



CdLS Foundation UK & Ireland

The Cornelia de Lange Syndrome Charity Reg. No. 1054033

Fundraising for CdLS a guide



Welcome

Thank you for choosing to fundraise for the CdLS Foundation UK & Ireland. By fundraising for the Foundation, you will be making a difference to the lives of people with CdLS and their families. So whether you raise pennies or thousands of pounds, we would like to say thank you on behalf of all those affected by CdLS.

The aim of the booklet is to give you advice and guidance that will support your fundraising adventures. If you would like more information or would like to discuss any of your ideas, please give the office a call on **01375 376439**

Happy Fundraising!!!



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What is Cornelia de Lange Syndrome (CdLS)?

CdLS is a rare genetic syndrome. There are four main features in this syndrome. Children with CdLS are small at birth and remain small compared to children of the same age. They are all slow learners but this varies from mild to severe. Many children have limb abnormalities which range from extremely small hands to complete absence of forearms or digits. The most striking feature of the syndrome is that all the children can look alike, like brothers and sisters. People with CdLS can often develop challenging behaviours.



Who will I help?

The CdLS Foundation UK & Ireland is part of a World Federation of CdLS Support Groups around the world. The groups have a common mission:

"The CdLS Foundation UK & Ireland is a family support organisation which exists to ensure early and accurate diagnosis of CdLS throughout the world, promoting research, and enabling individuals, families, friends and professionals make informed decisions and plan for the affected person's present and future."



In the UK the Foundation is run entirely by volunteers including parents and professionals. Through twice yearly family conferences, the Foundation provides families with the opportunity to meet each other and share experiences. World leading experts in the syndrome attend conferences and offer seminars and individual consultations. The Foundation funds ongoing research into the Syndrome and also publishes a magazine, 'Reaching Out' which covers news stories about research developments, news from our families and articles on issues affecting people with CdLS.



Your fundraising is the key to making sure the Foundation can continue all of its incredible work.

“ A family conference... It's the difference between being the only family in the room that stands out and is watched with inquisitive eyes, to a family that fits in and finally feels 'normal.' ”

A CdLS family member on what the twice yearly family conferences mean to her.



Planning your event

You should consider a few things including - what time of year would be best? What else is happening? Are there other big fundraising events coming up at the same time? Consider any clashes, locally or nationally, that might make it harder for your event to be a success. Remember you should give yourself time to manage the planning process and allow sufficient flexibility - particularly if you will need other people to help.



Where to hold your event

Book your event as early as you can, that way you have more time to plan and to publicise. Is it in a public place? Have a think - will you need an events/alcohol licence? Check out the practicalities of the venue itself - does it have a kitchen? Toilets? You need to know the venue's legal capacity and consider if you require disabled access.

Promoting your event

Get anyone and everyone you know involved and ask them to help to publicise what you're doing! Use Facebook, Twitter and other social media - a quick, simple and effective way of promoting events at little or no cost.

Visit the Foundation fundraising page for poster templates...



Involve your community

Ask your contacts in schools, businesses, churches etc to help you promote the event. Some may even have useful links to caterers etc. Why not ask your workplace to match-fund any donations you get: for every £1 you raise they give you £1 - easy! Lots of local businesses are often happy to donate prizes for raffles





A

Fundraising A-Z

Auction

Organise your own fundraising auction. Why not auction off your talents for the day or donate a percentage of funds raised through an eBay auction?

Arts and crafts

Get together with the kids and put your creativity to good use by selling your master pieces at a local fair/car boot sale!

Afternoon Tea

Put the kettle on and get baking. Entertain guests with raffles, auctions, tombolas & live music.

B

Bring and buy sale

Sell donated goods on a stall. Cakes, books, home-made jam, bric-a-brac and fairtrade goods are firm favourites.

Bike ride

Why not organise your own or get involved in a local/national bike ride, then get your friends and family to sponsor you?

Bingo

Organise a bingo event - devise your own calls for the numbers. Charge a fee per game.

C

Bungee Jump

Find your inner daredevil and get friends and family to sponsor you!

Cake sales

Cake sales are a great way to raise money!

Collections

Get in touch with the Foundation for a collection box - use your small change to make a big difference.

