action medical research for children

Spring/summer 2021

The Action Medical Research magazine

"Research is a lifeline, it gives us hope" Read Sophia's story about life with cystic fibrosis

Plus

COVID-19 and children: important new work funded Our impact:

Developing a cure for a life-threatening rare disease

From the editor

Dear Supporter,

As this issue of *Touching Lives* goes to press, we're all taking the tentative first steps towards emerging from the latest lockdown. This last year, especially now with the rollout of vaccines, has been a stark reminder of the huge difference medical research can make. Right now, the whole world is relying on the breakthroughs needed to help us live alongside COVID-19.

Sophia's story page 8

With your support, we're proud to be helping to ensure that children are not forgotten in the response to the pandemic. New research is already underway, which you can read about on page 4.

We hope you'll also enjoy reading about other projects made possible by your support. These include a study to help children with cerebral palsy participate in exercise, which is already making children, like lan on page 5, smile. Plus research to help children with cystic fibrosis, which affects our young cover star Sophia.

We're also delighted to share how Action funding has led to a new treatment being ready for trial in patients. This could have a life-changing impact on families facing the rare disease XLP.

We hope this year to get back to some of the fun and fundraising we know and love – please get involved if you can. Your support can make big breakthroughs happen.

Thank you, Clare Airey, Editor



Action Medical Research is the leading

children's lives through medical research.

Touching Lives is Action Medical Research's magazine

Front cover photo: Supplied by Sophia's family

UK-wide charity saving and changing



Events page 16

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We are keen to share, but you must ask first! If you see an article or a picture you would like to copy or reproduce for use elsewhere, please contact the editor.

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We'd love to see you back in

action with us this summer!

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Touching Lives is also available to download at action.org.uk





Continuing to bring hope to families

Despite the challenges of the past year, we remain resilient and committed to doing all we can to help sick babies and children. Thank you so much for your support.

The past year has been one like no other. The coronavirus pandemic saw research projects put on hold and many of our fundraising events cancelled or postponed. But, thanks to your ongoing support, we were still able to fund eight new research projects in 2020, and have just announced another 10 new projects that we're funding this year. These include five new studies to better understand the impact of COVID-19 on babies and children, which you can read more about on page 4.

We're also proud to be continuing our partnership with British medical research charity LifeArc, to fund over £1m of research to help children with rare diseases – and you can read about one of the latest projects on page 6.

We also continue, with your help, to fight for babies born too soon and to shine a spotlight on the devastation caused by premature birth.

Although many of our usual bike rides, team challenges and social events were cancelled in 2020, we adapted and developed new virtual ways to raise awareness and income, including online events like

My Cream Tea

Given the current challenges, we have

for supporters.

Editor: Clare Airey

Print: Newman and Thomson

Design: Paige Bowring-Martin

Davina's Night In last November, hosted by our wonderful Ambassador Davina McCall.

We're now looking forward to a vibrant summer and autumn of cycling, challenge and social events, all helping to support the charity and continue to raise funds for vital medical research to save and change children's lives. Please join us!

As many of you know, this is usually the time we would be sharing with you news about how you can order your Action Cream Teas in a box, delivered direct to your workplace or home.



taken the difficult decision to postpone this but hope to return in 2022. If you still want to enjoy a scone or two, we challenge you to get baking and host your very own cream tea! Find out more action.org.uk/mycreamtea

Protecting babies and children from COVID-19

Thanks to your support, we're funding five new research projects to better understand the impact of COVID-19 on babies and children. This work is vital to ensure they are not forgotten in the fight against this virus.

COVID-19 can affect children, sometimes with devastating consequences, and there is much still unknown about the risks in pregnancy and to babies. That's why last summer we launched our COVID-19 children's research appeal, to fund vital research across the UK – research that is now getting underway.

While children are generally less affected, some sadly develop severe COVID-19 and become critically ill with a much wider range of symptoms than adults – a rare condition known as Paediatric Multisystem Inflammatory Syndrome (PIMS). These children can face lasting problems that impact their health and wellbeing.

