



CF Family Advisory Council

ATLANTA, GEORGIA

Our History

In 2006, the Emory-Children's Healthcare of Atlanta pediatric cystic fibrosis clinics began taking steps to promote further parental involvement at the care centers. A brainstorming meeting was held seeking caregiver input on how clinic teams could best care for their CF patients. The initial meeting was constructive and staff members were open to listening to ideas presented by parents and family members. There was so much positive energy and excitement surrounding this conversation; the natural next step was to form the CF Family Advisory Council. All the ideas generated during the brainstorming session were recorded, and an idea bank was created.

In November 2007, the CF Family Advisory held its first official meeting. The meeting included parents from both pediatric CF clinics and the social workers serving as liaisons between the council and the CF care team. The council started working by prioritizing goals and projects taken from the idea bank.

Our Purpose

The Cystic Fibrosis Family Advisory Council works in cooperation with the staff to advocate the practice of family-centered care, and to offer educational opportunities and materials to CF patients and their families.

How We Work

The council meets the first Monday of each month from 6:30 p.m. to 8:30 p.m. We rotate our meetings between the two different pediatric hospital campuses. Members of the family advisory council represent caregivers from both pediatric clinics. At any given time there is a maximum of ten parents and two staff liaisons.

Our council is a working group. We discuss and work on projects during the meetings and occasionally additional work is required outside of the meetings.

Points Of Pride

- Hospital Guide
- Quarterly Sticky Notes Newsletter
- "This Eating is Hard Work" Cookbook
- CF Clinic Care Plan
- Established Social Media Presence
- Educational Events and Handouts
 - Respiratory Care Night
 - Nutrition Night
 - Caring for the Caregivers

Anyone interested in becoming involved with the CF Family Advisory Council should discuss opportunities with their clinic social worker.