



Patient and Family Advisory Council Toolkit:

An action guide to develop, structure, and sustain your PFAC

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What are Patient and Family Advisory Councils (PFACs)?

A PFAC is a formal group that meets regularly for active collaboration between clinicians, hospital staff, and patient and family advisors on policy and program decisions.

Agency for Healthcare Research and Quality
(AHRQ, 2013).

What are Patient and Family Advisors (PFAs)?

A PFA is a former or current patient and family member of the hospital, who is emotionally, physically, and mentally ready to volunteer and partner with the organization to make improvements. This is typically a patient who is interested in being actively involved in their care or the care of a family member and has offered constructive feedback in the past.

- Agency for Healthcare Research and Quality
(AHRQ, 2013).

Planning Committee

Who Should Attend

Suggested hospital staff should include:

- One executive leader (President, Chief Medical Officer, Chief Operating Officer, or Chief Nursing Officer). It is important for leadership to support the PFAC, staff members, PFAs, and the council's efforts.
- One staff physician
- One staff nurse
- One quality leader
- One nursing director or manager
- One volunteer services representative

Patients and Families:

Identify 2-3 patient and family members in your organizations to partner and help in the development stage.

Items to Discuss:

1. Recruitment ideas and action
2. Possible goals and objectives for the PFAC
3. Resources for PFAC- dinners, parking, small gifts of appreciation, celebration, etc.
4. Identifying a PFAC Staff Liaison
5. Identifying a PFA co-chair
6. Development of a work plan, bylaws, PFAC structure, and time line
7. Assigning specific duties to staff and PFAs
8. Volunteer vetting process
9. Interview and application process for patients and families

Patient and Family Advisory Council Membership

Ratio of staff and PFAs

Ideally the make up should be 30-40% staff and 60-70% PFAs. The reason for this is to make sure the group is not top heavy with staff and that PFAs feel comfortable talking about ideas, suggestions, and opinions. Too many staff members may be intimidating for PFAs.

Identifying PFAs and staff

The “READI Patient and Family Advisor” is a good way to look at the characteristics of PFAs. It is important that the PFAs on the PFAC do not have their own agenda and have a global perspective for the care of all the patients and families that come through the organization. In addition, PFAs must have had current care at the organization (usually within the last 1-5 years, maximum).

PFAC Structure

The structure of the organization’s PFAC is critical for success and sustainability. Some of the most important aspects for structure are:

- Ratio of staff to PFAs
- Having anywhere from 10-20 PFAs on the PFAC
- Identification of a PFA co-chair
- Identification of a staff liaison
- Meeting 10-12 times annually
- Bylaws/charter/guidelines
- Term limits for PFAs
- Senior leadership presence, support, and connection
- PFA leaders for membership and recruitment, speaking events, social events, and other activities to connect with the organization and community
- Training, education, and the Volunteer Services vetting process for the PFA
- The PFA understanding the organization’s goals and priorities
- Staff’s understanding of the PFAC structure and partnering with patients and families
- PFAs leading the PFAC projects and activities based on their experience and what they believe to be important for patients and families within the organization in collaboration with organizational goals and priorities.
- HIPAA training, health screening with vaccinations, and general safety training for all PFAs
- Keeping track of each PFA’s start date on the PFAC

The **READI** Patient and Family Advisor™ is someone who:

- Is **R**ESPECTFUL, collaborates, speaks-up, and listens with hospital staff.
- Has **E**XPERIENCE of care at University Hospitals and is able to share their experiences to enhance care.
- Is **A**PPRECIATIVE of other patients and families and hospital staff.
- Is **D**EDICATED to enhance safety, quality, and experience for all patients and families.
- Is **I**NVOLVED in his/her own or a loved one's care, and creates opportunity to partner with the hospital and other patients and families based on his/her experiences.

Technical reasons and demographics for choosing Patient and Family Advisors:

- Positive and negative experiences while receiving care.
- Diversity of background (socioeconomic, culture, ethnicity, gender, Medicaid /Medicare recipients), disease or other medical care (surgeries, outpatient services, etc.)
- What PFAs are passionate about (quality, patient experience, safety, document review, etc.) to enhance the PFAC and organizational initiatives and programs.

It is important that the PFAC reflects the community the organization serves.

Identifying a PFA co-chair

Another important aspect of the PFAC structure is identifying a PFA co-chair. PFA co-chairs help to guide the PFAC in sustainability, activities, communication, and structure. They partner directly with the Staff Liaison to ensure the goals of the PFAC are being met and what needs to be executed in order to meet those goals. They assist in the agenda for each PFAC meeting, co-lead PFAC meetings, oversee and provide direction in all PFAC activities, may put together ad hoc groups, help in interviewing new PFAs, are the official spokesperson for the PFAC, keep the PFAs informed of important information affecting the PFAC, and supervise preparation of reports coming from the PFAC.

The **READI** PFA co-chair™ is someone who:

- Is **R**ESPECTED by the other PFAC members and the organization's staff.
- Has the skills to **E**XECUTE the mission and vision of the PFAC.
- Is **A**CCOUNTABLE for the PFAC, PFAs, the structure, the activities, and leading, supporting, and assisting in the PFAC goals.
- Has **D**RIVE and is well connected, with the help of the Staff Liaison, to other hospital administrators and staff.
- Is **I**NSPIRATIONAL and sets by example the roles and responsibilities of a PFA.

Expectations and Responsibilities of Patient and Family Advisors

Patient and Family Advisors believe in University Hospital's mission: *To Heal. To Teach. To Discover*, and how that relates to each organizations' PFAC's mission and vision to help other patients, families, and the communities that University Hospitals serves. In order to make the most of the organizations Patient and Family Advisory Councils and participation in activities and meetings we ask all Patient and Family Advisors to:

Respect our colleagues and other PFAs.

- Arrive to meetings on time.
- Silence cell phones.
- Come to meetings prepared and ready to get work done.
- Minimize sidebar conversations and keep on task.
- Don't interrupt.

Be responsible.

- If you are unable to attend a meeting, let the PFAC staff liaison or PFA co-chair know.
- Be proactive and take on a task if you have the skills for the job.
- Meet deadlines to the best of your abilities. Ask for help if you need it.

Be a good communicator.

- Express your thoughts and ideas clearly, directly, honestly and respectfully.
- Be a good listener.
- Work cooperatively – **with** others – to get a job done.
- Expect occasional conflict - it is natural and to be expected. But if dealt with productively, conflict can lead to innovative problem solving.
More viewpoints = more possibilities.

Actively participate.

- Every PFA has value and contributes to our collective successes.

Be flexible.

- Consider different points of view and compromise when needed.

Ask questions if you need clarification.

Patient and Family Advisors are a reflection of University Hospitals. Having the ability and willingness to give back to the organization means a great deal to University Hospitals and can be a very rewarding experience to the PFA participating on a Patient and Family Advisory Council.

Identifying a Staff Liaison

Staff is just as important as the PFA. Look for staff members that champion Patient and Family Centered Care and have the willingness to partner and keep the PFAC connected with the organization. It is also critically important that senior leadership participate with the PFAC, even if it is rotating meetings. The most successful PFACs have senior leadership participating in their efforts. In addition, identifying a staff liaison will be critical for the success of the PFAC. Please see the following to identify a staff liaison and their roles and responsibilities.

Hospitals that are most effective in engaging PFAs designate a clinician or staff member to serve as a Staff Liaison. The Staff Liaison works with hospital leaders to put in place the infrastructure necessary for advisor engagement; prepares staff and clinicians to work with Patient and Family advisors; and recruits, trains, and support advisors (AHRQ, 2013). The Staff Liaisons' job is to facilitate partnerships, ensure that advisors are ready to participate, and ensure that staff is ready to engage in partnerships (AHRQ, 2013).

