



Be part of something amazing ...  
help save and transform  
lives through a **gift in  
your will**



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# Thank you

## A message from our Chair, Phil Hodgkinson

I feel privileged to chair Action Medical Research. It's a charity with such an extraordinary track record in supporting some of the most significant medical breakthroughs in recent history.

These successes have helped save thousands of children's lives and improved many more. This has only been possible thanks to the dedication of our valued supporters and volunteers.

As a supporter myself I'm determined that Action should continue funding top class medical research projects long into the future. That is why my wife, Julia, and I have chosen to leave gifts in our wills to Action. **It's comforting to think we can help save children's lives in the future, even after our own lifetimes.**

I hope that you will join me in supporting Action in this very special way. All gifts, large or small will help us fund more life-changing research and create a better future for children for many years to come.



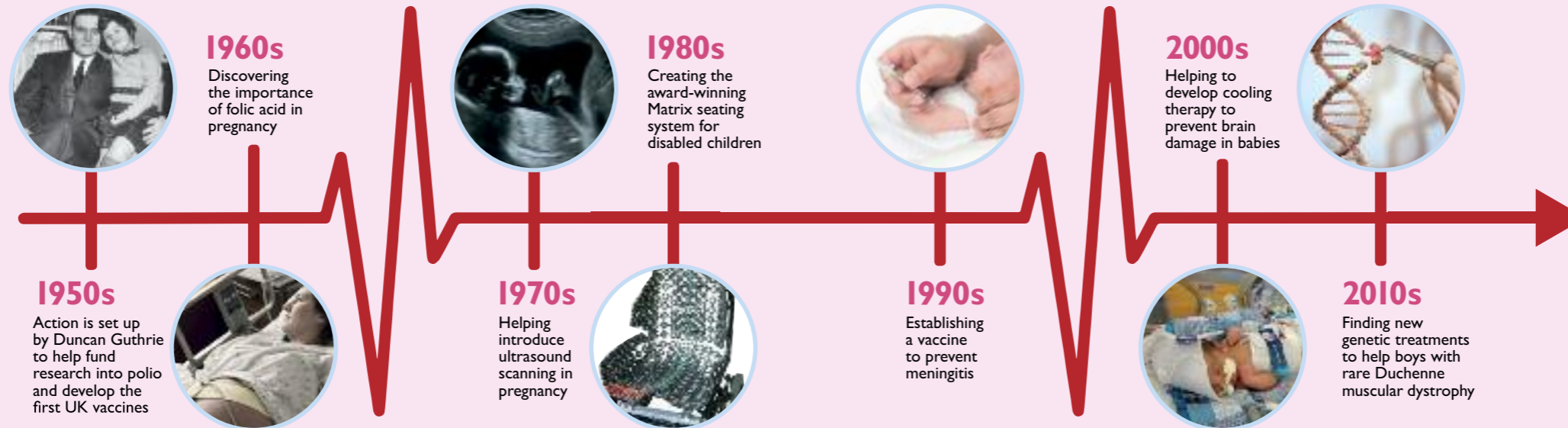
# A history of successes

Action Medical Research is the leading UK-wide charity solely dedicated to funding vital research to help babies and children. We fund a broad range of research which focuses on tackling premature birth and treating sick and vulnerable babies, helping children affected by disability, disabling conditions and infections and targeting rare diseases. The research we have funded over the last 65 years has saved and transformed thousands of lives.

Action was founded in 1952 by Duncan Guthrie in his quest to find a cure for polio, a condition that affected the lives of many thousands of children including his own daughter Janet. Thanks to this early research the first UK polio vaccines were developed, keeping children safe from the threat of polio and eradicating new cases of the disease in the UK.

Since then we have helped fund numerous research breakthroughs which have now been adopted as routine treatments, like the use of ultrasound in pregnancy; taking folic acid to prevent spina bifida; cooling therapy to prevent brain damage; and a vaccination to prevent a form of meningitis.

Our scientific advisory panel made up of world-class medical researchers ensures that the donations made to us are focused on the best doctors and researchers in children's hospitals, specialist units and universities across the UK. Because of this, many research projects we have helped to fund are now saving and transforming the lives of children worldwide.



