

action medical research
for children

Spring/summer 2017

touching lives

The Action Medical Research magazine

Living with
cerebral palsy
Read Tom's story

Plus

New cystic fibrosis
and sickle cell
disease research

Helping children
with DCD get the
right support



Dear supporter

We're delighted to be celebrating our 65th anniversary this year. We've been funding vital medical research since 1952, when we helped introduce the first polio vaccines in the UK. Since then supporters like you have helped fund more than £117m of research, resulting in some amazing breakthroughs.



But there is still so much more to do. Which is why we hope you'll enjoy reading about what we're doing now and new research we're funding. This issue features current projects to tackle complications caused by cystic fibrosis and to help babies who have suffered life-threatening brain damage at or around birth. Plus there's news of research to help children like our gorgeous cover star Tom who has severe cerebral palsy.

We're also excited to share some success stories, including how Action funding has made a global impact helping to diagnose and support children and young people with developmental coordination disorder – find out more on page 12.

As always, everything we do is only made possible through the support of people like you, who help us fund the very best research. We have recently updated our supporter promise and privacy policy – you can read more here action.org.uk/privacy-policy

Thank you for reading,

Clare

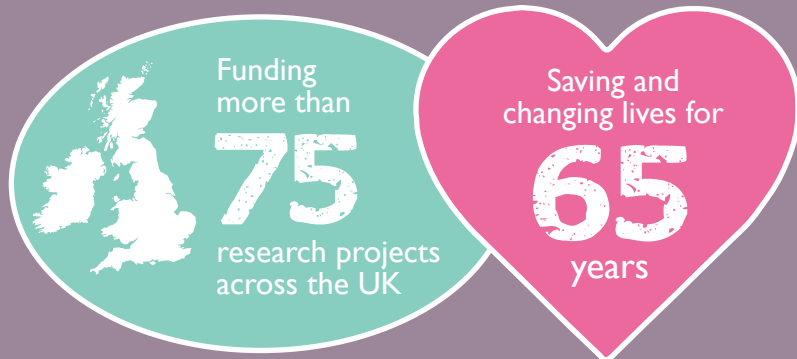
Clare Airey, Editor

PS Don't forget to join us for our Cream Teas fundraiser this summer! Visit action.org.uk/cream-teas

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

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

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

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Summer scones to save lives

We hope as many supporters as possible will order our Action Cream Teas this summer. Last year we raised almost £55,000 but with your help we know even more cream teas can be enjoyed!

It's super-easy to take part and an ideal treat to share with a group of friends, family or work colleagues. Each cream tea box contains everything you need, lovingly packed by our wonderful teams of volunteers, and is delivered directly to your door on 22 or 23 June.

Boxes cost £6 each and there is a minimum order of 10. Please – order yours, scoff a scone and help us fund big breakthroughs to save little lives.



Best of British Action Cream Teas IN A BOX

What's in the box

- 2 x classic plain scones
- Rodda's Cornish clotted cream
- 2 x Tiptree strawberry preserve
- Yorkshire tea
- Knife and serviette

22 AND 23 JUNE
delivered to your door!

Find out more
action.org.uk/cream-teas

What our celebrity supporters have been up to...

Our much-loved fundraising mascot **Paddington Bear™** takes to the big screen again this year with the release of the film *Paddington 2* in November. We can't wait to see what he gets up to!



British cycling's golden couple **Jason and Laura Kenny** (nee Trott) joined a star line-up at our Champions of CycleSport Dinner. The pair now have 10 Olympic gold medals between them. Also among those supporting Action was **Jody Cundy OBE**, winner of double gold at the Rio Paralympics. The event raised an incredible £280,000.



Current Miss Scotland, **Lucy Kerr** has pledged to raise funds for Action Medical Research during her year-long reign. She hopes to raise up to £50,000 to support Professor Robert Mairs' Glasgow-based research to improve treatments for children with neuroblastoma, a type of cancer.

Go West stars **Richard Drummie** and **Peter Cox** helped to raise £20,000 when they performed at our ladies' lunch in Kent last October.

Five-time British Rally Champion **Jimmy McRae** and former Grand Prix racer **Steve Parrish** joined guests at our annual Celebration of Motorsport Dinner in Belfast. Two-time Superbike World Champion **Jonathan Rea** and record-breaking road racer **Ryan Farquhar** also attended.



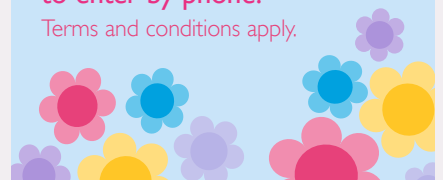
Win £1,000 this spring!

