



RARE DISEASE | UK

The National Alliance for people with rare diseases & all who support them

Fundraising Pack

Ideas for raising money to support
Rare Disease UK's work

Rare Disease UK

Unit 4D, Leroy House, 436 Essex Road,
London, N1 3QP

www.raredisease.org.uk

T: +44 (0)20 7704 3141 | F: +44 (0)20 7359 1447

E: info@raredisease.org.uk

An initiative of



Genetic Alliance UK
Supporting. Campaigning. Uniting.

A charity registered in England and Wales (no. 1114195)
in Scotland (no. SC039299).

A company Limited by Guarantee (Number 05772999)



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Hello and welcome to Rare Disease UK's fundraising pack.

We are delighted you are interested in raising money to support Rare Disease UK's work.

There is no science to fundraising – anyone can do it and there are endless ways of raising money. It just takes a little imagination, enthusiasm and determination.

The purpose of this pack is to help anyone who wants to fundraise for Rare Disease UK to get started. Inside you will find information about:

- Fundraising ideas – ways to raise money for Rare Disease UK.
- Tips and hints for successful fundraising
- Creating a fundraising page.
- Telling people about the work Rare Disease UK does and how the money raised will help people with rare diseases.

If you have any questions about fundraising for Rare Disease UK, please contact:

Helen Parr, Fundraising Manager, Genetic Alliance UK
helen@geneticalliance.org.uk

You can also contact Helen by telephoning the Genetic Alliance UK office on 020 7704 3141.

Rare Disease UK is an initiative of the charity Genetic Alliance UK, registered charity numbers: 1114195 and SC039299. Although any money you raise will initially go to a central account, if you let us know that you are fundraising for Rare Disease UK we will make sure that it is used to support Rare Disease UK's work.

You can find out more about the work Rare Disease UK does by visiting us online:

<http://www.raredisease.org.uk/>
<https://www.facebook.com/RareDiseaseUK>
<https://twitter.com/rarediseaseuk>

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Fundraising ideas – ways to raise money for Rare Disease UK

Take part in a challenge event

Get your friends, family, colleagues and neighbours to sponsor you. Sponsored runs, swims, bike rides and countless other challenge events take place all over the UK and participants are usually welcome to raise funds for a charity.

Organise your own event or activity

Involve your friends, family, work colleagues, neighbours, school, place of worship or club in an event or activity to raise money. You can do just about anything. The list below gives a few ideas:

- Coffee mornings, barbeques, garden parties, any sort of party!
- Concerts, pub quizzes, golf days, cricket matches, sponsored walks.
- Non-uniform and dress-down days at school or work.
- Sponsored diets, head shaves, beard growing.
- Babysitting, lawn-mowing, car cleaning, bag packing at your local supermarket.
- Unwanted gift/clothes sales, cake sale, car boot sales, auctions.

Make a Collection

Making a collection for Rare Disease UK is an easy way to raise money, but remember to consider whether you need to obtain a licence. Different collections have different rules associated with them. Some of the most common are:

Street collections - you will need to obtain a licence, either from your local authority, or if in greater London, the Metropolitan Police.

Private collections - if your collection is open to the public, but being held on private property such as within a shopping centre, hired venue, rail station or private house, no licence is required but you **MUST** obtain permission from the owner or manager.

Static collection boxes - boxes must be secure and tamper proof. You do not need a licence to place these in a shop or business, but **MUST** get permission from the business owner.

House-to-house collections - licences must be obtained from the relevant local authority or Metropolitan Police.

If you do need to obtain a charity collection licence, make sure you allow plenty of time. The time it takes to process applications varies greatly in different local authorities. In some areas licences can be obtained within a week, whilst in others it can take up to 12 weeks.

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Encourage your Company to Support Rare Disease UK

By making a donation

If you work for a company which makes donations to charities, you could suggest they consider giving to Rare Disease UK. Many companies say that they prefer to support charities that have a personal connection with a member of their staff.

