action medical research for children

Spring/summer 2018

touching lives

The Action Medical Research magazine

Born too soon – a little boy's battle to survive

Read Jack's story

Plus

Helping children like Finn to walk more easily

Stopping the spread of scarlet fever

From the editor

Dear supporter,

Welcome to your latest issue of *Touching Lives*. I hope you'll enjoy finding out more about the life-changing research you're helping to make possible. Premature birth is a big focus for us at the moment and our cover star Jack's story really highlights why tackling it is so important. In many cases, like Jack's, doctors simply don't know why labour started so early. New research is looking at the role infection can play as a trigger. Plus we have an update on work that has now taken doctors a step closer to developing a blood test to identify women who have an increased risk of having their baby too soon.

Our Research Training Fellowship scheme supports some of the most promising doctors and researchers early in their careers. Many of these people go on to achieve big things, like Manju Kurian who you can read about on page 3. The scheme is 45 years old this year and I hope you'll feel proud that your support today is helping develop leaders of the future in children's research.

Of course, we continue to need your help to fund more medical breakthroughs. And our summer Action Cream Teas fundraiser is a fun and easy way to do this – we'd love you to get together with friends or colleagues and join us for a guilt-free tea-break treat!

Thank you, as always, for your support.

Clare

Clare Airey, Editor

Keeping in touch

Everything we do is only possible with the amazing support of people like you. We want to keep you updated on the vital research you are making happen, as well as ways you could get involved with Action in the future. As you may have heard, new data protection regulation comes into force this May. So we wanted to take the opportunity to set out how we handle your personal information and what it means for you.

You can read more about how we manage your data in our privacy policy and supporter promise **action.org.uk/privacy-policy**

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: **Adrian Sherratt**

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
@actionmedres

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

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Our award-winning researcher

Paediatric neurologist Dr Manju Kurian was awarded one of our Research Training Fellowships back in 2008. This kick-started her career in medical research and we've been delighted to see how successful she's since become. She's recently been the recipient of a string of prestigious awards in recognition of her ongoing work, including a L'Oreal UNESCO Women in Science award in 2017.

Dr Manju Kurian in the lab

Ten years ago Action funding allowed Dr Kurian to embark on her first piece of research, investigating the genetic basis of two devastating, life-limiting conditions that affect the development of the brain and nervous system in very young children.

Her research led to the discovery of one gene linked to early onset epilepsy and one gene linked to a Parkinson-like movement disorder. She also developed genetic tests for patients, meaning families could be given an accurate diagnosis and answers where previously they had had none.

Building on this success, Dr Kurian has gone on to establish her own new research group at the Great Ormond Street Institute of Child Health. She and her team, which now includes two current Action Research Training Fellows, continue to carry out groundbreaking work, investigating a range of childhood conditions.

Dr Kurian says: "Without Action, I wouldn't be here – thank you!"

Our Research Training Fellowship scheme has been running for 45 years. It supports the most promising doctors and researchers early in their careers, training and developing future leaders in children's research – people like Dr Kurian who go on to achieve big things.

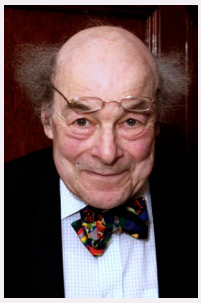
Remembering Heinz Wolff

We were sad to learn that Professor Heinz Wolff, best known for presenting the popular BBC TV show *The Great Egg Race* in the 1980s, died at the end of 2017.

Away from the small screen, Professor Wolff set up the Institute of Bioengineering at Brunel University after receiving funding from Action back in 1983.

Two further grants, totalling more than £400,000, allowed his team at the Institute to develop the groundbreaking 'Tools for Living' programme. This saw the invention of a succession of devices to help improve the daily lives of disabled and elderly people.

Today, the Institute is also involved in biomedical engineering work, such as developing smart tools for surgery, implants and sensing systems.



action Weekly Lottery

Loyal fundraiser wins top prize!

Congratulations to Petronella Keeling, founder member of our Spalding Committee, who won £500 in our Weekly Lottery.

For just £1 a week you can have the chance to win cash prizes every week. It's easy to play – you can enter online at **action.org.uk/weeklylottery**

Terms and conditions apply.

"After 50 years of supporting Action, I believe more than ever that the conditions the researchers aim to address are really worth fundraising for. Playing the lottery is a great way to help fund this vital research and win big prizes. I was delighted to learn of my win!"

Petronella Keeling,
Action Weekly Lottery winner

Improving major head surgery for young children

At just 10 months old Finley had his first major operation to rebuild his skull. With Action funding, specialists are testing a new treatment approach which could improve surgery in the future for children like him.

Finley with his big sister before his first operation

Finley was born with Apert syndrome – a rare condition that causes a range of health problems including craniosynostosis which affects the skull.

In craniosynostosis the plates of the skull fuse together too early, while the baby is still in the womb. The head shape is distorted and, as the child grows, there is restricted room for the brain. This can lead to pressure within the skull and the need for major surgery.

