

acrodysostosis
support and research

Let's get

fundraising!

Together we can do this

Every child is unique in their own special way

But for some children, one of the things that makes them so special can also make it harder to live their life to the fullest. It's not fair.

And together, we're going to do something about it.

We're partnering with Great Ormond Street Children's Hospital to fund vital research to learn more about the rare genetic condition, acrodysostosis.

They're providing a successful research applicant quarter of a million pounds, giving so many children the chance to receive better care, support and treatment.

But there's one catch...
In order to secure this funding, **we need to raise £62,500** before April 2021.

We're asking you and everyone in our international family to help... to pull together, and to do something special for the people who need us.





With 90 families across the world, we figure if each family has a target of £700, we will reach our target of £62,500

Francesca's story

Francesca, aged 5, has Acrodysostosis Type 2 which affects many parts of her body. She has skeletal problems, can't walk any distance, is fed through a tube, has global developmental delay, hearing loss, serious neurological problems and has had brain surgery, plus suspected heart issues.

Francesca was born healthy and passed her new-born checks. At her one-year health check, Francesca was not attempting to stand or walk. She was small in stature with petite features. She was still not talking.

Francesca's parents, Kimberley and Alex were concerned, but reassured by their health visitor that Francesca was just small – that was until her finger became infected and a visit to the GP started the ball rolling for a diagnosis.

The family's GP noticed how small her hands and feet were, pointing out a flat



nasal bridge and referred Francesca to a paediatrician.

Kimberley, says: “we went in with an infection on her finger and came out thinking there was something wrong with our child.

“we searched online and found Acrodysostosis Support and Research. We looked through the family stories and the first girl that we found was three and she was the double of our Francesca. She had the same distinct nasal bridge. I also found

a family living less than ten miles away – incredible as there are less than 100 people with acrodysostosis in the world!”

In 2017, Francesca, then two, was referred to a paediatrician.

“The doctor compiled a detailed case history and referred Francesca to our City Hospital. In 2018 consultants from across the UK met to discuss her case. All of a sudden we were on a roller-coaster and we haven’t got off.”

Francesca’s is a de novo case, meaning no one else in the family has it. Francesca’s brother Archie, is unaffected.

Francesca now sees a physiotherapist, an occupational therapist and a speech and language therapist. Despite her medical needs Francesca now goes to a mainstream school, with one-to-one assistance. She has global development delay but is doing well in school.

“I do sometimes feel I can’t cope, as does Alex,” Kimberley says. “But if we don’t keep going, we’ll never get back up again. We take a look at Francesca and how she just gets on with whatever is thrown at her, so who are we to complain. Kimberley says: “For us, the charity Acrodysostosis Support and Research has been a lifeline. Meeting other parents who are going through the same thing is brilliant, they understand what it is like, what we are going through.”

That is why Kimberley, her friends and family are fundraising right now for vital research to learn more about the rare genetic condition, acrodysostosis.

Kimberley has already raised an amazing £315 of her £1000 target. She used [Facebook fundraisers](#), asking friends and family for donations to celebrate both her and Francesca’s birthdays.

Time to shine!

Are you a baker, knitter, swimmer or quizzer?

This booklet is chock-full of handy hints and tips to help make your fundraising a smashing success.

With your support, fund vital research to learn more about the rare genetic disease, acrodysostosis.

However you're planning to raise money for us, you're a Fundraising Superstar! So, let's get started!

Remember to tag us in all your photos of your fundraising activities:
#acrodysostosis

Five steps to success



Pick it Choose your fundraising activity from our A-Z, p9



Plan it Whether it's big or small, you'll need to put some thought into planning your event.

Use our facebook forum for swapping ideas and success stories. [facebook.com/acrodysostosis](https://www.facebook.com/acrodysostosis)



Promote it Think about who you'll be asking for donations and spread the word in any way you can. Find tips for using social media on p13!



Take pride in your achievements You've done something amazing for families living with acrodysostosis. We can't thank you enough for your support.



Pay it in Time to collect your donations and tally up your total. If you've used JustGiving, your donations will already be with us. If you've collected them yourself please bank via our donate button on our website: [acrodysostosis.org](https://www.acrodysostosis.org)

A-Z of fundraising ideas

A

abseiling
afternoon tea
auction
arts and crafts stall
arm wrestling

E

egg and spoon race
eating marathon
egg hunt
eyebrow shave
80's party

I

ice bucket
challenge
it's a knockout
ironing

B

bingo
baked bean bath
bring and buy
bike ride
bungee jump

F

fancy
dress
face-painting
fantasy football
fun-day

J

jelly eating competition
jelly bath
jewellery making
jail break
jumble sale
jazz evening

C

cake sale
car-boot sale
coffee morning
crossword contests
cook-off
chocolate ban

G

garden party,
game show
guess whose hand print
gardening
garage sale

K

karaoke
knit-a-thon

D

danceathon
dress down day
duck race
disco
darts tournament
donut eating competition

H

halloween party
head shave
hook - a- duck
hoopla
hike
half marathon

L

ladies night
litter picking
lottery
line dancing competition
left handed day

M

marathon
mini olympics
mud assault course
murder mystery night
matched giving from employer
masked ball
magic show

Q

quiz night
quad bike racing
quit a habit

U

underwear party/day
unwanted presents swap

N

nearly new sale
no drinking week/month
name the ???
non uniform day
nature trail
netflixathon
nintendo play off

R

raffle
run
race night

V

variety show
vehicle rally
video gaming night
vicars and nuns day
valeting
vintage day

O

odd jobs
odd sock day
onion peel competition
onesie day
office sweepstake

S

sit in a bath of soup
sky diving
swimathon
swap shop
swear box smartie tube

W

waxing
window cleaning
wheel barrow racing
wine tasting evening
walks
water sports
weight of the cake

