action medical research for children

Autumn/winter 2017

# touching lives

The Action Medical Research magazine

## Helping children with a cleft lip or palate

Read Robbie's story

**Plus**

**Our Saving Tiny Lives research campaign**

**New research into Crohn's disease**

# From the editor


It's always real family stories that best show the true value of the research we fund – and how important your generous support is. In this issue we feature a teenager who was born with a cleft palate and still struggles with his speech and a 10-year-old girl who faces daily, debilitating pain caused by a rare condition. Thanks to your help, new research is now underway and offers hope for the future for children like these.

As you read this, a new batch of research proposals are being assessed through our gold standard scientific review process. In October our Scientific Advisory Panel will meet and decide which are the strongest, ensuring we fund only the most promising work. Among these will be the first projects to be funded through our new Saving Tiny Lives research campaign – which you can read about on page 3. I look forward to updating you next time on the projects that are chosen and hope you will support the appeal.

And if you are already thinking ahead to 2018, then please check out the back cover for our latest fundraising events – including some great new ones.

Thank you for your support.

Clare

**Clare Airey**, Editor

**PS If you would like to read our supporter promise and privacy policy you can do so at action.org.uk/supporter-promise**

Funding vital research to help babies and children

Supporting more than 260 top researchers

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.

Editor: **Clare Airey**

Front cover photo: **Adam Cochrane**

Print: **Foundry Press**

Design: **Action design team**

**Please send all communications to:**

The Editor, *Touching Lives*, Action Medical Research, Vincent House, Horsham, West Sussex RH12 2DP

**T** 01403 327425

**E** editor@action.org.uk

**action.org.uk**

/actionmedres

@actionmedres

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



# Contents




3 **Fundraising news** Including our Saving Tiny Lives campaign, targeting research to help the most vulnerable babies

4 **New research** Recently awarded grants to help children with congenital heart disease, ADHD, Crohn's disease and a rare neurological disorder

7 **Legacy giving** The generous gift left by a dedicated doctor

8 **Cover feature** Being born with a cleft palate has made it difficult for Robbie's speech to be understood. Read about new research to help children like him

11 **Your support in action** Progress made in research previously funded with your help

12 **Our impact** How past Action funding has helped to map babies' brains and develop a new way of predicting future problems in those at greatest risk

14 **Fundraising news** Including a royal thank you, record-breaking marathon runners and an Action researcher going the extra mile

16 **Challenge events** Make it a date and sign up for one of our 2018 events

# Help save tiny lives

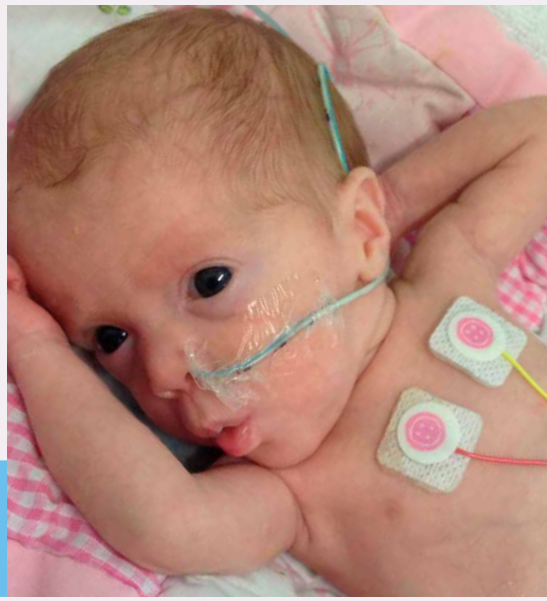
In the UK alone, around 61,000 babies are born prematurely each year and tragically more than 1,000 babies die each year after being born too soon, making premature birth the biggest killer of babies in the UK. It is also a leading cause of disability in those children who survive.

Despite the enormous impact on babies and their families, research into premature birth and other pregnancy complications is still under-funded, limiting efforts to develop new treatments.

This is why we've launched our new Saving Tiny Lives research campaign – because at Action we believe that only by investing in research can the devastation caused by premature birth and other pregnancy complications be stopped.

We've pledged to fund £750,000 of vital new research over the next three years through our Saving Tiny Lives research campaign and have begun fundraising to support this.

Please support us at **action.org.uk/savingtinylives**



## What our celebrity supporters have been up to...

Our loyal mascot **Paddington Bear™** came to cheer on **Davina McCall** at her Big Sussex Bike Ride in June. Davina joined 400 charity cyclists on the road, with the event raising more than £25,000. As this issue went to press the ever-energetic Davina was getting ready to represent Action in the Great North Run.

Meanwhile, **Paddington** is also about to become a very busy bear, with the UK release of his second live-action film *Paddington 2* on 10 November.