## Sophie's story

Natasha wasn't able to hold her daughter, Sophie, until she was five days old. Baby Sophie was born blue and totally unresponsive. She wasn't breathing properly as she had swallowed large amounts of meconium after a bowel movement in the womb. This led to Sophie being starved of oxygen. Doctors used a revolutionary therapy to reduce the risk of brain damage – her whole body was cooled down. Natasha said: "Sophie was cooled for 72 hours which doesn't sound like a long time but watching your poorly baby for that time, who is totally unresponsive, and being unable to cuddle her, makes it feel like forever."

The cooling treatment takes advantage of a therapeutic window that occurs after a newborn baby suffers oxygen shortage. By cooling the body to reduce brain temperature, doctors can alter the chemical processes that lead to brain damage. The baby is cooled then gradually warmed again.

"When they warmed her up it was like she was just coming alive", says Natasha. "She was moving her hands and feet and looking around and it was such a huge change in her. I think without cooling therapy she wouldn't be here." Sophie is now five and is doing really well.

Cooling therapy was adopted in UK hospitals in 2010 following a 20 year programme of research, to which Action contributed thanks to donations and gifts left to us in wills. **Each year, around 700,000 babies worldwide die or face lifelong disability due to brain damage at birth.** Cooling therapy will have a massive impact for these babies and their families.

“ When they warmed her up it was like she was just coming alive ”



## What a gift in your will could achieve

For over 65 years donations and gifts in wills have played a vital part in enabling us to fund medical research worth over £120 million.

We know that medical research can save and change children's lives, yet child health research is poorly funded in the UK. There is relatively little government or pharmaceutical funding for research into conditions that affect children, and so Action has a vital role to play in filling this funding gap.

Gifts in wills can help us to go on funding first-class medical research long into the future.

A gift in your will could help achieve something very special. You could help the thousands of families affected by the complications of premature birth each year, by helping us to invest in research aiming to find out why some babies are born too soon. You could help us to help children like Tom, pictured opposite, who has the rare condition Duchenne muscular dystrophy and is relying on research to help find treatments that can slow down this fatal disease. Over the next 20 years we hope to invest a further £50m in research, but we can only do that with support.

“ Over the next 20 years we hope to invest a further £50m in research ”



The work of Action Medical Research is driven by the belief that the diseases that devastate the lives of so many of our children can be beaten.

# Together

we can find the  
answers that will  
save lives.

## Every gift makes a difference

A gift in your will could unlock a future medical breakthrough, hold the key to a cure or treatment for a childhood illness, or simply make day-to-day life easier for children suffering illness or living with a disability.

**We are extremely grateful for all gifts in wills**, whatever their size, and every single gift helps us fund more vital medical research.

Your gift could take the form of a fixed sum of money, or a proportion of what is left once you have provided for family and friends. Please see page 16 for more details about the different types of gifts you can leave.



Please don't think that a gift in your will has to be large to make a difference. **It costs an average of just £280 to fund a day's research**, and although a typical research grant amounts to around £167,000, this is made up of many different elements. Your gift could help fund a crucial component, as the following examples from recent research projects show:



**£2,500**

Could fund a specially adapted trike for children with cerebral palsy to study whether regular exercise helps prevent heart disease and diabetes and improves mobility.



**£16,000**

Could fund a year of laboratory consumables to help develop a treatment for drug resistant childhood leukaemia.



**£200,000**

Could fund an entire research project looking at combined treatments which could help prevent babies from being born too soon.

## Make a will and protect your wishes and your loved ones

Making a will is the only way to ensure that the people and charities you want to benefit after you have gone are remembered. It's also the only way to ensure that you have a say in how the belongings and possessions that you leave behind are distributed. The rules of statutory intestacy are very strict on who inherits an estate and do not provide for unmarried partners or stepchildren. If you die without a valid will ('intestate') it could mean that your money and possessions go to the Crown or government rather than to the friends, families and charities that you intended to remember.



Intestacy rules in Scotland and Northern Ireland are different to those in England and Wales. We would always suggest seeking the advice of a solicitor.

Leaving no will behind can also be very stressful for your family and loved ones who may feel unsure about your wishes. If you write a will you can be clear about what you want, taking away any worry for those you leave behind. You can also be clear on arrangements such as plans for your funeral and can ensure you have your say on other important decisions like appointing guardians for children and pets.

## Steps to making a will

We strongly recommend that you use the services of a solicitor or other qualified adviser to write your will. You can find details of solicitors in England and Wales through The Law Society, through STEP (the Society of Trusts and Estates Practitioners) or for Scotland and Northern Ireland through The Law Society of Scotland and The Law Society of Northern Ireland.