P

poker tournament
picnic day, pub quiz
photo competition
paint-balling, parachute jump
personalised gifts
play-station play off
puddle jumping

T

table top sale
talent competition
tombola
toy sale
treasure hunt
tuck shop

welly throwing
water challenge
whiskey raffle
wine & cheese tasting
wood working
world record attempt

X

xmas evening
xmas hampers
xbox tournament
xtream sports

Y

yoga-thon
yo-yo competition
yodelling competition
yard of ale/beer

Z

zumbathon
zip wire
zorbing
zodiac evening
zoo party

**We know you will have plenty
more ideas of your own...**

Please share here: facebook.com/acrodysostosis

Online/covid safe ideas

zoom quiz
online auction
netfixathon
online club-night
gaming tournament

online raffle
ebay unwanted gifts/clothes
online record attempt
home gym challenge
online skill share/workshop

Kid friendly ideas

reading challenge
muddy puddle challenge
sponsored walk
duck race
electronic free month/week

sponsored gaming event
sponsored bike ride
chubby bunny challenge
tidy room challenge
old toy yard sale

Reach for the stars

Now you've got your idea, it's time to make your fundraising skyrocket.

A helping hand

Get your friends and colleagues involved.

Ask each of them to raise a smaller percentage of your overall target.

Or why not think up your own fundraising ideas and share them with our facebook community.

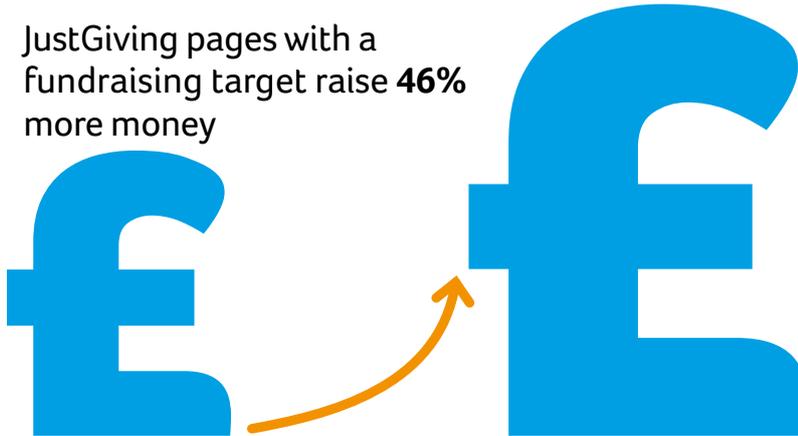
Ask your employer or another local business if they can match your fundraising total.



Raising money

Psst...

JustGiving pages with a fundraising target raise **46%** more money



**So how do you go about collecting the cash?
Don't worry – it's easier than you'd think!**

Setting up JustGiving or Facebook is a quick and simple way to let people know you're raising money.

Visit **JustGiving** or **Facebook** and follow the instructions to set up your own fundraising page.

Both of these are straightforward, secure, and you can even get creative with your page.

Add a photo and some info about why you're fundraising to encourage donations.

Sing and shout

Well, not literally – unless you want to! Sharing your fundraising on social media can send your donations soaring.



[acrodysostosis.org](https://www.acrodysostosis.org)

Here's how you can do it:

1. Keep reminding people what you're doing and sharing your JustGiving or Facebook pages.
2. Post in any group chats you're a part of and ask your friends to donate.
3. Tell your story using photos of you and your family on all your social media posts.
4. Create a Facebook event or start a hashtag on Twitter or Instagram to track your progress
5. Take loads of photos of your fundraiser events to share afterwards.
6. Thank people for donating, it means a lot and might remind someone else to donate too!

Use our fundraising assets kit to create your own promotional materials

Safety first

Whatever you're planning, it's vital that you keep safe and legal. So let's go through some health and safety basics.

Raffles

Raffles are a great way to drum up funds, but make sure you're aware of the legalities beforehand.

Find the latest advice and guidance at [gamblingcommission.gov.uk](https://www.gamblingcommission.gov.uk) or your local laws.

Food hygiene

Whether you're selling cupcakes or putting on a three-course dinner, food safety laws will apply.

Check in with [food.gov.uk](https://www.food.gov.uk) to be on the safe side, or your local laws.

Collecting money

If you're carrying out public street collections you'll need to obtain a licence first.

Due to the ongoing situation with coronavirus, for your health and safety, we ask you to follow all local government advise.

We recommend that another person is present when you're counting donations.

Insurance and licensing

We aren't responsible for your event and can't accept any liability. We recommend that you check with your local authority whether you need any special licences.

For health and safety advice, you must check your local rules and regulations

You made it!

First things first, we want to say a big thank you!

You've made a real difference funding vital research to learn more about the rare genetic disease, acrodysostosis.

Now it's time to get that money to the people who need it.

JustGiving and Facebook

If you've been fundraising using JustGiving or Facebook, your work here is done!

Any donations on your page (even ones made after your event) will be sent directly to us. No need to chase anyone.

Donate online

Using our website donate button, this will take you to our Paypal page.

Go to: [acrodysostosis.org](https://www.acrodysostosis.org)

Let us how you did

Send us an email so we know how you got on:

nina@acrodysostosis.org

Thanks

Super star

Really, you are!

The fact that people like you across the world are taking the time to fundraise means the world to us.

If we can raise this money, children (and adults) living with acrodysostosis have a better chance at having the same opportunities we all deserve in life.



[acrodysostosis.org](https://www.acrodysostosis.org)

Acrodysostosis Support and Research UK registered charity number 1182818