CDKL5 UK
Empowering Families
Embracing Hope

Volunteer Policy – CDKL5 Research Champions

At CDKL5 UK, we embrace individuals from all backgrounds and all walks of life. We particularly welcome CDKL5 Research Champions who have lived experience of CDKL5 Deficiency Disorder (CDD) and its associated co-morbidities, including epilepsy, neurodevelopmental delay, gastrointestinal issues, mental health challenges, and the impact on both personal and family life. We are an inclusive organization, open to people of all ages, genders, races, and ethnicities.

This policy outlines our approach to working with CDKL5 Research Champions, detailing what you can expect from us at CDKL5 UK, and what we ask of you if you choose to get involved.

Promotion

Ways in which we make people aware of CDKL5 Research Champions and involvement opportunities include:

- CDKL5 UK website and partner websites
- CDKL5 e-newsletter and partner e-newsletters (to those who have opted-in)
- Direct e-mails to those who have opted-in
- CDKL5 Research Champion mailing list (to those who have opted-in)
- Partner networks and mailing lists (to those who have opted-in)
- Social media – Facebook and LinkedIn
- CDKL5 Centre of Excellence (at routine appointments or via e-mail)

For some groups, we may provide information in a different way, such as in an additional language or to make information accessible to people who have disabilities.

Recruitment

You can sign up to become a CDKL5 Research Champion here: CDKL5 Research Champions - CDKL5 UK.

We ask for basic details, like your name, email and phone number, and how you would like us to contact you in the future.

Once you have signed up, you will receive a confirmation email. You will then receive another email within 3-5 working days, which will contain some more information about what it means to be a CDKL5 Research Champion.

It is important that we can tailor research involvement opportunities to you, and the type of experience you have with CDD – for example, if you are a parent you will have different experiences than that of a sibling.

At this point, you will be asked to complete a short form which will capture some more in-depth information about you (so that we can find out more about you, to tailor each opportunity to each member of the network).

Once you have completed this form and your contact preferences, you will be contacted as and when relevant involvement opportunities arise.

You can read more about how we use your data, and how we store it, in our Data Protection Policy here.

What you can expect from us

As a platform for sourcing and promoting involvement opportunities relevant to the CDKL5 community, you can rely on CDKL5 UK to provide you with:

1. **Clear Role and Expectations**
   CDKL5 Research Champions can expect to receive clear instructions and information about their role, including what tasks they will be responsible for, how to perform them, and any necessary training. This ensures CDKL5 Research Champions feel confident and supported in their work.
2. **Training and Support**
   In most cases, involvement opportunities are looking for your honest opinions, experiences and feedback as a person who has lived experience of CDKL5 Deficiency Disorder (CDD) and/or it's many co-morbidities, such as epilepsy and effects of the condition family life and mental health. In most cases, you are already the expert, and you will not need any formal training. However, we aim to provide CDKL5 Research Champions with regular support via e-mail, any relevant training where necessary, information and resources, ongoing guidance and support and access to people who can answer any questions or concerns.
3. **A Positive and Inclusive Environment**
   CDKL5 UK is committed to creating a welcoming, respectful, and inclusive space for all CDKL5 Research Champions. You can expect to work in an environment where your contributions are valued and where you feel part of a team that shares common goals.
4. **Recognition and Appreciation**
   We recognize the time and effort that CDKL5 Research Champions contribute to our cause. CDKL5 Research Champions will be appreciated and acknowledged through regular thank-yous, events, and recognition initiatives. Your hard work does not go unnoticed!
5. **Meaningful Impact**
   CDKL5 Research Champions can expect to see the tangible difference they are making in the lives of those we serve. No matter the opportunity, your involvement will have a positive and lasting impact.

6. **Opportunities for Growth**
   We encourage CDKL5 Research Champions to develop their skills and experience through their roles. CDKL5 Research Champions may have opportunities to take on new responsibilities, expand their network, and even participate in leadership or development programs.
7. **Clear Communication**
   We prioritize transparent and open communication with our CDKL5 Research Champions. You'll receive updates on charity initiatives, events, and opportunities to get involved. If there are changes to schedules or activities, we'll keep you informed.
8. **A Safe Environment**
   CDKL5 UK ensures a safe environment for all CDKL5 Research Champions. We adhere to best practice, safety guidelines and provide the necessary tools and equipment to perform tasks safely. CDKL5 Research Champions will be supported by our team to ensure well-being during their time with us.
9. **Team Spirit and Social Connections**
   Being a CDKL5 Research Champion is about building connections, both with the people you're helping and fellow Champions. You can expect to be part of a supportive and social community where teamwork and collaboration thrive.
10. **Flexible Volunteering Opportunities**
    We understand that CDKL5 Research Champions have busy lives, so we strive to offer flexible hours and various ways to get involved, whether it's through one-time events or ongoing roles. This way, you can take part in a way that fits your schedule and lifestyle. You can decide which involvement opportunities to take part in, there is never any obligation. If you do not want to, or cannot take part in an opportunity that is shared with you, you can decline. This will not affect future involvement opportunities.
11. **Confidentiality and Respect**
    CDKL5 Research Champions can expect their personal information and any sensitive data related to their role to be kept private. We also ensure that CDKL5 Research Champions are treated with respect and are provided with a space to voice any concerns or feedback they may have.

