



Patient Family-Centered Care

Patient Family-Centered Care Strategic Plan: 2018 – 2023

**Family, Guest &
Volunteer Services Department**

Patient Family-Centered Care Program

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Addendum A

(This addition lists detailed goals, strategies, and measures for major initiatives)

INTRODUCTION

The Patient and Family-Centered Care program is a system-wide approach to pediatric care based on the assumption that the family is a child's primary source of strength and support. We recognize that parents and other close family members are experts on their own children and hold essential information that can enhance the care of their child. We acknowledge that involving families in hospital planning, evaluation, and policy-making improves children's care and that best practices are shaped by families and professionals working together.

One of the primary goals of the St. Jude Children's Research Hospital strategic plan is to improve the patient and family experience. Many facets of this portion of the plan will engage parents and caregivers as partners in work groups and implementation activities such as the Family Commons, parent app, in-room education and entertainment system, and design of new housing and outpatient facilities.

This strategic plan will outline the direction the Patient and Family-Centered Care program will go in over the next five years and beyond. It will also provide all parent advisers with a road map to ensure our efforts stay focused and on target.

I. ROLE AND FUNCTION

Patient Family-Centered Care sits within the Family, Guest and Volunteer Services Department at St. Jude Children's Research Hospital, reporting to the Patient Experience Officer. This department consists of Guest & Concierge Services, Family Centered Care and Volunteer Services. Each team is focused on the central theme of improving the patient experience.

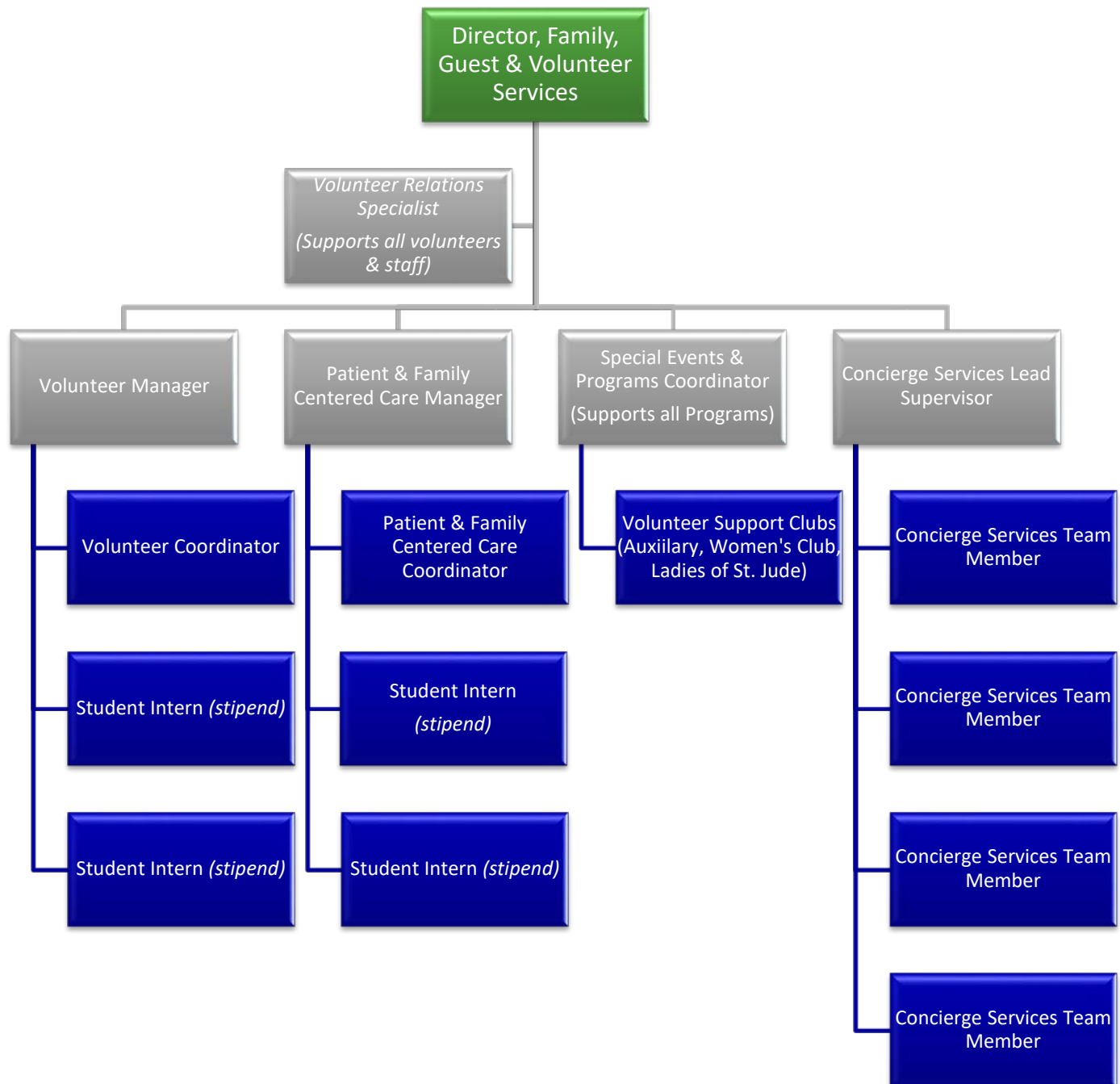
VISION of Family, Guest and Volunteer Services:

To be an outstanding and innovative team, committed to effectively engaging volunteers across all organizational levels while offering exceptional guest services to our families, patients and staff.

MISSION of Family, Guest and Volunteer Services:

Effectively engage volunteers in high quality, innovative programming while also providing professional guest services in partnership with staff and families, resulting in patient experience excellence.

Family, Guest & Volunteer Services Department Organizational Chart:



The Quality of Life Steering Council is operated under the direction of the Division of Quality of Life and Palliative Care. This Division is an integral partner with Patient Family- Centered Care staff, providing leadership, experience and guidance by engaging bereaved parent advisers in all facets of PFCC programming. The Family, Guest and Volunteer Services department provides administrative support and structure, program development, travel support, and budget for bereavement parent adviser initiatives. Both teams collaborate closely as they partner with parents, ensuring processes and systems for engaging parent advisers remain consistent.

The organization chart is as follows:



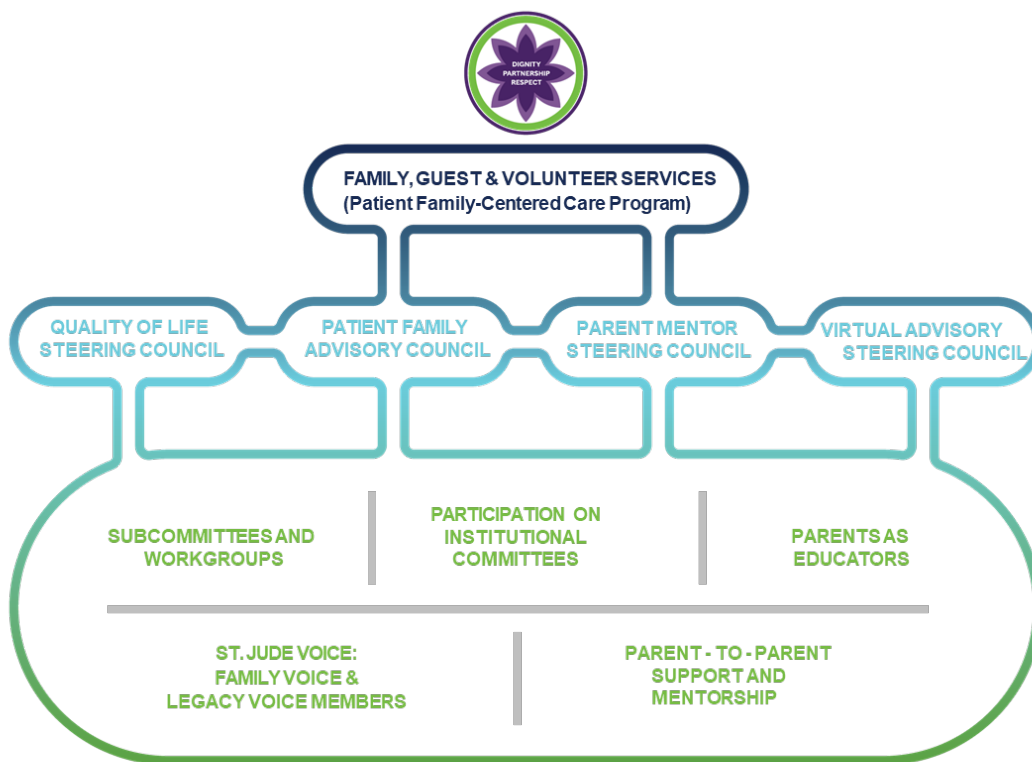
Bereaved Parent Adviser Engagement:

Bereaved parent advisers provide their unique perspective in many ways such as:

- Serving as parent educators to faculty, fellows, nurses and the psychosocial teams.
- As faculty presenters at local and national conferences, ensuring we share our knowledge and expertise with the global community to advance the field.
- Partners with staff to develop family educational materials such as *The Seasons of Change*, and *Bereavement Resource Guide*.
- Provide parent to parent support through the Parent Mentor Program and as Stay in Touch program.
- Through the structure of the Quality of Life Steering Council, bereaved parent advisers contribute to broad discussions and work groups across the institution.

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Organizational Chart of PFCC Programs:



THE DIVISION OF QUALITY OF LIFE AND PALLIATIVE CARE

is an integral partner with Patient Family-Centered Care staff, providing leadership, experience and guidance by engaging bereaved parent advisers in all facets of these programs.

- **Subcommittees and Workgroups** – advisers are brought together, often in focus-group style, to offer their parent perspective and feedback on a particular issue. Examples include Food Service menu items, School Programs service offerings, and design of the Family Commons.
- **Participation on institutional committees** – advisers are engaged in sharing the parent perspective by participating in hospital committees across all levels of the institution. These efforts are typically long term, depending on the membership guidelines of the committee. Examples include advisers serving on Facilities, Design and Construction, Quality Improvement, Grievance Committee, and Nursing Unit Councils.
- **Parents as Educators** – advisers serve on panels, speak to small and large groups, take part in conferences and symposiums and share their personal experiences with staff inside and outside the institution.
- **Parent - to - Parent Support and Mentorship** – advisers help other parents make the most of their St. Jude journey by providing them the support that only another parent can provide. This may be as a parent mentor or through one of the many parent-to-parent educational sessions, information tables, or Family Talk sessions.
- **Virtual Advisory Communities** – St. Jude Voice is an online advisory community where parents and caregivers share their perspectives about the hospital using surveys, forums, and other online activities. Those taking part can also keep up with the latest St. Jude news through posts, newsletters, articles, and videos featured on the member hub website. St. Jude Voice is made up of two communities. Family Voice represents our active and post-treatment families. Legacy Voice represent our bereaved families.

II. CURRENT STATE AND CONTEXT

For more than ten years, parent advisers have partnered with St. Jude staff. Efforts began in 2008 as a grass-roots initiative, and since then, parent advisers continually seek to advance family-centered care culture throughout the institution. Advisers ensure that patient family populations at St. Jude are well represented by serving on the Patient Family Advisory Council, Quality of Life Steering Council and Parent Mentor Steering Council. In these 10 years they have been instrumental in starting and championing many initiatives including creating and implementing the recommendations to improve the quality of palliative and end of life care and the creation and implementation of the parent mentor program. Additionally, parent advisers serve as educators, mentors and have joined many work groups, committees and focus group efforts across all levels of the organization. PFAC and QoL Steering Council meetings have allowed a venue for staff to come to one place, present ideas and gain feedback. The Virtual Advisory Communities have allowed a virtual adviser forum to enhance communication and garner diverse parent feedback.