"We hope to identify risk factors that can affect disease severity and outcomes in children "

Dr Nazima Pathan

Based at the University of Cambridge, Dr Nazima Pathan aims to identify biological factors that affect a child's risk of becoming very ill as a result of COVID-19. This could lead to earlier and more personalised treatments to help give these children the best possible outcome.

This research also expects to uncover new knowledge about why children are generally better protected from the virus than adults – information that could help now and in fighting future pandemics.

Infection in pregnancy

We're also funding new research that could inform how to protect pregnant women and their babies from any potential risks from the virus, both now and in the future.

It's thought that thousands of pregnant women in the UK are likely to have been infected with the virus that causes COVID-19, many with no symptoms. Professor Kirsty Le Doare, at St George's University of London, is leading a study that aims to screen women from

Your support makes research happen

Thanks to supporters like you, we've been funding research to develop breakthrough treatments, vaccinations and cures for <u>children for</u>

nearly 70 years – and our response to this pandemic is no

different. We need to raise $\pounds 1$ million to help drive forward our new COVID-19 research.

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



hospitals across England to identify how many have been infected – and whether the virus or protective antibodies are passed from mother to baby during pregnancy, delivery or breastfeeding.

"We hope that our findings will help to reassure pregnant and breastfeeding women about how to safely care for their babies. It will also help inform future decision-making about vaccinating pregnant women to help protect them and their babies from infection," says Professor Le Doare.

Read more about this and other new COVID-19 research at action.org.uk/tacklingCOVID

Helping children with cerebral palsy

RaceRunning, a sport for people with disabilities, has had a big impact on lan, who is nine. He's enjoying regular coaching sessions through a pilot study made possible with Action funding – and his potential as an athlete is already shining through.

Cerebral palsy is the most common serious physical disability in children and affects many babies who were born prematurely, as lan was.

lan's cerebral palsy affects one side of his body, causing difficulties with muscle strength, stiffness, balance and coordination. He uses walking aids and, part of the time, a wheelchair.

Ian has always loved trying out new sports and in August 2019 his mum Sheena came across RaceRunning, an innovative sport for people with impaired balance. It involves using a custom-built tricycle without pedals. "Ian has really taken to it and he loves to compete," says Sheena proudly.

The group lan trains with is part of a pilot study funded by Action and the Chartered Society of Physiotherapy Charitable Trust. Led by Dr Marietta van der Linden at Queen Margaret University in Edinburgh and Dr Jennifer Ryan of Brunel University in London, this research is investigating the potential health benefits of RaceRunning for children like lan. Children with cerebral palsy can find it challenging to take part in physical activities. This can lead to a lack of exercise that starts in early childhood and persists throughout their lives.

"It gives children physical independence and a sense of achievement. Their faces light up"

Low levels of physical activity can impact on a child's everyday mobility and quality of life. It also increases their risk of developing certain diseases, such as heart disease and type 2 diabetes which are more common in people with cerebral palsy. "Finding new ways to increase exercise in children with moderate to severe cerebral palsy could have long-lasting positive effects on their health and wellbeing," says Dr Ryan.

For Sheena, it is the inclusive. freeing aspects of RaceRunning that make Cerebral palsy the most difference to affects around children with disabilities: "When I see the children there, their faces light up. It's giggle, babies born in the giggle the whole time. UK each year RaceRunning gives them physical independence and a sense of achievement," she says.

"It takes the worries away. Children can simply be in the moment, enjoying independence and having fun, as well as developing physical strength. It's also about breaking down barriers and giving children a sense of belonging."



Improving pregnancy care for cancer survivors

Doctors suspect that women who had a bone marrow transplant as a child face a higher risk of pregnancy complications and premature birth. New research is investigating this further.

Thanks to advances in treatment and fertility technologies like IVF, more childhood cancer survivors than ever before are reaching adulthood and starting families of their own. But sadly it's believed that women who've had a bone marrow transplant are more likely to experience problems during pregnancy, especially if they also had radiotherapy to their womb area. This includes a high risk of having their babies very early.

