**Primary Children’s Hospital**

**Heart Center Family Advisory Council Guidelines**

**ARTICLE I**

**NAME**

The name of the organization shall be Primary Children’s Hospital Heart Center Family Advisory Council (hereinafter referred to as “HC-FAC.”)

# ARTICLE II

# MISSION

The HC-FAC provides a collaborative partnership for families and Primary Children’s Hospital staff and administration to promote the delivery of patient and family centered healthcare.

**ARTICLE III**

**MEMBERS**

**1. Membership**

The HC-FAC shall consist of up to 15families (“Family Advisors”), represented by individuals or couples, up to 15 Primary Children’s Hospital staff, and Administration.

**2. Duties**

The Family Advisors may attend HC-FAC meetings either in person or virtual when available. Meetings should be attended in person at least two times a year. The Family Advisors shall maintain active participation in HC-FAC meetings, activities and committees. Family Advisors may be excused from a meeting by notifying the Co-Chairs prior to the meeting. Family Advisors should have no more than three absences in a calendar year, excused or unexcused.

**3. Meetings**

1. The HC-FAC has adopted a schedule of regular meetings. These meetings are scheduled quarterly on the third Thursday of the last month of the quarter, 6:00p.m. – 7:30 p.m. Dinner will be served.
2. The Annual Training Meeting will be held in the month of October. This meeting is for new Family Advisors and for those who have not attended one in the past two years.
3. Meetings shall be scheduled by the Caregiver Co-Chair or other designated Caregiver.
4. Primary Children’s Hospital staff or others wishing to attend the HC-FAC meetings and or give presentations to the HC-FAC may make such requests of the Caregiver Co-Chair in order to have their issue placed on the agenda.

**ARTICLE IV**

**HEART CENTER FAMILY ADVISORY COUNCIL (HC-FAC)**

**1. Composition**

The members of the HC-FAC shall be:

1. Parents or immediate family members of patients who have experience with Primary Children’s Hospital’s Heart Center.
   1. In order to achieve representation from the population served, there shall be parent representatives from inpatient and outpatient services as they relate to Heart Center operations.
   2. Members shall represent not only specific diagnoses but also the geographic areas and cultural diversity of the population served.
   3. A member may represent more than one of the aforementioned groups.
2. Caregiver Co-Chair and Advisor Co-Chair.
3. Members from the hospital staff and administration are appointed by the Caregiver Co-Chair.

**2. Duties**

1. Caregiver Co-Chair provides administrative support to the HC-FAC, oversees and approves all agenda items, new members, and works with the Advisor Co-Chair in all matters regarding the HC-FAC. The Co-Chairpersons facilitate the HC-FAC meetings.
2. Primary Children’s Hospital HC-FAC Caregiver Co-Chair and Advisor Co-Chair shared duties are as follows:
3. Educating staff about the roles of Family Advisors and opportunities for working with them;
4. Overseeing the recruitment and selection of Family Advisors;
5. Communicating with Family Advisors in a timely manner about recruitment status and potential opportunities;
6. Training Family Advisors and helping them understand how the organization works;
7. Overseeing Family Advisor activities, providing mentoring and coaching, and facilitating the ongoing engagement of Family Advisors;
8. Primary Children’s Hospital HC-FAC Caregiver Co-Chair duties are as follows:
9. Bringing concerns of Family Advisors to hospital leaders or helping to create direct connections between Family Advisors and leaders;
10. Tracking and communicating Family Advisor accomplishments.
11. Working with hospital administrators to get their buy-in and commitment for working with Family Advisors;
12. Keeping leadership apprised of Family Advisors’ activities and accomplishments’
13. Assisting staff with developing plans for involving Family Advisors on specific projects or workgroups;
14. Problem solving in challenging situations;
15. Obtaining the necessary resources;
16. Cultivating opportunities for Family Advisor involvement
17. Minutes shall be kept of all HC-FAC meetings and shall be distributed to HC-FAC. The Caregiver Co-Chair may designate someone to prepare progress reportsdescribing the activities of the HC-FAC and identify matters which may require Primary Children’s Hospital Administration’s attention.
18. All HC-FAC Family members shall complete the Annual Training Meeting at least every other year and in their initial year of service.

**3. Terms of Service**

The term of service of the HC-FAC members shall be a minimum of one term of three years. HC-FAC members may serve two terms of three years each. HC-FAC members wishing to terminate their membership or request a leave of absence should provide written notice of one month to either the Caregiver Co-Chair or the Advisor Co-Chair. If the leave of absence exceeds two years, then the member will have to reapply.

**4. Removal from Position on the HC-FAC Committee**

Any member of the HC-FAC Committee may be removed at any time by the Co-Chairs, or HC-FAC majority if, in the judgment of the HC-FAC majority, such removal shall be in the best interest of the HC-FAC.

**ARTICLE V**

**HC-FAC COMMITTEES**

**HC-FAC Standing Committees**

1. Standing committees may be designated from time to time. The Co-Chairs shall appoint the Committee Members and Committee Chairpersons, with approval of the HC-FAC.