Craniosynostosis can occur with no known cause or, like Finley's, be linked to a genetic condition. In Apert syndrome, it is especially complex and Finley has experienced hearing, sight and breathing problems, and issues with his jaw.

When he was just 10 months old, surgeons painstakingly dismantled and reshaped Finley's skull, creating a new forehead. Before this, his eye sockets were so shallow that he couldn't close his eyes.

"We had to place our child in somebody else's hands. It was terrifying," says Diane. "But if Finley had been left to develop pressure on his brain, it would have affected all of his development. You are between a rock and a hard place."

Further surgery when Finley was four was particularly traumatic: "He was in a lot of pain and kept saying 'help me, help me Mummy'. It was the hardest time of our lives as parents," says Diane.

Now nine, Finley attends mainstream school and is doing well. But he is likely to need further surgery in the future.

With Action funding, researchers hope to spare children with craniosynostosis from repeat operations and make less invasive procedures work better.

Lead researcher Dr Dagan Jenkins, at the UCL Great Ormond Street Institute of Child Health, says: "While current surgical procedures are very effective, they can be complicated and require many hours under general anaesthetic."

The team have identified a drug – already approved to treat other conditions – which could be helpful.

"We hope that applying this drug to the site of surgery will improve the effectiveness of less invasive procedures without the need for follow-up operations – meaning that affected babies can look forward to a more typical childhood," says Dr Jenkins.

For families like Finley's this would be very welcome. "With any surgery and any general anaesthetic there are risks," says Diane. "Anything that makes the surgery more effective and reduces the number of operations needed could have a huge impact on families."

Around 350 children are born with craniosynostosis each year in the UK

"We had to place our child in somebody else's hands. It was terrifying"

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

Stopping the spread of scarlet fever

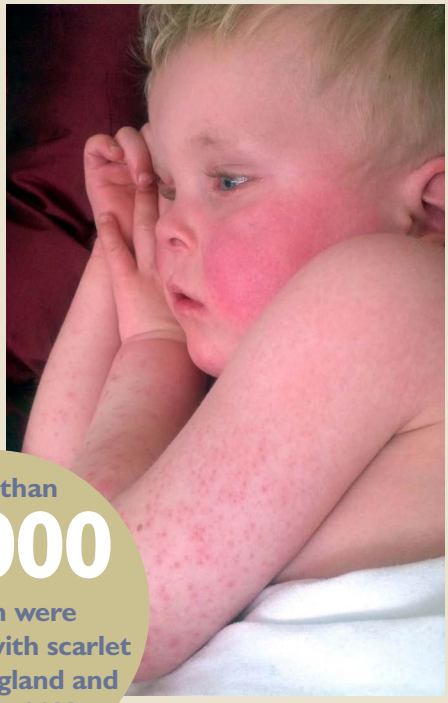
Scarlet fever is currently experiencing a worrying comeback and the bacteria that cause it can sometimes trigger more dangerous illnesses. New research aims to reduce the spread.

After decades of decline, scarlet fever infections hit a 50-year high in England last year – the largest reported spike in a century. Thanks to modern antibiotics, it is usually not serious and symptoms, including a blotchy rash, sore throat and high temperature, usually clear up within a week.

But the strep A bacteria that cause the infection can have a darker side. In rare cases they can trigger life-threatening illnesses such as pneumonia, meningitis, toxic shock and sepsis.

Action funding of more than £188,000 is supporting an important programme of work led by Professor Shiranee Sriskandan at Imperial College London, together with experts at Public Health England. This research will help inform public health strategy in the future.

"Given the current magnitude of scarlet fever outbreaks, it's really important that we find out how we can control it better," says Professor Sriskandan. "We aim to build our understanding of how scarlet fever infects children and spreads so we can identify the best ways to slow down transmission in future outbreaks. We hope that this will, in turn, save children's lives from more dangerous conditions caused by the same bacteria."



More than 19,000 children were diagnosed with scarlet fever in England and Wales in 2016

The team plan to identify key attributes of the bacteria that help them to spread and find out which antibiotics are the best at slowing them down. They will also test whether current hygiene recommendations and treatment guidelines for schools and nurseries are enough to limit the spread of scarlet fever during an outbreak.

Exercise to help children with cerebral palsy

Daily physical activity is important for healthy growth and development. But sadly, that's not always easy for children with cerebral palsy – the commonest childhood physical disability.

Almost 2,000 babies born each year in the UK have cerebral palsy

Children with cerebral palsy face lifelong difficulties with movement and coordination. While problems vary from child to child, many children with cerebral palsy spend a lot of time sitting down. They tend to be less active and less fit than other children.

Lack of physical activity can reduce children's endurance levels and muscle strength. It may also cause secondary conditions, such as long-term pain, fatigue and osteoporosis. And children are also more likely to become overweight and develop insulin resistance, which can lead to diabetes. It may even affect academic performance.

Professor Helen Dawes, who leads the Movement Science group at Oxford Brookes University, is assessing the feasibility and benefits of a school-based exercise programme for children with cerebral palsy.