Link to web pages listing 2018 accomplishments:

www.stjude.org/PFCC

Link to 2018 annual report:

<https://s.stjude.org/multimedia/volunteer-services/2018/>

Information and Data on the Current State:

- Current customers include staff/teams/initiatives who wish to engage parent advisers and the parent advisers themselves. Additionally, customers include all caregivers of patients, as they represent their voice and provide parent to parent support.
- Parent Advisers **come from all over the United States and oftentimes cannot meet at St. Jude/in person, making reliance on AV and virtual technology required.** This also requires that the involved parent adviser have access to a computer, wireless internet, and the skills to navigate to a WebEx meeting or phone conference.
- **Parent advisers are onboarded as volunteers.** They are screened and interviewed by various staff members and parent adviser leaders, background checked, oriented and trained for the role they are assigned. All involved parents, regardless of assignment are consistently referred to as parent advisers.
- Additional training is needed for both staff champions and parent advisers to ensure all staff are supportive in their partnership with parent advisers and that advisers are effectively engaged.

	2017	2018	2019	2020	2021	2022
New Parent Advisers	26	19				
Total Number of Parent Advisers	237	293				
Total Number of Volunteer Hours	3,065	3,168				
Adviser Engagement Events with Staff	25	61				
Patient Family Advisory Council Members (Parents)	20	11				
QoL Steering Council Members (Parents)	7	7				
Parent Mentor Steering Council Members (Parents)	2	2				
PFCC Staff Champions	31	26				
Virtual Advisory Steering Council Members	N/A	N/A				
Virtual Advisory Council Members	180	220				
Parent Mentors	PAIR (20) QoL (22) H (6)	PAIR (23) QoL (26) H (4)				
Mentor/Mentee Matches	116	81				
Parent to Parent Events	7	12				

Strength, Weaknesses, Opportunities, Threats Analysis (SWOT)

Element and Questions to consider	Feedback
<p>STRENGTHS (internal)</p> <ul style="list-style-type: none"> What are our accomplishments or strengths? What is unique about us? What do others (internally / externally) see as our strengths? 	<ul style="list-style-type: none"> Passionate and committed members 10 years of history and programming experience Structure of PFAC as forum/ and system to engage parents Staff can present to one audience and receive immediate feedback Members from all over the US - diverse regions St. Jude allows a budget for travel Members are able to give input in a positive manner; able to transition from a parent to adviser Tech tools to help us communicate and stay organized are available PFAC is well organized Platinum Partner program exists to ensure all members stay connected More staff resources now under FG&VS Support from upper administration
<p>WEAKNESSES (internal)</p> <ul style="list-style-type: none"> What could we improve? What are activities we should avoid? What are others likely to see as a weakness? 	<ul style="list-style-type: none"> Lacking wide range of diversity in culture, diagnosis, socio economic status and language Members aren't local which makes meeting in person challenging Currently not cohesively working toward a common goal - need for common strategic plan Lack of engagement between meetings via e-mail and other modes of communication Some staff don't know how to partner with parents - more education needed; in turn advisers may not know how best to partner with staff There is not a robust secondary training for advisers Culture institutionally is hard to change Some staff may see parents as "overstepping" Need more parent advisers (ratio of supply and demand is not even)

