CDKL5 UK
Empowering Families
Embracing Hope

Embracing Hope
for CDKL5

Fundraising Pack

Registered Charity No. 1207922

Thank you for your support

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Empowering Families
Embracing Hope

Your support makes a difference!

CDKL5 UK is a small charity dedicated to supporting individuals and families with a diagnosis of CDKL5 Deficiency Disorder (CDD). We do this by:

- sharing relevant and up to date information about the condition
- organising face-to-face family days, and online events
- delivering training for health and social care professionals
- supporting patient participation in the latest clinical trials
- providing a platform to empower individuals and families to be involved in
- the design and implementation of research projects, using their lived
- experience to help others on a similar journey

Our **Mission** is to provide help and support to individuals and families affected by CDD. Our **Vision** is a world in which CDD and its effects are overcome by way of effective treatments and ultimately, a cure.

At CDKL5 UK our aim is to provide support for families and carers, whether that's through sharing information about the condition, organising family days to supporting participation in the latest clinical trials. We share the same goal, to help children, adults and families affected by CDD live life to the full.

This pack is full of top tips to make your fundraising a huge success, whether it's a bake sale, a birthday, a 10km run or walk, a marathon, or even an inflatable 5K! We will support you every step of the way, so please get in touch. Thank you for your support, and good luck with your fundraising!

Hints and tips to help you

Whatever you are doing to raise money, there are a few simple things you can do first to maximise your chances of success. Making the effort at the start will make all the difference at the end, so follow these tips.

1.Where to start

- Set a date for your event
- Select a venue - think about size, facilities, transport and disabled access
- Set a budget and stick to it - always ask stores for charity discounts or donations of goods. If you get in touch with the team at CDKL5 we can supply you with a letter of support
- Register your event with us

2. Set yourself a target

It can be helpful to set a target. It's a great way to keep yourself motivated all the way until the big day.

3. Don't forget to Gift Aid it

Make sure all UK taxpayers tick the Gift Aid box when they make a donation to your cause. This can greatly increase the amount of money you raise for us. Check whether your employer offers it, if they don't, ask if they would like to support your fundraising and make a donation.

4. Stay safe and keep it legal

You'll be responsible for carrying out necessary risk assessments and taking precautions for health and safety and insurance cover for your event.

Get involved and support our work

There are so many different ways you can fundraise for us. From setting personal challenges for yourself, to challenging your family, friends and colleagues!

If you need some ideas, why not get in touch with us, and we'll support you ever step of the way. You can start by having a look at some of the suggestions below.

Fundraising ideas

Run, walk or cycle

Why not set yourself a solo goal by running or cycling a set amount of miles or attending a local event!

Birthday fundraiser

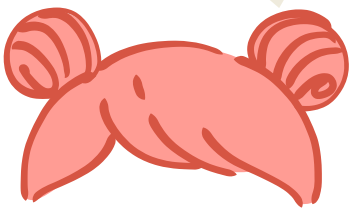
Create a birthday fundraiser for CDKL5 UK. Ask friends, family and colleagues to donate instead of buying you a gift this year.

Bake sale

A local bake sale always goes down a treat! Ask family, friends, and colleagues to donate baked goods so that you have a variety of delights to offer.

Dye your hair

Set yourself a target and let your supporters know that once this target is reached, you'll dye your hair or beard a crazy colour!



