

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.

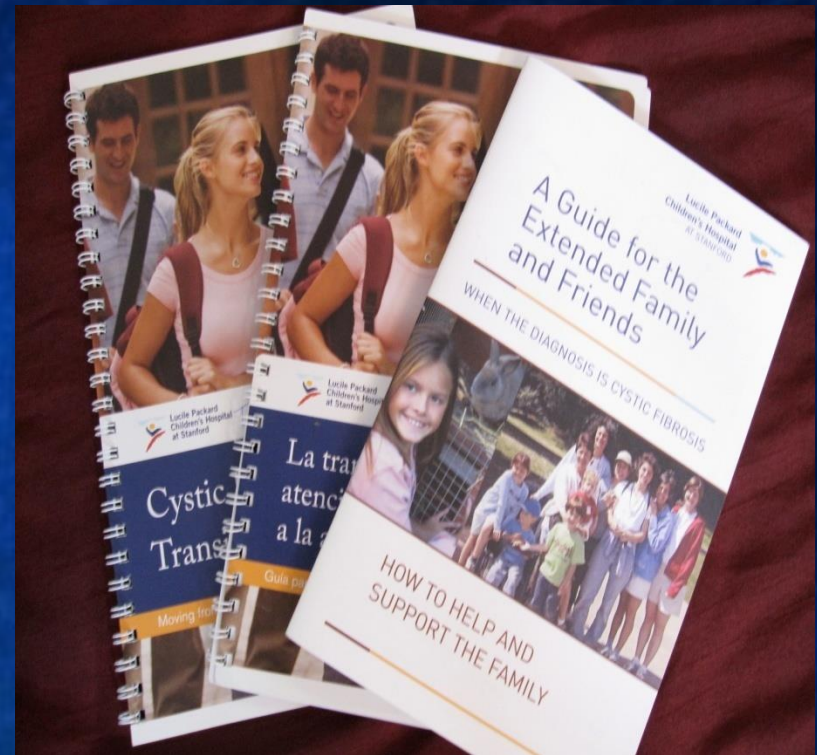
QuickTime™ and a
TIFF (Uncompressed) decompressor
are needed to see this picture.

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

The Cystic Fibrosis Center at Stanford - Stanford University School of Medicine 2/25/11 9:09 AM

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NEWS BRIEFS **CYSTIC FIBROSIS** **CYSTIC FIBROSIS RESEARCH**

CF Education Day



SAVE THE DATE
CF EDUCATION DAY
MARCH 5, 2011



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 18 years or older.

*****TAKE OUR SURVEY*****
For Families of Pediatric Patients

Dear Patient:

As partners in your care we are very interested in learning about your experiences with the CF center. We would like to ask for a few minutes of your time to share your experiences through the following surveys

What Are Clinical Trials?



Clinical Trials: Volunteers Needed

Why Volunteer for Research?

Frequently Asked Questions

Research on the cause, biological mechanisms, new and better forms of therapy and, ultimately, the cure for CF is an important part of our CF Center activities. You can be an important part of that research!

To find out how, call a research coordinator

<http://cfcenter.stanford.edu/> Page 1 of 2

- 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

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 Rosie Flores by email at RFlores@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 Center 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 *Burkholderia cepacia* (*B. cepacia*) or who have cultured Methicillin-resistant *Staphylococcus aureus* (MRSA) within the past two years, or who are currently culturing a bacterium resistant to all antibiotics (pan 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://cfcenter.stanford.edu>

Contact us by phone at (650) 549-5102, or by email at stanfordCFAC@gmail.com

Applications to be an Advisory Council Member are available online, in clinic, or by contacting the council.

[click here](#)

 Created by the Stanford Adult CF Advisory 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 an: inpatient outpatient

Name (optional):

You can contact me by (optional) (ie phone, email, home address):

I would like the Stanford Cystic Fibrosis Advisory Council to know (feel free to continue on back side):



NEWS BRIEFS

CF Education Day



SAVE THE DATE

CYSTIC FIBROSIS

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CYSTIC FIBROSIS RESEARCH

[What Are Clinical Trials?](#)

[Clinical Trials-Volunteers Needed](#)

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Research on the cause.





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STANFORD ADULT CYSTIC FIBROSIS ADVISORY COUNCIL

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Adult CFAC

About the Council

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

Address:
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 c/o Colleen Dunn
 770 Welch Rd, Suite 350
 Palo Alto, CA 94304
 Email: stanfordcfac@gmail.com
 Phone: (650) 549-5102

Contact Us Maps & Directions