

**action** medical research  
for children

# Your guide to writing a will

Unlock a future medical  
breakthrough for children  
with a gift in your will



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# Change children's lives forever by leaving a gift to medical research

Action Medical Research funds life-saving and life-changing research projects to help babies, children and young people. We have an extraordinary track record in supporting some of the most significant medical breakthroughs in recent history. From conditions like asthma and epilepsy to disability and premature birth, we fund the scientists who are making a real, tangible difference to children's lives.

Thank you for considering leaving a gift in your will to fund future vital medical research for children. Recent advances in science and technology mean that the prospects for developing game-changing new breakthroughs are better than ever. This incredibly kind and generous act could make all the difference. Your gift could play a crucial part in the next new discovery.



**Research leads to improvements in treatments, which means fewer families who are forever incomplete. This is why the work of Action Medical Research is so important.”**

Louise, mum of Jessica who had a rare heart condition and sadly passed away aged just six



## Making a difference for children

Over the past 70 years, Action Medical Research has helped to make some of the most important and groundbreaking discoveries in children's medicine. From the UK polio vaccines to ultrasound scanning in pregnancy, we have remained committed to improving children's health through world-class scientific research.



**The next big breakthrough in children's health could be possible thanks to a gift in your will.**

# 1952

Action is set up by Duncan Guthrie to help fund research into polio and develop the first UK vaccines



# 1960s

Discovering the importance of folic acid in pregnancy



# 1970s

Helping introduce ultrasound scanning in pregnancy



# 1980s

Creating the award-winning Matrix seating system for disabled children



# 1990s

Establishing a vaccine to prevent meningitis



# 2000s

Helping to develop cooling therapy to prevent brain damage in babies



# 2010s

Developing new advice to reduce the risk of stillbirth leading to a Sleep on Side public health campaign



# Your legacy

Your gift could play a crucial part in the next new discovery





**We wouldn't be here  
as a happy family if it  
wasn't for all the research  
that goes into prematurity”**

Rosie, mum of Fletcher who was born 16 weeks early

# What we do

Action Medical Research is the leading UK-wide charity dedicated to funding vital research to help sick babies and children. We're on a mission to save and change children's lives through medical research, developing treatments, vaccinations and cures.

## ● We want to make a difference in:

- tackling premature birth and treating sick and vulnerable babies
- helping children affected by disability, disabling conditions and infections
- targeting children's rare diseases.

## ● We are doing this by:

- finding and funding cutting-edge medical research across the UK most likely to deliver real benefit to babies, children and young people
- assessing the impact of the research we fund and sharing the results
- raising funds to make this vital research possible.



**Gifts in wills help to fund vital life-saving medical research**



**Research funding from Action has been critical for my personal scientific development through my PhD and funding of research on meningitis that has added important knowledge over the past 25 years.”**

Professor Sir Andrew Pollard, Director of the Oxford Vaccine Group



# Our life-changing research programme

## ● Who we fund

We fund leading researchers in hospitals, specialist units and universities across the UK. Our Scientific Advisory Panel of world-class medical researchers helps to select the projects.

## ● High quality research

It is really important to Action that we fund quality research most likely to make a difference. We carefully assess the impact of research projects and share the results with doctors, researchers and families.



## ● Developing research leaders

We also run our own prestigious Research Training Fellowship scheme to help promising doctors and researchers early in their careers. Some of the leading children's researchers today were part of this scheme, like Professor Sir Andrew Pollard. Professor Pollard recently helped to develop and test the Oxford/AstraZeneca COVID-19 vaccine.

## Best practice

- We are a founder member of the Association of Medical Research Charities (AMRC). They have awarded Action Medical Research a certificate of 'Best practice in medical and health research peer review'.

A member of the:

**amrc**  
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

**Change children's lives forever by leaving a gift to medical research**

## James' and Samuel's story

Thanks to supporters leaving a gift in their will to Action Medical Research, we can fund research into rare conditions like X-linked lymphoproliferative disease (XLP).

James was a lively, articulate boy, who loved to sing, run and climb. However, a few months after he turned three, he was taken ill. "He had a chest infection, was extremely lethargic, and slept constantly. He stopped talking and would just babble like a baby," his mum Rachel recalls. After undergoing a battery of tests, James was diagnosed with encephalitis – a rare but serious type of brain inflammation.