Top 5 tips for fundraisers

1

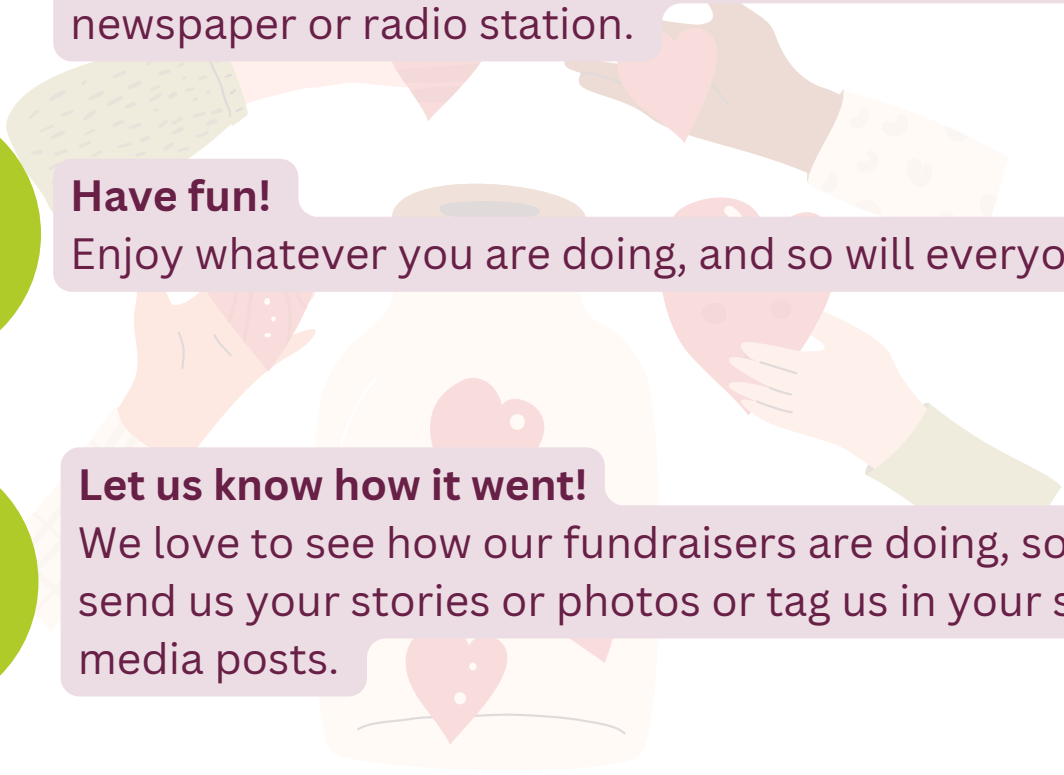
Register your event with us
Email admin@curecdkl5.org to let us know your fundraising plans! Remember, we are here to help you, wen can provide you with charity materials, and help to promote your fundraiser.

2

Set up a Just Giving or Given Gain page
The easiest way to raise money for your event. Personalise your page and email the link to family and friends, or share in on your Facebook page.

3

Tell everyone what you're doing
Your friends and family may be able to help, or local shops and businesses could offer support. Use opportunities such as social media to widen your audience or even send a press release to your local newspaper or radio station.



4

Have fun!
Enjoy whatever you are doing, and so will everyone else!

5

Let us know how it went!
We love to see how our fundraisers are doing, so please send us your stories or photos or tag us in your social media posts.

Set up a Fundraising Page on your preferred site

How to set up your Given Gain Fundraising page

It's quick and easy to set up a Fundraising Page on Given Gain. Just follow the steps below:

1. If you don't have an account, click 'Sign Up'. If you already have an account, click 'Log In'
2. Use the search bar or browse through the causes to find CDKL5 UK.
3. Once you are on the CDKL5 UK page, click 'Start Fundraising' or 'Create Project'. This will take you to the fundraising project setup form.
4. Create an engaging title for your page, set a realistic fundraising goal, share why you're fundraising and what CDKL5 means to you. Be personal and authentic. Upload photos or videos to support your story.
5. You can customise your link for your fundraising page to make it easier to share. This is optional.
6. Review your page and lick 'Create Project' or 'Publish'
7. Your page is now live and can be shared with family, friends and colleagues!

Congratulations! You have set up your fundraising page. It's now ready to accept donations. The money that you raise will be sent directly to CDKL5 UK on a weekly basis. Now you can personalise your page and share it with your family, friends and colleagues!

Set up a Fundraising Page on your preferred site

JustGiving™

How to set up your Just Giving Fundraising page

It's quick and easy to set up a Fundraising Page on Just Giving. Just follow the steps below:

1. Create an account, or into your an exciting account and click 'Start Fundraising'
2. When asked 'Are you fundraising for a registered charity?', select 'Yes, continue'
3. Select CDKL5 UK
4. Let us know whether you are taking part in an event, celebrating an occasion like a birthday, fundraising in memory of someone you love, or doing your own thing.
5. If you can't see your event listed, select 'Add your own' at the bottom of the page and tell us a little bit more about your activity
6. Choose your web address - this is the link you'll be sharing with your friends and family when asking them to donate
7. Tick 'Yes' if you are running a bake sale, or selling tickets to an event, raffle or auction. Donations to your Page won't be eligible for Gift Aid.
8. Click 'Create your page'

Congratulations! You have set up your fundraising page. It's now ready to accept donations. The money that you raise will be sent directly to CDKL5 UK on a weekly basis. Now you can personalise your page and share it with your family, friends and colleagues!

How to comply with legal regulations

It's really important when you start fundraising, that you do it in a safe and legal manner. Here are some tips to help you out.

Collecting Donations

On private property

For example, a shop, pub, or supermarket. Ask the owners permission in advance. Leave plenty of time in case the person you ask has to check with someone else.

On public property

For example, a park, street or square. For this you will need a licence. You can get these from your local council, but this can take a few weeks or even longer. So make sure you allow plenty of time before your collection date. You will need to inform your local police about the event.

