

The Stanford Adult Cystic Fibrosis Advisory Council

Mission Statement

The Stanford Adult Cystic Fibrosis Advisory Council (hereafter the Advisory Council or ACFAC) provides feedback to and partners with members of the healthcare team to improve the patient and family experiences and care at Stanford University Hospital (SUH) and in the SUH Cystic Fibrosis Adult Clinic. 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.

Bylaws

Purpose and Responsibility of the Advisory Council

- Serves as advisory resource to administration and staff of the CF Center and its programs.
- Promotes improved relationships between patients, families and staff.
- Provides a vehicle for constructive communication between patients, families and staff.
- Provides an avenue for patients and families to offer input into policy, new program and facilities development.
- Actively helps implement changes.
- Provides input into the educational program for staff.
- Collaborates as partners with staff, physicians and administration in the planning and operation of specific programs.
- Provides a safe venue for patients, families and medical staff to offer input in a setting where they are receiving/giving medical care.
- Serves as a coordinating mechanism for patients, families and medical staff.

Structure and Size of the Advisory Council

The Advisory Council shall be comprised of at least nine and no more than 15 voting members, each serving a two-year term. At any given time, Advisory Council membership is limited to no more than two active council members per family. The Advisory Council, at its discretion, may approve the addition of adjunct or non-voting council members. Additionally, at least 1 CF adult physician and one Stanford Health Care administrative liaison will serve as non-voting advisors.

The Advisory Council strives to have CF adults (persons over age 18 with cystic fibrosis) make up the simple majority of voting members whenever possible. In order to ensure the widest representation of the CF Adult Community, the breakdown of the Advisory Council shall be as follows:

- CF adults: minimum of two members.

- CF family members, significant others or partners, or CF community friends: minimum of one member.
- CF health care team professionals: maximum of four members not including the Stanford Health Care administrative liaison and a CF Center physician. CF health care team members may share a position on the Advisory Council; however, each member is required to serve no less than a continuous 6-month term.

Membership Qualifications

The Advisory Council shall be made up of members who are inspired to participate in and contribute to ongoing efforts to improve the quality of patient care at the Stanford Adult CF Center. This requires participation in regular meetings, either in person, by teleconference or via WebEx.

Specifically, we seek CF adults, 18 years or older, who are patients at Stanford University Hospital and/or clinic, their family members, members of the CF healthcare team and CF community friends. In addition, we welcome family members of patients in transition to adult care at the Stanford CF Center.

All CF adults are invited to be members of the Advisory Council. If an applicant for membership has a sputum culture that prohibits face-to-face interaction with other CF adults, that applicant can still participate through WebEx, teleconferencing or any other non-contact tool in use by the Advisory Council.

Any person applying for Advisory Council membership must be able to:

- **See beyond his/her own personal experiences and represent the concerns of the community as a whole.**
- Respect the CF Center at Stanford cross infection guidelines.
- Voluntarily not attend Advisory Council meetings 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 Advisory Council meetings in person due to the cross-infection risks to others with CF. If you would like to attend via WebEx conferencing, please see our council meeting blog (<http://cfacmeetings.blogspot.com>) for instructions on how to attend (at the bottom of each month's agenda).
- Understand that confidential information not be shared beyond the Advisory Council.
- Abide by the Health Insurance Portability and Accountability Act (HIPAA).
- Be committed to serve a two-year term except in the case of medical personnel applying for a shared term.
- Attend a minimum of 66% of Advisory Council meetings (minimum of 8 of the 12 meetings per year) whether in person, by teleconference or through WebEx participation (the Council's meeting minutes will be used to track member attendance. Members hold

the responsibility to note any errors in their attendance before each month's meeting minutes are approved).

Membership Application and Selection Process

Applications for membership are always available. Applications can be requested through Stanford Health Center CF clinic personnel. The application can also be downloaded from the Advisory Council website found at <http://cfcenter.stanford.edu/acfac/>.

