



Patient &  
Family  
Partner  
Program



**2016** Annual Report



# Welcome Letter

As we reflect upon 2016, we celebrate the tremendous growth of our program, both in terms of Patient & Family Partner volunteers, and requests for patient & family engagement. The program saw over a 40% increase in organization requests for patient & family partnerships from 2015, all while still being able to match nearly 100% of requests. This success would not be possible without our dedicated Patients & Family Partners volunteering their time, whether it is becoming a Patient & Family Advisory Council member, speaking at an event, joining a committee, or consulting for an improvement project.

In addition to Stanford Health Care, the program received its first requests from Stanford University and the School of Medicine, most notably from the Design School to interview patients and families to better design a patient and family centered health care system. 2016 was also the year of physician engagement with Patient & Family Partners as we partner with physicians, medical schools, patients, and families to develop a medical school elective and engage patients and families in simulation for student and staff trainings.

Although there are many important accomplishments achieved through the incredible work being done across the organization, we have highlighted a few notable achievements from 2016:

- Stanford Health Care awarded Carolina Tejada, Patient & Family Partner, the “Volunteer of the Year” Award
- Stanford Health Care awarded the Breast Imaging workgroup, including Patient & Family Partner, Mary Robertson, the 2016 Malinda Mitchell Award for Quality and Safety, for their work in reducing wait times and improving patient experience in mammography
- 7 Patient and Family Partners and 10 staff were invited by the Institute of Patient & Family Centered Care (IPFCC) conference to present best practices on patient and family engagement at Stanford Health Care at IPFCC’s international conference in New York City
- In addition to IPFCC, Stanford Health Care staff and Patients & Family Partners were invited to present on patient & family engagement at the 2016 conferences for the Beryl Institute of Patient Experience, Cleveland Clinic Patient Experience Summit, and the Institute for Healthcare Improvement
- 6 Patient & Family Partners were invited to participate in the Magnet Re-accreditation Survey for nursing excellence – Stanford Health Care achieved re-accreditation, with the surveyors noting that one of the top 3 exemplars was patient and family engagement with nursing through the Patient and Family Partner Program

We are most grateful for those patients and families who have joined our councils, workgroups, become speakers and consultants, all in the hope of improving care for other patients. We are also grateful for the staff and physicians who have joined our councils

and requested patient and family partnerships in the work that they do, recognizing that partnering with patients and families is essential to improving healthcare.

As Stanford Medical Center continues to learn from our patients and families, the opportunities to further collaborate in 2017 become more important as we determine new strategies to further increase value for patients and families, deliver better patient care, and share our learnings with other organizations across the globe sharing these goals. Thank you for all your support and dedication in building this partnership.



Alpa Vyas  
Vice President, Patient Experience



Joan Forte Scott  
Former Administrative Director, Patient & Community Engagement



Bryanna Gallaway  
Director, Service Excellence



Mary Song  
Patient & Family Partner Program Manager



Barb Gandarela  
Former Executive Assistant to Joan Forte Scott

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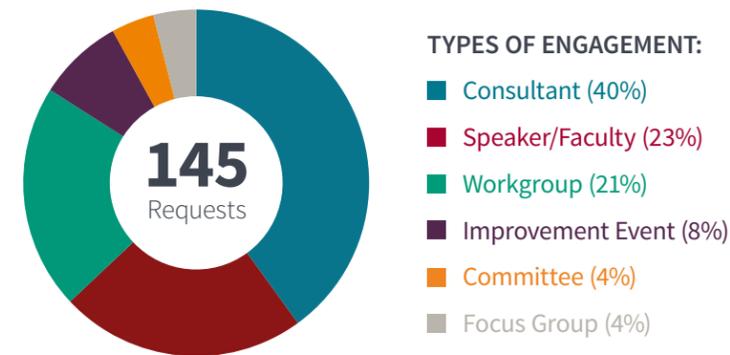
# Patient & Family Partner Program 2016