Best-selling crime author **Peter James** invited guests to join him for afternoon tea at a sell-out event in our hometown of Horsham. The Sussex-based writer even gave the highest bidder the chance to name a character in one of his future books!

TV medic **Dr Dawn Harper** hosted her White Summer Party in July, which raised almost £5,000.

Our Champions of CycleSport Dinner is again gearing up to be one of our biggest fundraisers of the year. Held in November, the guest list for this year's hot-ticket event already includes cycling legend **Chris Boardman MBE**, along with **Jody Cundy MBE** and **Dani King MBE**.

Finally, **Tony Hadley** has just taken to the fairways for the annual Tony Hadley Golf Classic, organised by our Peterborough Committee of fundraisers.

## A fond farewell

It is with great sadness that we mark the loss of Paddington Bear creator Michael Bond CBE, who died in June. Michael was involved with Action for over 40 years, following a meeting with our founder Duncan Guthrie in 1976 where it was agreed that Paddington would support the charity as its official mascot.

Through this very special relationship with Paddington Bear we have been able to attract thousands of new supporters who together have raised millions of pounds to help sick babies and children.

# Tackling Charcot Marie Tooth disease

**Supported by Action, new research aims to develop a treatment to help children like Isla, who suffers from a debilitating neurological condition that damages the peripheral nerves.**

Charcot Marie Tooth disease (CMT) is a rare, inherited condition. Its symptoms can include muscle weakness, numbness and problems with balance. Hands, arms, legs and feet can all be affected and sadly symptoms can become worse and more disabling over time.

Isla, now 10, had just started school when she first showed signs of having the condition. Initially she hadn't seemed badly affected but gradually her feet began to turn in and her walking and balance suffered. She's needed surgery to lengthen the tendons in both feet and now regularly uses a wheelchair.

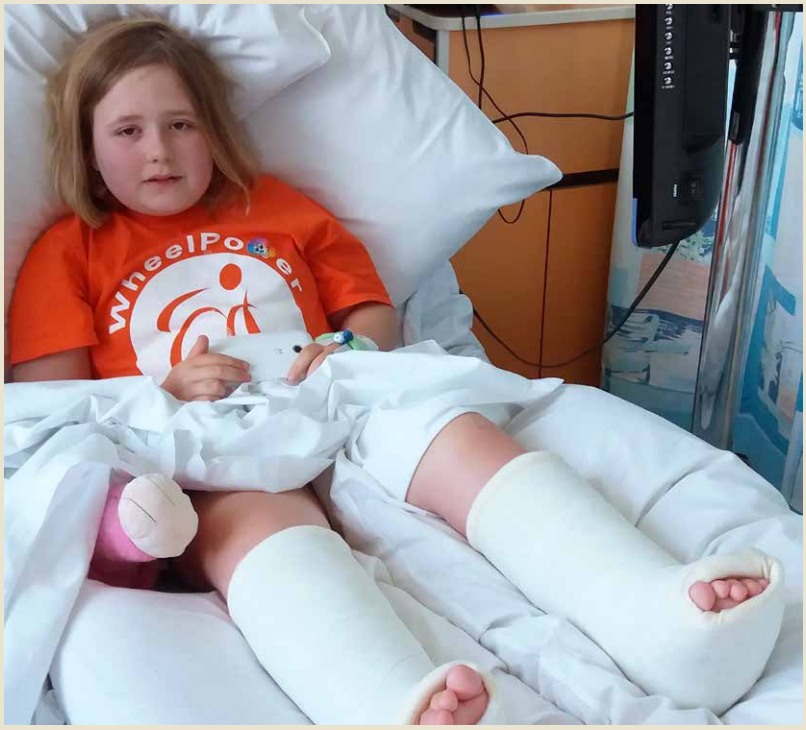
Isla also suffers severe pain in her legs which gets worse as the day progresses: "Sometimes by the evening she wants to hold my hand all through dinner because she's in so much pain," says her mum Karen.

Although Karen also has CMT she has never been affected by nerve pain so her daughter's suffering has come as a shock.

Isla takes daily medicine to help relax the nerves in her legs and regularly needs painkillers. For walking short distances she wears special shoes, provided by her local hospital, as the shape of her feet has changed. She also has physiotherapy and wears splints on her legs at night time.

"I suspect Isla will need further surgery and we've accepted that she's going to be using a wheelchair long term. For us, the biggest issue is pain management," says Karen.

Despite the challenges she faces, Isla remains positive and is a competitive swimmer. "She wants to swim in the Paralympics one day!" says Karen proudly.




Isla in hospital following surgery on her feet

There's currently no cure for CMT and no way to slow its progression but new research hopes to change this. Action funding of almost £200,000 is supporting a three-year study at the University of Oxford. Professor David Bennett and his team are in the early stages of developing a new treatment – a form of gene therapy – to help children with CMT type 1A. This is the most common form of the disease and the type that Isla has.