The Staff Liaison is someone who has good rapport with leadership and clinicians. They also have the ability to work with many different departments and may already work in patient and family education, quality, safety, or administration (AHRQ, 2013). Clinical Staff Liaisons are also excellent because they can keep the PFAC closely tied to the hospital units and current unit projects, initiatives and programs.

The **READI** Staff Liaison™ is someone who:

Is **R**ESPECTFUL of the
patient and family perspective.
Is well connected and **E**NGAGES and educates
PFAs on how the hospital works,
and staff and clinicians on partnering
with patients and families.
Leads, **A**PPRECIATES and champions
Patient and Family Centered Care.
Has patience and is **D**EDICATED to learn, persevere,
and see strengths in all people in all situations.
Looks for and **I**DENTIFIES opportunities
for PFAs to be involved
throughout the organization.

What are the Staff Liaison's Responsibilities?

The Staff Liaison has a unique role in keeping closely connected to hospital leaders, clinicians, patient and family advisors, and other staff. They mentor, consult, and educate all those that they work with about the PFAC and Patient and Family Centered Care. According to AHRQ's Guide to Patient and Family Engagement (2013) there are several responsibilities for a staff liaison. Because of these responsibilities it is strongly suggested that the Staff Liaison have an Admin that is assigned to support the PFAC.

Responsibilities to hospital leadership:

1. Working with administration to get their buy-in and commitment for working with PFAs.
2. Keeping leadership informed about the PFACs activities, accomplishments, and goals.

Responsibilities to staff and clinicians:

1. Educating them about PFAs and opportunities to work with them
2. Helping staff with developing plans for involving advisors in specific projects and workgroups.
3. Helping staff understand how to interact with PFAs and how to implement their suggestions or to provide feedback about why changes may not be possible.
4. Problem solving in challenging situations.

Responsibilities to PFAs:

1. Obtaining necessary resources.
2. Cultivating opportunities for PFA involvement.
3. Overseeing the recruitment and selection of PFAs.
4. Communicating with PFAs in a timely manne4r about recruitment status and potential opportunities.
5. Training PFAs and helping them to understand how the organization works
6. Overseeing PFA activities, providing mentoring and coaching, and facilitating the ongoing engagement of PFAs.
7. Bringing concerns of PFAs to leadership, or connecting PFAs with organizational leadership.
8. Tracking and communicating PFA accomplishments.

It is important that the Staff Liaison is well respected by his/her peers and is well connected with many areas of the organization. This will help to strengthen the Patient and Family Advisory Council and help to successfully engage PFAs in many initiatives and opportunities.

Agency for Health Research and Quality. *Guide to Patient and Family Engagement: Working with Patient and Families as Advisors*. AHRQ, 2013.

Roles of Patient and Family Advisors

The Patient and Family Advisor serves as a very unique volunteer to health care organizations. The work of the PFAC must be purposeful and meaningful to the PFA. They typically have a beginner's to advanced understanding of the hospital system, have received care at the organization, and have a loyalty to the health care organization to see it succeed and be the best it can be. Patient and Family Advisors may have different tasks and activities once they join a PFAC and their roles within the organization can vary depending on the activities they may want to be trained, educated, involved in, and have the time to commit to.

Examples of different PFA roles:

- Trained and educated to serve on quality, safety, root cause analysis, or patient experience committees at varying levels (senior leadership committees, board of directors, etc.).
- Trained and educated to serve on hospital units and/or departments working with inpatient or outpatient patients and families.
- Document and literature review.
- Organize social events for hospitalized patients and families.
- Trained and educated to speak publicly and educate physicians, nurses, students, and other hospital staff about their own story as a patient or caregiver, PFACs, Patient and Family Centered Care, and Patient and Family Engagement.
- Recruitment of other potential Patient and Family Advisors.
- Public speaking at community events.
- Based on budget, PFAs may attend local, state, or national conferences to learn more about being a PFA, Patient and Family Centered Care, safety and quality, and more.
- Development of creative ideas and initiatives to help patients and families who may be hospitalized or in the outpatient setting.
- Assisting and partnering in hospital initiatives and programs.
- Some PFAs may get involved in other local, state, or national organizations also serving as a PFA.

What Patient and Family Advisors Do, and What They Mean to a Healthcare Organization

Patient and Family Advisors partner on PFACs and other organization committees to offer the patient or caregiver perspective based on their experiences within the organization. They typically have a sense of loyalty and want to give back whether they have had positive or negative experiences. In general, PFAs have a global perspective and want to help other patients and families who are in the hospital or outpatient setting to navigate, and teach about what they have learned going through the hospital or outpatient experience. There may be a desire to collaborate with clinicians and administration, and to learn more about how the organization works and how their perspective may assist and help other patients and families in making enhancements to care delivery, patient education, patient experience, safety and quality, and many other areas of health care.

Bringing patients and families to the organizational table, almost always, changes and enhances the conversation. They are able to provide and give insight to what it really means to be a patient or caregiver within the organization. Many may offer their insights based on what they have experienced or what they have learned to what may make care transitions smoother, enhance the patient's experience, processes in safety and quality, or important suggestions that should be added to patient education literature.

For organizations that have not had the experience of working with patients and families, they will find that it can be an enlightening experience. They will learn a great deal about how their organization is functioning and delivering care, and how they may approach different strategies or techniques to enhance care. It is important to keep PFAs and PFACs involved, *from the beginning*, in the development of new strategies, initiatives, and programs, to ensure they are patient and family centered and integrate the patient and family perspective. Following up with PFAs and PFACs during the development of programs and initiatives is important in maintaining the organizational/PFAC relationship. If there are suggestions from PFACs and it simply cannot be done, an explanation should be given along with the education for the PFAC to understand why.

Just like working with any new colleague, it can take some time to get “used to” working with patients and families. It is possible the organization may hear things that they don't want to hear, so keeping an open mind is critical while starting to work with PFAs. Over time, the organization will be able to recognize the value of having PFAs partnering with them for success, and that incorporating them as a team member will become second nature. The experience is rewarding, not only for the organization, but also for the Patient and Family Advisor.