We have some amazing cash prizes just waiting to be won in our Spring Superdraw, including a fantastic first prize of £1,000! Entries are just £1 each and with every entry you buy you'll be helping to save and change children's lives, as well as increasing your chances of winning.

Closing date for entries is 10 May, with the draw taking place on 12 May – so don't miss your chance to win.

Enter today at
action.org.uk/superdraw
or call **01524 753247**
to enter by phone.

Terms and conditions apply.



Protecting newborn babies from brain damage

Researchers funded by Action are investigating whether a commonly used diabetes medicine could help babies who've suffered life-threatening brain damage at or around birth.

Aiden endured a traumatic start to life and his survival was uncertain. Complications at his birth meant he was deprived of oxygen for more than 20 minutes and needed prolonged resuscitation.

"For the first two hours I didn't know whether our beautiful son had survived or not," recalls his dad, Keith.

Doctors began to reduce Aiden's body temperature to protect him from further brain damage, a process known as cooling therapy. This breakthrough treatment is now routine in the UK and was the product of a 20-year programme of research to which Action Medical Research contributed more than £1m.

"Aiden was cooled for 72 hours," says Keith. "His little body was wrapped in an ice jacket helping prevent the spread of further brain damage. Without this vital treatment our little boy may not be here now."

But while cooling therapy gives babies like Aiden a better chance of surviving and can protect against or at least limit disability, sadly it doesn't save all babies. Neonatal encephalopathy (NE), a form of brain damage that is usually caused by a shortage of oxygen at birth, still kills around one in five affected babies in the UK. Many others develop lifelong problems such as cerebral palsy and learning disabilities.

Action has awarded funding of more than £193,000 to Dr Ahad Rahim of University College London, who says there is an overwhelming need for



Three-day-old Aiden in his ice jacket, with mum Fleur

Each year around **700,000** babies worldwide die or face lifelong disability due to brain damage at birth

further improvements in the treatment of this condition.

Dr Rahim and his team are investigating whether a diabetes medicine, called exendin-4, could help more babies. The drug is thought to have protective effects on the brain and clinical trials are already underway to find out if it benefits people with Alzheimer's and Parkinson's diseases.

If successful, this means that it should be faster to develop it as a treatment for babies affected by NE rather than a totally new medicine. The drug could then be used either alone or in combination with cooling therapy to help more babies who are at risk.

Aiden's mum, Fleur says: "More research is so important. Without previous research Aiden's outcome could have been even more severe. By undergoing cooling we were given hope. NE affects increasing amounts of babies and those babies and their families deserve to have the hope that we did."

"We didn't know if our beautiful son had survived or not"

Preventing infection in children with cystic fibrosis

Children with cystic fibrosis are susceptible to chest infections which can be very difficult to treat. These can cause long-term ill health and reduce life expectancy. New research aims to diagnose infections sooner and prevent them from taking hold.

Cystic fibrosis is a serious, inherited lung condition with no cure. It's typically diagnosed when babies are just 26 days

old and some children eventually need a lung transplant as adults.

Around one third of children with the condition develop a long-term lung infection with *Pseudomonas* bacteria by their late teens. These

infections are usually harmless and short-lived in people with healthy lungs but for children with cystic fibrosis they can become impossible to treat.

Action funding is helping Dr Jo Fothergill of the University of Liverpool to investigate how these infections take hold. She and her team believe it may be possible to diagnose them at their earliest stages by taking regular nasal swabs from children with cystic fibrosis.

Dr Fothergill says: "If *Pseudomonas* infections are diagnosed quickly, it's possible to get rid of them using intensive antibiotic treatments. But if a long-term infection sets in, it's almost impossible to eliminate it from the lungs. Families and patients have described these infections as devastating."

Action Medical Research and the Cystic Fibrosis Trust are together funding this study.

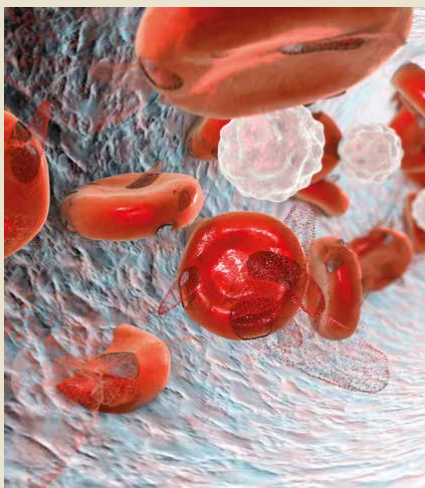


Image courtesy of the Cystic Fibrosis Trust

More than
4,000
UK children have
cystic fibrosis

Could an asthma medicine help children with sickle cell disease?