**142** Active Partners  
**33** Joined in 2016

**14** Patient & Family Advisory Councils  
**2** Started in 2016

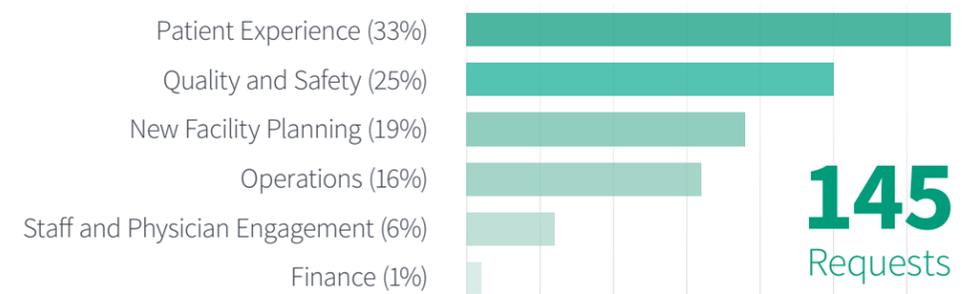
**49** Unique Departments/Services Requesting Patient & Family Partners

## Patient & Family Partner Requests



**40%**  
**INCREASE**  
 in number  
 of requests  
**FROM 2015**

## Patient & Family Partner Requests by Strategic Dimension



## Languages Spoken by Patient & Family Partners

Burmese • Cantonese • Croatian • Farsi • French • German • Hebrew • Hindi • Mandarin  
 Marathi • Punjabi • Russian • Spanish • Tamil • Toy-shanese • Vietnamese

# Patient & Family Advisory Councils

Patient & Family Advisory Councils (PFACs) provide a forum for ongoing partnership among patients, families, staff, and physicians. In 2016, Stanford Health Care added 2 additional Patient & Family Advisory Councils, Emergency Department and Pain Management Center. The Chair of each PFAC is a Patient & Family Partner who co-leads the council with a Staff or Clinical Advisor. The Chair and Advisor of each PFAC are part of the Patient Family Partner Program Board which meets quarterly to share best practices and provide governance to the program. For patient privacy, advisory council members' names are not listed within their PFACs, but are listed at the end of the annual report with all Patient & Family Partners. All PFACs have made tremendous impact at Stanford as you will see covered in this section.

# Adolescent Young Adult (AYA) Cancer

## Patient & Family Advisory Council



### 2016 KEY ACCOMPLISHMENTS

- Added 2 family members to the PFAC
- Added 2 volunteers to the program
- Added 12 peer mentors
- Continued collaborating with HopeLab to develop tool to connect AYA patients and to help build community
- Provided fertility consultations for nearly 100% of patients referred to SAYAC and coordinated cryopreservation when possible
- Created Facebook page for patients to plan events, provide PFAC guidance, and build community
- Held 2 events for patients within the program
- Provided feedback to Stanford University students designing a caregiver support tool
- Partnered with Headspace, a meditation app, to offer free one-year subscriptions to AYA patients, survivors, family, and staff
- Dr. Gary Dahl (physician advisor), Pam Simon, and Jacob Lore (child life specialist) presented about SAYAC at an AYA cancer conference
- Evaluated interview survey tool that UCSF uses for research into treatment decision-making
- Initiated Fitbit/iPad study about patient activity
- Implemented Coping Skills Workshop for patients, focusing on stress management and targeting physical symptoms

### 2017 PROPOSED GOALS

- Continue adding AYA peer mentors and enable them to work more effectively
- Improve patient education and advocacy around fertility and preservation
- Build community and provide support for AYA patients and survivors by developing resources to support psychosocial and emotional needs and improve inpatient care
- Increase recognition of SAYAC locally, regionally, and nationally

# Cancer Center

## Patient & Family Advisory Council



### Year Established

2015

### Patient & Family Chair

Jasan Zimmerman

### Staff Advisor

Pam Simon

*Program Manager/Nurse Practitioner, Stanford Adolescent Young Adult Cancer Program (SAYAC)*

