How your support
is helping save and
change children's lives

Re:action

Autumn/winter 2017

action medical research for children

In your new *Re:action*

Preventing brain damage at birth

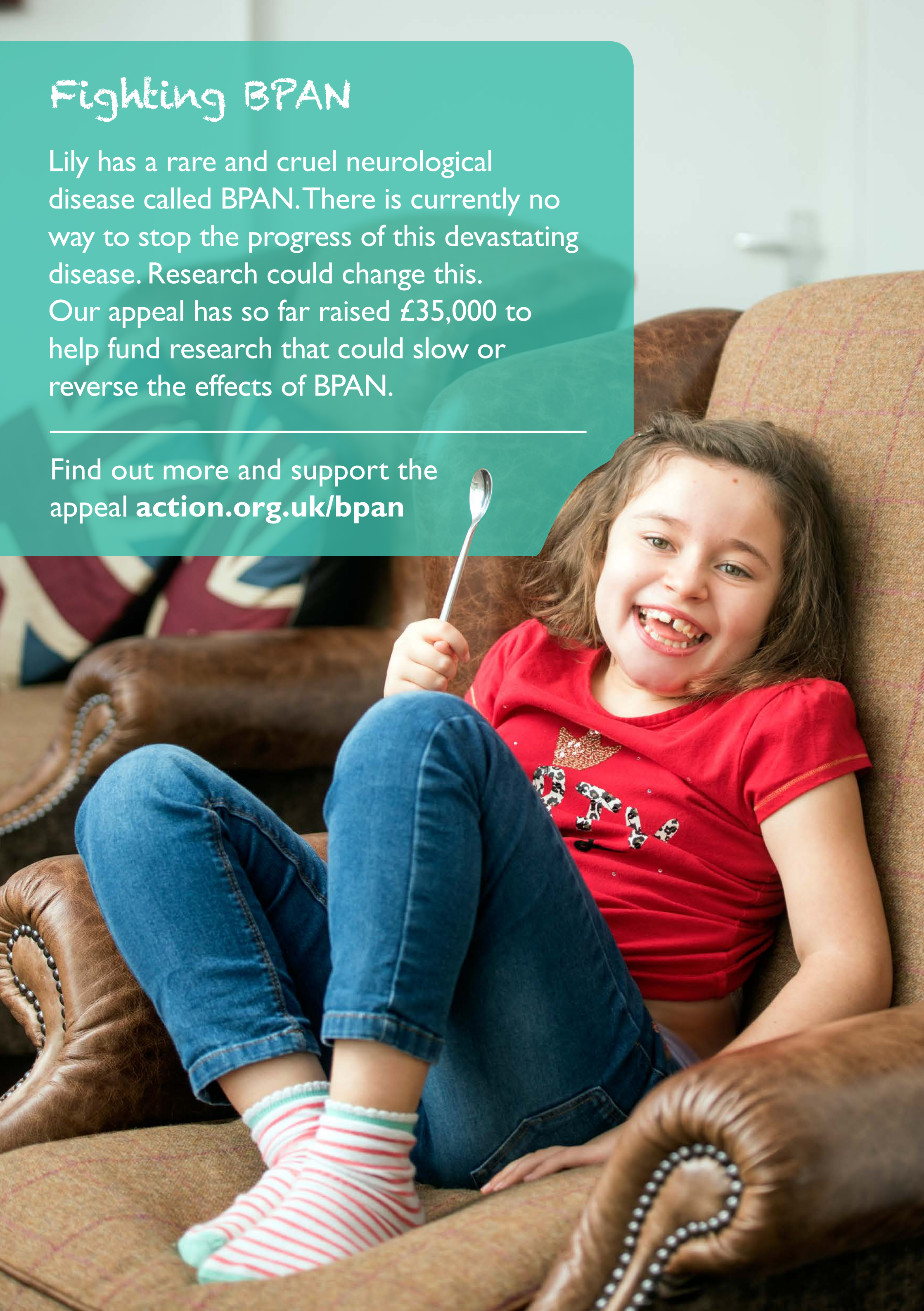
Fighting a serious lung disease

Helping children with a cleft lip or palate

Fighting BPAN

Lily has a rare and cruel neurological disease called BPAN. There is currently no way to stop the progress of this devastating disease. Research could change this. Our appeal has so far raised £35,000 to help fund research that could slow or reverse the effects of BPAN.

