Participation & Partnership: The CF Parent Advisory Council at LPCH

Siri Vaeth, MSW
Lead Parent
Cystic Fibrosis Parent Advisory Council
Who Are We?

- We are a group of concerned parents whose children receive care from the Stanford CF Center. We work in partnership with members of the pediatric CF clinic care team to support the provision of the highest quality of care and service to patients and families.
Who Are We Specifically?

Parents:
Amy Baugh
Linda Burks, Ph.D.
Sandy Schumacher
Siri Vaeth, MSW

CF Team:
Zoe Davies, NP
Colleen Dunn, RRT
Cassie Everson, RRT
Elizabeth Foley, MD
Mary Helmers, RN
Cathy Hernandez
Carlos Milla, MD
Kristin Shelton, RRT
Sruthi Veeravalli, MSW
Just to be clear, men are welcome too.
The CF Parent Advisory Council is part of the Department of Family Centered Care at LPCH.

**Family Members Are a Central Part of Our Health Care Team**

Lucile Packard Children’s Hospital provides a unique approach to medical care called “family-centered care.” At the heart of family-centered care is the belief that when families work in partnership with their health care team, the child receives the best possible care.

Members of the CF Advisory Council go through a detailed orientation and training process in order to participate, and may serve on the hospital-wide Family Advisory Council.
Life with CF is an ongoing balancing act.
What Do We Do?

Since its inception, the group has spearheaded many projects which include:

- Developing support materials: *Supporting Loved Ones: A Guide for Family and Friends; What To Expect During Your Admission to LPCH.*
- Working with CF Care Team to create Infection Control Brochure.
- Advocating for “CF College 101” Workshop.
- Inspiring the organizational component of the “Binder Project.”
Other Projects

- Provision of social support events for parents of newly diagnosed children;
- Mentoring other parents;
- Presentation of a class for parents of newly diagnosed children;
- Sharing of parental input during CFF site visit.
- Assistance with website updates to address issues/unmet needs of teens.
- Working in partnership with Care Team to create the Transition Guide for teens;
What Are We Working On Now?

- Monitoring the website for content, seeking strategies with Care Team to direct people to the site for information and surveys: http://cfcenter.stanford.edu/

- Encouraging people to visit the Center’s Facebook page - a vehicle for more interactive information sharing.

- Addressing unmet needs of the Center’s Spanish-Speaking patients and families;

- Exploring support services for newly diagnosed families;
Other Council Activities

• Share strategies to increase participation in clinical trials;
• Serve as resource to other LPCH departments for input on hospital-wide policies that have direct impact on CF patients and families.
• Advise Sruthi on social support programs for families;
• Seek solutions for improved care and communication between service lines.
• Advocate for Peer Mentoring;
• Strengthen communication with Adult Advisory Council so as to share knowledge address transition issues for teens/young adults.
The Power of Parental Participation

• We want to increase participation & expand family input to the CF Center! We are seeking creative ways to do this.

• Issue-driven participation? Skype? Give us your feedback so that we can address unmet needs of families.

• Questions? Email Siri: svaeth@lpch.org
Thank you!

KEEP CALM AND CURE CF