CF Family Partner

Department

Pulmonary Medicine, Cystic Fibrosis Care Center

Supervisor

The Division Chief is the supervisor, with collaboration from the Director of Health Outcomes and Quality of Care Research, and direct oversight by the Pediatric Nurse Practitioner/QI.

Purpose of the Family Partner position

The purpose of a family partner is to increase our capacity to improve outcomes, value, and experience of patients with CF and their families at CCHMC. The Family Partner will increase our capacity to improve by:

- 1. Collaborating in designing and testing innovations to improve care and outcomes,
- 2. Communicating with the patient/family community to ensure that this perspective is appreciated and incorporated into improvement efforts
- 3. Facilitating outreach and education to patients/families to increase involvement in improvement and care.

Education/Work Experience:

- Bachelor's degree or higher
- Direct experience with a child with Cystic Fibrosis
- Experience with social media and community building
- Experience with innovation and quality improvement

Responsibilities:

Collaborating in designing, testing innovations

- Develop and identify innovative solutions to better meet the needs of all families
- Work with others to test innovations/interventions
- Collaborate on the design of communications campaigns and interventions
- Serve as a collaborator on selected CF Center improvement initiatives

Ensuring appreciation of family/patient perspective

- Provide feedback on clinical improvement work to ensure the patient perspective is an equal part in all healthcare discussions
- Build and maintain a strong social media presence in order to serve as a trusted voice for patients/families with CF
- Interface with internal and external stakeholders, both virtually and face-to-face, to ensure a representative perspective of the patient/caregiver community
- Co-lead/facilitate CF Center patient/family advisory group sessions for feedback and collaboration, as needed.
- Provide education and training to staff that relate to system care impact on families.

Increasing family/patient in improvement and care

- Engage patients and caregivers as partners in managing their health outcomes
- Develop and lead social media engagement strategies and communication campaigns
- Identify, recruit, and organize additional patients and parents to support these efforts

Outcome Data

- Develop and maintain tracking mechanism for family involvement in care center improvement initiatives; collect data and develop reports
- Strengthen communication and collaboration among patients, families, caregivers and staff
- Promote Patient & Family advocacy and involvement through communication campaigns



Develop a formal PFAC for the CCHMC Pulmonary Department

Qualifications

Skills and Competencies:

Facilitation: Effective team facilitation skills

Diversity appreciation: Understanding and showing respect and appreciation for the uniqueness of all individuals, leveraging differences in others' perspectives and ideas; appreciating cultural differences and adjusting one's approach to successfully integrate with others who are different than onself.

Relationship Management: Setting the stage for constructive relationships by being accessible, approachable, and interpersonally engaged; developing and sustaining meaningful and productive working relationships with others based on mutual respect.

Independence: Pursuing work with little supervision or assistance; directing one's own efforts.

Organization: Possess strong organization skills and attention to sound judgment, diplomacy, tact, and professional demeanor.

Analysis: Basic ability to analyze data to make judgments and recommendations.

Communication: Advanced/Excellent verbal, written, and interpersonal skills.

Cystic Fibrosis: Advanced knowledge of patient/family issues in cystic fibrosis.

