

**CYSTINOSIS**  
FOUNDATION UK

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# FUNDRAISING GUIDE

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The Cystinosis Foundation UK is a UK Registered Charity (Charity No. 1074885). To find out more please visit: [www.cystinosis.org.uk](http://www.cystinosis.org.uk)

**THANK YOU FOR ORDERING THE CYSTINOSIS FOUNDATION UK FUNDRAISING PACK. THIS PACK CONTAINS INFORMATION AND ITEMS TO HELP YOU ORGANISE A FUNDRAISING EVENT AND RAISE MONEY FOR THE CHARITY.**

**WE HOPE IT IS HELPFUL TO YOU AND GIVES YOU INSPIRATION WITH YOUR FUNDRAISING ENDEAVOUR – AND PLEASE LET US KNOW HOW YOU GET ON.**

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# 1 WHATS IN THIS PACK?

This guide will give you ideas for your own fundraising event and how to go about organising it. There are also the following to help out...

## Checklist

A simple aide-mémoire to organising your event.

## Promotional Poster

Helping to advertise your event.

## Sponsor Form

To help you collect.

## Publicity form

Please complete and return this form to let us know what you are doing and when. We will add your event to our website and, where possible, help tell others about what you are doing.

## Post event form

After your event, please complete the post-event form, so we can promote your good work.

## Making extra copies

Whilst copyright of this material remains with the Cystinosis Foundation UK, permission is given to reproduce the items in this pack to help you with your event. However, rather than using the original materials that come with this pack, it is suggested that you photocopy them and use the photocopies – this way you will always have blank, higher quality originals to copy again as you need.

## Electronic Version

An electronic version of this pack can be ordered if required. This version will allow you, with use of a printer, to reproduce all the material as many times as required. Please contact the Foundation – contact details are given later in this document.

## Additional Help

We are a small charity with all the day to day running of the foundation done by volunteers. However, if there is any way we can help, please just ask.



# 2 ORGANISING AN EVENT

You have already taken the first step to holding your fundraising event by requesting this pack. You will probably also have an idea of what you want to do (but if you don't we have plenty of ideas listed on page 8).

## First Thoughts

Whatever you decide to do, there are a few important things to consider:

### Can we do it and will we enjoy it?

There is no point organising something you have no hope of achieving. Think about how much time will be required and what skills will be needed. If you organise a sponsored cycle, will everyone have access to a bike? Is the distance manageable? And whilst the obvious aim is to raise money, it is better to do something you enjoy and is manageable for you – if you do, you will be more successful and your enthusiasm will rub off on the others involved.

### Is it safe?

Some events will have little element of risk (e.g. a stall at a local fete), others will have more (e.g. a mountain expedition). Judge the element of risk you feel is acceptable and appropriate to the skills and experience of those involved. You may need to consider insurance in some circumstances.

### Will the costs be more than will be raised in sponsorship?

The aim is to raise money for Cystinosis and whilst some outlay costs are sometimes necessary, it is important to judge whether the money spent will be worthwhile in comparison to the money raised.

### Novel ideas capture attention.

The more people who know about your event, the more successful you are likely to be in terms of help, participation and sponsorship. A novel idea, or an aim that captures peoples' hearts and imagination, is more likely to stay in their minds. For example:

- Are you raising money for Cystinosis for a friend or relative who lives locally (remember to ask them before using their name) and will be known by sponsors?
- Saying you are swimming a length of a pool for every person who has Cystinosis, for example, is more memorable than swimming a random number of lengths.

### When?

Once you have decided what you want to do, you need to consider when to do it. Give yourself enough time to organise it and ensure that you give those you wish to involve sufficient forewarning. You also need to consider what is happening around the time of your event – this can be positive or negative. Try to avoid clashes with large events which may keep people away. However, it may be possible to partner with other events (eg. local fetes, festivals, sports days etc) to maximise the attendance.

### Where?

You also need to think about where this event will take place. Do you need permission for access to facilities? (Even use of public parks may need council permission and possibly insurance!)

### Equipment

Most fundraising events do not need too much in the way of equipment but, where necessary, ensure all participants are suitably kitted out. It is amazing what people and companies are willing to donate

if asked and, where this is the case, it is important to acknowledge/credit your suppliers and sponsors.

### Get People Involved

The more people you involve the more help you will have and the greater your reach in terms of raising money and access to skills and equipment. However, the larger the number of people involved, the more for you to manage.

### Promotion

Remember to advertise your event. You may wish to contact local press (radio, newspaper, TV) – they are usually interested in such news. Putting posters up (such as those included in this pack) in appropriate places also helps and if you complete our publicity form, we can place an article on our website where appropriate.