The family agreed to undergo genetic tests to try to find out what was causing the inflammation. The results from the tests found that James had X-linked lymphoproliferative disease type 1 (XLP1).

XLP is a rare genetic condition that affects boys. Without treatment, around seven in every 10 boys with XLP will die by the age of 10. James' parents were told to test all their children as XLP is genetic. The results showed that James' brother Samuel sadly also has XLP.

Bone marrow transplants can cure the condition, but this means finding a donor who is a good match. For transplants to work well, it's best to carry them out early in the disease process. If transplants come too late or donors cannot be found, boys with XLP are at risk of losing their lives.

Both James and Samuel underwent a bone marrow transplant. "It was an incredibly worrying time for us all," Rachel recalls. "James was very unwell going into his operation and experienced difficult side effects."

Sadly, James sustained considerable brain damage from his encephalitis. He has severe learning disabilities and mobility issues, requiring 24/7 support for the rest of his life. "James is not able to communicate very well. His mobility comes and goes – he can walk but is unable to run. We live day to day – long-term thinking went out the window a long time ago," says Rachel.

“

**Samuel is doing very well and will go on to lead a full life. James is a miracle as the odds were against him and he really shouldn't have made it. It's only due to the brilliance of medical research that he has”**

James and Samuel's mum, Rachel

Action Medical Research is funding a project to develop a new treatment for XLP. This will use cutting-edge gene-editing technologies to correct the faulty gene in a child's blood stem cells. This exciting new approach has the potential to cure the disease by repopulating the immune system with healthy cells.



# How to write a will – **your questions answered**

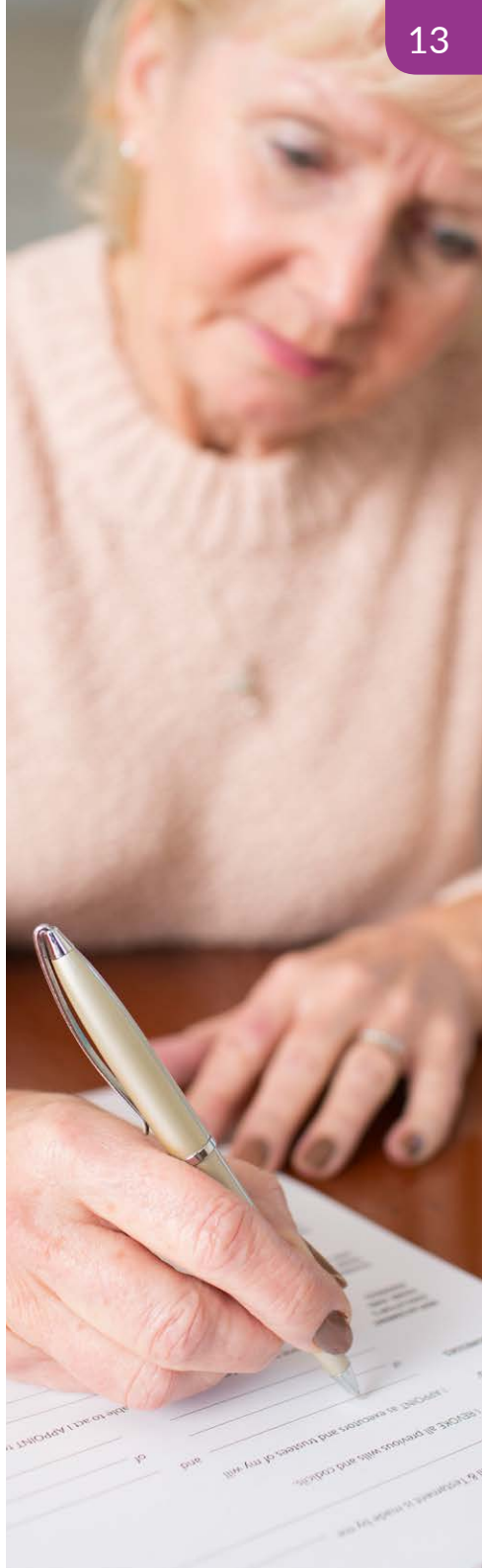
## ● Does everyone really need to write a will?