Sickle cell disease is an inherited condition that affects the red blood cells. While many children are able to lead normal lives most



Sickle cell disease affects red blood cells

of the time, the disease makes them more vulnerable to serious health problems.

Some children with sickle cell disease also have learning difficulties. These can be caused by suffering a stroke – which these children are at greater risk of – but Professor Fenella Kirkham, of UCL Great Ormond Street Institute of Child Health, believes night-time breathing problems might also be partly to blame in some, disrupting their sleep and affecting concentration during the day.

With funding from Action, Professor Kirkham and her team

are investigating a new approach to treating sleep apnoea in children

with sickle cell disease. They are trialling the use of a common asthma medicine in a group of children aged between three and eight years old.

Professor Kirkham says:

"If this medicine helps, it might mean fewer children need surgery to remove tonsils or adenoids, an existing treatment option for sleep apnoea which is something parents worry about. It might also improve the overall health and learning abilities of children with sickle cell disease."

Around
12,500
people have
sickle cell disease
in the UK

Fighting a condition that causes multiple tumours

Neurofibromatosis type two causes tumours to develop in the nervous system, typically in the brain and spine. Although not cancerous, these can cause devastating symptoms. Dr Sylwia Ammoun hopes to develop a much-needed new treatment for this rare genetic disease.

Around 40 people, most of them teenagers or young adults, are diagnosed with neurofibromatosis type two (NF2) each year in England. It's caused by a gene defect, which can be inherited but can also happen by chance before birth. This results in the body being unable to produce a tumour-suppressing protein called Merlin.

People with the condition can suffer from 20 to 30 tumours at any one time. Those inside the head commonly cause hearing loss, tinnitus and balance problems, as well as facial pain and paralysis, speech impairment and swallowing problems. Sufferers are also at risk of developing cataracts that can lead to blindness. Spinal tumours cause back pain and often paralysis, and tumours that cause pressure on the brain stem and blood vessels can be life-threatening. Sadly symptoms tend to get worse over time and lives can be cut short.

Treatment options are currently limited. Surgery may be possible but can be high-risk and depending on where tumours are located, is sometimes just too dangerous.

Dr Sylwia Ammoun, of Plymouth University, has been studying tumour cells donated by people with NF2 and discovered it may be possible to treat them using existing



Dr Sylwia Ammoun

drugs. Funding from Action is helping her to investigate further.

"We've found that certain sequences of DNA, which originally came from viruses that have inserted themselves into our chromosomes over millions of years and are normally inactive, become active within NF2 tumour cells," says Dr Ammoun.

"We think the unusual activity of this DNA may cause these tumour cells to grow. We have shown that some drugs, which are used to treat viral infections, seem to block the action of this DNA and slow down the growth of tumour cells. We are investigating this further to see if we can develop a much-needed new drug treatment."

She adds: "We are immensely grateful to Action Medical Research for this vital grant which will help us to move closer to finding the best drug to deal with this pernicious and debilitating condition, which can rob children and young adults of quality of life at an early age."

"This will help us move closer to finding the best drug to deal with NF2"

People with NF2 can suffer from as many as

20 to 30
tumours at any one time

Thank you – these are just some of the new research projects we're funding with your support. Find out more at action.org.uk/latest-research

Happy memories and a lasting legacy

In the 1980s Paul Simpson was the youngest person in the UK to benefit from a revolutionary walking device that was developed with funding from Action. For his parents Anne and Stuart, remembering the charity when they made their wills was incredibly important.

Paul Simpson was just two-and-a-half years old when, by chance, his mum Anne saw a television programme that would see the start of a long relationship with Action Medical Research. It was about a new design of walking frame for people with spinal conditions. And Anne was determined to find out if it could help her young son, who had spina bifida and was paralysed from the waist down.

Paul had been born with an open lesion on his spine, which took several months to close, and at around six months old he was also diagnosed with hydrocephalus and needed surgery to fit a shunt to drain away excess fluid that was building up on his brain.

Anne describes her son as a beautiful, bonny baby, who grew into a very happy little boy and was popular with all who met him. He was also a fighter from his earliest days and his parents were always determined to help him live life to the full.

After making enquiries, Anne discovered that a walking aid like the one she'd seen was being developed here in the UK – research which was being supported by Action. Her

persistence paid off when Paul was chosen as the youngest of just five volunteers to pilot test this new frame, called a Reciprocating Gait Orthosis (RGO).