The team are looking at ways to stop, slow down or even repair damage to a substance called myelin. Myelin normally forms a protective coating around the peripheral nerves but in children with CMT it becomes damaged.

Karen says: "It's nice to know that CMT is getting noticed and that this work is going on."

**In the UK, around 25,000 people are thought to have CMT**

**"Sometimes she holds my hand all through dinner because she's in so much pain"**

These are just some of the new research projects we're funding thanks to your support.

# Improving life-saving surgery for tiny hearts

**Babies born with a heart defect can need complex surgery if they are to survive. Dr Emilie Sauvage is looking for ways to improve the design of 'patches' of specially engineered tissue which are often used to correct the shape of the heart or its vessels.**

Around one in every four babies born with a heart defect has a type of problem called cyanotic heart disease. It means the heart cannot pump blood to the lungs properly and this can give the skin a blueish tinge, especially on the lips, fingers and toes.

Sadly these defects are usually life-threatening, requiring urgent, major surgery. During these operations surgeons often enlarge or reshape abnormal parts of the heart by adding a 'patch' of specially engineered tissue.

But even if surgery goes well, babies must keep seeing a heart specialist regularly as complications can develop later on – patches may become stiffer over time, or too small as the child grows, meaning further treatment is needed.

With a Research Training Fellowship of more than £155,000, Dr Emilie Sauvage aims to improve understanding of how implanted patches can affect the success of heart surgery.

Dr Sauvage is a biomechanical engineer, based at University College London. She is creating computer simulations of children's hearts and using these to study how changes in patch design, such as shape, size and material, affect blood flow through the heart. She is also using the computer models to predict the effects of a child's growth.

She says: "It could pave the way for the design of new, more personalised patches that perform better over time and cause fewer complications as children grow and develop. I hope to give doctors invaluable information on the best way to use these patches during heart surgery and give babies a better chance of doing well after their operation."

# A drug-free treatment for ADHD

Attention deficit hyperactivity disorder, or ADHD, is one of the most common behavioural disorders in the UK and can have a serious impact on everyday life.

Children with ADHD tend to be hyperactive and impulsive. They have short attention spans and struggle with self-control and timing. This can affect how well they do at school and their relationships with other people, and difficulties often continue into adult life. They are also prone to problems such as depression and anxiety.

**Around one in 40 children in the UK has ADHD**

Medication is a treatment option but it doesn't always work and benefits are often only short-term. Many teenagers dislike taking it, there can be side effects and the longer-term effects of using these treatments are unknown.

With Action funding, researchers at King's College London are investigating the potential of a new treatment which combines playing a specially designed video game with electrical brain stimulation.

Lead researcher Professor Katya Rubia says: "Brain scans show that children with ADHD typically have poor activity in a region of the brain called the right frontal cortex. Our new approach is designed to stimulate activity in this region without using drugs. The ultimate goal is to give children with ADHD a new, drug-free treatment option."

This project has been funded by a generous donation from the Garfield Weston Foundation.

Find out more at **action.org.uk/latest-research**

# Looking for causes of Crohn's disease

**Children with Crohn's suffer distressing and unpredictable symptoms and the number of young people affected is increasing. Dr James Ashton has been awarded a £240,000 Research Training Fellowship for a three-year study into what triggers this debilitating illness.**

Crohn's disease primarily affects the gut, causing inflammation and in turn symptoms such as diarrhoea, abdominal pain and tiredness.

Up to one third of people with the condition are under 21 years old when it is diagnosed and the numbers of children and young people affected is rising. This is especially worrying since children are usually more seriously affected than adults.

While there are treatments that can help, there is currently no cure and many children have to undergo surgery to remove damaged parts of the bowel within 10 years of their diagnosis.

Dr Ashton, who is based at the University of Southampton and also cares for patients with Crohn's at Southampton Children's Hospital, believes more research is urgently needed.

"Children with Crohn's disease tend to have more severe symptoms and it can have a significant impact on their lives – for example, their growth, schooling and psychological wellbeing can all be affected," he explains.

**At least 115,000 people have Crohn's disease in the UK**

"A lack of understanding of what causes Crohn's disease is hindering efforts to develop better treatments and use the treatments we have effectively," he adds.

Crohn's can be unpredictable, with times when symptoms are very mild followed by severe flare ups. With Action funding, Dr Ashton and his team are investigating what initially triggers the disease in children and also what causes symptoms to suddenly increase. "No-one knows exactly what causes the condition, but it's thought that a combination of genetic and environmental factors are involved," he says.

He will be studying two groups of children – one made up of children who have just been diagnosed and have yet to receive any treatment and one of children who have had Crohn's for a while. He will look at the community of bacteria living in the children's gut (known as the microbiome) and how this might interact with two other factors to trigger disease. One is the children's genetic make-up and the other is their immune system. All three are thought to play a role.

