bag to manage his body's waste.

It was a deeply distressing time for the new family. "I cried a lot," says Imogen quietly. "We felt so helpless."

Wilfred stayed in hospital, more than an hour away from home, for four months. Finally, following a successful operation to reverse his stoma, he was ready to go home, weighing 7lbs.

After so much trauma, taking Wilfred home was joyful but terrifying: "You get so used to the hospital 'bubble' and all the support," says Imogen. "We were petrified. We really wanted to go home, but it was very daunting."

Wilfred, who recently turned three, has now been diagnosed with cerebral palsy but thankfully is mildly affected, leaving his left side a little weak. He wears a splint on his left leg and family life includes

regular orthotics appointments and physiotherapy.

He is a little behind his peers in terms of speech and vocabulary, but is very chatty: "He's a happy, determined little character and takes everything in his stride," says his proud mum.

For Imogen, the experience of premature birth left her with many questions and, as she bravely and honestly admits, feelings of jealousy and anger. Seeing pregnant women at full term was difficult: "Why did they get to full term, but not me?" she says.



Wilfred spent four months in hospital

During her second pregnancy, with Wilfred's baby sister Edith, Imogen did finally get some answers, when an issue with her cervix was discovered. But despite treatment to try and prevent another early delivery, Imogen's waters still broke at 33 weeks, meaning that Edith was also born prematurely.

Imogen is in no doubt that research to prevent premature birth is vitally important, so that other families might be spared the experiences hers has been through.

New research aimed at preventing premature birth

With your support, Action is funding research that aims to develop more effective treatments that could safely stop premature contractions, reducing the risk of early birth.

Although the causes of premature birth are complex, it often occurs because the mother goes into spontaneous early labour – like Wilfred's mum, Imogen.

Unfortunately, there are no treatments currently available that can reliably prevent premature contractions while being risk-free for mother and baby. For example, many drugs that work to reduce contractions may also relax blood vessels and affect blood flow to the womb or placenta, endangering the baby.

With Action funding a team of researchers, based at Newcastle University, is looking for new ways to

specifically target the muscles of the womb, without affecting its blood vessels or those of the placenta.

"We've recently established that these three tissues react differently to certain drugs, suggesting they possess key differences at a molecular level that we could potentially exploit," explains Professor Mike Taggart, who is leading this research. "We urgently need to develop safer, more effective treatments that can help stop premature labour."

Action is jointly funding this research with Borne.

**THANK
YOU!**

At Action Medical Research we fight for medical breakthroughs. We fight to help children like Wilfred.

Thank you for joining us and making this vital research happen.



"This work is really important – to know that research is trying to ensure that people don't have to go through premature birth"

Wilfred's mum, Imogen

A new target for treating leukaemia

With your support, a research team has identified a new target to direct treatment at and kill leukaemia cells. Their exciting results could lead to new ways of fighting the most common childhood cancer.

Acute lymphoblastic leukaemia (ALL) is a cancer of the blood and bone marrow, and most often affects very young children who are less than five years old. With today's care, most have a high chance of surviving. But treatment is tough, lasting several years and causing unpleasant side effects. Sadly, a small number of children will still die.

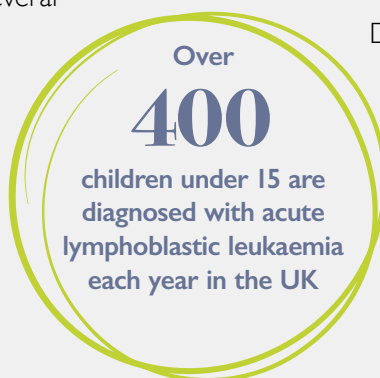
With Action funding, Dr Owen Williams and his team, at University College London's Institute of Child Health, focused on a mutated, cancer-causing gene – and how this hijacks the function of another healthy gene. This rogue gene, known as TEL-AML1, is present in up to a quarter of children suffering from ALL.

This work led to a better understanding of the disease biology – and the discovery of a signalling pathway that allows leukaemia cells to survive and multiply.



The team then showed in laboratory experiments that blocking this pathway causes patient leukaemia cells to die. This helped them identify a target for developing a drug treatment.

Significantly, it is believed these findings could be relevant to other subtypes of ALL – an exciting development that was unexpected.