The research turned out to be life-changing for Paul and the RGO became part of the family's daily routine. "Without a doubt it transformed his life," says Anne. "It did him so much good physically but I also think it had a lot of psychological benefit too. It helped to give him a sense of normality."

Being upright and weight-bearing for short periods each day, supported by the RGO, meant Paul could avoid some of the health issues that sitting for prolonged periods can cause, such as kidney problems. And at his mainstream school it allowed him to spend time on the same level as his peers.

Paul's story captured hearts at Action and he went on to feature in a poster campaign for the charity and attended some of our most high-profile events – something his parents say he loved.

Sadly, Paul died suddenly aged just 14 as a result of an unforeseen complication. But his parents say they are left with the most amazing memories and his legacy lives on in many ways. One of these is in their decision to leave Action a gift in their will.

"For us it's a given," say Anne and Stuart. "The charity holds a very special place in our hearts. As well as the RGO, there's the research that has since proven the link between taking folic acid and preventing spina bifida – a hugely significant development – and also research into hydrocephalus is so important.

"The impact that research can have on people's lives cannot be underestimated and when you realise life is so precious you want to help. It gives us warmth in our hearts to know Paul's legacy will live on."

If you would like to find out more about leaving a gift in your will please contact Sharon on 01403 327413 or email sgearing@action.org.uk You can also read more on our website: action.org.uk/legacy



Photo: Ben Rector

Helping children like Tom

“He’s still a little boy and we want him to have a normal childhood and just have fun”





Tom was less than a year old when he was diagnosed with quadriplegic cerebral palsy. Everyday life is challenging for him and he will need a lifetime of care. But, as his mum Maria explains, he is a bright and determined little boy, who refuses to let his disability define him.

“Tom is really funny and very brave and wants to be involved in everything that’s going on,” says his proud mum Maria. “In his imaginary play he’s not disabled – he’s a fireman or an astronaut.”

He is a happy little boy, but sadly Tom does have a severe physical disability. His cerebral palsy affects both sides of his brain, governing control of both his arms and his legs and his torso. He finds it extremely hard to control his limbs, has a lack of balance and suffers from muscle stiffness and weakness.

“Tom uses a wheelchair and we have been told it is unlikely that he will ever be able to walk unaided,” explains Maria. “Even using a special walker that fully supports his body, he finds it difficult to move very far.

“Everyday activities such as eating and playing with toys are challenging. He will need immense levels of care throughout his life,” she adds.

Each year around 2,000 babies born in the UK are diagnosed with cerebral palsy. It is a lifelong condition, affecting muscle control and movement, and is caused by damage to the brain before or during birth.

Photos: Ben Rector



Tom with dad Terry, sisters Iris and Molly, and mum Maria

Tom was diagnosed shortly before his first birthday and discovering that their baby son would face a lifetime of disability was heartbreaking for Maria and husband Terry.

The couple had had a nagging sense that something was not right from their son's earliest days. He'd always seemed very stiff and had great difficulty feeding. He hadn't made eye contact until he was about seven months old and his hands were always held tightly in fists. As he grew older he struggled to sit and couldn't grasp things. But initially medics had dismissed the family's concerns.

Eventually a new doctor confirmed their worst fears. The family, which also includes Tom's older sister Molly and his twin sister Iris, had hoped that he would not be too severely affected. But sadly an MRI brain scan revealed serious damage.

Doctors say that Tom's cerebral palsy was caused by a type of brain injury called periventricular leukomalacia. This most often occurs when parts of the brain are starved of blood and oxygen. The cause of this injury is not known.

Maria and Terry were told it was unlikely that Tom would ever walk unaided, may develop vision problems, and might also be affected by epilepsy.

It was devastating news but, Maria says, "At least we had a name for what we were dealing with. As time goes on, the worst case scenario becomes something you can deal with. And we'll never forget how fortunate we are that our little boy can speak, because many

"Research to help improve outcomes for children with cerebral palsy has got to be a really positive thing"

children with quadriplegic cerebral palsy aren't able to."

Now six, Tom attends a school which offers a specialist form of education for children with cerebral palsy. He has developed a rare type of epilepsy and takes medication every day to control this, as well as medicines to improve his muscle tone and help his digestive system to work properly.

He has also endured muscle-release surgery on his legs and hips, because his muscles were pulling his joints out of place.

Life can be difficult for Tom and his family but his mum says: "We adore Tom just exactly as he is and we are determined that he should lead as normal a life as possible. He's still a little boy and we want him to have a normal childhood and just have fun."

Maria feels that research that could help children like Tom is vitally important. "Anything that helps improve outcomes for children with cerebral palsy, and helps parents make the right decisions for their children, has got to be a really positive thing," she says.