**ARTICLE VI**

**FRIENDS OF THE HC-FAC**

**Ad-Hoc Members to the HC-FAC**

1. There will be two groups of Alumni: (1) *Active Alumni*; and (2) *Inactive Alumni*. The *Active Alumni* shall consist of members of the HC-FAC who have served their full terms or were on a temporary leave of absence on the HC-FAC. *Active Alumni:*
   1. will support HC-FAC goals and may be invited to serve in a supportive role on HC-FAC committees and projects.
   2. may be invited to attend the annual HC-FAC training meeting in October; they do not have quarterly meeting requirements or voting privileges.
   3. will be a resource to the HC-FAC for additional input and recommendations, as well as sharing their story and giving support to medical and clinical providers at Primary Children’s Hospital.
   4. will be invited to attend social and recognition events throughout the year.
   5. will be supported by the HC-FAC.
2. *Inactive Alumni* are past members of the HC-FAC who are unable to continue to serve as an *Active Alumni*.

**ARTICLE VII**

**GUIDELINES AND AUTHORITY**

The HC-FAC has authority given to it by Primary Children’s Hospital. It cannot enter into agreements or bind Primary Children’s Hospital in any other fashion. HC-FAC Family Members must complete the Volunteer application and requirements prior to the October’s annual training meeting and keep their Volunteer status current. Events organized by the HC-FAC on behalf of Primary Children’s Hospital are done so with prior approval of Primary Children’s Hospital. Each HC-FAC member is issued an identification badge to be used only for HC-FAC activities including meetings. Upon resignation or termination from the HC-FAC, the badge shall be returned to Primary Children’s Hospital.

**ARTICLE VIII**

**CONFIDENTIALITY**

To maintain appropriate and confidential handling of personal information, patient and/or family members shall not be discussed by name in HC-FAC meetings and strict compliance with all state and national laws including HIPAA. Confidentiality agreements may be signed annually by all HC-FAC members. In addition, physicians and caregivers shall not be discussed by name in HC-FAC meetings. If a HC-FAC member would like to discuss specifics surrounding a particular caregiver, that member will consult privately with the Primary Children’s Hospital Caregiver Co-Chair.

**ARTICLE IV**

**PARLIAMENTARY AUTHORITY**

The rules contained in the current edition of Roberts Rules of Order Newly Revised shall govern the proceedings of the HC-FAC in all cases in which they are applicable and in which they are not inconsistent with these guidelines and any special rules of order that the HC-FAC may adopt.

**ARTICLE X**

**AMENDMENT OF GUIDELINES**

The guidelines will be reviewed annually. Amendments will be made as needed by the Caregiver Co-Chair, Advisor Co-Chair and/or staff representatives of Primary Children’s Hospital.

**AMENDMENT 1**

GUIDELINES FOR SOCIAL MEDIA

1. Purpose:

To guide members in expressing their experiences at PCH while maintaining respect for health care providers and the hospital

1. Definition and Usage:

Social media is defined as forms of electronic communication (as Web sites for social networking and microblogging) through which users create online communities to share information, ideas, personal messages, and other content (as videos)1. Examples include, but are not limited to: Facebook, Twitter, Instagram, You Tube, message boards, blogs, and personal webpages.

Social media offers many benefits for members of the HC-FAC related to the experience of having a child at PCH. These benefits include: being able to share stories, connect with other families, offer and receive support and guidance, and engage in the community.

1 Definition from Merriam Webster Online:

<http://www.merriam-webster.com/dictionary/social%20media>

1. Guidelines:

Members of the HC-FAC should conduct themselves in the following manner while using social media:

Use general information whenever possible. Avoid using names or other specific details of health care providers.

Share information related to your experience. Avoid sharing information about other families without their permission, including references to current condition or hospital admissions.

Describe experiences and opinions in a constructive manner. Avoid making negative or disparaging comments about health care providers or PCH.

If there is a need to discuss specific names or negative experiences, have conversations in a private manner. Examples of this include: private email exchanges, private messaging, text messaging, phone calls, and in person meetings.

1. Responding to Comments made by Others

If members of the HC-FAC receive or are aware of comments made by others in a social media setting, members may respond to those comments. However, it is not a requirement that members respond to comments made by others. Any responses made by members should follow the guidelines above. Some example responses are outlined below to assist with response and can be used or altered as needed:

Have you tried contacting Patient Advocacy? They want to hear from you and may be able to help address the situation or find a resolution. You can call them at 801-662-6315. You can also call the Family Advisor Liaison at 801-662-6559.

I understand this can be really frustrating, would you like to discuss this further in private?

I know of another family with the same situation/condition. Would you like me to put you in contact with them? They may be able to offer helpful suggestions.

1. Questions, Examples, Case Study:

Contact the Caregiver Co-Chair with any questions or for examples of blog posts, Facebook pages, etc. that follow these guidelines.

Case Study:

Your child has been experiencing ongoing symptoms of lack of appetite, abdominal pain, and vomiting. She has been seen by Dr. Smith in the Emergency Room, Dr. Jones in Gastroenterology, and Dr. Adams during a hospital admission. Multiple tests have been run and no cause has been identified. The doctors have suggested a watch-and-wait approach and supportive treatment. You feel like there is something wrong, more testing is needed, and that you are not being heard by the doctors. You want to seek advice on a message board, how do you do this?

Appropriate example: My child has been having lack of appetite, abdominal pain, and vomiting. We have seen several doctors with no answers. I am not sure what to do next and maybe want a fresh set of eyes. Does anyone have any recommendations on doctors or treatments that have worked for them?

Inappropriate example: My child has been having lack of appetite, abdominal pain, and vomiting. She has seen Dr. Smith, Dr. Jones, and Dr. Adams. None of them have a clue, won’t do anything to help, and won’t listen to me. DO NOT take your child to see any of them. Does anyone know a doctor that will actually do something?

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