Dr Williams says: "This would not only benefit children suffering from this subtype of leukaemia, but may also be applicable to a much wider range of leukaemias, including those that are more difficult to treat by standard chemotherapy."

The team is now working to identify existing drugs that could be repurposed to hit their new target.

If successful, they envisage clinical trials in patients within the next five years.

Action jointly funded this research with Great Ormond Street Hospital Children's Charity.

Gene therapy for a life-threatening rare disease

Moving closer to developing a life-changing new treatment for XLP, Action funding has helped power research towards a clinical trial in children due to start next year.

X-linked lymphoproliferative disease, or XLP, is a rare and life-threatening immune system disorder. It affects boys and, tragically, without treatment around seven in every 10 with the condition would die by the age of 10.

Medicines can help and bone marrow transplants can be a cure but rely on finding a donor who is a good match. Sadly, if transplants come too late or donors can't be found, boys with XLP remain at risk.

Building on earlier research, also funded by Action Medical Research, Professor Bobby Gaspar and Dr Claire Booth, of University College London's Institute

of Child Health, are developing a new gene therapy treatment. This involves replacing the faulty gene that causes XLP with a healthy copy.

Recent Action funding has enabled the team to modify the faulty gene in T-cells, from the child's own immune system, using a special gene transfer system. These modified cells have now been shown to correct some of the symptoms of XLP in the laboratory. Dr Booth says: "This would not have happened without Action funding – we have shown this approach can work."

Action jointly funded this research with Great Ormond Street Hospital Children's Charity.

Transforming the lives of children with severe dystonia

Action funding has helped to improve a surgical treatment that can dramatically improve the quality of life for children suffering from a condition that causes uncontrollable muscle spasms.

Dystonia is a serious and unpredictable movement disorder in which abnormal signals from the brain trigger uncontrollable, sometimes painful, spasms. It can cause repetitive movements and parts of the body may be twisted into unusual positions. Growth and development of muscles and bones can also be affected, leading to deformities.

Children with severe dystonia can find all aspects of life difficult, including walking, speaking and eating. Some suffer ongoing spasms, requiring heavy sedation and long hospital stays. For some it can even become life-threatening.

How we helped

In 2012 Action awarded funding to a team led by Dr Jean-Pierre Lin, a consultant paediatric neurologist at London's Evelina Children's Hospital. He sought to improve how a surgical treatment, called deep brain stimulation (DBS), was used to treat children suffering from severe dystonia. The method

involves the insertion of electrical wires into specific areas of the brain, through which electrical pulses are delivered via a battery to control the spasms.

With Action funding, the team took highly specialised scans to make maps of children's brains.

These new images helped to more clearly identify different areas which could be treated with DBS. They also helped doctors decide when, or not, it was a suitable treatment option and informed neurosurgeons of the best areas to insert wires.

These developments have improved the use and chances of success of DBS, and the techniques are now being used to help dramatically improve children's lives.

Children are already benefiting and, for most, there has been a clear and lasting improvement in their symptoms. Some have had astonishing results, such as being able to walk independently within two to four years.



THANK YOU!

Your support has helped refine this pioneering surgical technique which is already changing children's lives.

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

Dr Jean-Pierre Lin (left) and neurosurgeon Professor Keyoumars Ashkan (right), with Martin, Charlotte and Edward.



Edward with dad Martin and mum Charlotte

Edward's story

Edward developed debilitating dystonia when he was 16 months old – and his case was one of the worst doctors had ever seen.

Edward is now a happy, energetic eight-year-old. He's in mainstream school and runs around in his walking frame. "He plays football twice a week," says his dad, Martin, proudly. "And comes home with bruises where he's fallen over, chasing his friends."

But five years ago, life was very different. Edward had been a healthy baby but then things took a terrifying turn for the worse. His parents, Martin and Charlotte, noticed he was struggling to stand up, so took him to a GP.

Edward's condition went rapidly downhill. Within a few months the toddler, who had previously

started walking and saying his first words, could no longer lift up his arm to take a toy. He could no longer sit up, and then no longer eat.

He now had severe symptoms of dystonia and needed 'huge volumes' of medication to keep him comfortable. "If he wasn't medicated or asleep, he was in rigid posturing, in pain and crying," recalls Martin.

"To sit him up, he'd need his waist, legs, arms and head strapped into place. He was in incredible discomfort, and being fed through a tube. It was a terrible time."