However, the most powerful form of promotion will be word of mouth – tell your friends and family what you are doing and encourage others involved to do the same. And remember to tell people why, where and when!

Cystinosis is a rare and complex disorder and, hence, not many people know what it is and explaining it can sometimes be hard. Try to ensure that those involved with the event are capable of explaining what Cystinosis is, even if this is at a superficial level (e.g. "it is a complex genetic disorder that usually requires round-the-clock medication").

### Online Donations

[www.justgiving.com/cystinosisuk/](http://www.justgiving.com/cystinosisuk/)  
[uk.virginmoneygiving.com/](http://uk.virginmoneygiving.com/)

The Cystinosis Foundation UK is registered with JustGiving and Virgin Money Giving to provide on-line sponsor forms. We strongly recommend you set up a page for your event to help in the raising of sponsorship. It is simple, secure and quick to do so – it also saves you from having to chase friends up for money after the event too.

From experience we believe an online donation page has doubled, if not tripled, the amount raised from certain events, so we cannot emphasise enough what a simple and effective tool this is.

# 3 IDEAS FOR EVENTS

**Disco/dance/ceilidh:**  
Organise a dance and help support the charity.

**Walking:**  
Sponsored walk in your locality or further afield, e.g. the West Highland Way.

**Swimming:**  
Why not have a sponsored swim at your local pool?

**Dress down day:**  
in the office or school.

**Cross-selling:**  
The aim of the event is to raise money and awareness for Cystinosis. As well as your main event, you can help to raise even more by having secondary activities. This could be as simple as selling Cystinosis Foundation UK branded wristbands (available from the Foundation), or organising a small raffle along with the main event.

**Puzzles:**  
Creating and selling word searches and quizzes.

**Car boot sales:**  
Clear out that garage and do some good at the same time.

**Running:**  
Most areas have local fun runs in which you can participate. The calendar [www.activeeurope.com](http://www.activeeurope.com) lists many events.

**Sporting event:**  
e.g. football match between 2 local teams. Could be combined with stalls selling cakes, raffles, games, etc.

**Local gala:**  
Run a stall at your town gala day, with raffles, games, etc.

**Coffee mornings:**  
Enjoy catching up whilst doing some good.



## 4 THE EVENT ITSELF

Providing advice for the event itself is quite hard due to the variety of activities that people undertake. However, accompanied with this pack is a checklist that will help you remember those important things you need/want to do. Above all, enjoy what you do. As well as raising money for a good cause, a charity event should be fun or challenging or ideally both! You will be more successful if you are enjoying what you are doing and your enthusiasm will rub off and encourage others.

**ENJOY  
THE DAY!**

**TAKE LOTS OF  
PHOTOGRAPHS!**

**HAVE A  
LAUGH!**

**GIFT  
AID IT**

**SMILE!**

**COLLECT  
THE MONEY**

# 5 AFTER THE EVENT

Once you have held the event, many believe everything is done. However, some of the most important activities are yet to be completed. Foremost, remember to collect in the sponsor money you were promised and make sure all those involved in raising money collect in their money too – sometimes it can take a while, but persistence usually pays off.

### Post-event publicity

It is as important as the pre-event publicity. It is important that people are aware that what they were involved with was worthwhile and the money is being used effectively. Sponsors usually appreciate the publicity. Try and let people know how much you raised and what difference it will make. We at the Foundation are keen to know how you got on and, where possible, we like to report on events on our website, so please remember to let us know – completing and returning the “post event” form helps us greatly.

### Ensure prizes are given out, borrowed equipment returned...

By choosing to support the Foundation, you are seen as representatives for the Foundation. If you choose to organise future events, people will be more willing to help a second time, if you are reliable the first time round.

### Finally...

You will want to ensure that the money raised reaches the Foundation. Our preferred method of payment is a cheque made payable to “The Cystinosis Foundation UK”. Our address can

be found in the contact section in this guide (page 14). We encourage you to complete and return our “post event” form and include any sponsor forms and gift aid forms with the cheque. For accounting purposes, it is important that we know where the money originates from and without sponsor forms and gift aid forms we may not be able to reclaim gift aid from the taxman – remember gift aid can make the money you raise worth nearly 30% more.



## 6 CONTACT US

We are pleased you are considering helping the Cystinosis Foundation UK. It is through the voluntary efforts of people like you that we are able to support medical research, promote awareness and help those affected by Cystinosis. And remember, the small events matter just as much as the larger ones – we appreciate your commitment and effort towards fundraising as much as the amount raised. With your help we can make a difference.

