



Rare Disease Day Media Toolkit

On Rare Disease Day, the IFCR wants to help raise awareness of CDKL5 Deficiency Disorder. If you would like to share your CDKL5 story with your local media, this info packet will help guide you. It contains:

- TIPS: How to Reach out to the Media
- Email Template
- Follow-up Template

Rare Disease Day is February 28, which means you would need to **reach out to your local media in January**. This gives editors and reporters enough time to connect with you and put together a story.

The IFCR is here to help – you can reach us at info@cdkl5.com if you have any questions about sharing your story.



TIPS: How to Reach out to the Media

- **Contact the right person.** Whether for newspaper, television, or radio station, you will need to contact an editor or reporter. Typically, this will be the reporter in charge of Health, Lifestyle or Features. Their contact information is usually on the website or you can call the main number and ask.
- **Email a pitch.** Use the email template we have created for you and email it to your contact.
- **Follow up.** Wait a week and send a follow-up email if you have not yet heard back. Do not follow-up more than once; reporters and editors have a lot of stories and may not be able to use this one. That's okay; we want to maintain a cordial relationship in case they are interested in covering our story in the future.
- **Be available to talk.** Reporters and editors work on very tight deadlines. When they reach out, make sure you are available to talk or get back in touch with them as soon as possible.



Email Template

Subject line: PITCH: Local Family Knows Why Rare Disease Day Matters

Dear **(name of reporter/editor)**,

Would you be interested in a story about Rare Disease Day and a local family affected by a rare genetic disorder? Rare Disease Day is February 28th.

I live in **(name of town)** and my **(daughter/son)** has CDKL5 Deficiency Disorder. This is a rare genetic condition caused by mutations in the CDKL5 gene, which provides instructions for making a protein essential for normal brain and neuron development. Most children affected by CDKL5 deficiency suffer from seizures that begin during infancy and continue throughout their entire lives; most also experience severe physical and developmental delays.

For Rare Disease Day, I am hoping to share my family's story so we can raise awareness of CDKL5 Deficiency Disorder and the struggle of all who live with rare diseases.

If that story would be of interest, please contact me at **(phone/email)**. Sometimes my child needs my attention so I cannot pick up, but I will always get back to you quickly.

Sincerely,

(Your name)

(Your preferred phone number and email address)



Follow-Up Email Template

Subject line: Follow up on local Rare Disease Day story

Dear **(name of reporter/editor)**,

I wanted to follow up with you to see if there was any interest in the story I proposed for Rare Disease Day.

If there is, please let me know when it would be a convenient time for us to talk.

Sincerely,

(Your name)

(Your preferred phone number and email address)