Application, Interviewing, and Volunteer Services

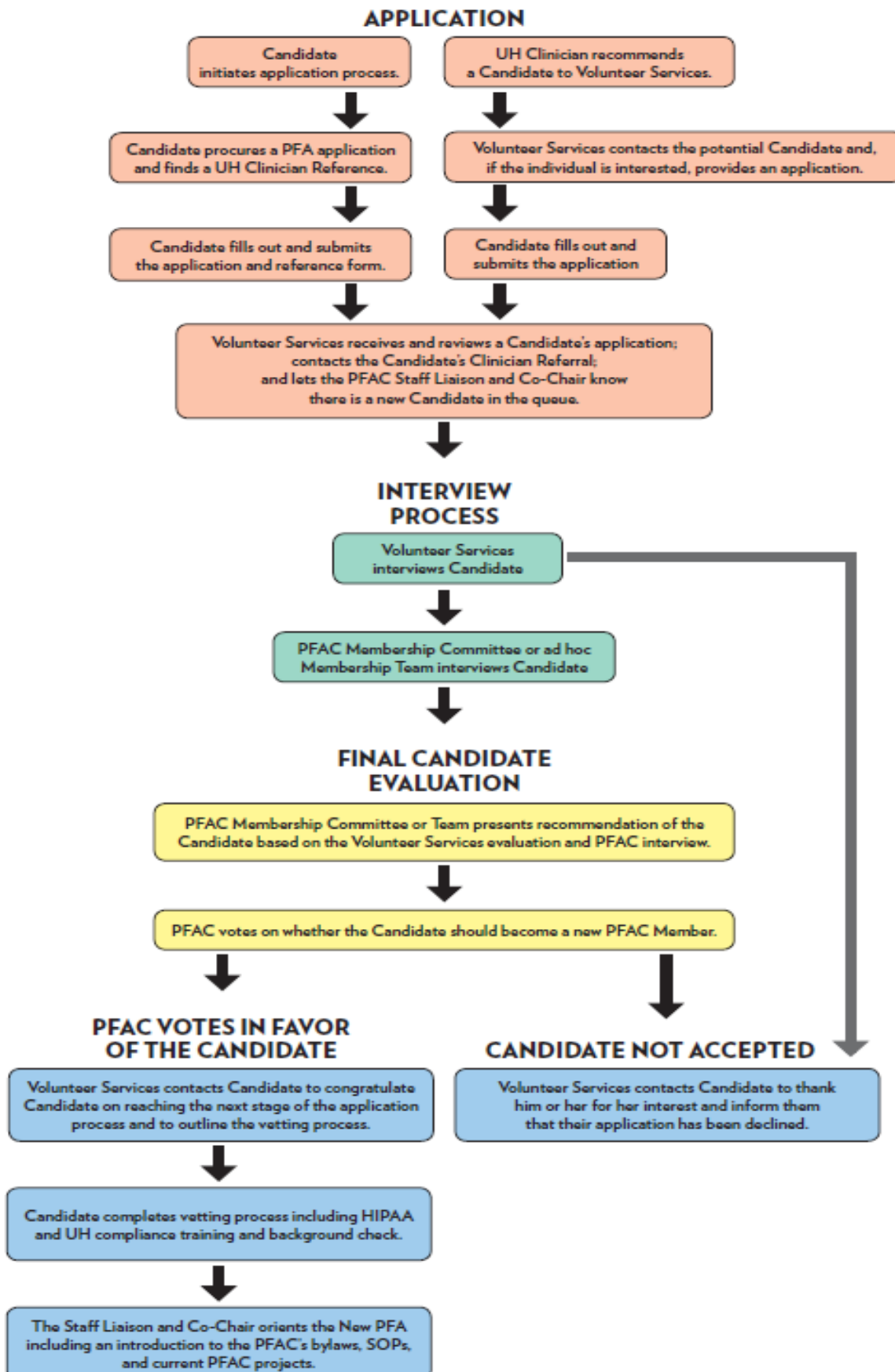
Like any job role it is important to have potentially interested patient and families apply, go through interviewing, and the vetting process with volunteer services. It is also important to have a process like this in place to screen for potential personal agendas, recent care experience, the passion and desire to give back of the patient or family member, to hear the story of the patient and family member, availability to be involved, time commitments, and much more.

The following will provide examples of interviewing and application strategies for PFAs joining PFACs. In addition, there is a Volunteer Services Orientation Folder in the back of the toolkit to look through the process for volunteer services and on-boarding. There will also examples of PFAC applications, interviewing questions, and referral forms from some of our own UH PFACs that have been found to be best practice and effective for application and interviewing of PFAs. Last, is a PFA checklist that can be utilized so the new PFA can be sure they have covered all the necessary steps and requirements for joining an organization's PFAC.

The next few pages will contain examples of PFAC applications, interviewing questions, referral forms, and membership procedures. It is important, just like with any other type of interview, to ask behavioral questions, to rule out any grievances with the organization, and to ensure the patient or family member has not been through a recent traumatic life event. In addition, as the interviewer you will want to listen for many of the attributes in the READI Patient and Family Advisor acronym. Ask about professional experience, as well as other councils or committees they may have participated on in the community. Ask how they deal with conflict and if they are open to learning from others. Make sure the PFAC candidate uses phrases that speak globally to the organization's patients and families, listen for their passion in healthcare, and how their experiences could benefit the safety, quality, or experience for other patients and families and help to enhance the programs or initiatives at the organization. Make sure the candidate understands and has the availability to make a commitment to the PFAC; however, that if they or their loved one becomes ill, it is understandable to take a respite. Last, and most important, listen to their story, this will tell the interviewer a great deal about the candidate.

The last document in this section is a checklist for Patient and Family Advisors to ensure they have taken all the necessary steps to become a volunteer and member of the PFAC.

PFAC Volunteer Selection Process





Patient and Family Advisory Council Application

** The *mission of Patient and Family Advisory Council (PFAC)* is to improve upon the quality and safety of cancer care at University Hospitals in partnership with patients, families and healthcare providers.

Critical functions of the council include, but are not limited to:

- Provide insight to administration, faculty and staff about patients and family health care needs
- Work with faculty and staff to improve patient and family services
- Participate in the planning of patient care areas and patient programs
- Serve as a resource to the health care team on patient related issues, including patient safety, staff recruitment & orientation, program planning, services and policies.

The Patient and Family Advisory Council is comprised of University Hospitals Seidman Cancer Center current and former patients and those they have designated as family members along with clinical and administrative staff and faculty.

The Patient and Family Advisory Council meet the first Monday evening of each month at the Seidman Cancer Center on University Hospital's Case Medical Center in University Circle. Membership is a two year commitment.

To apply for the Patient and Family Advisory Council you will need to submit a completed application package which includes this application and a PFAC Nomination Form completed by a Seidman physician and/or clinical staff member. Applicants will be contacted by University Hospitals Volunteer Services Department. The PFAC application process includes: interviews, background check, tuberculosis test, Volunteer Services orientation, and PFAC orientation.

Name _____

Address _____

Daytime Phone _____

Home _____

Cell _____

E-mail Address _____



Healthcare Provider Referral: Please provide the name of the Seidman Cancer Center healthcare doctor and / or staff member who is recommending you:

Please indicate:

- | | |
|--|---|
| <input type="checkbox"/> Patient in treatment | <input type="checkbox"/> Family member of patient in treatment |
| <input type="checkbox"/> Patient in follow up care | <input type="checkbox"/> Family member of patient in follow up care |
| <input type="checkbox"/> Cancer Survivor | <input type="checkbox"/> Family member of cancer survivor |
| <input type="checkbox"/> Bereaved family member | |

Please indicate any areas of special interest:

- Seidman Cancer Hospital Special Events
 Speakers bureau
 New Patient Orientation
 Patient Ambassador
 Other _____

Family Members are not required to be related legally to patients; but if you are applying as a family member what is your relationship to the patient?

Type(s) of cancer:

Year of original diagnosis: _____

Year treatment completed (if applicable): _____

Check all care you or your family member received:

- Chemotherapy
 Hormone Therapy
 Immune Therapy
 Radiation Therapy
 Surgery

Complementary/Non-traditional

Why would you like to become involved in the Seidman Patient and Family Advisory Council?

Describe your best healthcare experience:



Describe your worst healthcare experience:

What changes would you recommend to assist with this problem?

Please list your areas of special interest:

For background purposes, have you been an Ohio resident for the past 5 consecutive years? Yes No

Have you ever been convicted of a violation of law other than a minor traffic violation? Yes No

(University Hospitals Case Medical Center, Volunteer Services Department conducts FBI background checks. A conviction does not necessarily disqualify an applicant. Failure to disclose may result in disqualification or termination.)

If yes, please identify under what name, location, date, charge and current status of charge



I certify the statements made in this application are true and I understand the misrepresentation and/or withholding of information may result in the rejection of this application or my discharge if discovered after volunteer service begins. Current PFAC members will interview and choose volunteers they feel are best suited based on group consensus. I am authorizing the PFAC members, by signing this, to discuss my participation in the program with my clinical care staff.

Applicant's Signature: _____ Date: _____

Patient name: _____ Signature: _____
Date: _____

Please return your completed application to:

Ms Marge Galla

Seidman Cancer Center - Volunteer Services Department

University Hospitals Case Medical Center

11100 Euclid Avenue

Cleveland, OH 44106

216-844-1504 phone

216-844-8796 fax

Margaret.galla@uhhospitals.org



**RAINBOW BABIES AND CHILDREN'S HOSPITAL
FAMILY ADVISORY COUNCIL
MEMBERSHIP APPLICATION**

FULL NAME:

_____ **Date:** _____
Last First MI

ADDRESS:

_____ *Street City Zip*

PHONE:

HOME _____ **CELL** _____ **WORK** _____

EMAIL: _____

CHILD(REN) RECEIVING SERVICES FROM RB&C:

<i>Name</i>	<i>Age</i>
_____	_____
_____	_____
_____	_____

I AM MOST FAMILIAR WITH THESE PATIENT CARE DIVISIONS AT RB&C (HOSPITAL FLOORS, DEPARTMENTS, ETC.) Circle all that apply.