She says: "School-based activities enable all children to benefit, whatever their background. Our new programme involves children taking regular breaks during lessons to stand up and join structured physical activity sessions in their classroom, with help if needed."

The research team will look at the effects on children's academic performance, strength, mobility and overall health and wellbeing using a range of tests.

This project has been jointly funded with the Chartered Society of Physiotherapy Charitable Trust.

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

Giving children the best possible start

Children naturally develop at different rates but missed milestones can be an early sign of problems. Dr Samantha Johnson and her team are fine-tuning a questionnaire, which aims to make it easier to spot developmental delay and learning difficulties so children can get help sooner.

Parents know their children best and will often notice if their little one doesn't reach a developmental milestone as expected. Their child may seem late to walk or talk. Or they might notice differences in the way they play, learn, speak, act or move. But since all children develop differently, it can be hard for parents to know if professional help is needed.

Dr Samantha Johnson, a psychologist and expert in child development from the University of Leicester, aims to help. "What happens in early childhood can affect a child's health and wellbeing throughout their whole life," she says. "That's why it's so important to check children's early development to identify those who need support."

Questionnaires completed by parents are often used to spot children who might need extra help. With Action funding, new research will see an existing questionnaire, currently used to identify problems in children who were born prematurely, adapted to make it suitable for use with all young children.

The research team are using information from more than 6,000 questionnaires, completed on children born at full term, to create new standardised scores. These children did not have any birth-related complications that are known to affect development. So this will show what sort of scores young children, aged around two, typically get and allow health professionals and researchers to identify whether a child's development is delayed relative to this.

Around **one in 10** babies is diagnosed with developmental delay

The questionnaire takes just 10 to 15 minutes for parents to complete and less than 10 minutes to score. And it will be made available free of charge online, so health professionals and researchers worldwide can use it with parents of all young children.

Dr Johnson says: "It will provide a quick, inexpensive and easy way to assess children's development early and identify those who may need support.

"We hope this will ensure that those with developmental problems – even just mild difficulties – can receive timely intervention, at a critical point in their development, with the aim of reducing the lifelong impact of those difficulties and giving children the best possible start in life."

"What happens in early childhood can affect a child's whole life"

Dr Samantha Johnson

Remembering baby Fintan

The Heading family are close to raising an incredible £10,000 through a Tribute Fund set up in the name of their baby son. Through this special fund they hope Fintan's memory can help other sick babies and children in the future.

It was a huge shock for parents Annie and Paul Heading when instead of cuddling their newborn son he was whisked off to neonatal intensive care. Baby Fintan was born in April 2015 and although he'd needed to be delivered four weeks early, he weighed a healthy 6lb 5oz.

"We didn't know what lay ahead for Fintan but believed he would be ok," says Annie. Initially the doctors were mainly concerned about his blood sugar levels. But then they began to suspect Fintan might have a genetic syndrome. "This was because of some of his facial features and his central tone was floppy," explains Annie. "He also didn't have a sucking reflex so needed to be tube fed."

Various tests were done to try and find answers but then things took a tragic turn for the worse. Fintan developed a condition called necrotising enterocolitis or NEC. This devastating bowel infection typically strikes the smallest or most vulnerable babies – those who have been born very prematurely or, like Fintan, those who are already poorly.

Sadly the disease was very aggressive. "Doctors battled to save his life but he didn't respond," says Paul. "It was a terrible shock to everyone how quickly he went." It's believed that Fintan had an undiagnosed syndrome, which left him unable to fight NEC.

Determined to do something positive to remember their precious son, Annie and Paul discovered Action. "We did a Google search and saw that Action was supporting research into NEC and thought this was amazing. We hoped that we might be able to help prevent another family going through what we went through," says Annie.

"We set up a Tribute Fund to reflect the love the whole family and our friends felt for Fintan. We thought it would be nice for everybody to see the fund growing and it has allowed people to contribute who might find it difficult to support us in other ways. People feel so helpless. They want to help ease things for us but they might find it difficult to know how to show that they care."

Amazingly, almost £10,000 has now been raised towards Fintan's fund, which is a big focus for the family during the toughest times around his birthday and anniversary. "It gives us something to focus on and to pour our energy into," says Paul. "And it gives us a chance to talk about Fintan with people."

In their first year of fundraising, the family held a coffee morning. Last year they set their sights higher – 175 feet high, persuading family and friends to join them on a zip wire challenge over Belfast's River Lagan.

"Our gorgeous baby boy gave us so much joy, love and happiness in 11 short days," says Annie. "We feel privileged to have had the time that we did. We know not everybody gets to have even that.

"For us, the Tribute Fund means his memory can continue to light up the lives of people in the future, especially babies and children who are affected by sickness and illnesses around the UK."

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

Born too soon

a little boy's battle to survive

"Without research, we wouldn't have medical advances, and Jack probably wouldn't be here"

Photo: Adrian Sherratt

When Jack was born more than three months early, his parents were told he had a fifty-fifty chance of surviving. After a traumatic start, he has made remarkable progress. But he continues to face health issues as he grows up, as his mum Jenny explains.

