

Volunteer With Us

We are always looking for committed volunteers who will bring creative ideas to our efforts. Volunteers must have the time and energy to take action with the Board Lead and team. We will be depending on your follow-through. Committees tend to meet monthly. There may be tasks outside of meeting times. **We are always looking for skills that may help our cause.** If you have the time to share your skills with us, please reach out. We are looking for videography skills. We are also looking for families willing to share their CDKL5 story.

Volunteer Title	Description	Helpful (but not required) Skills	Board Lead
Family Support Program Committee Member	Help the IFCR support CDKL5 families to thrive with this diagnosis.	Informed, Active in Community	Paul Miller (pmiller@cdkl5.com)
Fundraising Committee Member	Work to increase donations to the IFCR. Help the IFCR to recognize and thank our donors.	Enthusiastic, Data Mining, Marketing, Public Speaking, Connected	Marissa Bishop (mbishop@cdkl5.com)
Awareness Committee Member	Share ideas and take action to help the IFCR spread awareness about CDKL5 and our organization.	Creative, Social Media, Marketing, Public Speaking	Marissa Bishop (mbishop@cdkl5.com)
Family Support Representative (FSR)*	Provide 1:1 support to CDKL5 families as needed. Host virtual support group Zoom sessions.	Empathetic, Good Listener, Available	Paul Miller (pmiller@cdkl5.com) Kristin Kozera (kkozera@cdkl5.com)
Conference Planning Committee Member	Help the IFCR to plan and execute our biennial CDKL5 Family Conference or other in-person events.	Detail Oriented, Dependable	TBD

*this is a trained position