- | | | |
|-----------------------|---------------------|--------------------------------|
| Neurology | Neurosurgery | NICU |
| Oncology / Hematology | Sedation Unit | Family Practice |
| Rehabilitation | ER | Cardiology/Cardiac Surgery |
| ENT | Radiology | Plastic/Reconstructive Surgery |
| Mental Health | Allergy | Autism |
| Transplant | Endocrinology | Pulmonary/Cystic Fibrosis |
| Dialysis | Dermatology | Epilepsy |
| Gastroenterology | Nephrology | Infectious Disease |
| Pain Management | Ophthalmology | Autoimmune |
| Rheumatology | Urology | Sports Medicine |
| Burn | PICU | Dental |
| Genetics | Asthma | Diabetes |
| Palliative Care | Adolescent Medicine | Surgery |



I AM INTERESTED IN SERVING ON RAINBOW’S FAC BECAUSE

I AM USUALLY AVAILABLE Circle all that apply.

Mornings Afternoons Evenings Weekdays Weekends

I UNDERSTAND THAT BEING A MEMBER OF RAINBOW’S FAC MEANS THAT I AM COMMITTING SOME OF MY TIME AND ENERGY FOR THE BETTERMENT OF RB&C. I AM CONCERNED THAT MY FULL PARTICIPATION IN FAC MAY BE CHALLENGED BY THE FOLLOWING . . .

Circle all that apply.

1st Language Childcare Transportation Financial Hardship
Other _____

I WOULD DESCRIBE MY FAMILY’S EXPERIENCE(S) WITH RB&C AS

I BELIEVE THAT I HAVE THE FOLLOWING SPECIAL SKILLS AND / OR EXPERIENCES TO OFFER AS A MEMBER OF RB&C’S FAC

I HAVE INTEREST AND/OR SKILLS IN THE FOLLOWING AREAS

- | | | |
|------------------------------|------------------------|--|
| Hospital Committees | Recruiting | Advocacy |
| Hosting Social Events | Secretarial | Legal |
| Financial | Telethons | Writing/correspondence |
| Marketing | Public Speaking | Visiting with patients/families |
| Web Design | Communications | Focus Groups |



SIGNATURE _____
DATE _____

Please mail completed application to:

**FAMILY ADVISORY COUNCIL (FAC)
RAINBOW BABIES AND CHILDREN'S HOSPITAL
C/O PEDIATRIC NURSING ADMINISTRATION
11100 EUCLID AVENUE, MAIL STOP RBC 6001
CLEVELAND, OH 44106-6001**



Seidman Patient and Family Advisory Council Nomination Form

Dear Faculty and Seidman Cancer Center Staff –

- ◆ In 2010 Seidman Cancer Center launched the Patient and Family Advisory Council (PFAC).
 - ***Our Mission Statement*** is to engage patient and family advisors as partners in improving quality, safety, and the patient/family care experience.
- ◆ We are actively recruiting patients and family members representing a diversity of age, gender, economic status, educational background and family structure.
- ◆ Candidates for this group should represent a diversity of cancer diagnoses and clinical experiences from University Hospitals Seidman Cancer Centers at Case Medical Center, Chagrin Highlands, Landerbrook, Westlake, Sharon Center, or the Breast Center.
- ◆ Patient Candidates can be: in active treatment, follow up care, or a cancer survivor of the Seidman Cancer Center.
- ◆ Family Candidates can be: someone who journeyed with a Seidman Cancer Center patient or former patient and who was designated as “family” and is not required to be legally related.
- ◆ Candidates should be able to attend evening meetings the first Monday of each month and commit an additional 2-3 hours a month on projects or committees.
- ◆ Candidates should be interested in serving as advisors, comfortable in speaking in a group with candor, able to use their personal experience constructively, and able to see beyond their own experience.
- ◆ If you have a patient or family member to nominate to the Seidman Patient and Family Advisory Council please contact Marge Galla, Volunteer Services, 216-844-1504 / Margaret.galla@uhhospitals.org with the following information:

Your Name: _____

Nominee Name: _____

Age: _____

Gender: _____

Diagnosis: _____

Any other relevant information:



Patient and Family Advisory Council (PFAC) Membership Committee SOP

Patient and Family Advisory Council (PFAC) Nomination Process

1. A potential Seidman Cancer Center PFAC patient or family advisor can be nominated by any clinical staff member or can be self-nominated.
2. The potential SCC PFAC patient or family advisor will complete the PFAC Advisor application.

Patient and Family Advisory Council (PFAC) Application Process

1. Seidman PFAC Advisor application package will be completed and submitted to University Hospitals Case Medical Center Volunteer Services.
2. UH CMC Volunteer Services will acknowledge to applicant that PFAC Advisor application package was received.
3. UH CMC Volunteer Services will solicit SCC Clinical staff feedback/nomination on potential applicant.
4. UH Volunteer Services conducts a phone (or in person) interview with the potential candidate.
5. If the potential applicant is declined by either UH CMC Volunteer Services or SCC PFAC Staff Steering Committee and Co-Chairs, skip to step #9. If applicant is approved by Volunteer Services and there are no objections by Seidman Staff, process continues.
6. Members of SCC PFAC Membership Committee (at least one Patient/Family Advisor and one PFAC Staff member) conduct an interview with applicant. (The preferred interview method is “in person,” but a phone interview is also acceptable).
7. Following the interview, the SCC PFAC Membership Committee members will formulate a recommendation to “accept” or to “decline” the applicant. This recommendation will be presented at the next monthly SCC PFAC meeting.
8. A majority vote by a quorum council at a SCC PFAC monthly meeting will be required to accept an applicant.
9. All applicants, accepted or declined, will be notified in writing by UH CMC Volunteer Services.
10. An “accepted” applicant becomes a New Member and then completes UHCMC Volunteer Services Orientation, background check, finger printing and SCC PFAC Orientation. (UHCMC Volunteer Services on-boarding will be abbreviated Applicant is already a UH Volunteer.)

The Seidman Patient or Family Advisor PFAC Application Package includes:

1. Seidman PFAC brochure
2. UHCMC Volunteer Application Form
3. Seidman PFAC Clinical Staff Nomination Form
4. Seidman PFAC potential advisor Application Form

The Seidman PFAC Membership Committee SOPs

1. The Membership Committee shall be a Standing Committee of the Seidman Patient and Family Advisory Council. It shall be composed of 2 - 4 PFAC Patient/Family members and 1 - 2 PFAC Staff members. Patient/Family members shall serve for at least one year. Staff members may serve "ad-hoc" or for one single term.



A Checklist for Patient and Family Advisors Joining a Patient and Family Advisory Council

Checklist

Date

- I understand that by being a PFAC member, I am volunteering my time to University Hospitals and PFAC related activities.

- I understand that all University Hospitals' patient and family Information is strictly confidential.

- I acknowledge that I do NOT have any grievance(s) with University Hospitals or any of its employees.

- I have been in contact (telephone, e-mail etc.) with my PFAC mentor and/or Staff Liaison.

- I understand that my PFAC mentor, staff liaison, or is my PFA co-chair is my first contact should I have any questions regarding PFAC activities.

- I understand that I am expected to let the PFAC PFA co-chair or Staff Liaison know if I am unable to attend a monthly meeting, or if I am planning to participate in a meeting via conference call.

- I have reviewed the PFAC Bylaws/Charter and agree to the terms of PFAC membership.

- I understand that I am expected to be an active member of the PFAC and actively participate in PFAC related activities.

- I have completed my interviewing with the PFA co-chair and Staff Liaison.