If you're over 18, it's important to have a will that is up to date and clearly expresses your wishes for everything that's yours after you die ('your estate').

Your estate includes your money, property and possessions. It also includes anything where you share ownership with other people. If you owe any money, such as a mortgage or a credit card debt, the amount remaining will need to be taken from your estate.

A will sets out in writing how you want your estate to be distributed after you have died. The instructions in your will have to be followed by law. You can also include details about who you want to look after your children if they are under 18 and any particular wishes for your funeral.

If you die without a will, the law decides who inherits your estate, which may not be what you want to happen. So it's really important for everyone to consider making a will.



## ● Do I have to have a solicitor?

It's best to use a professional will-writer or solicitor to write or update your will. They will make sure that the will is written properly and is legally correct.

## ● Is it difficult and expensive to write a will?

No! We have carefully chosen two partners who can help you to write a simple will for free.

You can write your will for free with a local solicitor using our partner, the **National Free Wills Network**. Or you can write your free will online or over the telephone with our partner, **Farewill**.

If you would like to use a local solicitor via the National Free Wills Network, please visit **[www.action.org.uk/freewill](http://www.action.org.uk/freewill)** and complete the online form. You will then receive a pack in the post with details of your nearest participating solicitors for you to contact.

If you'd prefer to make your free will online with Farewill, visit **[www.farewill.com/action-free](http://www.farewill.com/action-free)** to start making your will.

Alternatively, you can call Farewill on **020 8050 2686** to make an appointment for a telephone consultation to make your free will. Please note that you must notify the Customer Service team that you are an Action Medical Research supporter at the start of the call.

You don't need to leave a gift in your will to Action Medical Research in order to use these services. Please consider a gift to help babies and children if you can.