Dr Melanie Griffin, based at University Hospitals Bristol NHS Foundation Trust, is investigating further. Using data from population studies, her team will study pregnancy complications experienced by women who had a bone marrow transplant when they were younger. They will also



see if this still increases the risk of preterm birth even when women did not have radiotherapy to their entire body.

Researchers will then look at what care is currently given to affected women and develop recommendations for the future.

"If we can prove that these women have an increased risk of pregnancy problems, they could be offered specialist care before and during pregnancy to reduce the risk of their babies being born too soon," says Dr Griffin.

This research is jointly funded in partnership with Borne and with generous support from The James Tudor Foundation.

in the

blood

and

Fighting a potentially deadly heart condition

Hypertrophic cardiomyopathy is a leading cause of sudden cardiac death in young people. New research aims to improve diagnosis and monitoring.

Hypertrophic cardiomyopathy is an inherited condition that causes thickening of the heart muscle. Although it is rare, and may cause no symptoms, sadly it can cause heart failure and sudden death.

Current treatments can help manage the condition but do not target the underlying cause, or prevent it developing in those known to be at risk.

Dr Juan Pablo Kaski and his team, based at University College London, want to gain a better understanding of the early features of the disease and how it progresses over time.

They have recently developed a simple blood test to diagnose the condition in adults and measure disease severity. They will now see if this test also gives accurate results in children, including those who are known to be at risk but have not yet shown symptoms.

The researchers also aim to identify new biomarkers

Hypertrophic cardiomyopathy affects around children and young

urine that people in the UK are specific

- to children. and correlate these with disease
- severity and progression.

This could result in faster and cheaper diagnostic tests, new tools to monitor the disease and ultimately new treatments.

This research has been jointly funded with LifeArc.

Write or update your will for free

Paula, who works in Action's fundraising team, explains why she made her will using our free will offer, and how it has helped to bring her peace of mind.

"I've seen the impact of someone dying without a will, and I wouldn't want to put anyone through that," says Paula. "I made a will about fifteen years ago, when my children were small, but it needed updating so I jumped at the chance to use Action's free will offer. Naturally, I trust the charity, and it's a great offer so it was an easy decision."

A few days after completing the request form on the Action website, Paula received her free wills pack in the post."We chose a local solicitor from the list in the pack and it couldn't have been easier, even during lockdown!" she explains. "We had a video call with the solicitor where she talked us through writing the will. We then received a draft version in the post so we could check it and after making a couple of changes the solicitors posted us the final will to sign."

Despite lockdown restrictions, Paula managed to have her will witnessed safely."My neighbours looked in through the window to witness me signing the will, and then I passed it through the window to them so they could sign it using my car bonnet!" she says."We completed the whole process without even leaving the house. It was very straightforward even in these strange times."

Paula decided to include a gift to Action in her will, saying: "By providing this service, Action have helped us to make sure everything is in place for our children if anything were to happen and we felt it right in

return to leave a gift which the charity can use to help fund future research for children. Who knows, it may even help a future great-grandchild somewhere down the line! I would absolutely recommend the free will service to others. It was so easy to do and is a big weight off my mind."

Writing a will is something we all need to do, but it's easy to put it off until later. Our free will-writing service enables you to make or update a will, either through a local solicitor or online at home. If this has been on your to-do list for a while, we hope this will help you.

You do not need to leave a gift to Action to use this service, but many people do choose to donate a percentage of their



estate to fund future medical research for children. We are very grateful for all gifts made this way.

Visit action.org.uk/freewilloffer for more information or call us on 01403 327413.

"It was so easy to do and is a big weight off my mind. It may even help a future great-grandchild"

Research is a lifeline for families like Sophia's

Sophia is a lively toddler but because she has cystic fibrosis, her daily life revolves around physiotherapy, treatments and medications. The constant risk of infection damaging her lungs has also made the COVID-19 crisis an especially scary time, as her mum Sarah explains.

Two-year-old Sophia is a spirited and curious toddler who loves music and dancing. Watching her playing with her older brother Thomas is a simple but profound joy for Sarah and her husband Sam. Sophia's diagnosis with cystic fibrosis at just two weeks old was, her mum says, a horrendous shock.

