

Committees

Membership Committee

Membership & Support Group

Contact: Leslie Gill

julian10251@msn.com

Technology Committee

Contact: Jennifer Jeffery

jenljeffery@gmail.com

Advocacy Committee

Contact: Kerry Doyle-Shannon

kdsandbls@verizon.net

Quality of Care Committee

Infection control Issues

Targeting goals for improving CF care

Contact: Bethann Deveney

pencf@aol.com



We would love to have you join our efforts on the Council generally or on a particular project that is important to you. Even if you are unable to work with us at this moment in time, we would love to hear from you about issues that you would like addressed.

A.I. duPont Hospital for Children
Cystic Fibrosis Family Advisory Council
Cystic Fibrosis Clinic
1600 Rockland Road



“Families working together to make a difference in the quality of care at our Cystic Fibrosis Care Center”



Contact us at kyork@nemours.org

Mission Statement

It is our goal to improve the quality of clinical and psychological care of patients with Cystic Fibrosis treated at A.I. duPont Hospital for Children.

The Cystic Fibrosis Family Advisory Council began in September 2008. A group of parents and our CF Care Team social worker, Kim York, came together to plan how to improve the care and lives of our children with CF. We made plans to work on a variety of issues affecting out-patient care, in-patient care, and insurance issues.

We are a motivated, energetic and optimistic group of parents with children ranging in age from young children to teens as well as a representative from the Hospital's CF Care Team. We are the first group of families to work with the hospital around a common disease or condition.



Our Accomplishments

Created an online forum (listserv) for families to help each other with common questions that arise while living with CF.

Gained a seat for a representative on the Hospital's Family Advisory Council so that we can work on issues that affect both families with CF and other families as well.

Organized committees that work on issues such as Advocacy, Technology, Membership, and Quality of Care,

Brought concerns regarding infection control protocol, scheduling, staffing, helping families of newly diagnosed children, and more to the attention of our CF Care Team so that we could work together to improve the care of our children.

Participated in creation and revision of written materials for families on matters including pulmonary function tests, spirometry, and information for newly diagnosed families.

Worked with Nemours staff to establish the taking of vitals and blood work in the exam room to improve infection control and improve the experience of patients and caregivers at the hospital.

Held a Staff Appreciation Luncheon for our CF Care Team that allowed families to express their thanks to the team for the family centered care and their personal attention.

Organize regular roundtable events where experts speak with caregivers regarding issues that matter to families, which include research, nutrition, respiratory care, and psychological/social issues.

Additionally, we work with the Cystic Fibrosis Foundation on issues that are of concern to both of us.



Application

Name _____

Phone Number _____

e-mail _____

Best time to reach you _____

How are you connected to CF?

CF parent Grandparent

Other _____

What Committee are you interested in?

Please write a little about yourself and what you would hope to accomplish on the Council.

All Applications should be turned in to Kim York in the CF Clinic.