What is expected of you as a CDKL5 Research Champion

As a CDKL5 Research Champion for CDKL5 UK, we rely on your commitment, enthusiasm, and dedication to help further our mission. Being a CDKL5 Research Champion is a voluntary role. Here's an outline of what's expected from you as a CDKL5 Research Champion:

1. **Commitment to the Cause**
   CDKL5 Research Champions are volunteers and are expected to have a genuine interest in and passion for the cause we support. Your involvement helps us deliver on our mission, and we encourage volunteers to take ownership of their roles.

2. **Punctuality and Reliability**
   Time is valuable for everyone, so it is essential that CDKL5 Research Champions arrive on time and are consistent with their availability. If you are unable to make it to a scheduled opportunity, please let us know as soon as possible, so that we can offer the opportunity to another Champion.

3. **Respect and Professionalism**
   Treat all team members, fellow volunteers, researchers, doctors, beneficiaries, charity representatives, and fellow community members with respect and kindness. CDKL5 Research Champions represent CDKL5 UK, and it's important to maintain a positive and professional demeanour at all times.

4. **Adherence to Policies and Guidelines**
   CDKL5 Research Champions are required to follow the charity's guidelines, and any specific instructions related to their tasks. This ensures a smooth and effective operation while ensuring the safety of everyone involved.

5. **Collaboration and Teamwork**
   Being a CDKL5 Research Champion is a team effort. CDKL5 Research Champions should be open to collaborating with others, sharing ideas, and working together to achieve common goals. Team spirit is essential to making a meaningful impact.

6. **Confidentiality and Privacy**
   CDKL5 Research Champions may come into contact with sensitive information about research project, clinical trials or research results. It is expected that all CDKL5 Research Champions respect the privacy and confidentiality of any information they encounter during their role.

7. **Positive Attitude**
   We ask our CDKL5 Research Champions to approach their tasks with a positive attitude and a willingness to help. Whether you're reviewing a lay summary, taking part in a focus group or attending a workshop or event, your enthusiasm can make a big difference in the experience of those you serve.

8. **Flexibility and Adaptability**
   In a research environment, things can change quickly. CDKL5 Research Champsions are expected to remain flexible and adapt to any changes or challenges that arise during their involvement opportunity. If you are unsure about anything, you can get in touch with a member of the CDKL5 UK team.

9. **Feedback and Communication**
   We encourage CDKL5 Research Champions to share their experiences and feedback, helping us to improve our programs and services. Open communication with us is essential to ensuring everyone is supported and motivated. On occasion, we may send you a feedback form so that you can tell us how you felt about a particular opportunity.

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Using your lived experience

As a CDKL5 Research Champion, you will use your lived experiences to help researchers. You do not need any formal qualifications, or training, you only need your personal experience of what it's like to be affected by CDKL5 Deficiency Disorder (CDD). This may include your experiences as a person who is diagnosed with CDD, or as a parent who cares for a child or young adult with CDD, or as a sibling, whose brother or sister has a diagnosis of CDD.

You may be asked to share experiences of what it's like to live with CDD, or what it's like to live with and care for someone who has the condition. You may be asked to share your experiences of attending appointments, your diagnosis, and/or any challenges you have faced throughout your CDD journey.

Your personal experiences and opinions are incredibly valuable, and by sharing them you can help researchers to make their projects more relevant to people with CDD, so their research has more impact to the day to day lives of the CDKL5 community.

Frequency of involvement

You can be involved in as many research involvement opportunities as you like, there is no limit. Equally, if you do not wish to be involved in a certain opportunity when you are approached by the CDKL5 team, you can decline the offer to be involved without giving a reason. Declining an involvement opportunity in this way will not have any effect on whether or not you can take part in other opportunities in the future.

Reimbursement

Being a CDKL5 Research Champion is a voluntary role. However, some researchers will want to reimburse you for the time you take to be involved, in line with the National Institute for Health and Care Research (NIHR) guidelines. This is often in the form of a voucher (Amazon or similar) up to the value of £25 per hour for attending a focus group, or £12.50 for reviewing a lay summary or similar document. However, not all opportunities will include reimbursement. This is because some opportunities may be pre-application, which means that researchers are in the process of applying for funding, so they do not have access to funds for reimbursement yet. Sometimes you may be reimbursed if a funding application has been successful. Sometimes the opportunity is on a voluntary basis only. Details of any reimbursement available will be included with each opportunity advertisement sent to you by the CDKL5 UK team.

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If you have any questions or concerns please email admin@curecdkl5.org

Version Control - Approval and Review

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