



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 who have a child diagnosed with cardiomyopathy to take on a leadership advisory role as a CCF Ambassador. CCF Ambassadors take a leadership role in expanding CCF's reach and impact in their community.

Ambassadors will offer informational and emotional support to diagnosed families and provide CCF with "on-the-ground" feedback to ensure that their needs are being met. A CCF Ambassador can be an advocate for families affected by cardiomyopathy and an important voice in their community and beyond.

Ambassador Responsibilities

Ambassadors will have a range of responsibilities during the year and may work on any of the below. CCF will work closely with Ambassadors to identify priority areas, facilitate discussions, and oversee project milestones.

- Provide feedback on CCF's patient support and outreach initiatives
- Evaluate patient education materials and implementation of patient programs
- Raise awareness of pediatric cardiomyopathy during National Heart Month and Children's Cardiomyopathy Awareness Month through social media, awareness activities, and advocacy efforts
- Provide follow-up support to newly registered CCF parents/caregivers, including information on CCF's Cardiomyopathy Centers of Care
- Support CCF's advocacy efforts on cardiomyopathy-related legislation
- Assist in medical outreach, which includes strengthening relationships with Cardiomyopathy Centers of Care, representing CCF at local medical/health conferences, and reaching out to local pediatricians and pediatric cardiologists.

Continued

Time Commitment

- Participate in a 2-hour orientation and training session
- Two-year commitment with option to renew term
- Maintain communication with CCF and participate in monthly check-ins with CCF Manager
- Attend quarterly planning meetings
- Participate in surveys of patients, parents, and caregivers to determine priority needs and initiatives

Qualifications

- Interest in pediatric cardiomyopathy and experience managing the care of a child (age 18 and under) with cardiomyopathy
- Child should be receiving care at a CCF Cardiomyopathy Center of Care hospital
- Willingness to serve and help other cardiomyopathy parents
- Strong interpersonal, organizational, and communication skills (oral/written)
- Basic computer skills including use of email
- Minimum age of 21 years of age
- No criminal history
- Personal interview with CCF staff
- Reference checks must be provided

Application Process

- Contact Jasmin Patel, Director of Family Outreach & Support
jpatel@childrenscardiomyopathy.org
- Submit application and include reasons for being an Ambassador
- If selected, interview with CCF staff and do reference check