Car wash

Charge your friends and family and members of the local community to wash their cars.

Competitions

Devise your own competition or use tried and tested ideas such as 'guess how many sweets in the jar.'

D

Dress down day

Ditch the suit and tie and dress down for work/school for a small donation.

Disco

Put on those dancing shoes and disco the night away. Remember to charge an entry fee.

E

Dance-athon

Dance all day in a sponsored dance-athon. Download your sponsorship form from the website. You could even challenge your friends to a dance off!

Easter egg hunt

Edible hide and seek. Charge entry fee and ask confectioners to provide the eggs.

Eating Marathon

Get sponsored to stuff your face with as many baked beans/ grapes/pies etc. as possible.

F

Fireworks

Weather permitting, firework displays are massive fundraisers. Check out safety precautions.

Football Tournament

Schedule fixtures and charge teams to enter. You could ask local businesses for prizes.

Fun Day

Arrange games, music, competitions and stalls at a nearby hall or sports club.

G

Garage Sale

Sell off all your unwanted belongings.

H

Garden Party

Sell tickets or invite guests to make a donation.

Greeting Card

Make and sell cards for every occasion, donate the proceeds to the Foundation.

Hair beading, braiding and plaiting

Put your creative talents to good use. Make your friends look cool and raise money for CdLS.

Hopscotch

Organise a Hopscotch contest in the playground, and challenge your friends. Pay to play.

Head Shave

Shave your hair off and raise some cash!

I

It's a Knockout

Organise an It's a Knockout competition - fun for all the family. Either make it a sponsored event or pay to play.

Indoor games

Organise an indoor sports event. Rain won't stop play and you'll have fun challenging your friends and raising money for us too.

J

Jumble sale

Fundraising is the perfect opportunity to hold a jumble sale. See if you can turn your trash into cash.

Jewellery making

Buy your own beads and get threading. Sell your products at markets and craft fairs.

K

Karaoke

Impress your friends with your singing ability - try out your favourite tunes. Pay per tune.

Knitting

Put your knitting skills to the test. You could sell or auction your work of art too.

L

Line dancing

Friends and family can have hours of fun with a line dancing event. You could even organise a line dance-athon. Charge a fee to take part.

Loud tie day

Look to make a difference amongst your friends: see who can wear the most outrageous tie to school or work. You could even design your own tie. Only those who have paid to display can take part.

M

Marathon

Get sponsored to run a traditional 26-mile race. Contact the Foundation to see if there are any spaces left for the next London Marathon.

Musical evening

Show off your talents and organise an evening of musical entertainment - charge an entry fee.

Matched giving

Double the money you raise fundraising by asking local businesses to support your cause!

N

Name the teddy

Does your mascot need a name? Charge your mates to come up with the most interesting suggestion. You could raffle the teddy at the end too.

Netball tournament

Challenge your friends, teachers or parish to a netball tournament. To add to the fun, why not play your matches in fancy dress too?

New Year's resolutions

Get sponsored to stick to your new year's resolutions.

O

Outward Bound

Go climbing, hiking, camping, etc. Seek sponsorship.

P

Odd clothes day

Turn your non-uniform day into an odd clothes day - mix up those socks and clash for cash.

Odd job Day

Charge a fee for all those odd jobs around the house that need doing.

Plant sale

For those with green fingers, sell your produce in a plant sale.

Penalty shoot-out

Show off your skills in a sponsored shoot out as part of a football fundraiser.

Q

Quizzes

Create your own quiz to test your friends' knowledge. Hold a quiz night and raise money for CdLS by charging per entrant.

Quiet in the classroom or office

Sponsored silence. Remain quiet for a few hours, or even a whole day. Remember to get sponsored too!

R

Raffles

Get friends and family or local businesses to donate prizes and raffle them off to raise funds.

S

Rugby match

Challenge your friends and colleagues to a rugby match. Each team pays to play.

Race night

Get your pals together and host a race night.

Sponge toss

Players pay to chuck sopping wet sponges at whoever's in the stocks.

Skydiving

Free fall your way back to earth - for sponsorship.

Scavenger Hunt

Variation on the treasure hunt where participants have a list of items to collect. Charge friends to enter.

Swimathon

Get sponsored per length.