"Jack is inquisitive – very inquisitive!" says his proud mum Jenny. "He asks lots of questions and he's a very smiley little boy."

Jack's early arrival, in late 2013, was sudden and a terrible shock to Jenny and her husband Matthew. After a seemingly easy and problem-free pregnancy, Jenny started bleeding at 25 weeks and was rushed to hospital.

"I wasn't in active labour, and I was so naïve that I thought as soon as they stopped the bleeding, I'd just go home," recalls Jenny.

But two days later Jack was delivered by emergency caesarean section.

"I was given a general anaesthetic and Matthew wasn't allowed in the room with me. He thought he was going to lose me and our baby," she says.

Tiny baby Jack weighed just 1lb 15oz at birth and needed oxygen, help with his breathing and feeding tubes to survive.

Jenny and Matthew knew their newborn son was extremely vulnerable and they were plunged into a world of tests and twice-daily meetings with his medical team.

"The doctors were always very cagey about Jack's outcomes, because they didn't want to give us false hope," says Jenny. "Suddenly we had to try and take in all this new terminology

Jack spent four and a half months in hospital

about oxygen levels, blood gases and brain scans."

Sadly Jack suffered from a collapsed lung and brain bleeds during his first few days of life. Then, when he was six days old, he developed a bloated tummy. Doctors feared he had necrotising enterocolitis (NEC), a life-threatening infection of the bowel that very premature babies are especially vulnerable to. Jack needed to be transferred to another hospital for urgent treatment. But he was so small and so sick it took specialist staff four hours to stabilise him and transfer him from the hospital incubator to the transport incubator: "It was the most traumatic thing," remembers Jenny.

Jack survived life-saving surgery in the middle of the night, where it was found that he did have NEC. During the operation he had a piece of his bowel removed. This was to be the first of seven operations during his first six months of life.

The months spent in hospital were a time of enormous anxiety for Jenny and Matthew, since doctors could give no reassurance as to Jack's prognosis. "At one point the medical staff said that if they felt Jack wasn't going to develop, they would withdraw his support," Jenny says.

But, thankfully, Jack recovered from each setback and after four and a half months he was finally allowed home. "He was still on oxygen, so the canisters came too," says Jenny. "We were just so relieved to be home."

Jack caught up with his weight in his first year and is now a happy four-year-old. But he has experienced some developmental delay. "Physically he is behind, but he can walk, run and jump," says Jenny.

Jack has chronic lung disease due to the oxygen he needed in his early months and there are concerns about his eyes. He may also be affected by epilepsy due to the brain bleeds he suffered as a newborn baby.

But Jenny says: "We are so lucky to have him. There's no stopping him!"

Jenny believes passionately in the value of research into premature birth and conditions like NEC which can devastate tiny lives. "Without research, we wouldn't have medical advances, and Jack probably wouldn't be here," she says.

Jack's little sister, Alice, was also born prematurely in 2016 and has been diagnosed with cerebral palsy. So finding out what causes premature labour is especially important to Jenny. "Anything that helps identify why women go into labour too soon is vital," she says.

Our research

Every year, around 61,000 babies in the UK are born prematurely. Babies like Jack, who have been born extremely early, face the greatest risks and sadly more than 1,000 die each year.

We believe that only by investing in research can the devastation caused by premature birth and pregnancy complications be stopped. Working in partnership with the charity Borne, we are now funding two new projects which aim to help reduce the number of babies born too soon and give the best possible outlook for affected families.

What causes premature birth is often unknown. But evidence suggests that infection is involved in four out of 10 women who experience an unexpected early labour.

At University College London, Professor Donald Peebles aims to develop a new treatment that targets such infections. He explains: "Bacteria, usually found inside the mother's vagina, can sometimes get into the womb where the baby is growing. This is bad news, as this infection can trigger inflammation that may cause premature birth and damage to the developing baby's brain."

Professor Peebles and his team are testing a potential new treatment that's designed to boost the body's natural defences against these infections. "Our hope is it could both reduce the numbers of premature births, as well as reduce the risk of brain damage and its long-lasting impact on children's lives," he says.

Find out more about our fight to stop the devastation caused by premature birth and pregnancy complications

action.org.uk/fightback

A new treatment to fight neuroblastoma

Around 100 young children a year are diagnosed with a cancer called neuroblastoma. Sadly some, like Felix, don't survive. Research funded by Action has tested new drug combinations aimed at making treatment more effective, to try and save more lives.

Felix was just four years old when doctors discovered a mass in his abdomen. "Our life completely changed that night," says his dad, Matthew. The little boy was diagnosed with high-risk, stage four neuroblastoma, a cancer that starts in the nerve cells and can spread rapidly.

Most affected children are very young – less than five years old – and, sadly, high-risk neuroblastoma can be very difficult to treat. Around one third of children lose their lives within five years of being diagnosed.

Felix endured two years of aggressive treatment, including chemotherapy, multiple operations, radiotherapy and a stem cell transplant. "The toughest thing was when he was in pain and lost a lot of weight," says Matthew. "While his twin brother was growing, Felix was shrinking."