After many tests, Dr Lin and his team decided that Edward was suitable for DBS surgery, which took place just after his third birthday.

"It's a phenomenal transformation. I'll never be able to put into words how grateful we are"

Edward's dad, Martin

It was more successful than his family dared believe possible. Within a day of the operation, Edward's medication was halved.

"We saw immediate improvements, followed by more gradual ones over time," explains Martin.

"The original goals were blown right out of the water. Edward has had one of the best responses to surgery, having had one of the worst manifestations of dystonia."

10 amazing years of the CycleSport Dinner

Attracting some of the biggest names on two wheels, our Champions of CycleSport dinner has raised £1.8 million over the last decade.

Held in London, and generously supported by Garmin, BDO and Rouleur, 2019's 10th anniversary event saw more than 400 guests rub shoulders with some of cycling's elite – including Olympic and World Track champion Dani Rowe MBE, who has attended almost every dinner since the start.

And, as always, there was also the chance to bid on some fantastic dream auction prizes for cyclists.

The next Champions of CycleSport Dinner will be held on Thursday 3 December, and we would love to break the £2 million raised mark! For details visit action.org.uk/champions



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

Corporate supporters in action

Company support makes a crucial contribution, allowing us to fund more research to help sick babies and children.

We were delighted to win a staff vote and secure the continued support of **Liberty Specialty Markets**.

This relationship has already generated more than £100,000 over the last three years and includes an annual donation, runners in the London Marathon and office-based fundraising.



We've also been chosen as **DMH Stallard's** Sussex Charity of the Year. The law firm, which has offices around the county, is supporting us in a number of

ways, and we're grateful to our good friend Richard Skerritt, of Skerritt's Consultants, for introducing us.

Davina McCall attended the annual **GFI Charity Day**, which meant Action benefited from more than £50,000 in donations for the fourth consecutive year. The event commemorates the 9/11 disaster by raising money for good causes from the trading floors in the City. Some of our lovely families who support us, like Freya's (pictured), also attended.



Businesses on bikes



Fundraising on two wheels is something of an Action speciality and we run a number of corporate cycling events each year. These include a 200-strong staff and client networking ride for **Willmott Dixon** in Hertfordshire, the **Aon Insurance** ride in Essex and the **Garmin Ride Out** in the New Forest.

In 2019 our third construction industry event, Ziggurat, saw another 60 riders head to France. Generously sponsored by **Grafton, Brett** and **Finning CAT**, this ride has now raised more than £300,000. And new for 2020 is our first insurance industry-led event, Raptör, kindly sponsored by **BRIT**, taking another 60 riders from London to Paris.

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!

Beth's big run for babies born too soon

Mum-of-two Beth says she's 'not a natural runner' but the traumatic early birth of her eldest daughter has inspired her to take on the challenge of the London Marathon.

As this issue went to press, Beth Wood was in her final weeks of training for the Virgin Money London Marathon. "Friends who've known me for years are shocked – one actually said the Beth he knew wouldn't run for a bus!" she jokes. But Beth has a very precious reason for pushing herself through those long winter training runs.

In September 2015 her eldest daughter, Bronwyn, was born nine weeks early, weighing just 2lb10oz. Beth had developed severe pre-eclampsia and was dangerously ill, so Bronwyn was delivered by emergency caesarean.

Remembering seeing baby Bronwyn in neonatal intensive care, Beth says: "There was a little teddy inside the incubator that my mum had quickly bought from

the hospital shop. She wasn't much bigger."