Match Funding

Some employers are keen to support any fundraising activities undertaken by their staff to support charities and will match £1 for every £1 that you raise.

Charity of the Year

Does your organisation operate a Charity of the Year scheme? If they do, please tell us how Rare Disease UK could be put forward for selection by emailing Helen Parr at helen@geneticalliance.org.uk

Easy Fundraising!

Shopping online

Genetic Alliance UK is registered with a number of online shopping clubs. This is a really easy way to raise money – just register and shop as normal. You can find Genetic Alliance UK on:

- [Kidstart](http://bit.ly/ZI2uvq) - <http://bit.ly/ZI2uvq>
- [The Giving Machine](http://bit.ly/UHzarX) - <http://bit.ly/UHzarX>
- [All4charities](http://bit.ly/SXUvBx) - <http://bit.ly/SXUvBx>

Re-cycling

Register with [Recycle 4 Charity](#) to receive free-post envelopes for your used print cartridges and old mobile phones. Just send them off and raise money for Genetic Alliance UK.

If you let us know you are fundraising for Rare Disease UK by shopping online or re-cycling, we will make sure that any money you raise is used specifically to support Rare Disease UK's work.

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Tips and hints for successful fundraising

Organising Events

- Check the date - make sure that nothing else is happening locally (or even nationally like a major sporting event) that day. Consider piggy-backing another local event if appropriate.
- Location - choose somewhere suitable and try to get it for free. Make sure your agreement is confirmed in writing and the venue is suitable for your event and easily accessible. Check whether you need any special equipment.
- Get a good idea or theme, and think about who you are trying to attract. Consider minimum and maximum number of guests.
- Break down the event planning into manageable actions. Develop a timetable working back from the event date. Get people involved in helping you and spreading the word. Make sure everybody knows what is expected of them.
- Be realistic - it might be better to start with a few smaller events which work well, rather than one large event.
- Have a contingency plan - for example for bad weather.
- Keep it safe and legal - you are responsible for your event. You may need to check with your local council or the police; you may need to consider first aid cover, insurance or an entertainment licence. Check fire regulations, max numbers etc.

Getting Sponsorship for a challenge event

- Set a target and tell people about it. Aim high!
- Be proud of what you are doing – you are not asking for money for yourself but to help people with rare diseases.
- Create a fundraising page. Make sure it is compelling and explains your motivation. (See the Section below, Creating a Fundraising Page).
- Ask everyone you know – friends, work colleagues, family, school, neighbours – and ask them to ask their contacts too.
- Start early and time your donation requests – people are more likely to be generous after payday.
- Start high – ask close friends and family to donate first as other people may then match their generosity.
- Don't forget to ask for Gift Aid. Gift Aid increases the value of the money you raise by allowing us to claim tax on donations.
- Spread the word through social media – Facebook, Twitter and blogs. Some fundraisers even prepare a video diary for YouTube.

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Creating a fundraising page

Just Giving

Genetic Alliance UK – Rare Disease UK is registered with Just Giving (<https://www.justgiving.com/rare-diseaseuk/>). You can set up your own fundraising page (or pages – there is no limit) and this means that the money that people donate comes straight to Rare Disease UK. Donors are automatically asked if they would like to Gift Aid their donation.

Setting up a Just Giving page is easy.

- Go to the Just Giving website <https://home.justgiving.com/>
- Search for “Rare Disease UK”. Our page is called Genetic Alliance UK – Rare Disease UK.
- Click on the “Start Fundraising” button (right hand side of the page).
- Follow Just Giving’s instructions from there.
- Ask Helen (Helen@geneticalliance.org.uk) for help if you have any problems.

Making the most of your fundraising page

Tell your story

People will be much more interested in your fundraising if they know your story. So make sure you tell them about why you’re doing what you’re doing on your fundraising page and in any letters or emails you send out.