### Number of Members

9 Patient Partners  
2 Caregivers  
1 Physician  
4 Staff

### 2016 KEY ACCOMPLISHMENTS

- Designed, developed and implemented PFAC Partnership Operating Model. Based upon preference, patient & family members partnered with staff on 3 initiatives:
  - Cancer Care Navigator Design—Informed Cancer Care Navigator role, requirements, design and process flow; served as voice of customer; assisted with adoption and communication of role
  - PathWell—Interviewed representatives of 22 services about current practices, to assess and address family member needs, identify services for family members, and adjust program range to address and fill gaps
  - Patient & Family Education—Informed new patient education needs, concerns and scope; provided conceptual, design and content feedback for the new Patient & Family Resource Guide
- Contributed to additional Cancer Center projects, including:
  - eSurveys—Informed content and delivery
  - Cancer Express Menu and Patient Experience Project—Provided insights into improving meal nutrition and satisfaction for hospitalized cancer patients
  - SHC Patient Access Services—Responded to Universal Registration design and concept

### 2017 PROPOSED GOALS

- Integrate CCPFAC patient & family members into current work on four initiatives:
  - Cancer Care Navigator (Phase 2)
  - PathWell
  - Survivorship
  - Patient Reported Outcomes
- Host same-day feedback meetings with SHC leadership and staff who represent improvement efforts focused on patient experience (e.g., MyHealth, Financial Services and Patient Access)

### Year Established

2012

### Patient & Family Chair

Bev Anderson

### Staff Advisor

*Joan Forte Scott  
Administrative Director,  
Patient & Community  
Engagement*

### Number of Members

11 Patient Partners  
5 Leaders & Staff  
2 Physicians

# Cancer Center South Bay (CCSB)

## Patient & Family Advisory Council



### 2016 KEY ACCOMPLISHMENTS

- Participated in 100% of 37 staff interviews at CCSB
- Advised on program development including:
  - Mammography call-back process, adopted by SHC system-wide
  - Chemotherapy completion recognition
  - Brain tumor symptom intervention
  - Lab scheduling process
  - Letter to surgery patients
  - Radiation therapy fast track registration
  - Emergency response communication
  - New patient orientation/information
  - Real-time patient feedback
  - Signage improvement
  - Level one infusion naming conventions
  - Hand hygiene surveys
  - Loss prevention for RTLS badges
  - iPads for patients
  - Café hours, advice and implementation
  - Lobby music content and clinic art
- Presented at C-I-CARE Patient Experience Week, Health Experience Refactored, and 7<sup>th</sup> International Patient and Family Centered Care Conference
- Participated in Empathy Mapping and True Colors team-building
- Recruited and onboarded three new members
- Transitioned and redefined staff/leader roles

### 2017 PROPOSED GOALS

- Support new patient education and orientation (CCSB Nurse Coordinator New Patient Orientation to be piloted in colon and breast cancer and New Patient Resource Guide)
- Implement Peer-to-Peer program at CCSB, in collaboration with Nurse Coordinator New Patient Orientation pilot
- Continue involvement in staff improvement projects
- Develop family member resource network
- Recruit members and expand into community
- Participate in 100% of new CCSB employee interviews

# Collaborative Primary Care | Los Gatos

## Patient & Family Advisory Council



### Year Established

2013

### Patient & Family Co-Chairs

Rose Simmons and  
Donna Adam

### Staff Advisors

Sara Malm  
*Cancer Supportive Care  
Program Manager*  
Nancy Dickenson  
*Guest Services  
Supervisor/Librarian*

### Number of Members

11 Patient Partners  
1 Family Partner  
1 Physician  
6 Staff

### 2016 KEY ACCOMPLISHMENTS

- Reviewed Stanford Clinics Controlled Medicine Agreement
- Provided feedback on Patient Satisfaction Process and options to encourage feedback
- Discussed how to improve patient outreach between visits and Care Coordinator role, to improve efficiency and patient care
- Collected data on top diagnoses of clinic patients to determine PFAC focus
- Researched local exercises and diet resources to make available to patients
- Collaborated with Stanford Health Library to improve access of information to patients on ebooks, articles, videos, risk assessment calculators
- Suggested 'Report Card' to raise patients' awareness and motivate them to exercise and eat healthfully
- Established Lifestyle and Wellness Room project. Plan to stock with resources and provide readily accessible information to patients and families, including paper books, ebooks, videos, posters, pamphlets, and access to Stanford Health Library
- Collaborated with MyHealth on patient experience improvements and cost-saving opportunities
- Discussed clinic support of Population Health needs