"We hope that our findings will help in the development of better ways to predict disease severity, as well as new and improved treatments, with the ultimate goal of improving children's lives," says Dr Ashton.

**"Children tend to have more severe symptoms than adults"**

Dr James Ashton

# The doctor who continues to make a difference

**As a consultant paediatrician Dr Malcolm Arthurton dedicated his working life to helping sick babies and children. He and his late wife Eve were also keen supporters of Action Medical Research and now his legacy lives on through a generous gift left to us in his will.**

Dr Malcolm Arthurton worked as a consultant paediatrician in Yorkshire from the early 1950s until he retired in the 1980s and at one point was the only consultant paediatrician in his area, serving four different hospitals!

He began practising medicine in a very different era – a time when the mainstream use of antibiotics was still very new. And one of his own early achievements, of which he was very proud, was successfully arguing the case for establishing the first special care baby unit at one of his hospitals.

"He very much appreciated and understood the need for research," says his daughter Amanda. "During his working life he saw some wonderful advances such as vaccinations for mothers who are rhesus negative. When my sister Isabel and I were small he used to get up in the middle of the night and go back to the hospital to do exchange blood transfusions on babies who had been affected by this – probably about once a week. It was a very common occurrence. Now this risk has been almost completely eliminated."

It was actually Malcolm's wife, Eve, who was the first in the family to support Action. She was a very active fundraiser for the charity, organising social events, and for many years was chair of our fundraising committee for the Shipley and Baildon area.

But the connection with Action was, of course, a natural one for Malcolm. "He was a very dedicated doctor and clearly had an interest in the charity because of his own work – he must have seen a lot of children who had very serious problems," says Amanda.

For more than 40 years Malcolm collected newspapers and scrap metal to raise funds for Action – something he started while still working as a busy hospital doctor and continued into his early nineties! Over those decades he collected 722kg of brass, 975kg of aluminium and 756kg of aluminium drinks cans. He raised at least £5,000 through recycling materials which would have otherwise gone to waste.

Malcolm died in 2016, aged 97, but his support for Action has continued through a wonderful gift of £10,000 left in his will. Such a generous gift will help to fund a significant part of one of our research projects – it costs around £230 to fund a single day's research. Malcolm's legacy could now be helping to unlock a medical breakthrough of the future – we truly hope so.

Amanda says: "Many, many people support charities but a much smaller number make provision to do so in their wills. My sister and I are deeply pleased and proud to think that his forethought has funded research after his death. It is a wonderful way of leaving a lasting legacy."

For information about gifts in wills please contact Sharon Gearing on 01403 327413 or email sgearing@action.org.uk

You can also read more on our website: **action.org.uk/legacy**

# Robbie's struggle to speak clearly

**"Older children ask, 'why do you talk funny?' and that's hard for a teenager to deal with"**

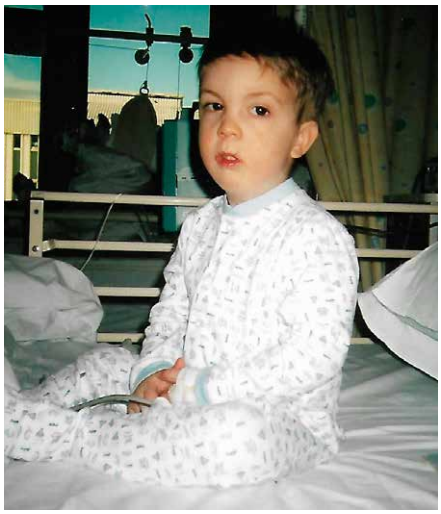
Photo: Adam Cochrane

**Robbie was born with a cleft palate and he and his family have had many difficulties to overcome. Even now, after three operations and years of speech and language therapy, it can still be hard to understand Robbie when he talks, as his mum Geraldine explains.**

Every day in the UK an average of three babies are born with a cleft lip and/or palate, which means they have a gap or split in their upper lip and/or the roof of their mouth. This can have a wide-ranging impact on a child's life, affecting the appearance of their lips and nose, their hearing, speech, face shape and teeth.

Discovering that their son Robbie, who is now 14, had a cleft palate was a shock for his parents, Geraldine and Stephen. "We weren't aware at all. During my pregnancy I did have a second scan after my routine 20-week scan, to look at Robbie's mouth area, but nothing showed up," recalls Geraldine.

But when baby Robbie arrived he had breathing problems and struggled to feed. Robbie had a cleft palate, meaning the roof of his mouth was affected, and this was part of a condition called Pierre Robin Sequence, which meant he also had a small, receding lower jaw. This leads to the tongue being more likely to fall backwards and obstruct the airways.



Robbie had his second operation on his palate as a toddler

Robbie's lips were not affected but the gap in his soft palate meant he was unable to breastfeed. "It was heartbreaking," says Geraldine. "I so wanted to feed my newborn baby."