In preparation for a meeting with a solicitor, it would be useful to consider the following:

### **Make a list of your assets**

This includes everything you own of value, such as property, vehicles, savings, investments and items of value.

### **Make a list of your liabilities**

Your liabilities are things that you owe including items such as mortgages, loans and other debts.

### **Make a list of those you would like to remember**

Write down the full names and addresses of the people or charities you would like to include in your will and specify what you would like to leave them. For charities include their full name and registered charity number.



### **Choose your executors**

Your executors will be responsible for carrying out your wishes and can be professionals such as solicitors or banks (who will charge for providing this service), or can be trusted friends or relatives.

Once you have made a will ensure your executors and loved ones know where your most up-to-date will is stored.



## Keeping your will up to date

Once written, it is really important to review your will from time to time to ensure it is kept up to date and still reflects your wishes. Most people tend to do this when their circumstances change or at different life stages.

If you already have a will and would like to include a gift, you don't have to re-write your will.

Minor alterations, such as adding a fixed cash gift or a specific item, can be made by writing a codicil, which is a legal document that can be kept together with your will. We would always advise that you speak to your solicitor or legal professional ahead of writing a codicil. You can find a codicil form at the back of this booklet.



## Inheritance Tax

There's usually no tax to pay on gifts left to Action and gifts left to charity are paid out first before inheritance tax is calculated, meaning that the amount of tax that is due will be reduced.

For those with larger amounts to leave, there's also a government scheme called Legacy 10. This reduces the overall inheritance tax on everything you leave – because you chose to give 10% of your estate as charitable gifts.

For detailed advice on your own circumstances and how you could be impacted by inheritance tax we would always advise that you speak to an independent financial advisor.



## Types of gift you can leave

There are several kinds of gift you can make in your will. The most common are:

### A percentage share (a residuary gift)

A share of what is left once all other gifts and expenses have been deducted.

### A fixed cash gift (a pecuniary gift)

A fixed sum of money.

### A specific gift

An individual item of value such as property, a painting or an item of jewellery. Speak with your solicitor if you would like to discuss leaving an alternative type of gift.

Unrestricted gifts are very valuable to us as they provide greater flexibility and ensure funds can be directed to the area of greatest need at the time. However, we also welcome gifts that are focused on one of our three research areas:

- treating sick and vulnerable babies
- helping disabled children
- targeting rare diseases



## Suggested wording for your will

### Gift of a percentage share

I give xx per cent/all of my residuary estate to Action Medical Research, Vincent House, Horsham, West Sussex, RH12 2DP (Charity reg. nos 208701 and SC039284) for its general charitable purposes and I declare that the receipt of the treasurer or other proper officer of Action Medical Research shall be a sufficient discharge to my executors.

### Fixed cash gift

I give the sum of £xx to Action Medical Research, Vincent House, Horsham, West Sussex, RH12 2DP (Charity reg. nos 208701 and SC039284) for its general charitable purposes and I declare that the receipt of the treasurer or other proper officer of Action Medical Research shall be a sufficient discharge to my executors.

### Supporting specific areas

I give (state the percentage share or the sum of money you wish to give) to Action Medical Research, Vincent House, Horsham, West Sussex, RH12 2DP (Charity reg. nos 208701 and SC039284) and request without obligation that it be used by Action Medical Research for research into – treating sick and vulnerable babies **or** helping disabled children **or** targeting rare diseases. I declare that the receipt of the treasurer or other proper officer of Action Medical Research shall be a sufficient discharge to my executors.

## Contact us

Please contact Sharon or Jane in our Gifts in Wills Team if you would like to talk to someone about leaving a gift in your will to Action or if you would like to find out more. You may have questions about our work or a particular area of research you wish to support.

You may also like to find out more directly from the researchers we are funding. We would be so pleased to invite you along to one of our regional events where you'll have the chance to hear from researchers first hand.

You can reach Sharon on 01403 327413, Jane on 01403 327414 or by email at [legacy@action.org.uk](mailto:legacy@action.org.uk)



## Thank you

If you have decided to leave a gift in your will towards our work, thank you so much. In doing so you are ensuring a future for Action and the children we exist to help. Together we can go on seeking the answers that will save and transform the lives of more children and their families. Children like Sophie and Eva – pictured opposite.