"When the midwife phoned to say newborn screening had raised some concerns, she asked me, is your partner in?" Sarah recalls, "I knew then that something was seriously wrong."

Children with cystic fibrosis experience a range of symptoms including a persistent cough, shortness of breath and frequent

chest infections, caused by sticky mucus clogging their lungs and airways. Medications and physiotherapy can help ease symptoms but sadly there is currently no cure.

"It was a strange kind of grieving. You're mourning a life you thought was going to be"

It was incredibly hard to process the difficult news, "We felt very vulnerable and anxious."



Ready for the beach, Sophia's safe space, with brother Thomas

remembers Sarah."Sam and I both felt it was a strange kind of grieving. No one had died, but you are mourning a life you thought was going to be, while having to come to terms with the reality that you may outlive your child – and you're feeling all these things whilst holding your tiny baby."

The future can seem very frightening: "Instead of wondering what they'll be when they're older, you're wondering if they are going to be here and living a quality life."

Sophia's condition requires constant care. From just six weeks old, she has received daily physiotherapy to help clear her lungs – and, if she becomes poorly, it's needed more often. She also needs enzyme treatment before and after every meal to help her absorb nutrients, plus three vitamins, antibiotics to help prevent infection and a drug called Orkambi, which is seen as a game-changing recent development in the treatment of cystic fibrosis.

Shielding from COVID

The start of the pandemic was a frightening time. Nobody then knew how the new virus might affect children with cystic fibrosis, so Sophia was classed as extremely clinically vulnerable.

"Sophia had to be shielded and we all had to shield with her. Normality was stripped away. We only felt safe in our house," says Sarah, who also stopped working as a nurse.

Confining a two and a four-yearold to the house for months on end was incredibly hard."We've always been determined that Sophia will not be defined by her illness, but being confined indoors, you become cystic fibrosis," she adds.

Thankfully, Sophia is well most of the time but the impact of cystic fibrosis on family life is enormous. "You have to discover a new normal," explains Sarah.

"It is all about managing risk. For instance, although both children love jumping in puddles, this is something we can't do as a family anymore, due to the risk of infection reaching Sophia's lungs. It's really hard managing things like this."

"Due to the salt water, the beach has become our safe space. We have, without realising it, made so many changes to our everyday life, to keep Sophia as safe as possible."

Bubbles make physiotherapy to clear the chest a little more fun for Sophia



Cystic fibrosis is the UK's most common life-threatening inherited disease. With your support, Action is funding research to develop new treatments and therapies to give affected children the best possible quality of life.

Thanks to medical progress already made, life expectancy for people with cystic fibrosis is improving but sadly it still claims the lives of two people every week in the UK.

Children with the condition face a range of challenging symptoms. The lungs are particularly affected, and over time mucus can block and damage the airways, leading to repeated infections and making it hard to breathe.

Action funding is helping researchers develop new ways to prevent lung damage, and fight infections that are dangerous for children with cystic fibrosis.

Research teams at the University of Oxford and University of Liverpool have focused on tackling

infections caused by Pseudomonas aeruginosa bacteria, which are a major threat.

While at UCL Great Ormond Street Institute of Child Health, Professor Stephen Hart and his team aim to develop a new type of treatment that could correct the mucus problem in children with cystic fibrosis, restoring normal function in their lung cells.

"We hope that our work will lay the foundations for a new inhaled gene therapy that can one day dramatically improve the lives of children born with cystic fibrosis," he says.

These research projects have been funded together with the Cystic Fibrosis Trust.



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

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

"Research into cystic fibrosis is so important - it's a real lifeline. It gives us hope"

Sophia's mum, Sarah

Future hope for children like Lily

Thanks to your support, research has revealed vital information to help fight a devastating rare brain disease and identified potential drugs that could help treat it.

BPAN or, to use its full name, beta-propeller protein-associated neurodegeneration, is a progressive, life-shortening condition. In their early years, affected children suffer severe developmental delay. Then sadly, in their teenage years they develop symptoms of dementia and Parkinson's disease.