- I have completed and returned my University Hospitals Volunteer Services application.

- I have completed my interview with Volunteer Services.

- I have completed by PPD / TB test and have received my flu vaccine (or turned in paperwork to indicate I have received it).



Date

- I have received my UHHS I.D. badge from Volunteer Services.
- I understand that I am expected to wear my UHHS I.D. whenever I am on campus for PFAC related business, and whenever I am acting as a representative of PFAC anywhere else in the community.
- I have attended a UHHS new volunteer orientation and training session.
- I understand that I am to submit my PFAC related volunteer hours at monthly PFAC meetings.
- I know what to do if I meet another parent who expresses interest in becoming involved with the PFAC. (Contacting the Staff Liaison or patient and family co-chair).

I would like additional information or orientation in the following areas:

Plan for more information or orientation:

Patient and Family Advisor **Date**

Staff Liaison **Date**

PFA PFAC co-chair **Date**

Recruitment Strategies

There are many different ways to recruit patients and families to serve on Patient and Family Advisory Councils. Much of their availability will depend on whether or not they are well, have the time to volunteer, and are able and willing to make a commitment to the PFAC.

Examples of recruitment strategies:

- Educate and speak to nursing, physicians, social workers, and other members of the care team in department meetings about the PFAC, the group's goals, the necessity of diversity, and recruitment
- Hold an open house to discuss exploration of a PFAC with potential patients and families. This can be done via telephone or US mail
- Design an internal brochure that could be placed in multiple places within the organization. Some patient and family members may self refer.
- Discuss the PFAC often, in various meetings, and the need to identify members. This will also start to integrate the utilization of the PFAC in the organization's culture
- Talk with your patient advocates within the organization. They have many insights with many patients and families and may be able and willing to identify potential PFAs for the PFAC
- More advanced recruitment would be marketing on the organization's website
- Review returned Press Ganey and HCAHPS survey comments, and recruit if a patient left their name
- Place an ad in the local community newspaper that the organization is looking for current or former patients and families to volunteer on a PFAC
- Recruit through University Hospital's Patient Experience Retreats
- Discharge follow up phone calls
- Appreciative Inquiry, PEARLS, or leadership rounds
- Educating and working with Primary Care Physicians for referral and recruitment

Time Commitments

Like any council or committee it is important to have different insights and perspectives to bring depth to the conversation. Term limits for PFAs on PFACs is important for the following reasons:

- Health care delivery is constantly changing, therefore patient and family experiences and perspectives may change.
- Other patients and families may be interested and should be given the chance to participate.
- New members bring new perspectives and new energy to the PFAC.
- Naturally, PFAs may want or need to come off the PFAC.
- To keep the patient and family perspective current.

Although term limits put a time line on a PFA's participation on a PFAC, it does not mean the PFA needs to stop sharing the patient perspective or volunteering. PFAs may graduate and find other opportunities on many different committees within the organization after they have reached their term limit on a PFAC. In addition, they may also still participate of the PFAC, but the PFAC may choose to have no voting privileges for those members.

In addition, the PFAC should meet at least 10-12 per year; this keeps the momentum of the group moving forward, and decreases the likelihood of PFAs not returning to the group.

Last, there can be "homework" in between meetings. It is important to remember that what the PFACs do in between meetings is just as important to what they do during the meetings. On average, the time allotted for other work really depends on how involved the PFA and PFAC is. If a PFA just wants to do document review it may be anywhere from 1-3 hours, whereas another PFA who wants to be at the organization interacting with staff, patients, and families, it could be 10-25 hours. It all depends on the availability and interest of the PFA.

Mission, Vision, Charter, and Goals

Every PFAC should have a mission and vision that illustrates how they would like to be seen and heard by the organization. In addition, by creating a charter, it will help the PFAC to stay structured, create healthy turn over of PFAs, and maintain focus on the PFACs goals. The charter should be reviewed once annually or as a topic is brought up by the PFAC. It is important when developing PFAC goals to encourage the group to drive what those goals might be. Although the group should be educated on the goals of the organization, patients and families may see other opportunities from the patient perspective that need enhancement or improvement.

Breakdown of Bylaws (what should be included):

- Eligibility of membership
- Term limits
- Meeting schedule
- Roles and responsibilities
- Required training and orientation
- PFA expectations
- PFA leadership role descriptions
- Current PFAC roster (PFAs and staff)
- Annual bylaw and other review process
- Processes/steps if PFA is struggling with commitment to the PFAC

The following pages will offer examples of PFAC missions, vision, charters and goals.

Missions and Visions

Rainbow Babies and Children's Hospital FAC:

Mission

To Partner. To Educate. To Lead.

Vision

The Family Advisory Council (FAC) partners with Rainbow Babies and Children's Hospital (RB&C) in the pursuit of excellence in Patient and Family Centered Care. Through patient and family feedback we:

- advocate for patients' preferences and needs
- assist in providing information and education for patients, families, and staff
- and help RB&C ensure physical comfort and emotional support of patients and their families.

By succeeding in these, we strive to be recognized as a national leader in Pediatric Patient and Family Centered Care.

Seidman Cancer Center PFAC:

The *mission of Patient and Family Advisory Council (PFAC)* is to improve upon the quality and safety of cancer care at University Hospitals in partnership with patients, families and healthcare providers.

Case Medical Center MedSurg PFAC:

To enhance the hospital experience for all patients and families.



Family Advisory Council Bylaws

I. PURPOSE

The UH Rainbow Babies and Children's Hospital (RB&C) Family Advisory Council (FAC), Parent Advisory Councils (PACs), and Parent Advisors are resource committees comprised of parents and staff that collaborate with RB&C administration to improve and enhance the patient and family experience.

1. FAC- The overarching group of RB&C parents and administration that collaborate to address the needs of patients and families
2. PACs- PACs are family-led, specialty specific groups of family members and staff who work together for quality, safety, and patient experience improvement
3. Parent Advisors- RB&C parents that sit on various improvement or initiative committees that do not necessarily participate on FAC or a PAC

II. RESPONSIBILITIES

1. To solicit and identify family needs, concerns, and suggestions to channel the information to RB&C administration
2. To promote better understanding of the mission, vision, programs, and services of RB&C among the parents, patients, guardians, and the community in which RB&C serves
3. To share community needs and concerns with RB&C administration
4. To develop a core group who are knowledgeable and committed to serve as advisors for RB&C's children and families, and its programs, policies, and services
5. To champion patient and family engagement (PFE) and activation improvement and initiatives for patients and families at RB&C
6. Addressing family needs through RB&C's FAC

III. STRUCTURE

- A. MEMBERSHIP:** Total membership shall not exceed sixteen (16) voting parents.
- B. OFFICER TERMS:** Election of officers for the upcoming year shall take place no later than November 30th of each year. Officers will serve a two-year term beginning January 1st and are eligible for re-election. Officers shall be elected by the majority vote of the members present.
- 1. PRESIDENT:** Duties shall be assigned by the FAC, including:
 - a. Call and preside over all FAC meetings
 - b. Provide overall direction for all FAC activities
 - c. Be the official spokesperson for FAC
 - d. Keep members informed of pertinent information affecting FAC
 - e. Supervise preparation of reports for FAC as appropriate for distribution.
 - 2. VICE-PRESIDENT:** Duties shall be those assigned by FAC or the president, including:
 - a. Performance of all duties in absence of the president
 - b. Assist the president with duties as requested
 - c. Schedule and distribute FAC meeting dates
 - d. Succeeds to presidency upon its vacancy
 - 3. SECRETARY:** Duties shall be those assigned by the president or FAC, including:
 - a. Record attendance and minutes of all meetings
 - b. Distribute minutes to all members prior to the next month's meeting
 - c. Notify members if meetings are cancelled
 - d. Send thank you notes as required to guest speakers, etc.
 - e. Send correspondence (e.g. Congratulations, thank you, etc.)
 - f. Maintain a current membership roster
 - g. Make available FAC notebooks to each new member
 - h. Finalize and compile FAC quarterly reports.
 - 4. PROJECT MANAGER:** Duties shall be those assigned by the FAC or the president, including:
 - a. Track projects from conception to completion
 - b. Monitor action steps through review committees
 - c. Provide a yearly update of FAC projects describing the activities of FAC and identifying matters that require further action

- d. Responsible for updating FAC accomplishments in quarterly reports to the office of the president

C. COMPOSITION:

1. At least one half of the members shall be parents/guardians of children who are currently or have been patients of RB&C within the last 5 years.
2. Those that serve at other community organizations that have a direct partnership with RB&C may be a FAC member.
3. RB&C FAC will be represented by but not limited to the following disciplines:
 - a. Physicians and residents
 - b. Family and child life services
 - c. Social work
 - d. Administration
 - e. Rehabilitation services
 - f. Quality and safety initiatives
 - g. Nursing
4. The UH Rainbow Babies and Children's Hospital Foundation may have one (1) full FAC member.
5. Other FAC *visitors* may be family members including parents, grandparents, brothers, sisters, or members of community agencies who serve children, but have no voting responsibility.