Our research

Problems affecting the hip joint are a key cause of disability for children with cerebral palsy and often result in significant pain and reduced mobility.

This is something that has affected Tom. Action Medical Research recently awarded a grant of more than £150,000 to a team based at the One Small Step Gait Laboratory at Guy's Hospital, London. They aim to develop a portable 3D ultrasound system for scanning the hip joints of children with cerebral palsy. This could eventually replace the use of repeated x-rays for monitoring these children, providing a safer and more accurate way of assessing their hip development. Since ultrasound scans could give more detailed pictures, it may also make it easier to predict early on which children are at greatest risk of full hip dislocation, meaning they can be treated sooner.

Action is also funding a team of specialists at UCL Great Ormond Street Institute of Child Health, who are investigating whether new MRI brain scans could help doctors predict the severity of movement difficulties children with cerebral palsy are likely to experience in the future. This could eventually make it easier to plan their care.

Action Medical Research has a proud history of funding research to help children with cerebral palsy and other disabilities.

Thank you for helping us make this vital work happen.

Finding answers for children like Eva

Ataxias are a group of rare neurological disorders. They affect balance and coordination, and can cause severe disability. Research funded by Action has identified new genes linked to these conditions and helped to increase understanding of childhood onset ataxias.

When Eva was first born, there was no cause for concern and she reached her early milestones. But as she got older her parents noticed her hands shaking and began to worry. After she struggled to crawl, stand and then eventually walk they asked their GP to refer her for tests.

Diagnosed with ataxia when she was three, life is challenging for little Eva. She has problems with strength, balance and coordination, tires easily and suffers from a type of tremor that becomes more pronounced when she moves, for instance when reaching for a toy.

Ataxia can be progressive, leading to severe disability, robbing some children of the ability to walk and affecting their speech. It can also be life shortening.

Eva, now five, is currently making good progress. But the future remains uncertain, as her mum Carla explains: "Eva's condition might be progressive, it might not be, we don't know. There's hope, but no guarantee that it won't get worse."

When children are first diagnosed with ataxia, it's often difficult to know why they have developed the condition. In 2012 Action awarded more than £173,000 to Professor Andrea Nemeth at the University of Oxford to investigate genetic causes of ataxia. This has led to improved genetic testing and better understanding of these conditions.

This research is already benefiting families who've received a clear genetic diagnosis and some have been able to make decisions about having more children. It has also allowed

doctors to give more information on what the future might hold and in some cases to provide reassurance that a child's condition will not deteriorate. In the future it could also lead to new treatments.

"The work that's been done gives us hope that more funding will become available to help answer other questions for us, not just for Eva's sake but for other children, too," says Carla.



Photo: Ben Rector

Better brain scans for children with epilepsy

Research funded by Action has allowed doctors to successfully test a new child-friendly brain scanning technique to identify children with drug-resistant epilepsy who could be treated by surgery.

Their results have led the team to make a business case for their test to become a new clinical service within London's Great Ormond Street Hospital and made accessible to other hospitals treating children with epilepsy.

Medication
doesn't work for
up to 1/3
of UK children
with epilepsy

Around 60,000 children and teenagers under 18 in the UK have epilepsy, and sadly medication doesn't work for up to one third of them. The seizures these children experience can be scary and unpredictable. They can make day-to-day life very difficult, sometimes even dangerous.

Brain surgery can be a life-changing option for some of these children but it is a major undertaking. It works by removing the part of the brain that triggers the seizures; so doctors need to be able to pinpoint where that is and the impact surgery might have.

Dr David Carmichael and his team were awarded an Action grant of £190,000 to develop the new technique, which combines EEG and fMRI scanning together. Significantly, they found that adding a third technique, called electrically source imaging or ESI, gave the most accurate results and this could identify brain abnormalities where other scans had previously failed to find them.

They also successfully tested a child-friendly approach by allowing children to wear headphones and watch cartoons inside the scanner. This helped to reduce movement inside the scanner, even in children as young as six.

The global tests now helping children with DCD

Action funding over several years helped UK researchers to devise new tests and guidelines that are now used all over the world to identify and support children and teenagers with Developmental Coordination Disorder.

Developmental Coordination Disorder (DCD), often also called dyspraxia, affects children's movement and physical coordination and can make everyday activities much more difficult. Things like using cutlery, getting dressed, playing sports or riding a bike can all be a struggle. And for many children with DCD, handwriting is an extremely difficult skill to master.

Although signs may be there early on, the condition is often not spotted until children start school at around age five – and it's estimated that up to one in 20 school-aged children in the UK is affected.