Families like Lily's, pictured, face a future of unimaginable heartbreak, as there are currently no treatments that can improve or cure this cruel disease.

In 2016, Dr Apostolos Papandreou was awarded an Action Research Training Fellowship to study BPAN. He and his team created a BPAN brain cell model, derived from cells taken from patients, including Lily. This allowed them to study the processes that damage the brain cells – and to test correcting the gene fault that causes this. The team also used these cells to test the

Crohn's and colitis findings for children

Results of Action-funded research have immediate implications for how best to treat children suffering from inflammatory bowel disease.

Inflammatory bowel disease (IBD), like Crohn's and ulcerative colitis, causes debilitating symptoms - and the number of children affected is increasing.

identify those at greatest risk of developing severe disease by analysing certain blood cells. So, with Action funding, Professor Matthias Zilbauer and his team, at the University of Cambridge, wanted to see if this test also worked for children.

The results were unexpected, with the marker predicting disease severity in adults not found in children. The study also found that IBD in children



effect of thousands of drugs and have identified which might be beneficial. These will now be tested further, in the hope they can be used in the near future.

This work was co-funded with the British Paediatric Neurology Association.

"Medical research like this is vital. Other children might benefit through Lily. We're so proud of her" Lily's dad, Simon

- "Our findings are of major importance as they strongly IBD behaves in children compared to adults," says Professor Zilbauer.

This work is set to have immediate clinical impact, having shown the test may not be suitable for prognostic test, more aggressive treatments should be considered sooner for all children, given that their disease is likely to be more severe.

More than people in the UK have Crohn's or colitis

Developing a cure for a rare disease

Your support has helped drive forward research to develop gene therapy for XLP, a life-threatening rare immune system disorder. This new treatment is now ready to begin clinical trials in patients.

Thousands of families across the UK are dealing with the fact that their child has a rare disease for which there is no cure, and no or limited treatments. Rare diseases are often life-changing and put an incredible strain on families.

X-linked lymphoproliferative disease, or XLP, is one such condition. It is caused by a single faulty gene and usually only affects boys. While very rare, it can have devastating consequences as the immune system is unable to function properly. Boys with XLP suffer recurrent infections, a third develop a type of cancer called lymphoma and many develop a life-threatening immune system over-reaction, which can be fatal.

Currently, the only cure is a bone marrow transplant, but finding a well-matched donor, at the right time, isn't always possible. Sadly, many lose their lives. More options to treat and cure this disease are urgently needed.

How Action helped

Between 2013 and 2020 Action awarded two grants, totalling more than £270,000, to support the development of a new treatment for XLP. The second of these was co-funded with Great Ormond Street Hospital Children's Charity. With this funding, Professor Bobby Gaspar and





"This work would not have happened without Action funding" Dr Claire Booth

Dr Claire Booth, based at the UCL Great Ormond Street Institute of Child Health, have developed a new gene therapy to restore immune system function in affected boys.

Professor Gaspar explains: "XLP is a genetic disease. We know which gene causes it and we know what that gene does. Our new treatment will involve putting a healthy copy of the gene into the cells in the body that need it."

The key benefit of gene therapy is that it uses the child's own cells, meaning there's no need to find a donor. There's also less need to suppress the immune system to avoid post-transplant rejection and other serious complications.

The new treatment uses T cells, a type of white blood cell, with the team's first Action-funded research showing this approach could work to fix some of the important immune system problems associated with XLP.

Based on these promising results, further funding was awarded, allowing the team to carry out further laboratory experiments - modifying patient's own T cells, refining their techniques and gathering more evidence on the safety and effectiveness of the new treatment approach.

This work again proved successful, and the next step is to now transplant corrected cells into patients in a clinical trial. The ultimate hope is that this will allow boys with XLP to live normal lives.

"We're not just trying to make these children a little bit better. We are trying to cure them," says Professor Gaspar.



The Hartley family's story

In 2003, David and Allison Hartley were told that all four of their sons had XLP.

loshua was then 12, Nathan 10, Daniel eight and Luke just four. Bone marrow

Without treatment $70^{0/}_{0 \text{ boys}}$

with XLP lose their lives by age 10

transplants were the only treatment and without them the boys were unlikely to survive their teenage years.