### 2017 PROPOSED GOALS

- Create usable resource room at clinic by July 30, 2017
- Increase clinic's Medicare Wellness visits to greater than or equal to 16 visits per month by December 30, 2017
- Add 2 members by July 30, 2017
- Increase Patient Satisfaction Wait Time top box score to greater than 97% by July 30, 2017
- Create patient feedback mechanism for referrals by December 30, 2017

### Year Established

2015

### Patient & Family Chair

Pei-Pei Yow

### Staff Advisors

Rachel Seaman, MD  
Sonia Singh, MD

### Number of Members

5 Patient Partners  
3 Physicians

# Cystic Fibrosis (CF)

## Patient & Family Advisory Council

### 2016 KEY ACCOMPLISHMENTS

- Produced Decision Tree Brochure – Inpatient to help patients address issues that occur while hospitalized at Stanford Hospital
- Produced Decision Tree Brochure – Outpatient to help patients address issues that occur during clinic or lab appointments at SHC
- Initiated informal research study on perceived benefits of CF patients monitoring FEV1 (Forced Expiratory Volume in 1 second) scores
- Authored CF Passport, to provide guidelines and emergency contacts for CF healthcare needs for clinics, Emergency Rooms, PCPs and hospital stays external to Stanford
- Developed and implemented Return Patient Questionnaire to support patients with clinic visits, ensuring they have all required information
- Continued maintaining collaboration and support tools for SHC CF community, including Facebook page and Council web page/blog; participated in needs development for MyHealth and an app to manage healthcare needs
- Worked with Cystic Fibrosis Foundation to develop strategies and support resulting projects, to improve healthcare for CF patients nationally

### 2017 PROPOSED GOALS

- Execute, capture results and plan subsequent activities based upon initial FEV1 home measurement research study
- Ramp up CF Encounters Project to identify educational opportunities for healthcare workers, to better understand patients' perception of their actions
- Complete informational documentation for CF patients on using masks; recommend best uses for mask-types available
- Support national projects managed by Cystic Fibrosis Foundation
- Assume lead role in developing advisory councils for CF patients at hospitals nation-wide

# Emergency Department (ED)

## Patient & Family Advisory Council

### Year Established

2009

### Patient & Family Chair

Brian Eddy

### Staff Advisor

Colleen Dunn  
*Clinical Research  
Coordinator, CF Center at  
Stanford Hospital*

### Number of Members

7 Patient Partners  
2 Caregivers/Volunteers  
4 Staff



### 2016 KEY ACCOMPLISHMENTS

- Designed and implemented Primary Patient Support program for the ED, to enable primary support person to stay with patient during rooming and provide critical information on patient if patient is unable, potentially improving patient care in the ED
- Recommended and implemented changes to the ED Lobby PowerPoint presentation
- Brainstormed and made recommendations on the Real Time Locating Tracking System for the new hospital (500 Pasteur) (Angel Shew, SHC Digital Solutions)
- Provided feedback on the After ED Visit Cards and Press Ganey surveys
- Observations were done in ED by PFAC members and feedback was given on caregiver involvement with triage and rooming patients
- Feedback and suggestions were provided to decrease perceived wait time before seeing an MD
- ED PFAC participated in a Family/Caregiver Workshop focusing on the ED- run by Joan Forte-Scott

### 2017 PROPOSED GOALS

- Clinical protocols (sepsis, pain, medications, TBI, HIT, etc.)
- Patient experience (likelihood to recommend)
- Role of caregiver
- Door to disposition

### Year Established

2016

### Patient & Family Chair

Vanessa Deen Johnson

### Staff Advisors

Viveta Lobo, MD  
*Clinical Assistant Professor,  
Associate Director,  
Emergency Ultrasound  
Program*  
Jason Francis, RN,  
BSN, CEN, CCRN  
*Assistant Patient  
Care Manager*