When an application is received by the Advisory Council, the membership chairperson will review the application and conduct a formal interview of the applicant either in person or by phone. The membership chairperson will then report back to the Advisory Council. The applicant will be approved or rejected by a simple majority of voting Advisory Council members.

Health Insurance Portability and Accountability Act (HIPAA)

Permission to contact any person is assumed providing that person has initiated contact with any member of the Advisory Council regarding council business.

Elections of Officers

Members of the Advisory Council will elect candidates for Advisory Council offices in January of each year. Election is by a simple majority vote of council members deemed eligible to vote. If a position should fall vacant prior to the end of the designated term, an unscheduled election will be held to fill the position. As we expect to build our initial membership over time, member terms will naturally be staggered so as not to have a complete turnover of members at any one time. We seek balance between returning and new members.

Advisory Council Officer Duties

The Advisory Council shall consist of the following officers and his/her respective duties:

- Chairperson:
 - Sets the meeting agenda and distributes the agenda to Advisory Council members, the SUH Advisory Council contact person and other interested persons two days prior to each meeting date. Advisory Council members may request that topics for discussion be added or deleted from the agenda. This will be done at the discretion of the Advisory Council chairperson.
 - Sends final agenda, via email, two days prior to meeting date to Advisory Council members and other interested persons, by request (who have provided a current email address).
 - Provides agenda for posting on Advisory Council meeting blog.
 - Leads the meetings in an orderly and respectful fashion.
 - Has the authority to determine if topics brought to the meeting, not included in the published agenda, can be included for discussion, as time permits.
 - Appoints committees and committee chairpersons as needed.
 - In the event that particular agenda items require confidentiality, the chairperson, with the consent of the Advisory Council, will convene a closed session during a

portion of any Advisory Council meeting. Both voting and non-voting Advisory Council members, Advisory Council medical and staff advisors, and the person(s) requesting confidentiality may be present during a closed session. At such a closed session, there will be no recording of the business discussed. It shall be understood that what transpires in that session will not be shared outside of the Advisory Council. Decisions made during the closed session will be announced, if appropriate, at the beginning of the open session for submission to the minutes of the meeting.

- Calls for election of officers as needed.
- Responds to any contact to the Advisory Council through the email address or phone number (stanfordcfac@gmail.com).
- Responds to any “We Want to Hear Your Voice” flyer contact, and adds the contact information to the council’s Google contacts (hosted at: stanfordcfac@gmail.com).
- Vice-Chairperson:
 - Supports the Chairperson.
 - Leads meetings in absence of chairperson.
 - During meetings, keeps a record of all items needing action and person(s) responsible for each action with a review of such items at the close of meetings.
 - Updates Advisory Council history, bylaws, new member resource page and Advisory Council accomplishments as needed.
- Secretary:
 - Takes meeting minutes, including a list of members attending and members absent, and distributes them to the Advisory Council members as well as other interested persons.
 - Provides meeting minutes for posting on the Advisory Council meeting blog.
 - Records any council votes in the meeting minutes.
 - Keeps council member contact directory current and distributes it to members as needed.
 - Notes each member's anniversary date (month and year) next to the member's name in the council contact directory
- Membership Chairperson:
 - Leads the Advisory Council efforts in the recruitment of Advisory Council members.
 - Reviews all Advisory Council applications, interviews prospective members, by either phone or in person, and reports back to the Advisory Council with a recommendation for or against Advisory Council membership.

- Notifies Advisory Council applicants as to their election or rejection to council membership.
- Keeps track of Advisory Council membership category distribution and communication permissions as required in these bylaws.
- Discusses with council members if they want to continue with the council after their 2 year term ends.
- Contacts members not meeting the attendance requirement (and cc's non-compliance notices to advisory council chairperson).
- Directs newly elected council members to new member information section of the Advisory Council blog (<http://cfacmeetings.blogspot.com/p/stanford-acfac-resource-page.html>).
- Website Revision Manager:
 - Collects, compiles, and creates documentation for the "Adult CF Advisory Council" section on the CF center website (found here: <http://cfcenter.stanford.edu/acfac/>) then forwards updates to the CF center website manager once a month.
 - Contacts new members for their bio entries on the ACFAC "About Our Members" page.
 - Ensures the website is reviewed bi-annually by the council and notifies the Chairperson when the bi-annual review is due.