Instead Geraldine expressed milk for Robbie and used a special teat to help him feed. But sucking was still very tiring for him and he spent three weeks in special care struggling to regain his birth weight.

Back home, the risk of breathing difficulties meant that Robbie could not be laid down on his back – even for nappy changes. For the first 18 months of his life he wore a sleep apnoea monitor every night. "It was a terrifying and really upsetting time," recalls Geraldine.

Robbie had his first operation on his palate at just three months old, followed by more surgery when he was a toddler. He then joined a long waiting list for the specialist speech and language therapy he needed, and much of his therapy had to be carried out at home: "It was a case of 'teach the parents'," Geraldine says. "We helped him make lots of different sounds in a fun way."

During his early years Robbie was also frequently referred to an ear, nose and throat specialist because he developed hearing problems every time he caught a cold.

Unfortunately, even with weekly therapy, Robbie's speech did not progress as well as hoped and at 10 years old he needed a daunting, major operation on his throat. "The surgery involved moving the back of Robbie's throat forwards and could have affected his breathing," explains Geraldine. "Thankfully, it went well and has made a massive difference."

Robbie is now in secondary school, doing well with his studies and enjoys playing the guitar. But despite three operations and years of speech and language therapy, his speech can still be difficult to understand.

"Older children ask, 'Why do you talk funny?' and that's hard for a teenager to deal with," says Geraldine.

Fortunately, Robbie has a quiet strength: "He is working out how to respond to people who give him a hard time and is quite robust about it," says Geraldine.

Robbie is also very keen to help others. "He has a caring nature and is already finding ways to support other children born with a cleft palate," says his mum proudly.

## Our research

**Like Robbie, many children born with a cleft lip or palate experience ongoing problems with their speech. With funding from Action Medical Research, Dr Joanne Cleland of the University of Strathclyde (pictured) is using ultrasound technology to help.**

**She is testing a new technique which involves placing a small ultrasound scanner under the child's chin and a camera in front of their lips. This enables therapists, and children themselves, to see images on a computer screen showing how the tongue and lips move when they speak. This could help therapists to make more accurate and detailed diagnoses, including detecting speech errors that cannot be easily distinguished by ear, and ensure each child gets the best possible treatment.**

**Robbie has tried the painless, non-invasive scanner for himself and Geraldine says: "It makes it easier for the child to be assessed and gives a wealth of detail. I just think it's invaluable."**

**This project has been jointly funded with The Chief Scientist Office, Scotland.**

Action Medical Research has a proud history of funding research to help children with many different disabilities.

**Thank you**
for helping us make this vital work happen.

# Vitamin D deficiency and pre-eclampsia

**Research funded by Action has provided important new evidence about how vitamin D affects processes in the womb that are vital for a healthy pregnancy.**

Baby Emily, pictured, was delivered six weeks early, weighing just 3lb 8oz, after her mum developed pre-eclampsia during pregnancy. Doctors were unable to stabilise her mum Tracy's high blood pressure. Scans also showed there was too little fluid around baby Emily – a sign that the placenta might not be working properly – and she seemed very small.

Allowing the pregnancy to continue was considered too dangerous for both mother and child so tiny Emily was born by caesarean section. Thankfully she is now a healthy toddler but Tracy says: "We were so lucky. At the time I didn't realise how much danger we were in."

Pre-eclampsia affects up to eight per cent of pregnant women worldwide and remains a leading cause of death and illness in both mothers and their babies. In the UK it's estimated that 1,000 babies die each year due to the condition.

With Action funding of £182,000 over three years, Mark Kilby, Professor of Fetal Medicine at the University of Birmingham, has been studying the link between vitamin D deficiency and pre-eclampsia. This has included comparing blood and tissue from the placentas of women with both uncomplicated pregnancies and those with pre-eclampsia.

The new information generated has for the first time clarified the specific effects vitamin D has on critical events in very early pregnancy. It is especially important for stimulating the healthy development of blood vessels in the womb and also appears to affect certain immune cells.

It's already recommended that pregnant women consider taking small amounts of vitamin D, but this research has given further evidence to support the need for trialling the use of higher dose supplements to reduce the risk of pre-eclampsia. Such a trial could start within the next three years.

Action Medical Research previously supported the research that discovered the importance of taking folic acid before and during pregnancy to prevent spina bifida.

# Protecting the most vulnerable from infection

Research funded by Action is helping to improve the treatment of a life-threatening infection in children with severely compromised immune systems.

Cytomegalovirus (CMV) is one of the biggest killers of children with weakened immune systems, such as those undergoing organ or bone marrow transplants or having cancer treatment. Those who survive can develop lifelong disabilities.

Resistance of viruses to drug treatments are a major concern when caring for children with such infections.