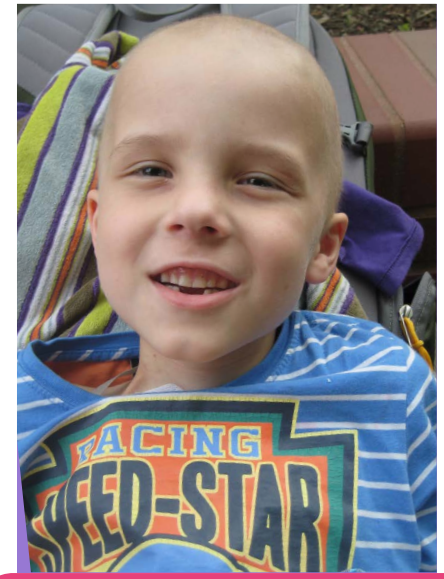
Throughout his illness Felix was cheerful and upbeat. He was unaware of the gravity and just wanted to be at home, playing with his brother and sister. Tragically he lost his fight, aged just six years old.

In 2014 Action awarded funding of almost £180,000 to Professor Robert Mairs, of Glasgow's Institute of Cancer Sciences. He aimed to enhance a treatment known as targeted molecular radiotherapy. This approach sees radioactive drugs, which seek and destroy cancer cells, injected into the bloodstream. It can be used to treat cancers that have spread and even destroy tumours that are too small to detect on scans.

The team investigated using additional drugs that are designed to make cancer cells even more susceptible to radiation-induced damage. Two of these were found to work well.

This 'holds promise as another component in the arsenal for the treatment of high-risk neuroblastoma' says Professor Mairs, who anticipates clinical trials in children with the disease will happen within two years.

This research was funded together with Neuroblastoma UK.



We are now funding more research into neuroblastoma. Find out more and support our appeal at **action.org.uk/cancer**

A test to predict risk of premature birth

Research funded by Action has made important steps towards developing a blood test that could be used in early pregnancy to identify women who are at high risk of going into labour too soon.

Research Training Fellow Dr Joanna Cook has been investigating the role of naturally occurring substances called microRNAs, which seem to be involved in controlling when a woman goes into labour. These can be detected in the blood and, importantly, their levels have been found to be different in women who go on to develop cervical weakness – a known cause of premature birth.

If diagnosed early enough cervical weakness can be treated and pregnancy prolonged. So a blood test used in early pregnancy would allow doctors to identify and help those women who are at risk.

Dr Cook says: "In our clinic we often see women who have already had very premature babies, but didn't receive special monitoring in their first pregnancies because we had no way of knowing they were at risk of early delivery. I hope this work will translate into a more personalised approach for these women in the future."

These promising results will now be tested in a larger group of women. If successful it is hoped that a commercially available test would be ready in around five years.

Helping children with dropped foot to walk more easily

Dropped foot can be caused by cerebral palsy, multiple sclerosis, stoke or injury and makes walking difficult. Action funding has helped to refine a technology called functional electrical stimulation, developing it into an effective, wearable device that is now benefiting both children and adults in the UK.

Children with dropped foot are unable to properly lift one or both feet. They struggle to move their ankle and toes upwards, which causes the front part of the foot to drop down, or drag.

This can make walking difficult, slow and tiring, with an increased risk of trips and falls. It can severely limit mobility and affect a child's confidence, independence and quality of life.

Conditions such as cerebral palsy, multiple sclerosis, stroke and some inherited neurological diseases can cause dropped foot. It can also be caused by brain or spinal cord injury.

How we've helped

From the mid-1990s, Action funding of £182,000 over seven years allowed researchers, led by Professor Ian Swain, to adapt and develop a technology called functional electrical stimulation (FES).

FES had previously been used in laboratories and hospitals since the 1960s but the systems were too bulky and complex for use outside of these settings. Professor Swain and his team, based at Salisbury District Hospital, in Odstock, and the Universities of Surrey and Southampton, aimed to bring its benefits to many more people.