Member Dismissal

Disqualification and/or reason for dismissal from the Advisory Council shall include poor attendance, not adhering to the bylaws, disruption of the meetings and/or interference with the mission of the Advisory Council. The Advisory Council has the right to remove, by a majority vote, any member violating the policies and standards of the Council.

Guidelines of Authority

The Advisory Council is in itself a majority-voting governing body. In times of controversy, the Advisory Council will seek advice from the Stanford University Hospital liaison and/or council medical advisor.

Voting Rules and Eligibility

- Voting on any issue before the Advisory Council can occur only when a quorum, defined as 50% + 1 voting members, is present.
- Every council member is a voting member with the following exception. If two or more immediate family members are serving on the Advisory Council, and one or more of those members is a CF adult, only the CF adults' votes will count.
- If family membership consists of 1 CF adult and 1 non-CF family member only the CF adult will be a voting member. If family membership consists of 2 CF adults, each of the CF adults is a voting member.

- Voting by Written Instruction is allowed by members unable to attend either in person or via WebEx. To submit a vote, a member must be well informed about the topic on which the member wishes to vote and must submit his/her vote in writing via a member attending in person.
- Voting may occur via email with the prior approval of the council.

Community Participation

All Advisory Council meetings shall be open to the public, either in person, by teleconferencing or via WebEx, unless otherwise stated. The CF Center at Stanford cross-infection guidelines shall be posted on all meeting announcements and at the meeting room entrance. Wording shall be as follows:

Advisory Council visitors are welcome, however, 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. 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 meetings in person due to the cross-infection risks to others with CF. If you would like to attend via WebEx or teleconferencing, please contact Rosie Flores at RFlores@stanfordmed.org. She will let you know how you can participate.

Any person wishing to address the Advisory Council, whether in-person, by teleconferencing or WebEx, must notify the Advisory Council chairperson via email by the 2nd Tuesday of each month stating the topic he/she wishes to discuss. (See website for the Advisory Council's email address.) All persons addressing the council and/or its advisors must do so in a respectful and constructive manner.

Infection Control Protocol

All CF adults serving on the Advisory Council in person are required to have follow-up sputum cultures every three months and to follow the infection control guidelines. If a culture result shows a hazardous and/or pan-resistant bacterium, participating CF adult members must agree to attend meetings via teleconferencing or to wear masks depending on the recommendation of the CF physician.

Respecting the safety of the other CF patients is essential. The entire Advisory Council relies on the good judgment of its Council Members.

All in person Advisory Council guests are required to follow the CF Center at Stanford cross-infection guidelines and infection control requirements for Advisory Council member attendance. If culture results are unknown, he/she will be required to wear a mask and sit apart from the Council members in addition to observing the 3-foot rule (distance in any direction between any two CF people must be 3 feet or greater).

Meeting Date, Time and Location

The Advisory Council will meet the third Wednesday of each month from 5:00 to 7:00 P.M. in the Blake Wilbur conference room unless it is determined in advance that a quorum (defined as at least 50% + 1 of voting members) will not be present. Meeting dates will be stated in the minutes and/or upcoming agenda and posted on the Advisory Council meeting blog. Any changes in date, time or location will be stated in the minutes and/or upcoming agenda whenever possible. Any change in meeting location must be adequate for good cross-infection protocol adherence, providing proper ventilation and the space necessary to follow the 3-foot rule.

Amendments Procedures

If amendments to these bylaws are warranted, the Advisory Council may vote on any such amendment and, by simple majority vote, change these bylaws.