With support from Action, Professor Judy Breuer and her team, based at the UCL Institute of Child Health and Great Ormond Street Hospital, have developed a new blood test for CMV to detect much earlier, faster and more accurately whether or not a child's infection is becoming resistant to treatment.

This means that doctors will be able to make more informed and timely decisions about which drugs to treat patients with.

The new methods developed in this project are already being used for further research and have led to a change in the CMV treatment protocol at Great Ormond Street Hospital.

This work was jointly funded with Great Ormond Street Hospital Children's Charity.

# Mapping babies' brains to predict and prevent future problems

**Premature babies are at increased risk of developing disabilities but it is difficult to know which are most likely to be affected. Action funding has helped to develop a computer-aided tool to read MRI brain scans and identify abnormal development in newborn babies.**

Having a baby prematurely usually comes as a complete shock to parents and causes a huge amount of worry about the baby's future. Being born too soon puts babies at risk of developing disabilities such as cerebral palsy, speech problems and learning difficulties. But these may not become apparent until months or even years later, meaning parents face an anxious wait and babies may miss out on receiving early treatment that could prevent or at least minimise future difficulties.

The months just before and after birth are crucial for the development of the brain and being born early can disrupt vital processes, causing lasting damage. The earlier a baby is born, the greater the risk.

Magnetic resonance imaging, better known as MRI, can be safely used to take detailed pictures of a baby's brain and could help identify areas of damage. But interpreting these images is difficult and time consuming, requiring specialist skills that only a few health professionals have.

Baby Sam at birth with mum Jo

## How we've helped

In 2009 Action Medical Research awarded more than £148,000 to researchers based at Imperial College London. Led by Professor Daniel Rueckert and Professor David Edwards, the team used MRI to produce a map of typical brain development in healthy newborn babies. They did this by taking scans and labelling each region of the brain visible, combining information from many images.

They could then compare brain scans of at-risk babies with their map of normal development to spot areas which may be developing differently. But all this labelling and comparison was done by hand and as Professor Rueckert explains: "It takes over a hundred hours for a highly trained scientist to manually label that many regions in a neonatal brain, which is impossible to do on a routine basis."

A year later, with support and additional funding from Action, the team secured a grant of over £1m from the Engineering and Physical Sciences Research Council to allow them to use their brain maps to develop a computer programme to automatically identify areas of abnormal brain development on MRI scans.

> **"Our work will make it easier to predict which babies are at highest risk of developing disabilities after being born prematurely"**
>
> Professor Daniel Rueckert

This new technique could allow doctors to tell whether or not a baby has suffered brain damage and is likely to develop a disability in the future. This could also guide earlier treatment. For parents, it could give invaluable information about what the future might hold and ensure babies get the best help as soon as possible.

"Difficulties in predicting which babies will go on to develop disabilities has been a major issue for people who care for them," says Professor Rueckert. "Better predictions will give us the chance to improve babies' care sooner rather than later, which could greatly improve their lives."

The potential of this research to change lives is huge. It could mean premature babies, and other babies who are at risk of brain damage, could eventually benefit from these scans as part of their routine care.

**Around 61,000 babies are born prematurely every year in the UK**

## Sam's story

Sam has just turned three and is having the time of his life. He chats constantly, runs everywhere at speed and is fascinated by all that that the world has to offer. "It's wonderful to experience life through the eyes of a toddler and watch him grow and develop," says his proud mum Jo, who is acutely aware that things could have been very different.

Sam was born 10 weeks early after Jo needed emergency bowel surgery during her pregnancy. She and husband Will knew that the earlier a baby is born, the higher the risk of serious complications, but when their tiny son arrived doctors could give them no predictions. "We were simply told that, at 30 weeks, you never quite know what the future is going to hold," she recalls.

Sam weighed just 3lbs 6oz at birth but seemed healthy. Never the less he spent his first five weeks in intensive care.

"We were incredibly fortunate that test after test showed he was growing outside of the womb as any other child born at full term," says Jo. "But although he seemed to make good progress he wasn't given the all clear until he was two years old.

"Until that time we lived with the worry that being born so early could affect Sam's development. We were all too aware that his prematurity could mean he would live life with a disability or special needs. I can still scarcely believe he's so fit and healthy, completely unscathed."

Jo recently gave birth to her second son, Thomas, who was born the day after his due date. "It's only now, when I'm so enjoying having a young baby who was healthy from birth and discharged without issue, that I realised I was wracked with anxiety in the early months of Sam's life," she says.

"We could have been spared endlessly worrying, had we been given the all clear much sooner. The work supported by Action is a vital piece of research that could be life-changing for prospective parents."

**"Until Sam was two years old we lived with the worry that being born so early could affect his development and progress"**

Sam's mum, Jo

With your help we are currently funding more new research to help the most vulnerable babies. **Thank you for your support.**

# A very special thank you

As HRH The Duke of Edinburgh embarks on his retirement from public engagements, we would like to take the opportunity to say an enormous thank you for the dedicated support he has given to Action Medical Research over the last 62 years as our Royal Patron.