D. MEMBERSHIP TERMS: Membership status may be granted and maintained under the following conditions:

1. Completion of a membership application form provided by the FAC president and Membership Committee chair
2. A thorough interview by the president, membership chair, and administrative liaison
3. Formal volunteer services screening, training, and interview
4. Attend at least eight (8) regularly held meetings during the calendar year
5. Members shall notify the president and administrative liaison by phone or email if they are unable to attend a council meeting, if at all possible, 24 hours in advance. If no contact is made it will count as an unexcused absence
6. Each member will serve a 2-year commitment, after 2 years, if in good standing; a member may reapply to serve an additional 2 years on FAC
7. If a parent is not fulfilling their role in FAC, they may be excused from their duties by the president, vice-president, and staff liaison
8. Resignations shall be submitted, in writing, to the president and administrative liaison

E. COMMITTEE STRUCTURE:

1. Committee officers shall be full voting members of FAC.
2. FAC members shall vote upon committee chairs. Each committee chair will serve one year and may continue to work within that committee after the year term has ended. This term may be extended with the availability of a new parent who has an interest and dedication to fulfill the committee chair role.
3. FAC members may choose and be interviewed for what committee they would like to serve with proper training before performing committee activities.

F. PARENT ADVISORY COUNCILS (PACs)

1. PACs are family-led, specialty specific groups of family members and staff who work together for quality improvement and the promotion of Patient and Family Centered Care within that specialty.
2. PAC groups can rely on FAC for support and guidance. PAC groups have full access to FAC programs, including Outreach, Family Faculty, Social Committee, and Membership and Recruitment. The PAC groups can rely on FAC for guidance and hospital administrative support through the relationship with the UH RB&C administrative liaison and the FAC president.
3. Leadership must consist of at least one family member and a staff liaison. One FAC member will be assigned to each PAC group to serve as its liaison to FAC if there is not already a FAC parent who regularly attends the PAC meetings. FAC liaison members will attend at least one PAC group meeting quarterly and report progress and concerns to FAC. Each PAC will meet regularly and minutes or a summary of their meetings will be shared with FAC, through the liaison, after each meeting. FAC strongly encourages PAC groups to establish goals and objectives.

G. PARENT ADVISORS

1. Parent Advisors are individuals who have personally or whose family members have utilized the services at RB&C. Advisors provide the parent/patient perspective on hospital committees, performance improvement projects, reviews of printed information, and other assignments as requested.
2. Parent Advisors may also be honorary members from FAC who want to continue to give back to RB&C and its patients and families.
3. Parent Advisors are also experienced parents that serve on individual PACs to support, educate, communicate, and perform Outreach with inpatient and outpatient families.

IV. COMMITTEES: All committee chairs will give an update or report at each monthly meeting. They will also provide an annual report of all activities.

A. OUTREACH

1. Visiting parents/patients in the hospital, with appropriate training, and reporting visit results to the FAC administrative liaison, unit nursing manager, and Outreach chair. Responsibilities include, but are not limited to:
 - a. Identify potential Outreach volunteers in conjunction with FAC recruitment.
 - b. Work with specific hospital units to identify families that could potentially benefit from an Outreach visit.
 - c. Gather information from families on how to enhance their hospital stay and experience.
 - d. Support and orient new FAC members who will serve on Outreach.

B. FAMILY FACULTY

1. Prepare and give presentations regarding but not limited to: parent/patient satisfaction and experience, children with complex medical needs, children with special needs, losing a child, Patient and Family Centered Care, patient and family engagement, hospital expectations, and communication with care teams. Presentations will be given to:
 - a. Staff orientation classes: nurses, residents, Child Life specialists, therapists, frontline staff, etc.
 - b. Medical and healthcare students
 - c. Public and private field-related seminars (Grand Rounds)
 - d. Division retreats

C. SOCIAL COMMITTEE

1. Social Committee members will be involved with the following events as necessary to promote FAC and offer parent support to those who are currently admitted in the hospital. Events include:
 - a. “Be Our Guest” luncheons and dinners
 - b. Mother’s Day brunch
 - c. Coffee gatherings or Ice Cream Socials
 - d. Dinners in the Ronald McDonald Room
 - e. Any special holiday or seasonal celebration event

D. MEMBERSHIP AND RECRUITING

1. Membership and recruiting member will work on new initiatives for recruiting. Extended responsibilities include:
 - a. Recruit and sustain a strong and diverse membership.

- b. Participate in the application process; the chair of this committee will interview candidates with the administrative liaison and FAC president.
- c. Provide appropriate training and orientation of new FAC parents including FAC responsibilities.
- d. Partner new parents with a FAC mentor for appropriate training.

F. AD HOC COMMITTEES

1. These committees will be set according to the necessary need for organization of projects and documents. They are time sensitive topic specific. (Example: rewriting of bylaws, marketing, etc.)
 - a. The president may at any time with the approval of FAC designate such standing and special committees as needed
 - b. Committee chair shall maintain accurate records and minutes of committee meetings
 - c. Committee chair shall advise the FAC president of committee activity via email reports
 - d. RB&C FAC will oversee any ad hoc group with one member (committee chair) of the ad hoc group committed to RB&C's FAC

V. PROCEDURES

A. MEETINGS

1. FAC will meet no less than 10 (ten) times per year taking off the months of January and July
2. All FAC members and representatives will receive a seven-day notice for regular meetings and ten-day notice of special meetings via email
3. Simple majority of the membership will constitute a quorum

B. VOTING: For issues that require voting, such as the election of officers, advisory recommendations, committee officer elections, or selection of members for tasks, the procedures shall be:

1. Each parent member shall have one vote

C. BY-LAWS: These by-laws may be amended at any time by a simple majority vote of FAC members, including administrative members, by presenting the amendment at the meeting. In addition, the bylaws will be reviewed annually for any changes, edits, or suggestions.

D. MEETING AGENDAS: The president, vice-president, and administrative liaison will develop all FAC meeting agendas with considerable input of hospital activities, administrative and frontline staff presentations, FAC parent issues, and other concerns regarding FAC.

VI. PLANNING, REPORTING, AND EVALUATION:

- A. The FAC will develop an annual report, including goals, objectives, and accomplishments which will be prepared for member approval at the August meeting.
- B. Minutes and attendance will be kept of all FAC meetings and distributed to the members by the secretary. If the secretary is absent, the vice-president will record minutes and attendance.
- C. All events organized by FAC or statements issued by it on behalf of RB&C will be carried out only with prior approval of the RB&C administrative liaison.

VII. CONFIDENTIALITY: No RB&C patient and/or family member will be discussed by name in council meetings. If council members have input regarding a particular patient or incident, that information will be channeled to the RB&C administrative liaison.