But the sooner the condition is identified, the earlier support can be given which can make all the difference.

How we've helped

Between 1999 and 2006 Action Medical Research funded several projects in this area, worth a total of more than £217,000.

At the University of Leeds, the work of Professor David Sugden and Dr Mary Chambers focused on younger children. They showed that simple interventions made at nursery, school and in the home could help children develop basic skills and improve their coordination, especially those more mildly affected.

They developed a set of practical guidelines for parents and teachers, detailing simple steps to guide children through tailored activities. These are now used in the UK and across the world to identify young children with DCD and help them to learn new skills before their lives are adversely affected.

Professor Sugden says:
"We now have a much heightened

awareness of the importance of motor skills in the early years and have shown that by intervening, both parents and teachers can make a huge difference."

Action's support, says Professor Sugden, played a vital part in the success of this work.

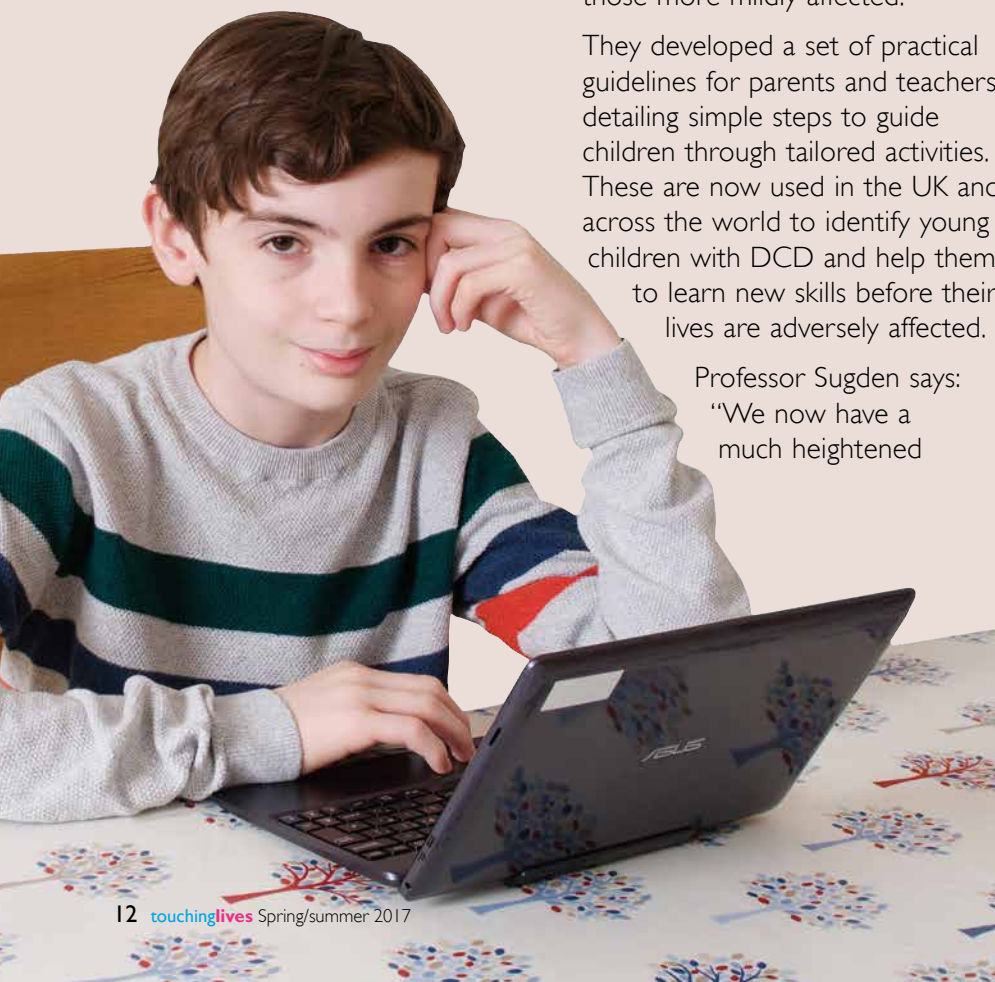
"Without help from Action Medical Research we would not have achieved a quarter of what we have done"

Professor David Sugden

At University College London and Oxford Brookes University, Professor Sheila Henderson and Professor Anna Barnett were also supported by Action, resulting in two new tests to help older children and teenagers.

Their research saw them successfully adapt an existing test used for younger children, called the MABC, to create the first suitable test for older children. The new version, called Movement Assessment Battery for Children-2 or MABC-2, is now one of the most popular and respected tests worldwide for the assessment of motor skills.