Over the last six decades the Duke of Edinburgh has hosted and attended numerous charity events. Most recently, welcoming 130 Action guests to a royal reception at Buckingham Palace, held in March 2017 in the impressive Picture Gallery. Here researchers representing six current studies funded by Action shared details of their vital work.

Our charity Chair, Phil Hodkinson, says: "We are extremely grateful to The Duke of Edinburgh, for his tireless support. He has supported the charity since its very early days and has generously hosted many receptions where Action supporters have been delighted to experience his continuing commitment and enthusiasm for the vital research the charity funds. We wish him all the best as he retires from royal duties this autumn."


# Brilliant business supporters

**From long-distance bike rides to fundraising balls, we're incredibly grateful for the support of our corporate partners.**


We were delighted to receive a £10,000 cheque from construction and property company **Lendlease**, part of the proceeds from their annual Guvnors Club charity ball. Pictured (L-R) are Sophie Bevington, Sarah Stevenson (from Action), Katrina Lamberton and back row Andy Lee from Lendlease. The money will go towards research into the rare genetic illness neurofibromatosis type two.

**One Stop** convenience stores across the country once again embarked on a fortnight of fundraising in June. More than 750 branches placed collection boxes on their countertops, with many also holding raffles. Some lucky stores even enjoyed a visit from Paddington Bear! And the funds don't just come from in-store activity – this year two employees, Property and Distribution Director Mark Williams and Rawtenstall Store Manager Karen Parkinson, ran the Virgin London Marathon and raised £9,700. A group of regional managers also took on an inflatable 5k obstacle run in Nottingham.

More than 100 eager riders took to the Kent countryside for the **Aon Benfield** Summer Bike Ride on a wet and windy day in June. The event raised more than £60,000. Pictured are the AON Team (L-R) Mike Weeks, Jeremy Lee, Glenn Francis,

Toby Russell and Lee Taylor. Special thanks to everybody who helped make this event happen.

Our inaugural construction industry bike ride **Ziggurat** took 46 cyclists from London to Paris. Generously supported by Mace, Brett, Glendining Highways and Dome, the ride was a huge success and raised more than £115,000. Next year's event will take riders to Brussels via Amsterdam and we are looking for industry partners now.

A team of 35 staff from **Black and White Hospitality**, owned by famous chef Marco Pierre White, also took part in our London to Paris bike ride this summer. We hope to have ignited their passion for cycling and to do another bespoke event with the company next year.

And a special mention to investment banking company **Evercore** who entered seven teams – 25 people in total – for our Race the Sun Isle of Wight challenge in July. This beat their own record for having the biggest group from a single firm on a Race the Sun event, set last year in the Brecon Beacons edition.

# Record-breaking runners

**Not content with just completing this year's 26.2-mile Virgin London Marathon, three amazing Action runners each broke official Guinness World Records!**

Sarah Dudgeon, from Abingdon in Oxfordshire, ran her first ever marathon and her first event for Action back in 2002 and since then has ran the iconic event at least seven times. More recently she's been joined several times by husband Max Livingstone-Learmonth and this year saw their friend Victoria Carter, from London, join them to form a record-breaking trio for Action – each was officially recognised for crossing the finish line in the fastest time dressed as a monk, a bishop and a nun!

It's not the first time Sarah has run in fancy dress for Action – she's previously set records for running the fastest time in a wedding dress (an impressive 3 hours 16 minutes) and in a nurses uniform (an even quicker 3.08.54).

And Victoria, supporting Action for the first time this year, also has three previous records to her name, including running three-legged with Sarah in 2016!

"The crowd especially love fancy dress and give you huge cheers the whole way," says Sarah, whose connection to Action is part of her family heritage.

Back in 1968 the charity provided vital funds for Sarah's grandfather Professor Alastair Dudgeon's groundbreaking research into the rubella vaccine. This research successfully demonstrated that the rubella vaccine gave long lasting immunity and was safe. Without this vaccine, if a woman becomes infected with rubella during the first four months of pregnancy, it can cause severe birth defects such as deafness, blindness and congenital heart defects.