You don't have to tell us about any gift you choose to leave, unless you want to; it isn't legally required. It is however really helpful for us to know. We wouldn't ask the nature of any gift; just knowing that people are making the amazing decision to remember Action in their will is enough to help us feel confident about funding our work in the future.

Please be assured that any information you choose to disclose will be treated in the strictest confidence.



## Eva's story

Eva is a happy, sociable and determined little girl but life is challenging for her. She has a rare condition known as ataxia. She has problems with strength, balance and co-ordination, tires easily and suffers from a type of tremor that becomes more pronounced when she moves. Ataxia can be progressive, leading to severe disability, robbing children of the ability to walk and affecting their speech. It can also be life shortening.

When Eva was first born, there was no cause for concern but Carla and husband Adam became worried when they noticed Eva's hands shaking. And when she struggled to crawl, stand and walk.

Aged just three, little Eva endured a lumbar puncture under general anaesthetic and a brain scan. Eventually, genetic testing identified an anomaly that was not hereditary – and had never before been described by doctors.



## Codicil form

If you have already prepared a will and would like to add a fixed cash gift (pecuniary) or to leave a specific item, to Action Medical Research you may use this codicil form.

We recommend that you consult your solicitor before completing this form, particularly if you already have one or more codicils.

How to complete your codicil:

- Complete and date the form.
- Sign your name in the presence of two witnesses. Your witnesses do not need to be the same people who witnessed the signing of your original will, but they must not stand to benefit themselves, or be married to anyone who stands to benefit from your will or codicil. All of you must be present while each of you signs.
- Keep this codicil with your will in a safe place, but do not pin or staple it to your will.

I (full name) .....

Of (full address) .....

..... Postcode .....

Declare this to be the (1st/2nd/3rd/other) codicil to my will, dated and made the ..... (date of original will)

I give to Action Medical Research

Vincent House, Horsham, West Sussex, RH12 2DP

Registered charity numbers 208701 and (Scotland) SC039284

(please tick one)

the sum of £ .....

the following specific item(s)

.....  
.....  
.....  
.....

for its general charitable purposes and I declare that the receipt of the treasurer or other proper officer of Action Medical Research shall be a sufficient discharge to my executors.

In all other respects I confirm my will and any other codicils thereto.

Signature .....

Date .....

Signed by the above named testator in our joint presence, and witnessed by us jointly in his/her presence.

**Witness one**

Full name .....

Address .....

..... Postcode .....

Occupation .....

Signature .....

Date .....

**Witness two**

Full name .....

Address .....

..... Postcode .....

Occupation .....

Signature .....

Date .....

In 2013, Action funding was provided for a research project which set out to find the causes of ataxia. The project was a very successful first step into understanding the genetic causes of the condition and is already benefiting families who have received a clear genetic diagnosis. The researchers involved believe that the project has successfully put childhood ataxias 'on the map', although there is still much more work to be done.

Carla hopes that more research will help give a clearer picture of Eva's future:

“ It's not just for Eva's sake but for other children too ”

Carla says. "There are so many rare conditions, and so many children are affected. It's very, very important.



# Action Medical Research

Over the last 65 years we have invested **£120m** in medical research

We are currently funding more than **65** individual research projects across the UK and 260 top researchers



Research we have funded is now helping to save and transform the lives of **thousands** of children across the UK and worldwide

## Tell us more about your gift

I would like to play a part in creating a brighter future for children through a gift in my will

- I have already left a gift to Action Medical Research in my will
- I intend to include a gift to Action Medical Research in my will

Title ..... First name ..... Surname .....

Address .....

..... Postcode .....

Telephone .....

Email .....

- Yes, I would like to be contacted by telephone .....
- Yes, I would like to be contacted by email .....

We'd like to keep you updated on how your support is helping save and change children's lives and to let you know about other ways you can help and support in the future. As a supporter of Action we will keep you updated by post but if you'd rather not hear from us in this way, please let us know by emailing [legacy@action.org.uk](mailto:legacy@action.org.uk) or by calling us on 01403 327413. If you would like to hear from us by telephone or email please add your details and tick the relevant boxes above. You can change how you hear from us at any time by contacting us using the details above. We will always keep your details safe and secure and will not sell or swap your details with anyone. You can read our Supporter Promise and full Privacy Policy online at [action.org.uk](http://action.org.uk) or call the number above to receive a copy in the post.

[Jane Tarrant, Action Medical Research, Vincent House, Horsham, West Sussex RH12 2DP](#)