Here are some questions to get you started:

- Why did you choose to raise money for Rare Disease UK?
- What event or challenge have you chosen to do?
- How will your fundraising help Rare Disease UK? (see Section below, Telling people about the work Rare Disease UK does)
- What do you hope to gain from the experience?

Get Gift Aid

Gift Aid increases the value of donations, because Genetic Alliance UK can reclaim tax back from the Government. Your donors don’t need to pay any more – they just need to be a UK taxpayer and tick the Gift Aid box when they sponsor you.

Keep updating your Just Giving page

Once you’ve told your story and made people aware of your fundraising, keep updating your Just Giving page to give them a reason to come back. Treat your page like a blog by adding photos and progress reports whenever you can. You could also send an email when you’ve updated your page, to let everyone know there are new things to see. People who have already sponsored you will be interested in how you’re getting on, and it’s a reminder for those who didn’t sponsor you the first time around.

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Keep on fundraising after your event has finished

Don't forget to keep on fundraising and asking people to sponsor you after your event has finished. A large amount of money is raised this way, and people who haven't sponsored you already may be persuaded when they see how much effort you put into your event.

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Telling people about the work Rare Disease UK does.

When you are telling people about Rare Disease UK – face-to-face, or through your fundraising page, letters or e-mails, you might find it useful to use some of the text below. You may also want to talk about your own personal experiences and what RDUK means to you – in fact, this can often be the most compelling way to explain what RDUK does.

Make sure you always remember to add Genetic Alliance UK's charity number to any information you produce: Rare Disease UK is an initiative of Genetic Alliance UK, Registered charity numbers: 1114195 and SC039299

About Rare Disease UK

1 in 17 people will be affected by a rare disease at some point in their life.

This amounts to approximately 3.5 million people in the UK.

75% of rare diseases affect children and 30% of rare disease patients will die before their 5th birthday.

There are over 6,000 recognised rare diseases.

Collectively rare diseases are not rare.

Rare Disease UK (RDUK) is the national alliance for people with rare diseases and all who support them. We believe that everyone living with a rare disease should be able to receive high quality services, treatment and support.

RDUK has successfully campaigned Health Departments across the UK to develop a UK wide strategy for rare diseases to ensure that patients and families living with these conditions have equitable access to effective services.

This document brings hope to the millions of people in the UK who are affected by rare conditions. Key features of the Strategy include:

- a clear personal care plan for every patient that brings together health and care services, with more support for them and their families
- help for specialised clinical centres to offer the best care and support
- better education and training for health and social care professionals to help ensure earlier diagnosis and access to treatment
- promoting the UK as a world leader in research and development to improve the understanding and treatment of rare diseases

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To achieve the UK-wide vision for rare diseases, there are 51 recommendations which all four countries of the UK have committed themselves to. You can read them here: <https://www.gov.uk/government/publications/rare-diseases-strategy>

A cohesive, well-implemented strategy for rare diseases would improve the health and quality of life of those living with a rare condition, as well as ensuring the most effective use of NHS resources. [This is why Rare Disease UK is now working with health services in all four home nations to create implementation plans to ensure that the UK Strategy for Rare Diseases is realised.](#)

About Genetic Alliance UK

Genetic Alliance UK is the national charity of over 160 patient organisations supporting all those affected by genetic conditions. Our aim is to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them.

Genetic Alliance UK's work involves:

Supporting

We seek to raise awareness of genetic conditions and improve the quality of services and information available to patients and families.

Campaigning

We actively campaign on issues of policy and practice to influence governments, policy makers, industry and care providers such as the National Health Service.

Uniting

We provide a united voice for all those affected by genetic conditions, enabling us to work together towards a common goal of making life better for patients and families at risk.

Genetic Alliance UK is a registered charity (numbers 1114195 and SC039299) and a limited company (number 05772999).

Rare Disease UK is an initiative of Genetic Alliance UK.

We really appreciate ALL your efforts to fundraise for Rare Disease UK – it doesn't matter how little money you raise, it all helps.

THANK YOU!

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