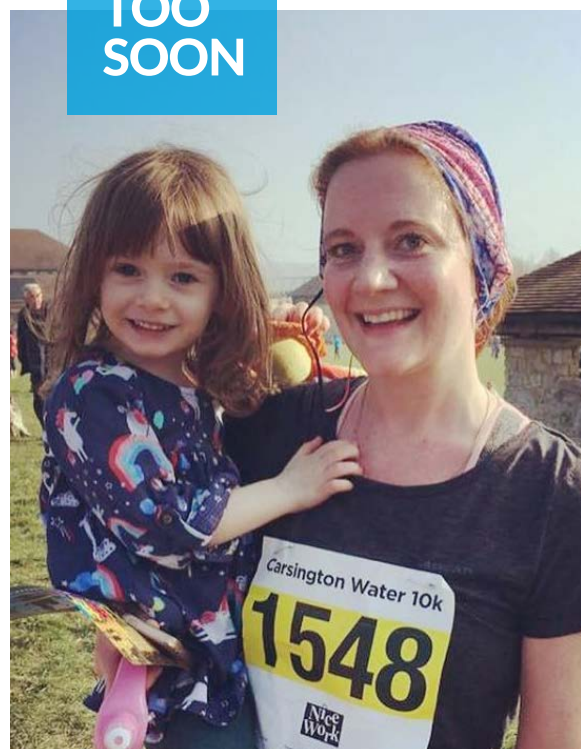
Tiny Bronwyn was transferred the night she was born to a hospital two hours away, and it would be almost a week before the family were reunited. "My husband, Simon, would call me with updates but I felt useless," says Beth. "I was terrified she'd die and I wouldn't be with her. I also had an overwhelming sense of failure – I'd not kept her safe, my body had let her down."

Thankfully, Bronwyn only needed a ventilator initially and was otherwise healthy, though very small. Beth says they feel very lucky that she's suffered no long-term health issues. "Bronwyn is now an intelligent, energetic and sometimes infuriating four-year-old, thanks to the amazing medical care we received," she says.

"Medical research has developed so much in the last few decades," adds Beth. "Helping to improve the chances for premature babies is something I really want to help with."

"A child has so much to give to the world, they should be given every chance possible"

**BORN
TOO
SOON**



Scones that save lives

Join us for our easiest, tastiest, summer fundraising event on 25 June.

Our Action Cream Teas boxes are filled with everything you need for the perfect summer tea break, all delivered direct to your door. All you need to do is get a group of friends, family or work colleagues together and place your order online. Best of all, every scone savoured helps us fight for little lives, so please join in.

Order online at: action.org.uk/tea





Challenge Events

RUNNING

- 26 April** Virgin Money London Marathon
- 23-24 May** Edinburgh Half Marathon, 5k and 10k
- 25 May** Vitality London 10,000

CYCLING

- 19 April** Vyking Ride, York **NEW**
- 3 May** Castle Ride 100, Kent
- 17 May** Suffolk Sunrise 100
- 9-21 June** Land's End to John O'Groats
- 14 June** Davina's 10th Anniversary Big Sussex Bike Ride
- 5 July** Maratona dles Dolomites
- 15-19 July** London to Paris with Sean Yates
- 16 August** Prudential Ride London-Surrey 100
- 6 September** Essex Ride 100

TREKKING

- 13-14 June** Snowdon by Night
- 28-30 August** Yorkshire 3 Peaks Weekend
- 4-6 September** Jurassic Coast Weekend

TEAM CHALLENGES

- 12-13 June** Race the Sun Brecon Beacons
- 4-5 September** Race the Sun Lake District

For more details and to register visit

action.org.uk/events
or call: 01403 327444
or email: events@action.org



Treble the fun, Race the Sun

Take on an incredible team race through majestic mountains and sprawling lakes. Enter as a team of four in our dawn-to-dusk, triple challenge event, where you'll cycle, hike and canoe together. On 13 June in the Brecon Beacons mountain range, South Wales, or 5 September in the heart of the beautiful Lake District National Park, a UNESCO World Heritage Site. Push your limits to complete the course of cycling, canoeing and hill walking between dawn and dusk – racing the sun!

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

Ride for a reason in 2020

Fancy a great day out in the saddle? Join us at one of our one-day cycling sportives across the country, taking place in Essex, York, Suffolk, Sussex and Kent. Or grab yourself a place in the UK's premier sportive, the Prudential Ride London-Surrey. Enjoy excellent cycling terrain while raising funds for vital research for sick babies and children. Our Ride 100 series has various route options to choose from, which will see you cycling from 21 up to 102 miles in one day, with first-class event support to take you on a great cycling journey.



Our cycling season starts this month with the new **Vyking Ride**, formerly the York 100. We have a fantastic new ride venue for 2020, the beautiful Ampleforth College, and a tough but spectacular new route.

Plus this summer we'll be celebrating the 10th anniversary of our annual ride with Davina McCall, our wonderful charity ambassador. Join us for **Davina's Big Sussex Bike Ride** on 14 June.