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Element and Questions to consider	Feedback
<p>OPPORTUNITIES (external)</p> <ul style="list-style-type: none"> • Are there new areas of interest that may benefit us if explored? • What strength or existing knowledge could be used differently? • Are there collaborations or partnerships that could be developed? 	<ul style="list-style-type: none"> • A lot of new parent engagement opportunities are on the horizon • Would like to see more involvement of members before decisions within the institution are made fully • Partnership and collaboration between PFAC and QOL steering council members • Looking at all advisers as part of the larger PFCC initiative • Effective usage of technology to help use strategy when selecting parents for needs • Identifying needs - creating an organized structure to allow staff to request parent adviser participation • Better tracking of parent adviser involvement and impact • Expansion of e-council – new more user-friendly web-based platform that allows two channels – active families and bereaved • Recruitment opportunities by setting up tables at key events • Advocate the value of the council by promoting data and impact • Communication through e-mail-based newsletters targeted directly at parent advisers • New nursing governance structure – can introduce best practice in working with advisers in chair/co-chair training
<p>THREATS (external)</p> <ul style="list-style-type: none"> • What obstacles we face, if any? • Are there areas in the healthcare and research industry that are changing that threaten our value and impact? • Could any of our weaknesses seriously threaten your area? 	<ul style="list-style-type: none"> • Matching advisers with an assignment that is not the right fit; maintaining program integrity • Perceptions of parent advisers (questioning value; potential conflict of interest) • Finding the right adviser who is also bilingual • Budget limitations for travel • Physicians and some staff lack understanding of the role of parent advisers or how to partner • Lack of understanding by some staff regarding the depth of how a parent can effectively partner • Receiving feedback by focus group only – and not diversifying parent adviser involvement

III. VISION, VALUES AND MISSION

Vision:

St. Jude Children's Research Hospital embraces a philosophy of patient family-centered care and seeks a respectful, collaborative partnership with the families of our patients, relying on their expertise as the primary source of strength and support for their children. We work with parent advisers in designing parent supportive services, facilities design, parent-to-staff education and adding parent perspective to delivery of care. We value families as central to patients' well-being and are committed to supporting them in this vital role from active treatment through survivorship and/or bereavement.

Values:

- We believe:
 - In creating partnerships with patients and families at all levels of care
 - In the sharing of information with patients and families in an ongoing and supportive manner
 - In respecting the diversity among families and viewing families as partners who contribute to the well-being of patients
 - In empowering all employees to be patient family-centered and focused on how they contribute to improving the patient experience
 - In providing a healing environment inclusive of facilities and programs appropriate to the developmental needs of children and families
 - In the creation of policies based on patient family-centered care concepts that promote efficiency, cost effectiveness, quality care, and flexibility
 - In providing supportive care to patients and families when their journey goes from active treatment to end-of-life and bereavement

Mission

Mission of Patient and Family-Centered Care: The Patient and Family Centered Care program intends to advance patient and family-centered care culture throughout the institution and assures that patient family populations at St. Jude are well represented when sharing experiences and perspectives. All programs within family-centered care aim to encompass the core values of dignity and respect, information sharing, involvement and collaboration.

Mission of the PFAC: The Patient Family Advisory Council is committed to serving as an organized and effective voice for patients and families through a centralized forum, allowing staff to present initiatives and gain important patient and caregiver feedback on numerous system-wide initiatives. Patient Family Advisory Council advisers collaborate and partner with staff to offer caregiver perspective into every aspect of our effort to prevent, diagnose, treat and cure childhood catastrophic diseases.

Mission of the QoL Steering Council: The Quality of Life Steering Council is committed to ensuring that children with poor prognosis for long-term survival receive the best possible treatment of disease, have the best possible quality of life, are supported along with their families in making difficult care decisions, experience a comfortable and peaceful death, and that bereavement support is provided for surviving family members and staff.

Mission of the Parent Mentor Steering Council: The Parent Mentor Steering Council guides the program by providing oversight of mentor recruitment, training and the overall direction of the program. In turn, the families of St. Jude Children's Research Hospital are offered a mentor with the unique understanding, encouragement, and support which only another parent who has walked a similar path can provide.