VIII. GUIDELINES OF AUTHORITY: The FAC has authority granted by the RB&C administration. The FAC cannot enter into agreement or bind RB&C in any matter.

IX. SUPPORT OF RB&C, THE FOUNDATION AND THE BOARD: All RB&C

- staff and the RB&C Board are committed to the mission of the Family Advisory Council and provide ongoing support to the activities of the FAC.
- A. The RB&C administrative liaison will work with the FAC president to coordinate activities and establish mechanisms for dissemination of FAC information to the RB&C administration, foundation, board, and other individuals as needed.
 - B. Members will receive parking validation.
 - C. Members who perform Outreach, Social, and Family Faculty activities including education, seminars, and travel may receive complimentary parking for their time at the hospital plus an honorarium.



SEIDMAN PATIENT AND FAMILY ADVISORY COUNCIL BYLAWS

Article I: Name

The name of the program is the Patient and Family Advisory Council of the University Hospitals Seidman Cancer Center (UH SCC).

Article II: Mission

To engage patient and family advisors as partners in improving quality, safety, and the patient/family (caregiver) care experience at all UH SCC locations.

In our patient and family centered care environment, we define 'Family' as individuals supporting our Patients in their personal lives.

Article III: Members

Section 1: Membership eligibility

Patients, family members, staff and faculty from the UH SCC are eligible to be members of the Council. Members should be committed to building a partnership between patients, caregivers, and staff to enhance patient care delivery.

Section 2: Council structure

The voting members of council should include:

- 16 - 20 diverse patients and/or family members
- 8 UH SCC staff and faculty members comprised of, but not limited to clinical, administrative and ancillary staff.

At least two thirds of council will be patients and family members and one third will be staff advisors=

Section 3: Participation

Members are expected to actively participate in monthly Council meetings (about two hours/month) and on committees or projects that may require an additional one-to-three hours per month.

Please see UH SCC Patient and Family Advisory Council Standard Operating Procedures – UH SCC PFAC SOP (provide reference)

UH Volunteer Services Coordinator will follow up with any member who has missed three PFAC meetings in a row without prior communication. Pending the outcome of



that dialogue, a recommendation may be made to the membership committee for a change in membership status, placement on a leave of absence, or removal from Council. This affords the Council an opportunity to ensure Council quorum.

Section 4: Term of membership

A term is two calendar years. It begins the January closest to membership enrollment – December. A term can be renewed no more than 3 times. (Recommend consecutive or non-consecutive terms for a total of six years)–The purpose of term limits is to encourage new membership each calendar year.

On Board	Term Begins	Term Ends
January – June 30th	January Current Year 1	December Year 2
July – December 31st	January Year 2	December Year 3

Section 5: Vacancies / Leave of Absence

Council members may resign or request a leave of absence from the Council at any time. A Council member may request a leave of absence when circumstances require they be absent from meetings and activities for 3 to 6 months. Please see PFAC SOP (provide reference)

Section 6: Recruitment

Council members, staff and faculty will be used to recruit and recommend future members. Patient and family members may also apply directly through UH Volunteer Services.

Section 7: Selection

Applicants must complete the SCC PFAC Volunteer Application and screening process. Please see PFAC SOP (provide reference)

Section 8: Emeritus Members

Members who have served three terms may become Emeritus members:

- Upon request,
- With the recommendation of the Co-Chairs and,
- With ratification by the Council

They will be welcomed at all Council meetings and their input will be valued. They will not have Council voting rights but they may represent the Council on committees and projects if they are able to and their volunteer status is current.



Section 9: Associate Members

A former active member may become an Associate Member to serve as needed:

- Upon request,
- with the recommendation of the Co-chairs, and
- with ratification by the Council

Associate Members will not have a vote, but may attend meetings and take part in the discussions. Associate members may serve on committees of the Council. A member may serve in an Active or Associate Member role for no more than a combined six years. Please see PFAC SOP (provide reference)

Article IV: Officers

Section 1: Officers and Duties

There shall be two Chairpersons, known as Co-Chairs, and a Secretary. One Co-Chair shall be a patient or a family member. They will be elected as set forth in Article IV, Section 2. The Staff Advisor Co-Chair will be the UH SCC Director of Patient and Community Programs. He/She will serve as UH PFAC representative and is responsible for all administrative functions of the Council.

The Co-Chairs are responsible for:

- setting Council meeting agendas (including guest presentations and projects coming before PFAC)
- facilitating and conducting meetings.
- coordinating activities between Council members and staff
- providing leadership for the Council members
- serving on UH SCC committees where the Chairs are requested.

The Secretary shall be appointed by the Co-Chairs. He/She will:

- take minutes and tally all votes at Council meetings
- finalize the drafted minutes after input from the Co-Chairs.

[Address the up-to-date record of Council accomplishments].

Other officers may be appointed by the Co-Chairs and approved by the Council. They may serve a term of two years, renewable for one term.

Section 2: Nomination Procedure

Candidates for the Patient/Family Co-chair position must serve as an active member for at least one year. Nominations can be made by any active member with at least one year of service.



Section 3: Election Procedure

Officer nomination will occur at the September meeting. Officer election will occur at the October meeting. Both processes require an affirmative vote of the majority of eligible members voting.

Section 4: Term

The standard term for officers will be two years. A member may not serve more than two completed consecutive or non-consecutive terms as Patient/Family Co-Chair. The term of office begins in January of the next year.

Section 5: Vacancies

A Patient/Family Co-Chair may resign from office at any time. The Council may choose to elect a replacement to complete the term of the Patient/Family Co-Chair or leave the position open until the next scheduled election. The completion of the partial term is not contributory to any term limit.

Following the completion of the vacated partial term, the interim Co-Chair would be eligible for nomination and election to a full two year term as outlined in Article IV, Section 4.

Article V: Meetings

Section 1: Regular Meetings

Monthly meetings of the Patient and Family Advisory Council will be scheduled at a time chosen by the Council. The meetings will last 2 – 3 hours.

Section 2: Special Meetings

Special meetings may be called by the Co-Chairs as needed as long as a quorum is met.

Section 3: Quorum

Any council meeting requires the presence of at least one half of the voting members to be called to order or to pass a motion.

Section 4: Voting

In addition to voting in person at the Council meetings, votes may be done electronically (email), except where specifically requested to be in person. Electronic votes require a response (yes, no, or abstain) from a quorum of all voting members. Absentee voting will be allowed for issues of council governance or any issue discussed at a prior meeting, per membership policies.



Article VI: Committees

Section 1: Standing Committees

Council will have standing committees on which members may serve. Committees shall be chaired by a Council member, either Patient/Family Advisor or Staff.

Section 2: Cancer Center Committees

The Cancer Center has several Committees on which Council members may be appointed to serve.

- UH SCC Operational committees (Quality, Patient Education, Chemotherapy Safety, Breast Cancer Task Force, etc)
- UH SCC Patient Experience Rounds and activities
- Patient/Family Advisor Co-Chair is appointed to serve on the Seidman Cancer Center Extended Leadership
- Patient/Family Advisor Co-Chair is appointed to serve on the Seidman Executive Quality Committee

Section 3: Special Committees

As needed, the Co-Chairs may convene a special committee or task force to further the work of the Council. This may also come at the request or recommendation of a Council member.

Article VII: Amendment Procedure

An amendment to the UH SCC Patient and Family Advisory Council Bylaws must be submitted in writing at a regular meeting and be included in the minutes of that meeting given to Council members.

A vote on the amendment can be made at a subsequent meeting by the affirmative vote of a two-thirds majority of members eligible to vote.

Article VIII: Bylaw Review

Bi-annually, the Council Bylaws shall be reviewed by an ad hoc Patient and Family Advisory Council subcommittee. Any proposed changes will go to the full council for vote.

Patient and Family Advisory Council Goals

Aligning the goals of the organization and the PFAC will help in addressing what activities, projects, and development of initiatives should be started and executed. It is important for the PFAs to understand the goals of the organization, but also very important for the organization and its leaders to understand the goals of the PFAC. By aligning, much can be accomplished and the PFAC can be more integrated on to working teams within the organization.