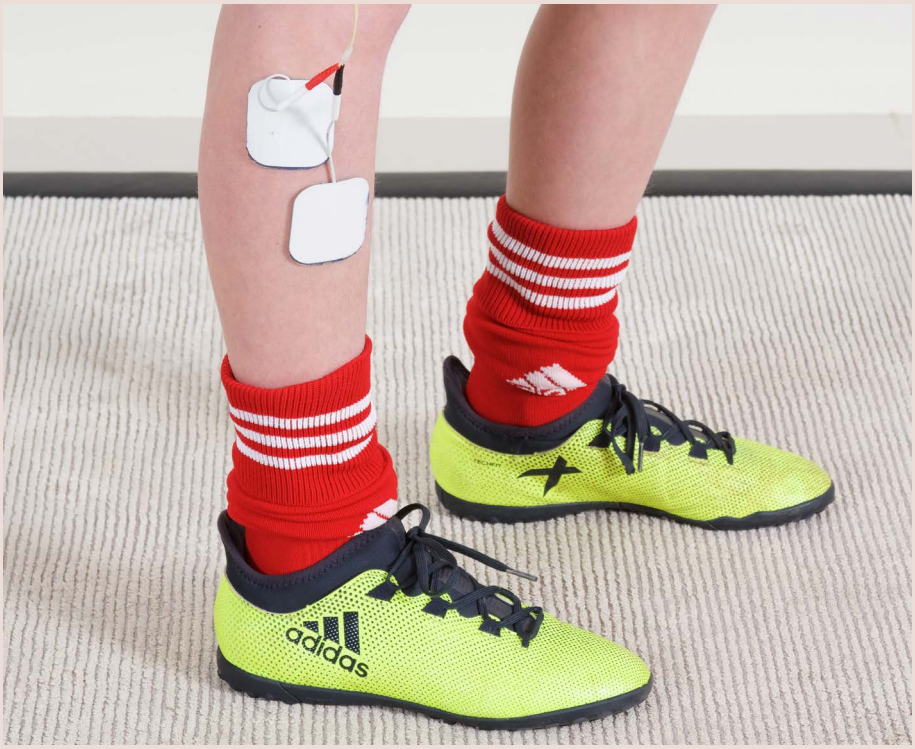
FES uses specially timed electrical stimulation of certain muscles to help lift the foot when walking. Usually signals, or small electrical pulses, travel along our nerve cells and tell our muscles when to contract, allowing us to move. But if these signals are disrupted, movement becomes difficult or impossible. FES involves wearing a special device that uses low energy electrical pulses to mimic the natural signals sent along the nerves.

The first Action grant allowed the researchers to improve and test a device they had already developed, known as the Odstock Dropped Foot Stimulator. Their new solution, tested on stroke patients, allowed two muscles to be stimulated at once instead of just one. This was shown to have much greater benefit, with improvements in walking continuing even when the device was not in use – something that hadn't happened before.

Further funding allowed more improvements to be made and since then the researchers have continued to work on this technology. The Odstock Dropped Foot Stimulator (ODFS®) is now sold worldwide and is estimated to have benefited 15,000 people in the UK alone.

"Funding from Action was key. It was our main source of funding in the late 1990s"

Professor Ian Swain



Finn wearing his FES pads

Finn with his mum Helen, dad Anthony and Dolly

While the device was first developed for adults, the team in Salisbury now run a dedicated children's clinic. This is managed by one of the original researchers on the Action-funded work, Dr Duncan Wood, and has treated children affected by cerebral palsy, stroke and head injury.

Children with dropped foot who use FES are able to walk faster, with less effort and fewer trips. But the most important benefits are associated with quality of life. Dr Wood reports young patients saying things like: "I can keep up with my friends" or "my walking looks more normal when I'm in town."

Over 20,000 FES drop foot stimulators have now been sold worldwide

Finn's story

Finn is 11 years old and has cerebral palsy affecting the right side of his body – a condition known as right-side hemiplegia.

His mum, Helen, has a background in nursing and since his condition was diagnosed, at six months old, she's thrown herself into researching every possible source of help. This led the family to find out about FES.

Finn finds it hard to lift his right foot when walking and his parents were so convinced that FES could help him, they fought their local authority for funding. Finn now attends the clinic in Salisbury twice a year and has experienced real benefits from using his device.

His dad, Anthony, says: "It has been fantastic, with great results. It makes a huge difference to his walking."

Explaining how the system works, Anthony says: "Finn wears a little box – about the size of two match boxes – attached to his belt, and wires down his legs. These attach to sticky pads on his calves. This system is wirelessly connected to a special switch inside his right shoe."

The pads allow electrical pulses to reach his muscles. One pad lifts his toes and the other turns them outwards. The switch under Finn's right heel controls the timing and strength of the pulses, which can be adapted according to how he's feeling.

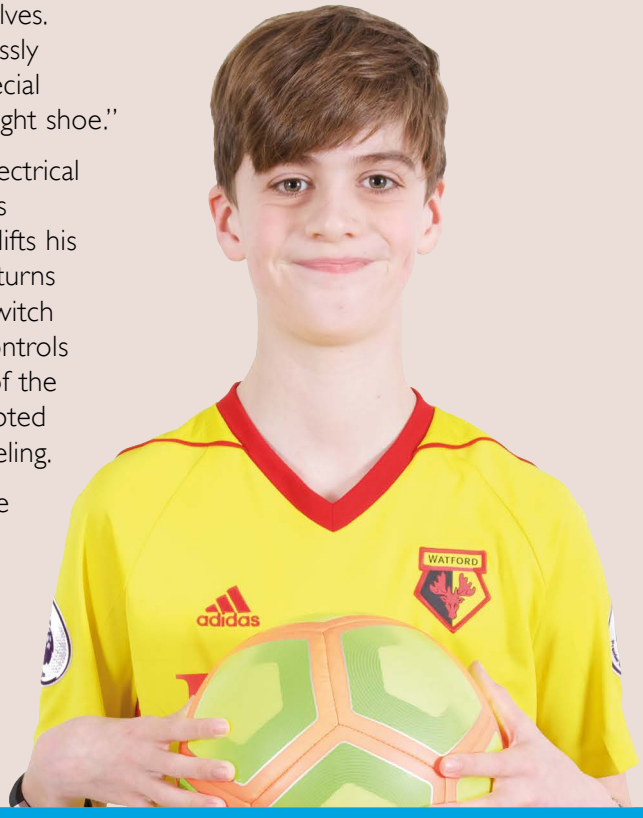
FES is helping Finn pursue his greatest passion in life: football. He plays for Chelsea Football Club under-12s team through the Chelsea Foundation's Disability Inclusion Programme.