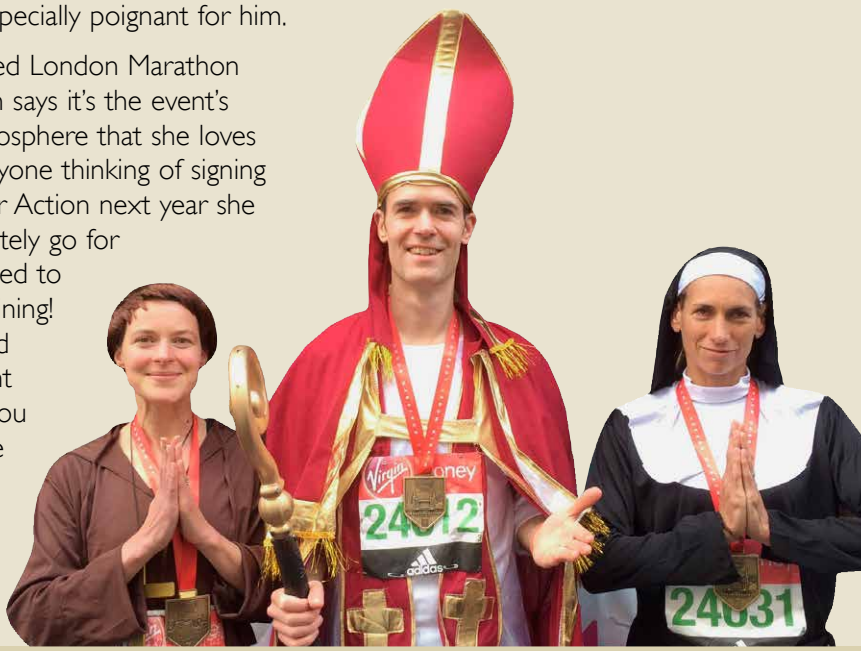
Max's father, who sadly died in January, was also a keen supporter of Action, making this year's marathon especially poignant for him.

As a seasoned London Marathon runner Sarah says it's the event's uplifting atmosphere that she loves most. For anyone thinking of signing up to run for Action next year she says: "Absolutely go for it! All you need to do is the training! But you need to really want to do it or you won't do the training."

> **"There's an amazingly positive, feel-good atmosphere"**

Overall, this year's wonderful Action marathon runners have raised more than £87,000. If you want to run for a reason in 2018, we have places in the London Marathon and also two new shorter events, the London Landmarks Half Marathon and The Big Half.

Register online at
**action.org.uk/running**




## Going the extra mile

Action-funded researcher Dr Shivani Bailey took on two charity challenges this summer. She cycled the 100-mile route of the Suffolk Sunrise and then headed to the Isle of Wight for our newest Race the Sun event.

Dr Bailey is dedicating her career to helping young cancer patients and was awarded one of our Research Training Fellowships in 2014. She hopes to develop a new treatment for germ cell cancers, one that improves survival rates and causes fewer long-term side effects.

She says: "I'm acutely aware that my research has been made possible by the dedication of the many committed individuals who have taken the time and effort to raise money for Action. I felt it was high time I joined their ranks!"

# Challenge events 2018

## London calling!

We have places for runners in two exciting new mass participation events taking place in the capital next spring. The Big Half on 4 March starts at Tower Bridge and takes in the best sights of East London before finishing by the Cutty Sark in Greenwich. And once you've conquered the half-marathon run there's The Big Festival to enjoy. This promises to celebrate London's diverse population, with food from around the world and the best young music acts from around the capital.

The London Landmarks Half Marathon follows on 25 March with a route that celebrates London's grand, quirky and hidden history. Starting on Pall Mall and finishing by Downing Street, runners will get fabulous views of the city's most iconic landmarks as well as some lesser-known gems.

Find out more and register at **action.org.uk/running**

Seen something that inspires you? Register on our website, give us a call or email us – we'd be delighted to hear from you.

## Scumrun charity drive

We're delighted to have been selected as charity partner for the annual Scumrun charity drive in May 2018. The fun, five-day road rally sees teams in creatively modified vehicles and fancy dress, travel hundreds of miles across Europe, with the aim of raising thousands of pounds. The route is always top secret and teams will need a car – the crazier the better – and some mechanical savvy to take part and complete this challenging mystery tour. Perfect for petrolheads and those who fancy doing something a little bit whacky!

For further details and to sign up visit **scumrun.action.org.uk**



## Running

**NEW The Big Half** 4 March

**NEW London Landmarks Half Marathon** 25 March

**Vitality London Marathon** 22 April

**Vitality London 10,000** 28 May

## Cycling

**RIDE100 Series** May to September

**Maratona dles Dolomites** 1 July

**Action London to Paris** 25-29 July

**Prudential RideLondon-Surrey 100** 29 July

## Team challenges

**NEW Scumrun Charity Drive** 17 May

**Trek the Night Cotswolds** 9-10 June

**Trek the Night South Downs** 14-15 July

**Race the Sun Brecon Beacons** 23 June

**Race the Sun Isle of Wight** 30 June

**Race the Sun Lake District** 1 September

## Mountain series one day treks

**Snowdon, Yorkshire 3 Peaks and Ben Nevis** June to September

You can register for an event on our website, give us a call or send an email:
**action.org.uk/events**
**T** 01403 327444 **E** events@action.org.uk