Find out more and support the appeal **action.org.uk/bpan**



Welcome

We hope you enjoy reading this latest issue of *Re:action* and finding out how your support is helping to save and change children's lives. We have new research projects and our Saving Tiny Lives research campaign to share with you, plus find out about upcoming events and how legacy gifts can help us.

Find out more!

With your support we're currently funding more than 70 groundbreaking research projects

action.org.uk/research

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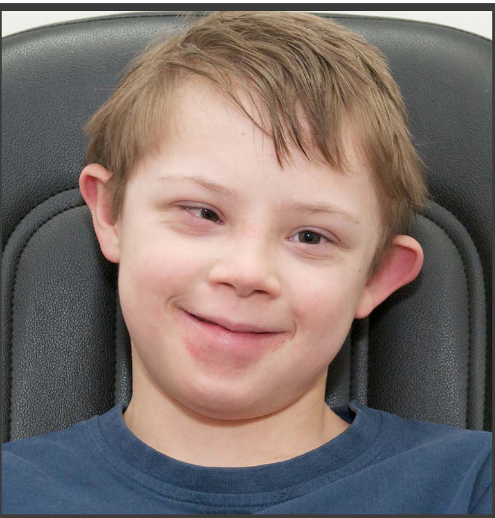
BY SUPPORTING ACTION,

HELPING TO TREAT SICK AND VULNERABLE BABIES



HELPING CHILDREN AFFECTED BY DISABILITY

Aiden's story…

Aiden endured a traumatic start to life and his survival was uncertain. He was deprived of oxygen for more than 20 minutes at birth. Following resuscitation, his body temperature was cooled using a special cooling blanket to try and limit brain damage and help save his life.

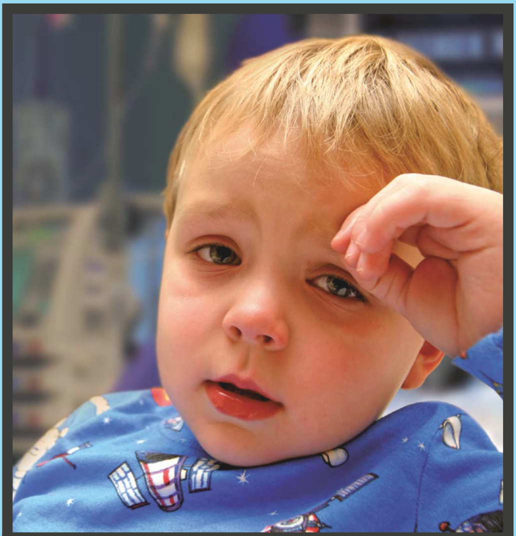
Action previously supported the development of cooling therapy in babies and it is now routine in the UK. But while it can give babies like Aiden a better chance, sadly it doesn't work for all.

Neonatal encephalopathy, brain damage that is usually caused by a shortage of oxygen at birth, still kills around one in five affected babies in the UK and many others develop serious disabilities.

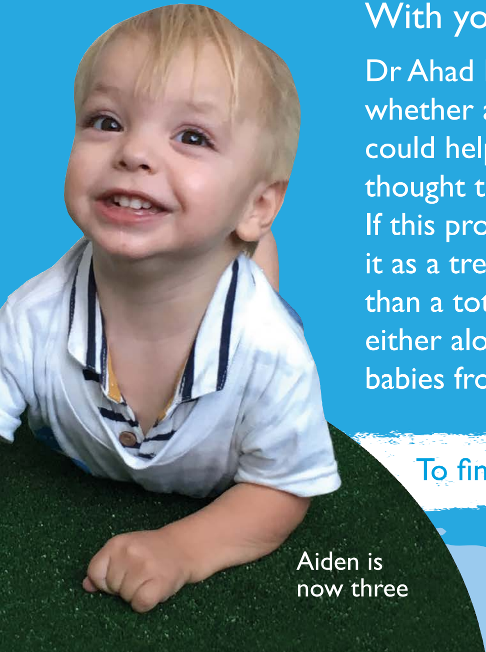
"Without previous research Aiden's outcome could have been even more severe. Research that could further advance treatment is so important," says Aiden's mum, Fleur.

YOU ARE...