He also plays for the Football Association's regional talent centre in the south east, in recognition of his skill and potential as a football player with cerebral palsy.

Aware that there is potential for hundreds more children and teenagers to benefit from FES, Anthony says: "The fact that charities like Action are prepared to put money into this is fantastic. Without this research, Finn simply wouldn't have the benefit of this technology. It's absolutely about giving opportunities to kids, to make a difference – a profound difference."

"It has been fantastic for Finn with great results. It makes a huge difference"

Finn's dad, Anthony



Photos: Ben Rector

We have a proud history of funding research that has improved the lives of children with disabilities. With your help, this work continues.

Cycling superstars help raise more than £1.5m

A host of cycling stars turned out to support our Champions of CycleSport dinner at the end of last year. And we were thrilled to see the total amount raised over eight years of this glittering event hit the magic £1.5 million mark.

Held in London, supported by Garmin, Maserati and BDO, the recent edition saw more than 750 guests rub shoulders with some of the nation's greatest riders, including former World Hour Record rivals Chris Boardman MBE and Graeme Obree.

They were joined by 2016 Olympic gold medallist Katie Archibald, plus Yanto Barker, Rochelle Gilmour, Dani Rowe MBE, Dan Martin and Steven Burke MBE.

Chris Boardman MBE said: "It has been an absolute privilege to be this event's Ambassador and I could not be more proud to see how it's grown. Action is a charity that I hold dear to my heart. My son George was born prematurely and I know the concern that parents have for their little ones' health. I am truly delighted to hear how much has been raised to help fund vital research."

Chris now hands over his Ambassador role to current road racing pro Alex Dowsett.

Action Ambassador Alex Dowsett

The date for this year's Champions of CycleSport event is Thursday 22 November. For details and table sales visit **action.org.uk/champions**

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

Company champions give fantastic support

Convenience store chain **One Stop** is celebrating a major milestone – raising an amazing £250,000. For one month every year since 2012, branches across the UK have proudly displayed Action collection boxes on their countertops.

We're excited to be starting a fundraising partnership with **Airport Parking and Hotels (APH)**. The company offers services at 26 UK airports and ports and will raise money through a series of staff-based challenges. Runners and cyclists will be collating their combined miles travelled throughout the year which will be matched in real money by the company.

The Big Give Christmas Challenge was a big success at the end of 2017. Thanks to everyone who donated, helping us fund vital research into devastating juvenile Batten disease. The generosity of our supporters meant we exceeded our target, raising almost £43,000.

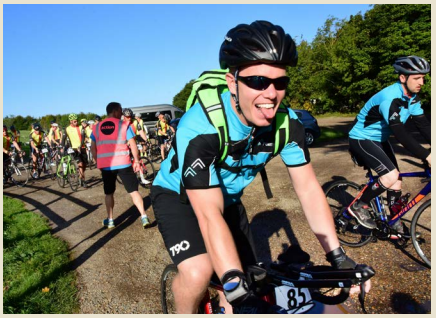
Celebrity supporter Davina McCall attended the **BGC Charity Day** at Canary Wharf along with amazing Aiden, one of our most inspiring young supporters.

The second **Willmott Dixon Classic** saw over 150 staff and clients on their bikes, raising £50,000 for Action. They were joined by former pro rider, now TV pundit, Yanto Barker.

The annual **Garmin Pro Ride** saw 800 cyclists join professional riders from Madison Genesis, Movistar Team, and Team Lampre Merida for a 50-mile spin in the New Forest. Sky News' Dermot Murnaghan hosted live interviews and Garmin demonstrated their new technology on stage. The event raised £49,000.

Arun Estates have raised well over £100,000 for Action over the last six years. Staff have walked, cycled and run, held quiz nights, football tournaments, cake sales and more. Their achievements have been led by their inspiring Group Managing Director David Lench, who has taken on a number of ambitious personal challenges for the charity.

We're also very grateful for the continued support of **Liberty Specialty Markets**, one of the world's largest specialty insurers. The company hosted a special reception for key supporters at their London HQ in the iconic Walkie Talkie building. They have also donated a significant amount towards new research into Crohn's disease and brain cancer.



Running for a reason

Why husband and wife Jim and Jeanetta Darrah took on the new London Landmarks Half Marathon.