Raffles, lotteries and prize draws

Activities such as raffles, lotteries and prize draws where a winner is chosen by chance, are governed by gambling legislation. These activities are permitted when they take place at a fundraising event and when the winner is announced at the event, otherwise a licence may be required. If you have any questions, you can reach out to a member of the CDKL5 UK team at admin@curecdkl5.org.

Gaining Permission

Av event held in a public place will need permission from the local authority first. You may also need persmission if you're planning an event that may impact on the area, the public, such as a noisy event or an event the public can be invited to.

Frequently asked questions

Q. Can a representative from the charity attend my event?
A. Due to our small team of only one paid member of staff, we are unable to send a representative to your event.

Q. Where will the money go?
A. The money you raise will help us to help people with CDKL5 Deficiency Disorder (CDD), their parents, siblings, families, friends and carers. We do this through sharing relative and up to date information about the condition, delivering training to empower professionals who care for people with the condition, develop resources and raise awareness of CDD within the research and medical communities, work with researchers on ensuring that the patient voice is at the heart of their CDKL5 research.

Q. Can I get a running shirt or vest to wear for my event?
A. We can send you a running t shirt in any size. E-mail admin@curecdkl5.org to arrange this.

Q. I need something to show that I am fundraising for CDKL5 UK?
A. We can supply you with a 'letter of authorisation' which will confirm our knowledge of your fundraising.

Q. Who do I make cheques payable to?
A. CDKL5 UK

Q. Can I get my event mentioned on CDKL5 UK's Facebook account?
A. Yes absolutely! Send us your photos and fundraising updates or story to admin@curecdkl5.org.

Gift Aid

Help us make your donation go further!

Did you know that if you are a UK taxpayer, for every £1 you donate, the tax office will contribute 25p. That means for every £100 we get an extra £25 so it makes sense to ensure you use Gift Aid wherever applicable.

Please note: we are only entitled to receive Gift Aid for sponsored events such as a skydive, running event, cycling event and for community donations. If you put on an event like a quiz night, bake sale, or raffle, we will not be able to claim Gift Aid.

When sponsors complete your online donation form or sponsor form, please ensure they complete the first line of their address and their postcode. Without this information, we are unable to claim.

If you wish to make a one-off donation, you can use the Beacon form on the website. More information is on the next page!

Many thanks,

The CDKL5 UK Team

Make a one-off donation

You can now make a one-off donation to CDKL5 UK via online form: https://curecdkl5.org.uk/fundraising-volunteering/fundraising/

View our policies, including Data Protection and our Fundraising Promise, here: https://curecdkl5.org.uk/our-policies/

Sponsorship and Gift Aid declaration form

Name of event: _____ Date of event: ___/___/_____

Fundraiser name: _____

Address: _____

_____

_____ Post code: _____

If I have ticked the box headed 'Gift Aid? ', I confirm that I am a UK Income or Capital Gains taxpayer. I have read this statement and The Royal Wolverhampton NHS Trust Charity to reclaim tax on the donation detailed below, given on the date shown. I understand that if I pay less Income Tax/or Capital Gains tax in the current tax year than the amount of Gift Aid claimed on all of my donations it is my responsibility to pay any difference. I understand the charity will reclaim 25p of tax on every £1 that I have given.*

Full name	Address	Post code	Amount pledged	Amount given	Date paid	Gift Aid

Sponsorship and Gift Aid declaration form

Full name	Address	Post code	Amount pledged	Amount given	Date paid	Gift Aid

Cheques should be made payable to:

CDKL5 UK

Please contact a member of the team at admin@curecdkl5.org to arrange to send/drop off sponsorship forms, cheques, donations if not online.

For office use only

Supporter no: _____

Total: _____

Total GA: _____

Total non-GA: _____

Event donation form

Please use this form to send any money you have through your event not paid in via your online fundraising page.

Full name: _____

Address:_____

_____

Post code: _____

Email: _____

Phone number: _____

Date of birth: ____/ ____/ _____

Contact

We would like to keep you informed of our work so that you can see how your gifts are making a real difference. If you would like to hear from us, please select the following options:

By post ☐

By phone ☐

Payment

If you are writing a cheque, please make it payable to CDKL5 UK.

Please contact a member of the team at admin@curecdkl5.org to arrange.

By bank transfer

Please visit https://curecdkl5.org.uk/donate-to-cdkl5-uk-via-bank-transfer/ or contact a member of the team at admin@curecdkl5.org

Please contact a member of the team at admin@curecdkl5.org to arrange to send/drop off sponsorship forms, cheques, donations if not online.

Notes

CDKL5 UK
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The voice for the CDKL5 community in the UK

CDKL5 UK IS A REGISTERED CHARITY IN ENGLAND AND WALES : 1207922

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