"The news was numbing," recalls David. "While the eldest boys had suffered some significant medical problems previously -Nathan had lymphoma at age three and Joshua had severe anaemia – nothing could have prepared us for the devastating news."

Their diagnosis saw the start of a high-profile, race-against-time hunt for suitable bone marrow donors. This would be followed by years of tests, operations and hospital stays.

Thankfully, all four boys eventually had successful transplants but their treatment was long and gruelling. While Nathan and Daniel made full recoveries, Joshua and Luke suffered severe complications. Luke needed a second operation after his first transplant failed, and both he and Joshua have endured chronic graft versus host disease. This occurs when the donor's T cells (the graft) view the patient's healthy cells (the host) as foreign, and attack them.

"Back when our boys were diagnosed, gene therapy was the great hope for the future," says David. "It will be a happy, happy day when it reaches

patients and will make a tremendous difference to affected families around the world."

"It will make a huge, huge difference to any boy facing XLP"

David Hartley



Your support has helped fund the development of a vital new treatment, with a trial in patients due to start soon.

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

Cycling champs return

Plans are underway to make this year's Champions of CycleSport Dinner the best yet!

Having missed out on one of our biggest fundraising events of the year in 2020, we're looking forward to an extra special Champions of CycleSport Dinner this autumn.

This night is a chance to celebrate all that is great about cycling, with around fifteen champion riders expected to join us. Past guests have included some of the biggest names on two wheels like Geraint Thomas, Sir Chris Hoy and Chris Boardman MBE.

We're delighted to already have generous support from title sponsors Garmin and support sponsors BDO.

The event returns to the Hurlingham Club in London on Thursday 18 November and tables are already selling fast! For details and more opportunities to get involved visit **action.org.uk/champions**

Rowing for babies like Elijah



GARMIN.

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Businesses in action

We're so grateful to the companies

who've supported us over this

Thanks to the amazing staff at

or cycling!

difficult last year, especially those

who've recently contributed to our

construction company Polypipe, who

recently took part in a five-week

fundraising challenge to collectively

race across the world, covering 25,000

miles in five weeks by walking, running

Law firm **DMH Stallard** have backed

kind donation. And long-term friends

us for the third year running with a

APH have also given their support.

We're also excited to have recently

with Touchstone Underwriting.

They already have great plans

social restrictions allow.

launched a three-year charity adoption

underway for some virtual challenges,

along with many other activities once

COVID-19 children's research appeal.

Rochelle Gilmore at the 2019 event

This December, Team Elijah's Star will embark on an epic

challenge to row across the Atlantic Ocean in just 37 days.

Elijah's Star is a four-man crew aiming to raise \pounds 100,000 for Action as they set their sights on completing a 3,000-mile Atlantic row, battling waves of up to 20 feet, in a 28 × 5-foot boat. The crew will push their personal boundaries by rowing and sleeping continuously in two-hour blocks, enduring sleep deprivation and salt sores, with physical limitations being broken on a daily basis.

They're rowing in memory of baby Elijah. He was born at 25 weeks and three days, weighing just 823g and lived for just 37 days. Subsequently 37 has become an important number for the team, who are aiming to make the crossing in just 37 days.

Crew member Dean Frost says: "We are taking on this epic journey to shine a light on the impact of premature birth and to encourage others to support Action. Financial support is great and donations can be made through either our website or through Action's. There's also the opportunity to spread the word, share your own premature birth story, attend events and cheer us along on social media."

Action is delighted to have recently secured sponsorship for Elijah's Star from Campbell Johnson Clark, leading advisers in the shipping sector. **Find out more at elijahsstar.com**

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



Cycling for babies like Sonia and Sophia

Last year's lockdown saw Adrian Orban rediscover his love of cycling and he signed up for this year's London to Paris ride. He's riding for a reason – his daughter Sonia was delivered prematurely and sadly her twin sister, Sophia, didn't survive.