They also developed the Detailed Assessment of Speed of Handwriting (DASH). Children with DCD, and some other conditions, may struggle to write quickly or legibly enough to cope with the



demands of school, putting them at a huge disadvantage, especially during exams. This test enables teachers and therapists to better understand these problems and provide tailored support or special arrangements to help them perform as well as they can.

Liam's story

Liam is a determined and confident 14-year-old who dreams of running his own business. "I'm half expecting him to become the next Lord Sugar!" says his proud mum, Lisa. He's recently started his GCSE year at a new college and is enjoying his studies but this hasn't always been the case. Liam was diagnosed with DCD at seven, having struggled from the moment he started primary school.

At home he'd been a happy baby and seemed to reach his milestones. "He spoke very well, had a vocabulary beyond his years and was very perceptive," says Lisa. "But when he started school he found it really difficult."

Liam suffered from exhaustion beyond the tiredness you would expect. He'd loved books as a toddler but struggled to learn to read and he found writing almost physically impossible.

"It felt like he was bottom of the class, which didn't seem to tally with his actual intellect," says Lisa. "He would often end up cross or in tears. Nobody really

understood what the problem was – or even whether or not there definitely was one."

Luckily, Liam was spotted by an occupational therapist who was visiting his school. She pushed for a referral and he was then tested, using the MABC-2, and diagnosed with DCD.

Having a diagnosis meant Liam could finally explain why he couldn't write and for Lisa it meant she could ensure he got support.

Liam was set activities to help him improve his fine and gross motor skills.

He began to use a laptop to make up for his problems with writing and he was also eventually diagnosed with dyslexia and had sessions with a private tutor, which helped improve his literacy skills.

He is now happy and doing well, and is generally able to manage his DCD. Lisa says they have accepted that he will never be able to write properly and he continues to use a laptop, having learnt to touch-type at speed.

There have been times when Lisa has had to fight to get the support Liam's needed and there have

been many occasions when people have failed to properly understand the impact DCD has, which is why both Liam and Lisa feel research is so important.

"One of the hardest things is that it is usually quite hidden. Studies into DCD are so important as they help to increase understanding and awareness; helping children to live better lives," says Lisa.

"DCD is usually quite hidden – it isn't immediately obvious. But it can make life really hard"

Liam's mum, Lisa

The MABC-2 test has now been translated into at least 15 languages



With your help we are currently funding more new research to help children with DCD. Thank you for your support.

Photos: Ben Rector

Davina's decade of fundraising

Our most recent Dine with Davina function was an extra special one. As well as marking the 10th anniversary of this popular event, we were delighted to honour our wonderful host Davina McCall for helping us raise a fantastic £500,000 over the last 10 years. She's one of the UK's busiest and most popular TV personalities and a mum of three but Davina still finds time to continue the family tradition of supporting Action – she was introduced to our work by her granny when she was just nine!

Each year she hosts her Big Sussex Bike Ride in June, as well as Dine with Davina in

Hampshire in the autumn. These two events combined have now raised half a million pounds – a huge contribution to help fund life-changing medical research for children.

And if that's not enough, Davina is also training to do the Great North Run for us later this year!

Thank you so much Davina!

Join Davina for her Big Sussex Bike Ride on 25 June. Ride 21, 40 or 68 miles. Sign up at action.org.uk/davinas-bike-ride



Celebrating corporate contributions

Our latest Action reception, held at London's BT Tower, was an ideal setting to thank existing supporters and inform new ones about the vital research they can help fund. Action's Chair, Phil Hodgkinson (pictured centre left), was also delighted to accept a cheque from **Skerritts Chartered Financial Planners**, who raised £100,000 for Action in 2016. Also pictured I-r are: Louise Hearn from Skerritts and Heidi and Richard Skerritt.



We're also grateful to have received support from **Liberty Specialty Markets**, one of the world's largest specialty insurers. Liberty's generous donation will help fund research for children with brain cancer.

And we're thrilled to have been selected by **DX Group** as one of their three charity partners. Staff at the mailing, parcels and logistics firm will fundraise throughout the year and the business has pledged to match the money raised up to £50,000.

Always ready to support Action, Davina McCall hit the trading floor to represent us at the annual **BGC Charity Day** last September. The annual event commemorates the World Trade Center terrorist attack of September 11 and is held in BGC offices across the globe.

Thank you to everybody who supported the matched-funding opportunity offered by the **Big Give Christmas Challenge** again last December. We exceeded our £30,000 target, with funds raised going towards research into developing personalised surgery for babies with heart disease.

We are proud to have been named as the charity partner for two cycling events this year, **Eroica Britannia** and the **Tour of Ayrshire**.

