Parent/Care Team Partnership: The CF Parent Advisory Council at LPCH

Kirsten McGowan and Amy Baugh
Lead Parents
Cystic Fibrosis Parent Advisory Council
What is our Mission?

• We are a group of parents whose children receive care from the Stanford CF Center. The CF PAC works in partnership with pediatric CF clinic care team to provide highest quality of care and service to patients and families.
Who Are We?

Parents:
Amy Baugh
Linda Burks, MS, EdD
Marianela Gonzales
Kirsten McGowan
Sandy Schumacher

CF Team:
Zoe Davies, NP
Colleen Dunn, RRT
Mary Helmers, RN
Cathy Hernandez
Carlos Milla, MD
Kristin Shelton, RRT
Sruthi Veeravalli, MSW
Family Centered Care

The CF Parent Advisory Council is part of the **FCC Department** at LPCH.

Patients, family members and health care providers work together in **partnerships** to create the best quality health care in:

- **Policy Creation**
- **Program Development**
- **Clinical Care**
- **Quality Improvement**
It’s Not Easy

- Pulmonology
- ENT
- Endocrine
- Respiratory Therapy/PFTs
- Transplant
- GI/Nutrition
- Other Rehab (PT, OT)
- School
- Extracurricular Activities
- Social Life
What Do We Do?

We have been in practice since 2003

- Develop **support materials**: *Transition guides, G-tube information, etc.*
- Enhance **communication** between Care Team and families: *CF binder project*
- Assist in **translation** of educational materials for our Spanish-speaking families.
- Serve as a **voice** for families receiving care at LPCH.
Other Duties/Projects

- Updates/participation in the CF Newsletter.
- Feedback for the website: [http://cfcenter.stanford.edu](http://cfcenter.stanford.edu)
- Promote CF Center’s Facebook page - more interactive information sharing
- Collaborate with CFRI to promote support/educational programs
- Sit on hospital-wide councils and FCC-driven workgroups to develop programs that have direct impact on CF patients and families.
- Strengthen collaboration with Adult Advisory Council to address transition issues for teens/young adults.
What Are We Working On Now?

- Mary working on educating ALL hospital groups about CF Infection Control guides (including **CF Passports** – a tool for families).
- Exploring support services for families with G-tube information
- Continued development of the “Binder Project”.
- Partnership with Diabetes PAC to enhance care for our CFRD patients
- Exploring support services for newly diagnosed families and other types of transition (newborn to peds; starting school; off to college, etc.)
- Developed Adult Transition Guide
- Advocate for Parent Mentoring
The Power of Participation

- Increase guest participation
- Expand family input
- Help address the unmet needs of families.

Questions? Email Kirsten: kmcgowan@stanfordchildrens.org
Thank You!