As this issue of *Touching Lives* went to press Jim and Jeanetta Darrah, from Suffolk, were, quite literally, pounding through the streets of the capital and hopefully enjoying the sight of an iconic landmark or two along the way! London's newest, closed-road, running event took place on Sunday 25 March, with 10 runners pulling on their Action vests to take part.

Speaking about the couple's motivation to run, Jim, 51, said: "Our daughter Abby was born very, very poorly and to be honest we were worried she would not survive.

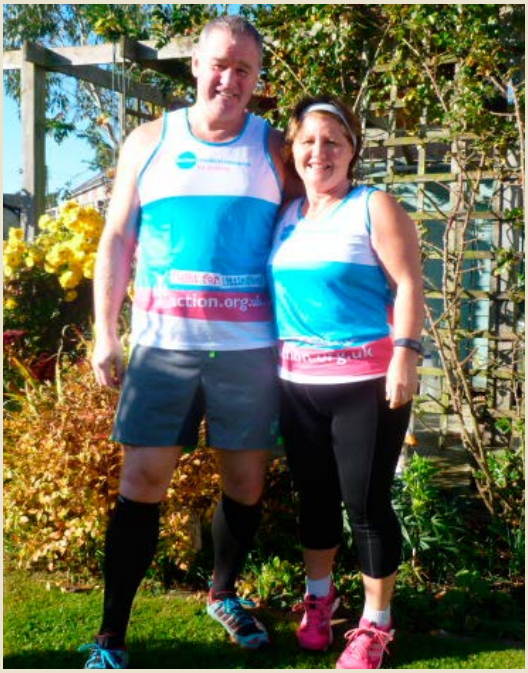
"We have a photo of her in the hospital bed with her very worried-looking older sister Zoe holding her hand. As a parent you just feel so helpless when your little ones are sick.

"Fortunately our Abby is now a healthy 26-year-old woman who has even run marathons herself.

We know not everyone is so lucky which is why we appreciate the invaluable work Action does."

Jim and Jeanetta, 53, have supported Action for 10 years and Jeanetta says she'd encourage anyone to sign up for a future event: "Look around you; do you know a child or family suffering from illness or fearing for the future due to the unknown? Do something, however small, to help make a difference," she says.

Team Action runners made a big difference in 2017, raising more than £108,000 – that's an amazing £72 per mile! If you want to run for a reason, please join us. We have places in various events across a range of distances – from the London Marathon to the Mud Monsters Run. Find out more at **action.org.uk/running**



"Our Abby is now a healthy 26-year-old who has even run marathons herself"

Can you find all the words in our word search?

U	L	R	E	S	E	A	R	C	H
E	V	E	M	N	T	S	L	S	F
R	G	N	A	D	W	N	E	G	T
U	L	T	R	A	S	O	U	N	D
T	O	I	A	S	Z	J	B	I	J
A	T	O	T	C	E	A	A	L	P
M	T	C	H	F	I	N	N	C	K
E	E	A	O	G	N	T	O	Y	K
R	R	E	N	E	C	T	E	C	T
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SCONES
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BABIES
MARATHON
ULTRASOUND
LOTTERY
CYCLING
JACK
FINN
RESEARCH

Complete the word search and pop this slip in the post to: Cream Teas Word Search, Action Medical Research, Vincent House, Horsham, West Sussex RH12 2DP

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Challenge events 2018

Running

Virgin London Marathon 22 April
Vitality London 10,000 28 May
Mud Monsters Run West Sussex, 3 June

Cycling

RIDE100 Series:
Castle Ride 100 Kent, 13 May
Suffolk Sunrise 100 20 May
Davina's Big Sussex Bike Ride 10 June
Trossachs Ton Scotland, 17 June
York 100 19 August
Essex 100 2 September

Prudential RideLondon-Surrey 29 July

Cycle Tours

Maratona dles Dolomites 1 July
London to Paris Tour Edition 25 to 29 July

Team Challenges

NEW Scumrun Charity Drive 17 to 21 May
Trek the Night Cotswold Way 9 to 10 June
Trek the Night South Downs Way 14 to 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 challenges*

Snowdon 9 June
Yorkshire 3 Peaks 17 June
Ben Nevis 8 September

Conquer the Mountain series

Grab your hiking boots and join us as we summit some of Britain's highest peaks this summer.

We have three events to choose from – Snowdon, Ben Nevis or our Yorkshire 3 Peaks in the beautiful Pennine range.

You can come solo or bring a team – these challenges are perfect for anyone looking to achieve a specific time or tackling it alone for the very first time with the full support of our crew along the way.

Find out more and register at
action.org.uk/mountain_series

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

The best tea break you'll have all year!

Join us for our easiest, tastiest fundraising event on Thursday 28 June. All you need to do is get a group of friends or work colleagues together and place your order online. Our Action Cream Teas boxes are filled with everything you need for a perfect tea-break treat, delivered direct to your door. Best of all, every bite enjoyed helps us raise vital funds to save and change children's lives.

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action.org.uk/cream-teas

Exclusive reader offer

Complete the word search overleaf for the chance to win a delicious Action Cream Tea for you and five friends!