Mission of the Virtual Adviser Community (VAC) and Steering Council: St. Jude Voice, our VAC, offers the caregivers of St. Jude Children's Research Hospital a virtual environment to offer their feedback and explore St. Jude news at their convenience. The VAC Steering Council guides the virtual content by providing content ideas and reviewing survey proposals as well as providing general guidance for goals and direction.

IV. GOALS, STRATEGIES, AND MEASURES

Goals, strategies and measures are listed in this section for each of the main areas including, Patient and Family Centered Care (PFCC), Patient Family Advisory Council, Quality of Life Steering Council, and Parent Mentor Steering Council. Goal strategies, measures and timelines for each main area are listed in the attached addendum.

Note: Patient and Family Centered Care goal/strategy implementation will be facilitated by staff in Family, Guest and Volunteer Services, with collaboration from all areas.

Progress against goals and strategies will be discussed and reviewed among the leaders of each main group, as well as at planned meetings at least two times annually. Additionally, "victories" will be reported through the established PFCC Alert Newsletter and at quarterly meetings.

Patient Family-Centered Care Goals

- Serve as an organized and effective resource to the institution by providing the structure for parent advisers to contribute to broad discussions and work groups that directly impact patients and families. Advance PFCC culture and engagement throughout the institution with the goal of improving the patient and family experience and widely express impact.
- Recruit adequate number of diverse parent advisers to meet institutional need.
- Ensure all parent advisers feel supported and are trained to be successful in their roles. Prepare staff partners to receive and engage parent advisers effectively.
- Support institutional efforts to improve patient satisfaction, safety, quality and communication specific to performance and improvement in the delivery of patient care, adding positively to the patient and family experience.

- Share our knowledge and expertise with the global community to advance the profession and field.

For strategies and measures, see addendum.

Patient Family Advisory Council (PFAC) Goals:

- Provide a centralized forum for staff to present initiatives and gain important patient and caregiver feedback on numerous system-wide initiatives.
- Represent and serve as an organized and effective voice for patients and families in ways such as serving on committees, work groups, policy development initiatives, providing education, and the development of educational resources for patient families.
- PFAC Parent Advisers facilitate and collect feedback from the broader St. Jude patient caregiver community and will apply the knowledge gained to drive projects, prioritizing efforts listed within the St. Jude Institutional Strategic Plan.
- Ensure the PFAC is operating with excellence and that member development and support is high priority.
- Spearhead and lead the implementation of all PFCC parent advisers and staff champion appreciation programs, awards, and parent to parent led programs and events.

For strategies and measures, see addendum.

Quality of Life Steering Council Goals (QOL):

- Provide quality training for parent educators.
- Improve provider understanding of factors impacting patient, family, and medical staff relationships.
- Increase the diversity of the Quality of Life Steering Council.
- Improve the accessibility of useful information to families.
- Improve quality and diversity of existing bereavement support.
- Implement new avenues of bereavement support to fill current gaps.

For strategies and measures, see addendum.

Parent Mentor Steering Council Goals:

- Train and make appropriate peer matches along the trajectory of care to receive support from someone who has experienced a similar journey.
- Recruit enough mentors to expand the program to all major medical services and points of transition allowing for any caregiver or patient who wants peer support to be considered.

- Contribute to institutional efforts to provide enhanced Adolescent and Young Adult support, programing, and peer to peer mentorship in collaboration with Child Life and other psychosocial disciplines.
- Ensure all mentors receive appropriate support and resilience care.

St. Jude Voice, Virtual Advisory Council

- Soft launch July, 2019 with formal launch October 1, 2019
- Establish the Virtual Advisory Steering Council of parent advisers and staff champions
- Create ongoing strategy and prioritization process for content
- Maintain at least 200 members and at least one activity conducted each month

For strategies and measures, see addendum.