### Number of Members

4 Patient Partners  
3 Caregivers  
3 Staff  
1 Physician

# Founding

## Patient & Family Advisory Council



### 2016 KEY ACCOMPLISHMENTS

- Comments on designs for 500 Pasteur, most notably regarding security and access for families to Emergency Department at ambulance entrance, led to changes in final design
- Collaborated with E3/F3 nursing residents to implement nursing bedside shift-to-shift report, improving communication with patients and families during shift changes
- Improved Food Services' low-salt menu, increased chef-patient dialogue and improved patient education
- Piloted HeartMath session, which introduces self-care/resilience-building techniques, to support hospital-wide program
- Provided feedback on E3 Virtual Art Exhibit by improving patients' and caregivers' awareness of location and value, and recommending logistical feedback to run the exhibit
- Provided feedback for implementing the "What Matters Most" Letter, to improve Advance Care Planning
- Provided feedback about "Care Packages", which was incorporated into Welcome Amenity Kits implemented on all nursing units
- Provided feedback to Housekeeping and Patient Navigation departments, Farewell to Falls and Gratitude projects, and Peer 2 Peer Mentoring and Patient Navigation programs

### 2017 PROPOSED GOALS

- Support Service Excellence leadership in addressing key challenges in patient experience
- Support key quality initiatives, including readmission and pain management
- Provide feedback to workgroups focused on cost savings
- Develop partnerships with School of Medicine
- Support plans for New Stanford Hospital/500 Pasteur

# Geriatrics

## Patient & Family Advisory Council



### Year Established

2009

### Patient & Family Chair

Lynn Fraher

### Staff Advisor

Mary Song  
*Program Manager,  
Patient & Family  
Partner Program*

### Number of Members

6 Patient Partners  
4 Caregivers  
3 Staff

### 2016 KEY ACCOMPLISHMENTS

- Provided guidance about Advanced Directives for Spiritual Care and Geriatrics pilot
- Consulted with Stanford Health Library about advertising program and raising patient and family awareness of library resources
- Explored Geriatric Care Center concept with Drs. VJ Periyakoil and Ankur Bharija, including personalized care plan, polypharmacy, preventive health through nutrition, stress management, exercise, home visits and care coordination
- Provided feedback to Michael Honeyman, Director of Self-Pay Management Office, Patient Financial Services, about patient billing customer service experiences, underscoring needs related to navigating insurance products and anticipated Medicare changes
- Served as ambassadors for trauma for Farewell to Falls, Stepping On and Matter of Balance programs
- Suggested improvements for H1, highlighting demonstrations of respect, increased communication between patient and staff, and reduced waiting time before tests and procedures
- Feedback on Palliative Care Program resulted in MDs speaking proactively with high risk patients; publishing of print and web patient and family member testimonials; and improved phone availability, 24/7
- Restructured and rewrote Aging Adult Services Resource Guide for family members

### 2017 PROPOSED GOALS

Having accomplished its goals and due to changing organizational responsibilities, the Geriatric PFAC stopped meeting after January 2017. Each patient and family member has elected to join another PFAC and/or to participate in other PFPP activities.

### Year Established

2015

### Patient & Family Chair

Sarah Deen

### Staff Advisor

Terese McManis  
*Manager,  
Aging Adult Services*

### Number of Members

7 Patient Partners  
3 Caregivers  
3 Staff  
1 Physician

# Heart Transplant

## Patient & Family Advisory Council



### 2016 KEY ACCOMPLISHMENTS

- Executed Fourth Annual Heart Transplant Reunion and Celebration, March 24, 2016, with Symposium, attended by approximately 325 heart transplant recipients, family members and Stanford staff
- Published two Heart Transplant Newsletters, distributed to all heart transplant recipients
- Continued to participate in Heart Transplant Peer2Peer program, with all 6 patients and family members trained
- Participated in Reducing HeartTransplant Clinic Cycle Times process improvement initiative with Heart Transplant Clinic, which has shortened cycle time by 25%, while continuing to focus on sustainability
- Worked towards revising Heart Transplant Patient Manual
- Continued PFAC liasons with partner organizations, including American Heart Association and Donor Network West
- Continued to participate in 500 Pasteur transition work groups
- Continued to participate monthly on Heart Transplant Quality Council

### 2017 PROPOSED GOALS

- Execute Fifth Annual Heart Transplant Reunion and Celebration, with Symposium, scheduled for March 23, 2017, to build community and provide education. Recruit 3 healthcare and 2 patient and family speakers. Expected attendance: 350
- Publish two semi-annual Heart Transplant Nwsletters
- Further develop Heart Transplant Manual, utilizing 2016/2017 PFAC design changes and updates, including new family member section
- Compile information for heart transplant family members to be included on website and in Patient Care Manual
- Invite Peer2Peer mentors to PFAC meetings
- Enhance Heart Transplant website