We also hope this guide has been helpful and inspired you to organise your own fundraising event, but we are always keen to improve it. If you have any comments or suggestions, please contact us.

**Again, thank you for your help.**

**Contact Us:**

Cystinosis Foundation UK  
1 Butlers Farm Court  
Leyland  
Lancashire  
PR25 1LF

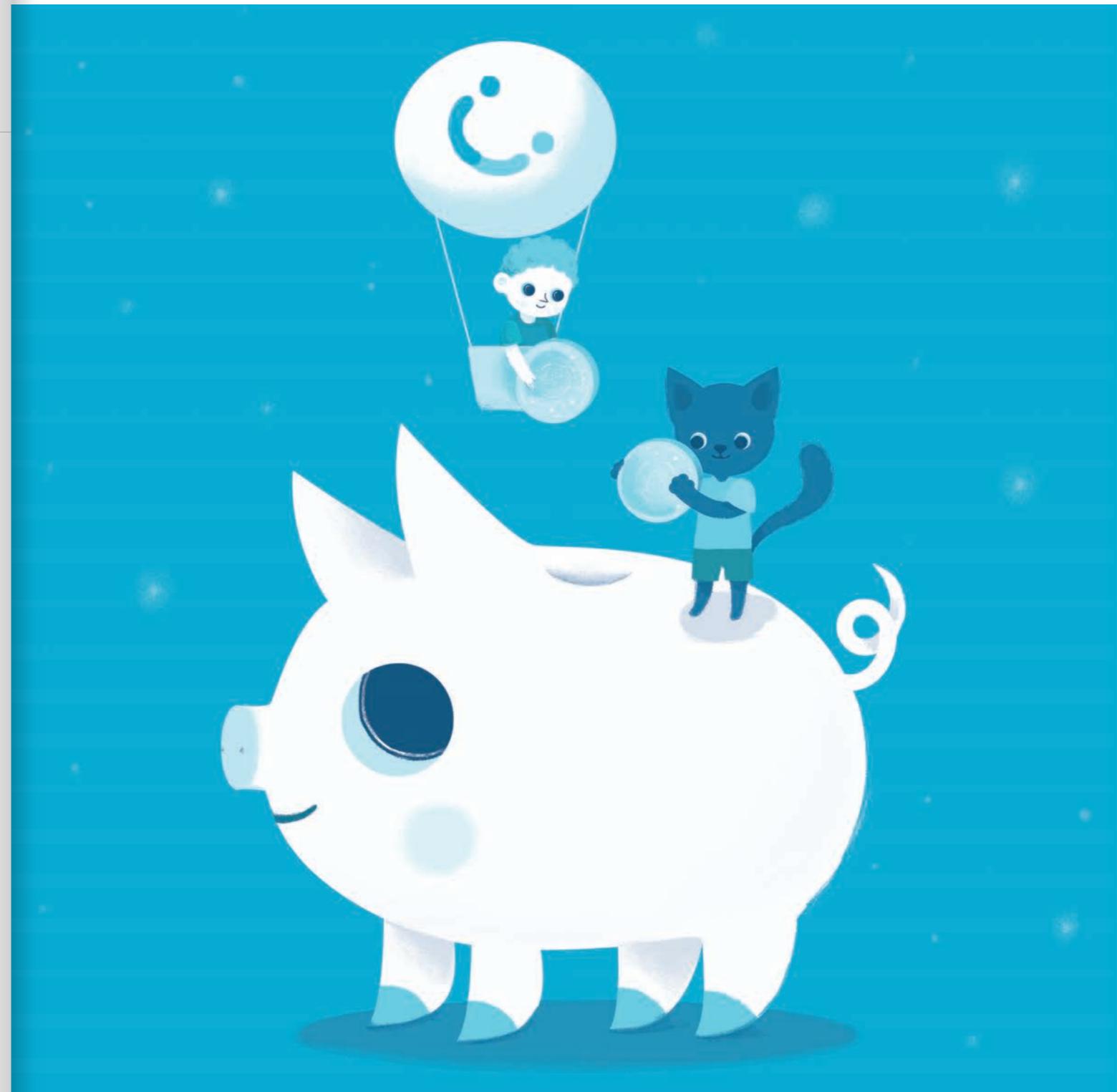
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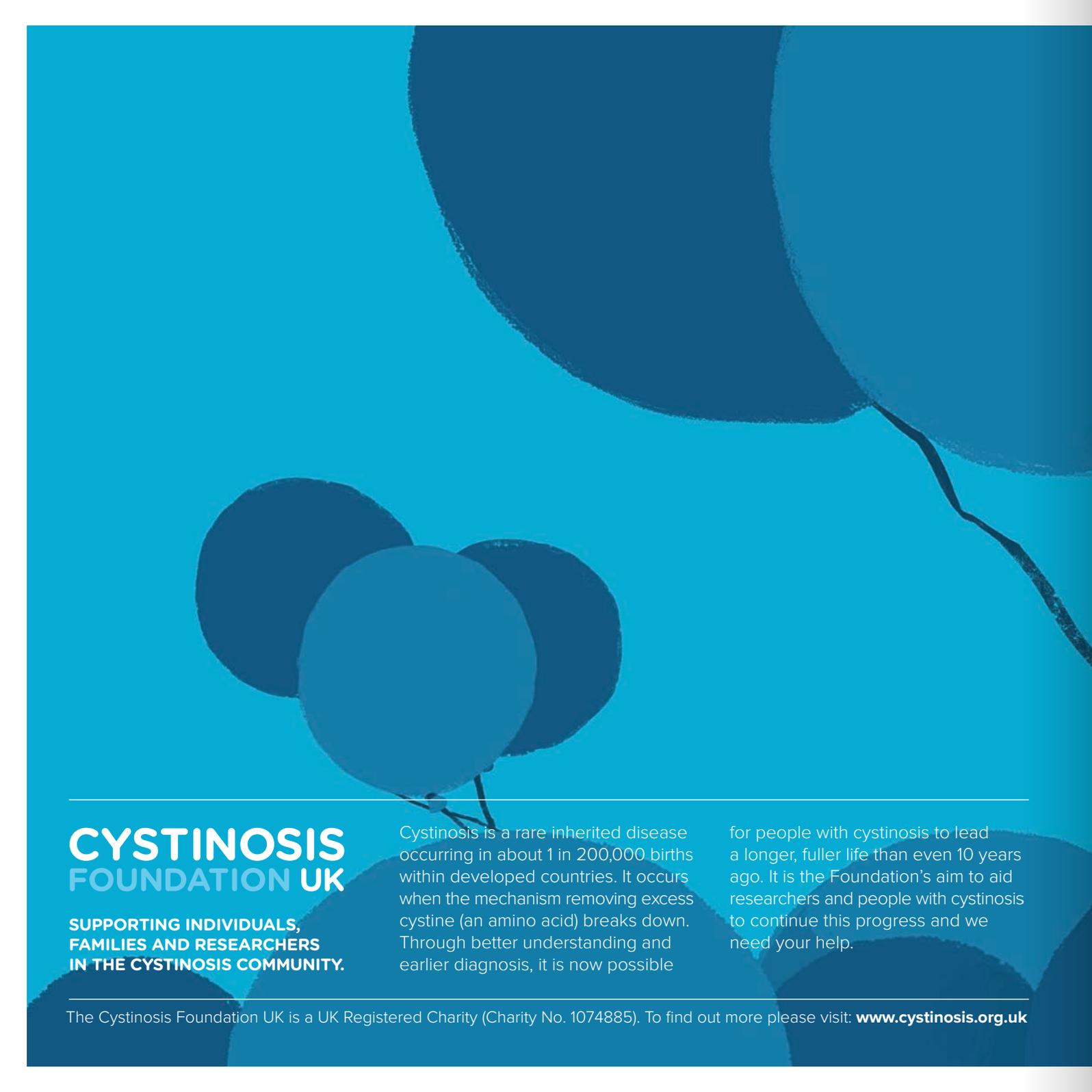
**[www.cystinosis.org.uk](http://www.cystinosis.org.uk)**

**Online Donations**

[www.justgiving.com/cystinosisuk/](http://www.justgiving.com/cystinosisuk/)  
[uk.virginmoneygiving.com/](http://uk.virginmoneygiving.com/)

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# CYSTINOSIS FOUNDATION UK

**SUPPORTING INDIVIDUALS,  
FAMILIES AND RESEARCHERS  
IN THE CYSTINOSIS COMMUNITY.**

Cystinosis is a rare inherited disease occurring in about 1 in 200,000 births within developed countries. It occurs when the mechanism removing excess cystine (an amino acid) breaks down. Through better understanding and earlier diagnosis, it is now possible

for people with cystinosis to lead a longer, fuller life than even 10 years ago. It is the Foundation's aim to aid researchers and people with cystinosis to continue this progress and we need your help.

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