"I will never forget April 28 of 2016," recalls Adrian. "It was about 11am when my wife, Amelia, called to tell me that doctors needed to start emergency birth procedures. It was a twin pregnancy, but they could only hear one heartbeat."



Amelia was already in the operating theatre when Adrian arrived at the hospital just half an hour later. Sonia was delivered safely, four weeks early, but sadly Sophia hadn't survived.

Adrian saw Sonia for a few moments while she was measured and weighed after birth. But it was several hours before the family were together, as Amelia recovered from surgery. They would soon be separated again, as Sonia was transferred to another hospital for a blood transfusion and specialist care.

"I was only able to visit her once a day," says Adrian. "It was horrible knowing she was there by herself, while her mum was in recovery somewhere else."

It was a time of very mixed emotions: "But we both believe that given the circumstances Sonia was born in, we had to have a positive attitude and didn't have the time to think about anything else but to see her safe,'' says Adrian.

Sonia thankfully recovered well from such a traumatic start. She is now about to turn five and, says her proud dad, is full of energy, extremely sociable and very keen to do her schoolwork, which has been helpful during the recent lockdown.

It was the first lockdown that saw Adrian get back into cycling. Finding himself furloughed, he bought a bike trailer and took Sonia and younger brother Luca out every day. "Pulling 40kg after the bike on a daily basis helped me lose 10kg!" he laughs. When the children returned to nursery in the summer, he went on longer rides.

New to Action, Adrian saw the London to Paris ride advertised on Facebook and was tempted. Then Amelia realised the charity funded research to help premature babies.



15

"Seeing all those babies in the incubators was something I never thought I'd see in front of my eyes," says Adrian. "You can truly understand someone's pain when you're in their shoes, and there we were. I want to raise as much as possible to help others."

"Seeing all those babies in incubators was something I never thought I'd see in front of my eyes"

Feeling inspired?

There are many ways you can still support us. See back cover for latest events news – and our Events team would love to hear your own ideas.

Challenge Events

2021

CYCLING

RIDE Castle, Kent 9 May RIDE Suffolk 30 May RIDE Davina's Big Sussex Bike Ride 13 June RIDE Essex 5 Sept RIDE Vyking, York 19 Sept NEW Maratona dles Dolomites -Enel 4 July SOLD OUT London to Paris 14-18 July

RUNNING

Vitality London 10,000 31 May

Virgin Money London Marathon 3 Oct 2021 or 24 April 2022

TEAM CHALLENGES

Race the Sun, Dawn to Dusk Triple Challenge: Brecon Beacons 12 June SOLD OUT Lake District 11 Sept SOLD OUT Lake District 18 Sept EXTRA DATE

TREKKING

Snowdon at Night 18 Sept and 16 Oct National Three Peaks Challenge various dates

VIRTUAL EVENTS

BIG Steps for Tiny Lives, plus more see action.org.uk/virtual

Back on the bike

With the fightback against COVID-19 underway and the rollout of vaccines, we can begin to think about getting back to doing the things we love. Last year showed that even with restrictions in place we were able to safely put on two of our UK rides in October, and we're more than ready to go again!

The RIDE series offers something for cyclists of all abilities, set against stunning country backdrops – from the



flat, forgiving terrain of the long-running RIDE Suffolk to our toughest event yet, the RIDE Vyking in Yorkshire. With first-class event support, we hope you'll join us and raise vital funds.

action.org.uk/ride

Marathon magic

Has lockdown given you the drive to tackle your own personal challenge? **Make 2021 the year to run the world-famous Virgin Money London Marathon for Action.** We've just a handful of places left in this ever-popular, world-famous event taking place in October. Or you can register your interest for April 2022. After the year we've all had, these iconic events should be more special than ever. If you'd prefer, there is also a virtual London option. **action.org.uk/running**





With so much uncertainty at the moment, let us reassure you with our Action Guaranteed, money-back-promise. Should an event be cancelled due to COVID-19, we will offer you a number of options.

We'll either postpone your event to a later date, you can join another similar event, transfer your place to another person, or receive a full refund of the registration fee you've paid.

For event details and to register visit action.org.uk/events Give us a call on 01403 327444, or email events@action.org.uk