V. TIMELINE FOR MAJOR ACTIONS/STRATEGIES

2018	2019	2020	2021	2022
PFCC evaluation of programs complete; strategic plan written. Processes and procedures revised to operate efficiently.	Focus on increasing engagement of parent advisers, and launching virtual adviser community. All advisers are provided with secondary training for their role. Staff are provided training in receiving parent advisers.	Focus on utilizing virtual adviser platform. Staff expansion. Family Commons programming comes fully on line. AYA programming is enhanced. Collaborate with Psychology on parent mental health projects.	SJ becomes premier resource for hospitals wanting bereaved parent experience and quality improvement of parent adviser engagement. Mentor program expands to develop a short term mentoring model to include families transitioning off treatment (TOP), AYA population and H Clinic.	Development of new strategic plan in tandem with institutional plan. Parent adviser engagement is system-wide in all new initiatives involving patient care.

VI. OPERATIONS AND MANAGEMENT

Staff needed:

(Note: 1.0 FTE equals a full-time position, 40 hours a week)

Current (PFCC focused) Staff Summary in Family, Guest & Volunteer Services related to PFCC

Programming:

.4 FTE Director
1.0 Manager
1.0 Coordinator
2.0 stipended student interns
.5 Special Projects Coordinator
.5 Volunteer Relations Specialist

Current (PFCC focused) Staff Summary in Division of Quality of Life and Palliative Care:

.2 Faculty
1.0 Grief Services Coordinator
.2 Program Education Manager

Additional staff needs within 5 years

3 - .5 FTE (1.5 FTE total), part time parent advisers to staff “genius” area of Family Commons

1.0 FTE PFCC Coordinator, focusing on comprehensive parent to parent support programs (mentor, Get in Touch, Family Talk, SJ101, Parent Share space in the Family Commons, etc.)

1.0 FTE Outreach Coordinator, Family, Guest & Volunteer Services; shared with Quality of Life

1.0 Stipended student intern (year-round), Quality of Life

0.4 Administrative assistant, residing in Quality of Life

0.2 Education coordinator, residing in Quality of Life

Technology needs:

- A new Virtual Advisory web-based platform is needed to ensure its user friendly for all and thereby more relevant and usable. Enterprise Technology has placed this in their FY'19 budget proposal. Collaboration with patient app to systematize promotion of E-council.

- Continue usage and expansion of Office 365 teams to enhance file maintenance and communication between various boards, councils, and groups.
- Manager and coordinators need mobile phone
- Coordinator (and future coordinators/ part time staff) will need a laptop and mobile phone access to e-mails.
- 3 iPads to be used by parent advisers for completion of forms and assisting families while on campus.
- Consistent/reliable/quality AV operations for meetings/training with capability for WebEx, sound and presentations on screen
- Access to the parent app and in room communication system to promote parent to parent activities.

Space:

- Office space will be needed for any new FTE.
- Currently Coordinators share a small office, individual offices are needed.
- Space within Family Commons for parent adviser volunteers to host events, educational sessions, parent to parent activities, virtual and in-person meetings.
- Meeting space for 25, with 10 chairs along the outer wall needed.

Links and partnerships:

- Senior administration involvement for the purpose of aligning expectations, providing feedback and reviewing progress on a regular basis.
- PFCC should be closely aligned and work in partnership with the Psychosocial Council, Patient and Family Experience Office, Division of Quality of Life and Palliative Care, Quality and Patient Safety, Nursing Division and all department leaders.

VII. FINANCIAL PROJECTIONS

With exception of the Virtual Advisor web-based platform, all finance needs are currently accounted for through the existing operations budget. We do anticipate the need for significant annual increase in operations expense from cost center 0667 to accommodate growth in numbers of advisers and their travel needs. Cost center 0668, Day of Remembrance will also have needs for growth to accommodate expanded parent adviser travel.