HELPING TACKLE RARE DISEASES IN CHILDREN



HELPING TO PREVENT CHILDHOOD INFECTIONS



Aiden is now three

With your support...

Dr Ahad Rahim and his team are investigating whether a commonly used diabetes medicine could help more babies like Aiden. The drug is thought to have protective effects on the brain. If this proves right, it should be quicker to develop it as a treatment for neonatal encephalopathy than a totally new medicine. It could then be used either alone or with cooling to help save more babies from death or disability.

To find out more visit **action.org.uk/aiden**

Remembering Michael Bond

It is with great sadness that we mark the loss of Paddington's creator Michael Bond CBE, who passed away 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. Through this very special relationship we have been able to attract thousands of new supporters who together have raised millions of pounds to help sick babies and children.

Our loyal charity mascot Paddington™ is about to become an even busier bear, with the exciting UK release of his second live-action film *Paddington 2* in cinemas from 10 November.

Thank you HRH

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, he welcomed 130 Action guests to a royal reception at Buckingham Palace where researchers representing six current studies funded by Action shared details of their vital work.

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.

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 the Saving Tiny Lives research campaign.

A partner has committed to match our investment, meaning we can fund an amazing £1.5 million of research to help save tiny lives.

action.org.uk/savingtinylives

action Weekly Lottery

£3,400 Rollover winner!

Miss Prescott
Wigan

Congratulations to Miss Prescott from Wigan, who last month won an amazing £3,400 in our Rollover Jackpot draw!

She said: "Winning the Rollover Jackpot was amazing news! I never win anything so to win such a lot of money was a huge surprise. I can't wait to start spending my winnings, starting with a trip to Turkey!"

Our Weekly Lottery is a fun and easy way to support us.

Enter today at **action.org.uk/weeklylottery**

Picture courtesy of the family

Saving Tiny Lives

Elijah was born prematurely at 25 weeks but, despite a positive initial prognosis, he died at just 37 days old as a result of necrotising enterocolitis (NEC) – a bowel condition that typically strikes the smallest, most vulnerable babies.

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.

Your support is helping to fight for little lives like Elijah's

Thank you

Find out more

action.org.uk/savingtinylives

Baby Elijah with brothers Amos and Jonah action HEROES

DEDICATED TO SAVING CHILDREN'S LIVES

KAI'S STORY...

KAI IS 12 YEARS OLD AND LOVES FOOTBALL. HE'S A TALENTED STRIKER AND PLAYS FOR HIS SCHOOL TEAM AND A LOCAL CLUB.

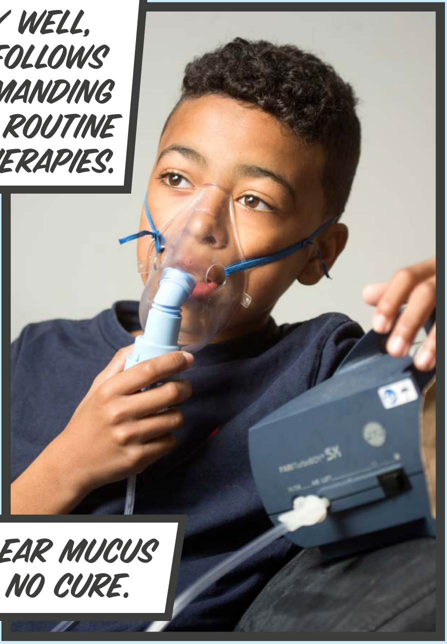
HE'S LOVED HIS SPORT FROM AN EARLY AGE

BUT KAI MAY BE UNABLE TO PURSUE HIS DREAM OF PLAYING PROFESSIONALLY...

...AS HE SUFFERS FROM A SERIOUS LUNG DISEASE CALLED PRIMARY CILIARY DYSKINESIA (PCD).

CHILDREN WITH PCD SUFFER RECURRENT CHEST INFECTIONS.

TO TRY AND STAY WELL, KAI FOLLOWS A DEMANDING DAILY ROUTINE OF THERAPIES.



ANTIBIOTICS AND PHYSIOTHERAPY TO CLEAR MUCUS FROM THE LUNGS HELP, BUT THERE IS NO CURE.