Goals of the PFAC should be visible during every meeting. It helps to keep the PFAC on track and to remain focused on what they would like to achieve. In addition, a review of these goals at every meeting, and current status, is beneficial. The goals should also be shared with many different departments within the organization, this keeps the PFAC aligned and other staff aware of what they would like to achieve in partnership and collaboration.

The following examples show goals that were produced out of a brainstorming exercise that included 4 different PFACs at University Hospitals. This exercise was conducted by 2 Staff Liaison's at a joint PFAC meeting that was held in July of 2014. This meeting included the Seidman, Case Medical Center MedSurg, Rainbow Babies and Children's, and Case Medical Center Psychiatric PFACs. In addition you will see the individual PFAC goals for Rainbow Babies and Children's Hospital and UH Parma for 2015.

Brainstorming Exercise

N=27 respondents

The first part of this exercise was to have conversation with other PFAC members about their journey to the group. There was much positive feedback about getting to know other members, sharing ideas and listening to the stories. The common themes for getting involved with the councils were the desire to:

- improve the overall hospitalization experience
- give back to the hospital
- feeling strongly about improving the communication with caregivers.

The second part of the exercise asked:

What (change) would you like your council to accomplish or be involved in?

1. Move our group forward as leaders in family centered care.
2. More representation on hospital committees, especially quality, safety and education
3. Share personal stories with all levels of caregivers
4. Teach family centered care at the university level (x3)
5. More diversity in membership (gender, race, socio-economic, single parents) to better reflect the community the hospital serves (x6)
6. To promote BCMH (children with medical handicaps) coverage
7. Formal training for outreach volunteers
8. Participate in staff in-services about the family's perspective and education and updates about the Council
9. Better communication and collaboration with staff (x6)
10. Arrange conference call or Skype option for meetings
11. More diverse membership (not staff). Rainbow have volunteers who move on when child is well
12. Arrange a yearly PFAC retreat
13. Continue advocacy for the elderly
14. Increase membership
15. To improve diversity on councils assistance with transportation and child care should be considered
16. Develop consolidated billing; add date of billing, date of service and provider who ordered service and billing contact number
17. Provide feedback on advance directive literature, especially before implementation
18. Participate in orientation of new nurses about patient and family centered care
19. Increase the availability of cancer support groups at the main campus
20. Better marketing of the PFACs both in the hospital and at community events
21. Regular involvement with menu review
22. Develop a booklet about abdominal surgery
23. Explore an app for a clinical trial search
24. Increase speaking opportunities to promote the PFACs (x2)
25. Direct outreach to patients and families in need of comfort



Overall Themes:

Teaching: Sharing personal stories, to clinicians (staff meetings) and at the university, in orientation of new nurses, speaking opportunities, booklet on abdominal surgery. Formal training of PFAC members. Use Skype or conference call for PFC meetings.

Safety: involvement of council members in committees

Hospital processes: billing, Advanced Directives, develop an app for clinical trials, review menus. Use PFC members as leaders in Patient and Family Centered Care.

Outreach: to patients and families, advocacy for elderly, BCMH coverage (for children with medical handicaps), and cancer support groups, marketing of PFC at outside events.

Membership: increase, focus on diversity

RB&C's 2015 FAC Goals:

- Transitions in pediatric care to adult care At UH
- Re-energize Outreach, peer to peer support, and education and training for PFAs
- Sending 2 PFAs to national conferences related to Patient and Family Centered Care or Patient and Family Engagement
- Ongoing bereavement services
- Advocacy goal of making sure RB&C specialists are covered by Benefits for Children with Medical Handicaps (BCMh)

UH Parma's 2015 PFAC Goals:

- Finalize and complete the structural framework of this committee including development of bylaws with mission and vision, increasing patient and family membership on the council by the end of the 2nd quarter of 2015.
- Grow awareness of the PFAC across all levels of the organization and in the community. Staff will be educated by the end of 2nd quarter of 2015 by means including, but not limited to, Computer Based Training, and standing agendas on RBC council, leadership meetings, and staff meetings. Physicians will be informed and educated through General Medical staff meetings as well as the Medical Staff newsletter. Community awareness will increase through PFAC advertising in community newsletter.
- UH Parma PFAC will be instrumental in helping organization strategize and implement system of identification of physician and staff caregivers for patients by the 4th quarter of 2015.

Budget Considerations

Sustaining and running a PFAC takes effort and resources. It is important to consider the PFAs volunteering their time, the PFACs successes, and whether the organization may decide to send PFAs to conference or other educational sessions.

Incentives and Awards for Patient and Family Advisors:

Although PFAs are aware they are volunteering time, it is always an appropriate gesture to offer lunch or dinner (depending on when the organization holds PFAC meetings) and parking. Other ideas for incentives are:

- Giving back to patients and families, and helping others
- Giving back to University Hospitals
- UH tote bags, pens, or lanyards when a PFA joins the PFAC
- Small honorariums for time spent on activities (this would be optional for the PFA to take)
- Letters of thanks and appreciation from the organization's president
- Annual meeting with organization's president to work on goals
- Annual celebratory dinner with recognition of goals and work accomplished
- Making a difference in the hospital and the lives of the patients and families we care for
- President letter to each PFA for appreciation and recognition

Annual Resources for a PFAC:

At UH Case Medical Center the average annual budget ranged from \$600-3660. This can vary greatly depending on the operating budget from which the resources are coming from (nursing, quality, auxiliary, operations, foundation boards, grants, etc.), and whether or not the PFAC may send PFAs to conferences or educational sessions.

Resources also depend on materials, brochures, food, activities (such as Be Our Guest lunches and dinners), travel (if any), or incentives or gifts of recognition for PFAs. The annual cost also depends on what the organization is willing to spend to maintain the group, provide further education, and other opportunities for the PFAs.

Best Practices for Successful Meetings

There are many ways to have successful meetings. Typically a PFAC's agenda is quite full, so pacing the group is important. Here are some of the best practices across the University Hospitals System for meetings:

- Tents with each PFA and staff's name and role
- Introduction of every member and guests
- Visible PFAC goals at every meeting for review and assessment
- Senior leadership presence (can be rotating) to actively support and educate the group
- Staff Liaison and PFA co-chair co-leading the meeting
- PFA secretary to record meeting minutes
- Agenda put together with PFAC input, by PFA co-chair and Staff Liaison
- Dinner provided
- Visible mission and vision
- Open discussion on ways to improve and other ideas
- Close every meeting with time for questions, staff contact information, comments, etc. This is what Seidman's PFAC calls "Speak Out".
- Time keeper to stay on track
- Annual visit (or more if time allows) from organization's president
- Visible annual PFAC goals at the meeting, on the agenda, or on a flip chart

Support and Sustainability

Senior leadership support and presence for Patient and Family Advisory Councils are critical for the successful utilization and sustainability of the groups. Some of the most successful PFACs across our nation's hospitals have at least one senior leader present at each PFAC meeting. By modeling the involvement and interest of the PFAC leaders can, like many other behaviors in an organization, show what the expectation is for PFACs and staff's involvement. It can also connect the PFAC to many other organizational initiatives and programs. In addition, PFAs can help to promote and publically speak about the organization in the community. This will help to grow loyalty of patients and families to the organization and shows that University Hospitals cares about and listens to the patient and family voice.

Staff Education:

All staff should be educated on what a Patient and Family Advisory Council, how it is structured, the goals, and the mission and vision of the group. It is also important to educate about the roles of the Patient and Family Advisors, how they are selected, and their desire to give back to the organization and patients and families. By providing education it gives staff the opportunity to learn about the PFAC, what it can do for their ideas, programs, and initiatives, and how to effectively partner with PFAs.

The next section is an example of a PowerPoint presentation the organization can customize to their own PFACs.