CF Parent Advisory Council
Who?

- We are a group of concerned parents whose children receive care from the Stanford CF Center who work in partnership with members of the pediatric CF Clinic Care Team to provide the highest quality of care and service to patients and families.
Who Specifically?

Parents:
Linda Burks
Sandy Schumacher
Siri Vaeth

CF Team:
Carlos Milla, MD
Mary Helmers, RN
Colleen Dunn, RRT
Kristin Shelton, RRT
Zoe Davies, NP
The FCC Model

The CF Parent Advisory Council is part of the Department of Family Centered Care at LPCH. From the LPCH website:

**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 Council go through a detailed intake and training process in order to participate, and can serve on the hospital-wide Family Advisory Council.
What Do We Do?

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

- Providing input for the Transition Guide for teens;
- Mentoring other parents;
- Developing support materials: *Supporting Loved Ones: A Guide for Family and Friends,*
Infection Control Brochure

The Advisory Council worked with the CF Care Team to develop the Infection Control Brochure. Parents and members of the Care Team brought their concerns and prospective solutions to the table.
Other Past Projects

- Provision of social support events for parents of newly diagnosed children;
- Presentation of a class for parents of newly diagnosed children;
- Provision of input for Family Survey;
- Review of CF Center Website content and provision of input for updated site;
- Sharing of parental input during CFF site visit.
What Are We Working On Now?

- Monitor the website for content, and work with Care Team to direct people to the site for information and surveys [http://cfcenter.stanford.edu/];
- Address issues/unmet needs of teens;
- Address unmet needs of the Center’s Spanish-Speaking patients and families;
- Develop support services for newly diagnosed families;
What We Are Working On Now (cont.)

- Share strategies to increase participation in clinical trials;
- Work with Adult Advisory Council to share knowledge and to address transition issues for teens/young adults;
- Advise Lindsey on social support programs for families;
- Develop Peer Mentoring;
- Increase participation & expand family input to the CF Center.
The Power of Parental Participation

- We need to hear from parents!
- Please explore the website and take the surveys (http://cfcenter.stanford.edu/).
- We are seeking to expand participation, and seeking creative ways to facilitate this.
- Questions? Email Siri: svaeth@lpch.org
Thank you!
Adult CF Advisory Council
ACFAC

Kriss Benson, Chair
We Want to Hear Your Voice

Our Mission
The Stanford Adult CF Advisory Council provides feedback to and partners with members of the healthcare team to improve the patient and family experiences and care at Stanford University Hospital. The Advisory Council is committed to the betterment and excellence of the entire Cystic Fibrosis Center at Stanford including pediatric, transitional, and adult care at Lucile Packard Children’s and Stanford University Hospitals.

Advisory Council visitors are welcome!
The Advisory Council meets the third Wednesday of each month from 5:00 to 7:00 P.M. in the Blake Wilbur conference room. Please feel free to join us.

If you have specific concerns or information you would like to share with the council members either in person or via video-conferencing (WebEx), please request to do so at least one week prior to a council meeting. This will allow us to set aside time in the meeting agenda. Also, please remember that all communication with the council must be conducted in a respectful manner.

If you would like to attend our meeting via WebEx conferencing, please contact Rocio Flores by email at RFlowers@stanfordmed.org at least 24 hours prior to our meeting time. She will let you know how you can participate remotely.

Please note: Attendees must respect the CF Centers at Stanford cross-infection guidelines. Please do not attend if you have an active viral infection or any other contagious condition. If you have CF, keep three feet between yourself and others who have CF. Avoid shaking hands with others. Additionally, individuals with CF who have ever had a confirmed positive sputum culture for Staphylococcus epidermidis (MRSA) or who have cultured Methicillin-resistant Staphylococcus aureus (MRSA) within the past two years, or who are currently culturing a bacteria resistant to all antibiotics (pae resistant) may not attend our sessions in person due to the cross-infection risks to others with CF.

Learn More About Us
For more information visit our section of the Stanford CF center website here: http://cf-center.stanford.edu
Contact us by phone at (650) 349-3102, or by email at stanfordCFAC@gmail.com
Applications to be an Advisory Council Member are available online, in clinic, or by contacting the council.

To give feedback to the Adult CFAC, you can email us at stanfordCFAC@gmail.com with the following information:
I received this form as a: □ inpatient □ outpatient
Name (optional): □
You can contact me by (optional): (cell phone, email, home address):
I would like the Stanford Cystic Fibrosis Advisory Council to know (feel free to continue on back side):
Cystic Fibrosis (CF) is one of the most common genetic (inherited) diseases in America. It is also one of the most serious. It mainly affects the lungs and the digestive systems in the body, causing breathing problems and problems digesting foods. It is a chronic disease that currently has no cure.

The CF Center at Stanford is an integrated disease management program that follows patients from diagnosis through adulthood.

With the current longer life expectancy for patients with Cystic Fibrosis, our clinic population includes patients of all ages. More than half the patients followed by the Stanford CF Center are adults aged 19 years or older.
Adult CFAC

About the Council

Mission statement:
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How to Contact the Stanford Adult CF Advisory Council
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