WE'RE CURRENTLY FUNDING RESEARCH INTO TWO MEDICINES THAT MIGHT HELP CHILDREN WITH PCD. KAI'S MUM AIMEE SAYS: "A NEW TREATMENT THAT MEANS KAI'S LUNGS COULD WORK NORMALLY COULD GIVE HIM HIS LIFE BACK."

YOUR SUPPORT IS HELPING FUND VITAL RESEARCH INTO PCD TO HELP CHILDREN LIKE KAI.

THANK YOU

READ MORE AT ACTION.ORG.UK/KAI

Every day an average of **three** UK babies are born with a cleft lip and/or palate

When speech is a struggle

Your support is helping to improve the treatment of speech problems in children born with a cleft lip and/or palate

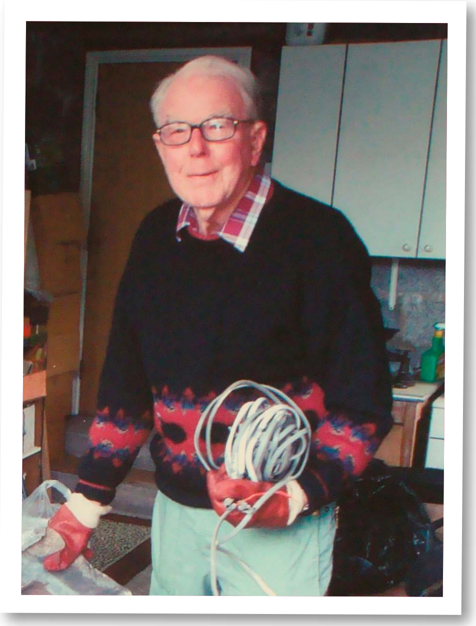
Babies born with a cleft lip and/or palate have a gap or a split in the upper lip and/or roof of the mouth. It is the most common facial abnormality at birth and will usually need surgery to close the gap. Even after this many children go on to struggle with their speech.

Dr Joanne Cleland of the University of Strathclyde is testing the use of ultrasound technology to better diagnose and treat speech problems in children born with a cleft lip and/or palate. A small scanner is placed under a child's chin and a camera in front of their lips so therapists, and children themselves, can see how the tongue and lips move. This could help therapists to make more accurate diagnoses, including detecting speech errors that cannot be easily distinguished by ear.

"Speech problems can have negative effects on a child's life, including their education and social development. If successful, we believe this technique could soon become part of routine practice," she says.

Action Medical Research is jointly funding this project with The Chief Scientist Office, Scotland.

A lasting legacy



Dr Malcolm Arthurton dedicated his working life to helping sick babies and children. He was also a keen supporter of Action Medical Research and now his legacy lives on through a gift of £10,000 left to us in his will.

Malcolm Arthurton worked as a consultant paediatrician, treating sick babies and children, from the early 1950s until he retired in the 1980s.

"He very much appreciated and understood the need for research," says his daughter Amanda. "During his working life he saw some wonderful advances. He also saw a lot of children with very serious problems."

For more than 40 years Malcolm collected newspapers and scrap metal to raise funds for Action – something he continued into his early nineties! Over those decades he raised at least £5,000.

Malcolm died in 2016, aged 97, but his support for Action has continued through the wonderful gift left in his will. It costs around £230 to fund a single day's research, meaning his gift will help to fund a significant part of a research project.

Dr Malcolm Arthurton's legacy gift could now be helping to unlock a medical breakthrough of the future. To find out more about leaving a gift in your will visit **action.org.uk/legacy**

Challenge events 2018

Running

NEW The Big Half 4 March

NEW London Landmarks Half Marathon 25 March

Virgin London Marathon 22 April

Vitality London 10,000 28 May

Cycling

RIDE100 series – one-day rides across the UK Various dates and locations, 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 – endurance hikes in the South Downs and Cotswolds June/July

Race the Sun – canoe, climb and cycle:

- **Brecon Beacons** 23 June
- **Isle of Wight** 30 June
- **Lake District** 1 September

Mountain challenges

Snowdon, Yorkshire 3 Peaks and Ben Nevis June to September

Sign up today **action.org.uk/events**

Action Medical Research at a glance

20
new
projects
funded
in 2016

Celebrating
65
years of
saving and
changing
lives

Funding vital
research to help
babies and
children

£230
can fund a
pioneering
research project
for a day

More than
70
projects
across
the
UK

Supporting
more than
260
top researchers