

Parent/Caregiver Ambassador Program

Mission

The vision of the Children's Cardiomyopathy Foundation (CCF) is to create a future of hope in which cardiomyopathy is detected earlier, more lives are saved, and all children with the disease can live full and active lives. CCF's mission is to accelerate the search for causes and cures for pediatric cardiomyopathy through increased **research**, **education**, **awareness**, **advocacy**, and **support** to affected children and their families.

Ambassador Program

The Children's Cardiomyopathy Foundation (CCF) is seeking parents and caregivers of children (living or deceased) with cardiomyopathy to participate in a leadership program as a CCF Ambassador. CCF Ambassadors take an active role in expanding CCF's reach and impact in their community.

Ambassadors will participate in a range of projects, such as offering informational and emotional support to diagnosed families, conducting outreach and community engagement activities, guiding CCF's family fundraising strategy, and providing CCF with "on-the-ground" feedback to ensure the needs of the CCF patient community are being met.

Ambassador Responsibilities

Ambassadors have a range of responsibilities and may work on one or more of the projects below with other Ambassadors. CCF will help to identify priority areas, facilitate discussions, and oversee project milestones. Ambassadors may work on:

- Providing individual support to registered CCF parents/caregivers through peer-to-peer connection, and sharing CCF's educational materials and resources
- Participating in the <u>CCF Connect</u> online community
- Providing feedback on CCF's patient support programs and outreach initiatives
- Evaluating patient education materials and implementation of patient programs
- Identifying needs for new patient educational materials, and assisting with the development and evaluation of said materials
- Raising awareness during American Heart Month and Children's Cardiomyopathy
 Awareness Month through social media, awareness activities, and advocacy efforts
- Supporting CCF's advocacy efforts on cardiomyopathy-related legislation
- Hosting a fundraiser or walk to support CCF and its mission
- Support CCF's outreach and marketing programs such as Heart Kids and providing a Great Nonprofit rating

Time Commitment

- One-year commitment with option to renew term
- Participate in a one-hour orientation and training session, with follow-up sessions specific to ambassador assignments
- Maintain consistent communication with CCF and participate in monthly check-ins with CCF's Director of Family & Physician Relations
- Attend quarterly Ambassador planning meetings
- Complete various duties/responsibilities in between meetings such as completion of surveys to help determine CCF's priority needs, and participation in focus groups to provide feedback on various topics

*The estimated monthly time estimate for ambassadors is generally 3-4 hours per month. This can fluctuate depending on current projects and time of year. We understand that your circumstances may change during the duration of your term as Ambassador, and will be happy to work with you if you are unable to meet these commitments during your term.

Qualifications

- An interest in pediatric cardiomyopathy and experience managing the care of a child (age 18 and under) with cardiomyopathy
- Registered with CCF
- Willingness to serve and help other cardiomyopathy families
- Familiarity with CCF's resources and programming
- Child should be receiving care at a recognized <u>CCF Cardiomyopathy Center of Care</u> hospital
- Strong interpersonal, organizational, and communication skills (oral/written)
- Basic computer skills including use of email and Zoom/Google platforms
- At least 21 years of age
- No criminal history

Application Process

- If you are interested in this meaningful opportunity, please complete the CCF Ambassador Interest Form by May 31, 2025.
- Upon submitting a completed interest form, candidates will be invited to meet virtually with CCF.
- Please contact Leah Mumm, Director of Family & Physician Relations, at <u>Imumm@childrenscardiomyopathy.org</u> if you have questions or would like additional information.

*If you are interested in becoming more involved with CCF, but looking for a volunteer position that is more flexible or episodic in nature, there is something for everyone! Please contact <u>us</u> to learn more.