Free will  
writing

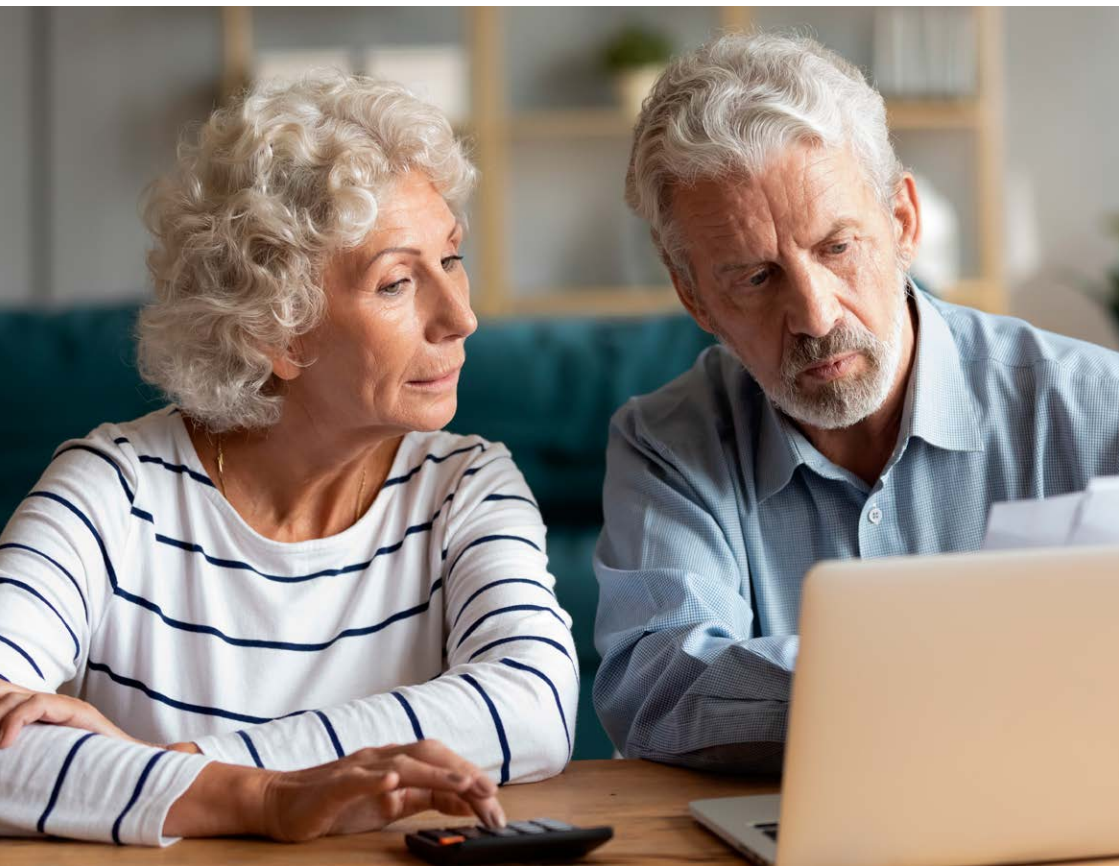


## ● What information do I need to write a will?

Before you start to write your will, it can be useful to make a list of valuable items and debts. This may include:

- Your property (and any mortgages)
- Your car (and any loans)
- Your stocks or shares
- Cash in your bank or building society accounts
- Any insurance policies
- Your pensions
- Any valuable individual items such as jewellery or artwork

You will also be asked to name an 'executor'. They will be responsible for carrying out your wishes once you've gone. This is usually your solicitor, a friend or a family member.





# ● What kind of gifts can I leave to a charity?

There are a range of different kinds of gifts that you can leave to a charity or person in your will, including:

**A share of your estate.** This can be a percentage of the amount left over once you have provided for any individual people, or it can be a share of your whole estate. This is also called a **'residuary gift'**. You could leave 100% to one person or charity, or you could share out your estate to as many people or charities as you like (such as 50% to a person and 50% to a charity, or 10% to 10 charities). These types of gift can be useful as it's a percentage rather than a fixed sum, so you don't need to worry if your savings go up or down in your lifetime.



## **A cash gift.**

This can be any amount that you choose.

This is also called a **'pecuniary gift'**. Remember to review any of these gifts over your lifetime as the value may reduce due to inflation.



## **An item.**

This can be any of your possessions, such as jewellery, shares or property. This is also called a **'specific gift'**.



## ● What is inheritance tax?

Inheritance tax (IHT) is a slice of your estate which gets paid to the government if the value of your estate is over a certain threshold. Any gift made to Action Medical Research in your will is exempt from IHT. A gift to a charity can also help to reduce the total amount of tax paid on your whole estate.

For further information, visit [www.gov.uk/inheritance-tax](http://www.gov.uk/inheritance-tax)

## ● How do I include a gift to Action Medical Research?

If you choose to leave a gift to Action, you just need to include our name, charity number, address and the percentage, amount or item in your will.

Our details are:

**Name:** Action Medical Research


Charity numbers: 208701 (England and Wales);  
SC039284 (Scotland)

**Address:** 5th Floor, 167-169 Great Portland Street,  
London W1W 5PF

We have changed the charity's name a few times over the last 70 years, and have been known in the past as:

- Action Research
- Action for the Crippled Child
- Action Research for the Crippled Child
- The National Fund for Research into Crippling Diseases

We can still receive gifts in wills left to these charity names. It's helpful to include our charity number along with our name so we correctly receive all gifts left to us.



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## Our promise

We know that your loved ones will always come first.  
We are very grateful for all gifts in wills that we receive.  
We will use your gift carefully and cost-effectively to help fund vital medical research for babies, children and young people. We will manage all gifts in wills with the utmost respect and sensitivity.

We respect your right to keep your decision private if you wish.  
We will keep any information that you share with us private.  
We would love to hear from you if you have left us a gift in your will, but we understand that not everyone wants to share this information.



**Action Medical Research is the leading UK-wide charity dedicated to funding vital research to help sick babies and children.**

We're on a mission to save and change children's lives through medical research, developing treatments, vaccinations and cures.

Find out more at

**[action.org.uk](https://www.action.org.uk)**



## Thank you

We're very grateful that you are thinking about leaving a gift in your will to Action Medical Research. Thank you for considering such a kind and generous act. Your support can make all the difference.

If you have any questions about writing a will or leaving a gift to Action, please call the Gifts in Wills team on **01403 327413**, email **[legacy@action.org.uk](mailto:legacy@action.org.uk)** or visit **[action.org.uk/wills](https://www.action.org.uk/wills)**