And our cycling events continue to attract corporate supporters, with international IT firm **Commvault** entering a team for this year's London to Paris ride for the third year. Meanwhile **Black and White Hospitality**, owned by Marco Pierre White, are building a team for their first outing. **Pure Storage** also has a team of 30-plus on our Paris to Geneva ride in September.

Action have also been beneficiaries of annual staff and client bike rides put on by **Aon Benfield**, which raised over £60,000, **Garmin**, raising £45,600 and **Willmott Dixon**, which was attended by special guest Jody Cundy OBE (pictured) and raised £100,000.



Dedicated to Daniel

Charlie Paterson has been one of our most loyal runners over the last decade and his various costumes have ensured he's popped up on TV screens too. His reason for running remains the same – to help babies like his son, who was born too soon.

Charlie, from Hull, first ran the Great North Run for Action Medical Research back in 2008, dressed as an eight-foot bottle of Newcastle Brown Ale. Since then he's taken on the half marathon almost every year for us, usually in a quirky outfit to add to the challenge. He's previously run as Darth Vader and last year was dressed as our fundraising mascot Paddington Bear™. In 2012 he even braved the London Marathon in the guise of Borat, complete with wig and skimpy mankini!

But running is not all about the fancy dress for Charlie. He runs and fundraises for Action because the cause is so close to his heart.

“Running for Daniel and other families has always inspired me. This year would have been his 10th birthday”

On 4 February 2007, Charlie's little boy Daniel was born after just 24 weeks of pregnancy – 16 weeks too soon. Sadly, he died 10 days later.

“I did a lot of running when I was much younger, mainly 10kms,” explains Charlie. “But I only started training properly again after my son died. It gave me a goal.

“Running for Daniel and for other families has always inspired me, both on the day and when doing the training. This year would have been his 10th birthday,” he adds.

Sadly premature birth is the biggest killer of babies in the UK. Around 1,200 babies die here each year after being born too soon and many who survive a very early birth develop lifelong problems such as cerebral palsy, blindness and learning difficulties.

“This is the reason why I decided to run for Action Medical Research,” says Charlie. “To help fund research trying to stop babies being born prematurely. Hopefully, through the research and funding, other families will not have to endure the suffering and heartache we went through. Even if Daniel had lived, the doctors explained the complications could have gone on for a number of years.”

Charlie has now completed 10 Great North Runs in total, seven of them for Action. His stand-out costumes have meant he's often picked out by the media and here he's also done a great job

helping the charity raise its profile and highlight our cause.

We're hugely grateful for the support of runners like Charlie. Every year we offer places in various events across a range of distances including the Vitality London 10,000 at the end of May, the Great North Run in September and the Virgin Money London Marathon.

To run for a reason and raise money for us, please visit action.org.uk/running to find out more and register.



Charlie on the Great North Run as our mascot Paddington Bear



Running

- Silverstone Half Marathon** 12 March
- Virgin Money London Marathon** 23 April
- Vitality London 10,000** 29 May
- Simplyhealth Great North Run** 10 September



Team Challenges

- Trek the Night Cotswold Way** 10 June
- Trek the Night South Downs Way** 15 July
- Race the Sun Brecon Beacons** 24 June
- NEW Race the Sun Isle of Wight** 8 July
See details opposite
- Race the Sun Lake District** 2 September

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



Cycling

- Suffolk Sunrise 100** 7 May
- Castle Ride 100, Kent** 14 May
- Trossachs Ton, Scotland** 18 June
- Davina's Big Sussex Bike Ride** 25 June
- Prudential RideLondon-Surrey 100** 30 July
- York 100** 20 August
- Essex 100** 3 September



Cycle tours

- Action London to Paris** 19 to 23 July
- Maratona dles Dolomites – Enel** 2 July



Mountain series one day treks

- Mount Snowdon** 10 June
- Yorkshire Three Peaks** 17 June
- Ben Nevis** 9 September



You can register for an event on our website, give us a call or send an email:
action.org.uk/get-involved
 T 01403 327443
 E events@action.org.uk



New for 2017



Cycle, trek, canoe

Our new team fundraising challenge will see participants racing by bike, on foot and in canoes across the beautiful Isle of Wight. Teams will set off at sunrise to cycle 44 miles to iconic landmark The Needles, then trek 12 miles along the Tennyson trail and canoe 1.5km along the River Medina – all before the sun sets.

This event is an addition to our highly popular Race the Sun series, which also includes challenges in the Lake District and Brecon Beacons.

For more information visit
action.org.uk/race-sun-isle-wight



Find your challenge
action.org.uk/events