Sponsored ideas/events

Remember when organising a fundraising event to think about adding a sponsorship element - it's a great way of collecting your money.

T

Tombola

Get friends and family to donate gifts and organise a tombola.

U

Treasure Hunt

Create a treasure hunt and challenge your friends to find what you have hidden. Pay to play.

Teddy bears' picnic

Organise a teddy bears' picnic and invite friends and family to attend in return for a donation.

Toy sale

In the run up to Christmas, toy sales can be big fundraisers.

Unwanted gifts sale

Arrange a post-Christmas sale of unwanted gifts. Ask traders to donate their takings.

Uniform free day

Ditch the uniform for a fee.

V

Variety Show

Comedians, magicians, singers, dancers & musicians all under one roof. Charge for entry.

W

Waxing

A hair-raising experience for the boys. Get sponsored to wax your legs or chest.

Walking

Organise a sponsored walk.

X

Y

Z

Word search

Create a themed word search and challenge your friends and family. Remember to charge a fee.

X-Factor talent show

Create your very own X-Factor event. Charge a fee for entry.

Yo-yo competition

Have you got a talent for yo-yoing? Then put your skill to good use and get sponsored.

Yoga Marathon

Get sponsored to do yoga for a day.

Zany Dress Day

People at your office or school pay a quid or two for the chance to come dressed as celebs, as animals, in their team's strip, or all in pink...



Money and sponsorship

There are many ways to handle the donations you receive. We've made a sponsorship form that you can download at:

www.cdls.org.uk/fund-raising

Online:

An easy way to collect online sponsorship money is to set up your own totally secure JustGiving page. Go to:

www.justgiving.com



You can ask people to sponsor you by email or on facebook and twitter by sending them a link to your JustGiving page.

In addition, you can make donations to the Foundation with MyDonate, with no commission cost to us. There is a link on our website.

Cheques and bank transfers

All cheques need to be made payable to CdLS Foundation UK and Ireland

To donate money by bank transfer directly into the Foundation charity account, please call the office on:
01375 376439



Gift Aid

Make your fundraising go further... Just ask sponsors who are UK taxpayers to tick a Gift Aid box. This enables us to claim an extra 25p per £1 you donate at no extra cost to you. A £10 donation will be transformed into £12.50! This makes a huge difference and all you need is the person's name, postcode and a tick in the Gift Aid box (see example sponsor form). Please ask your supporters to sign a Gift Aid form if they are eligible to do so.





Serious stuff - Legal Matters

Whilst we're sure you won't break the law on purpose, some fundraisers like raffles, lotteries and competitions with prizes have strict rules about how they are organised and some require licences. Find out more at:

www.gamblingcommission.gov.uk

Make sure you check with your local authority before holding events where collecting money on the streets or running market stalls are concerned.



Remember, the Foundation cannot accept liability for any loss, damage or injury suffered by anyone participating

in a fundraising event. Where necessary you should arrange adequate public liability insurance cover.

Remember to include our name and charity number on all your publicity material:

CdLS Foundation UK & Ireland. Charity No. 1054033

If you're not sure whether your event requires a licence or special permission have a look at The Institute of Fundraising's website:

www.institute-of-fundraising.org.uk

Keeping your event safe



Fundraising should be fun! Follow the tips below to keep it that way...

The best way to avoid any accidents or mishaps is to apply plenty of common sense. If you're using any equipment for your fundraising event, make sure you follow the manufacturer's instructions and guidelines. Always thoroughly check anything that's a possible source of problems by doing a risk assessment.

If your event is going to involve lots of people, make sure that there are enough qualified or appropriately briefed people to supervise.

If your event involves food preparation make sure you follow food hygiene rules for safe preparation, storage, display and cooking of food.

Events which involve strenuous activities such as running, swimming, etc. should clearly state that a medical check-up is recommended - particularly where a level of fitness is required. Often, great ideas arise out of a sense of bravado so it's really important no one is putting themselves or others at risk by attempting something that's too demanding, or even dangerous.

Where appropriate, it's a good idea to have a first aider at the ready or to arrange for St John Ambulance to attend your event.

Useful advice on all things related to health and safety, including risk assessment can be found at:

www.hse.gov.uk



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