

6th annual



*How far will you
go for CDKL5?*

Participation Guide

Everything you need to
Move CDKL5 Forward in June!



IFCR

International Foundation
for **CDKL5** Research

Creating Your Page

We need YOU to help us FUNDRAISE and reach our \$100,000 goal for CDKL5!

Starting a page is easy! Here's how:

1) Visit <https://move-cdkl5-forward-2026.raiselysite.com/>

Click "**Sign Up and get moving**" (you'll be directed to a new fundraising platform called Raisely.)

Click "Sign-up & Take the Challenge"

2) Indicate if you want to fundraise as an **individual, join an existing team** (click individual & find team), **or start a team** that others can join.

3) **Follow the prompts** to set up your/team page. (You will set a personal goal as well as a team goal if you choose to start a team. Do not use symbols in the amount)

4) **Personalize your page/team page!** You can upload a photo, a statement about why you are joining Move & even make your first donation.

5) **Track your Moves** by connecting to your Strava account or you can manually enter your miles.

Editing Your Page

Editing your page– Once your page is up and running you can edit it at any time by logging into your Raisely account, and in the upper right corner, hover over your profile picture/name and a drop down menu will appear, **click My Profile or My Team. Once on those pages you will see an “Edit Profile” Button under your name and picture.**

My dashboard Button next to the edit button brings you to your dashboard where you can track your progress and your team’s progress.

You can **connect your social accounts** from Facebook and X . (There is no integration for Instagram) but you can use items in resources and post them manually.

Email– You have the ability to send emails to supporters to ask for donations and thank.

QR Code – You will have a personalized QR code that will direct back to your fundraising page. This is an easy way for you to send people directly to your page.

Donations & Fundraising

Cash Donations-You will not have the ability to enter cash donations to you or a team's profile.

We encourage you to make those donations via your credit card.

Checks-If you receive donations via check made out to IFCR, please email us at **Fundraising@CDKL5.com** so we can give you instructions.

Fundraising isn't easy, but (in our experience) when you share your CDKL5 story, people want to help - Just ask!

1) **Send an email.** A simple message letting coworkers, friends, and family know about your fundraiser goes a long way. Share a bit about your child if you are comfortable and don't forget to share your fundraising link!

2) **Post on social media - many times!** It can be tricky to know who sees your social posts so posting often throughout the month is a must. Post with a photo and tag friends and family to publicly say thank you for their donations. It encourages others to give!

3) **Ask by mail (or text!).** For those friends and family not on social media, send them a letter about your fundraiser.

Unsure What To Say?

Fundraising is all about asking! But sometimes it's hard to know exactly what to say. There is no right way - it's usually best to **speak from the heart**, but here is some inspiration if you'd like it:

June is CDKL5 Awareness Month and I am fundraising for the International Foundation for CDKL5 Research (IFCR). As you may know, my son/daughter has a diagnosis of CDKL5 Deficiency Disorder. (tell a bit about your child here if you'd like) We want to help the IFCR "Move CDKL5 Forward" and we are asking for your help. Please help us reach our fundraising goals! (link to your fundraising page)

Thank you for helping to Move CDKL5 Forward! If you need support in any way with your fundraising efforts, please reach out!

Fundraising@CDKL5.com

By The Way

Fundraisers who set up their fundraising page by **May 15th** will receive a special thank you gift. We appreciate you!

You can order Move CDKL5 Forward event shirts and other CDKL5 designs in our [Bonfire store!](#) Order yours today!

Keep checking our Move CDKL5 Forward Campaign (<https://move-cdkl5-forward.raiselysite.com/>) to see the fundraising and mileage leaderboards!

EVENT PRIZES!

- Top 5 Individual Fundraisers!
- Top 5 Individual Mileage Movers!
- Top 5 Team Fundraisers!
- Top 5 Team Mileage Movers!

Sample Donor Letter

Dear _____,

I'm writing to share with you the story of my **son/daughter** _____ and to ask for your support to improve **his/her** life. **Share a short 1-3 sentences about your child and their life with CDKL5.**

CDKL5 Deficiency Disorder is considered a rare disease. One of the challenges of being "rare" is that the burden of fundraising for needed research is often left to the families affected.

Our CDKL5 community is fortunate to have a foundation that is leading the way towards a cure for this disease. The [International Foundation for CDKL5 Research \(IFCR\)](#) was started in 2009 by a group of passionate and dedicated parents who dreamt of a healthier future for their children. Their mission is to treat and cure CDKL5 Deficiency Disorder by funding scientific research, while helping affected individuals and their families to thrive.

The IFCR's work means the world to our family and gives us hope for _____'s future. Will you help us Move CDKL5 Forward by making a tax-deductible donation? Our family's fundraising link is _____.

Thank you for learning about my child. If you would like to hear more, I'd love to speak with you. I can be reached at **000-000-0000**.

With gratitude,

Your Name Here
City, State

thank you!

**From all of us at the IFCR,
thank you for helping us Move
CDKL5 Forward towards a
healthier future! We can't do
our work without YOU!**