# Intensive Care Unit (ICU)

## Patient & Family Advisory Council



### Year Established

2011

### Patient & Family Chair

Susan Roberts

### Staff Advisor

Helen Luikart  
*Research Nurse Manager,  
Heart Transplant*

### Number of Members

5 Patient Partners  
1 Caregiver  
1 Physician  
2 Staff

### 2016 KEY ACCOMPLISHMENTS

- Informed future projects by expanding knowledge of discussions occurring during E2 rounds versus topics not discussed
- Provided feedback and discussed involvement in ICU Diaries project with Dr. Muna Beg, to reduce cognitive impact and PTSD for patients/families after ICU discharge
- Designed and participated in research project comparing what is said with what is heard during rounds and family meetings, providing foundation for research project presented by two Patient Family Partners at Institute for Patient and Family Centered Care's 7th International Conference on Patient- and Family-Centered Care
- Provided patients' and family members' perspectives of the ICU during E2 Staff Meetings with RNs
- Recommended creating a new ICU library, including medical information, novels and magazines

### 2017 PROPOSED GOALS

- Promote Stanford Letter Project within ICU staff and at discharge with patients
- Complete PCORI research and move forward with IRB
- Expand family meetings to include video information and training about engaging entire care teams
- Create ICU specific library, to include medical information, novels and magazines
- Create ICU Diaries for family members and friends, with Risk Management disclaimer
- Incorporate volunteers with FASST nurses, to increase patient knowledge
- Promote post-care follow up (i.e., Trauma Survivor Reunion)

### Year Established

2015

### Patient & Family Chair

Laura Jammal

### Staff Advisor

Maureen Fay  
*Patient Care Manager, E2  
Med/Surg/Trauma/Neuro ICU*

### Number of Members

2 Patient Partners  
4 Caregivers  
1 Physician  
4 Staff

# Neuroscience

## Patient & Family Advisory Council



### 2016 KEY ACCOMPLISHMENTS

- Informed architecture firm designing of Neuroscience Health Center (NSHC)
- Represented patients, family members and leaders during opening of NSHC, including Day in the Life and ribbon-cutting events, promotional communication and post occupancy feedback
- Provided feedback to staff in Headache, Radiology, Stroke Awareness, Neurospine, Rehabilitation and Epilepsy clinics
- Provided reactions to patient satisfaction tool
- Supported development of new Neuroscience Supportive Care Program
- Initiated effort to install accessible push buttons in NSHC restrooms
- Launched proposal for Emergency and Pharmacy departments to provide contra-indicated medication lists for patients treated/admitted with Parkinson's disease, including alert in EPIC
- Continued focus on Neuro PFAC member-development and growth, encouraging members to remain engaged in variety of activities and improvement projects
- Added four patient and family members and two staff members

### 2017 PROPOSED GOALS

- Support new hospital construction
- Improve patient experience at NSHC
- Review patient access and satisfaction data, and plan improvement activities
- Host one sub-specialty speaker per PFAC meeting, emphasizing methods for PFAC support of clinicians
- Implement revised process for Emergency and Pharmacy departments to be alert for medication contra-indications for Parkinson's Patients admitted into Emergency Department; end goal: alert in EPIC
- Develop and implement Neuroscience patient programs
- Expand actively-participating, Neuro-related, clinical PFAC membership
- Add 2 family members to PFAC

# Pain Management Center

## Patient & Family Advisory Council



### Year Established

2013

### Patient & Family Chair

Jody Yarborough

### Staff Advisor

Jacque Keeling  
*Assistant Director,  
Clinic Operations*

### Number of Members

10 Patient Partners  
1 Caregiver  
4 Staff

### 2016 KEY ACCOMPLISHMENTS

- Launched council on March 31, 2016
- Reviewed historical development of Pain Management Center, to facilitate development of meaningful goals
- Identified 3 key areas of opportunity for the Pain Center to improve patient experiences
- Reinstated use of introductory materials previously developed for Pain Center patients
- Provided input to Pain Clinic Manager on how to improve information provided to new patients, to help improve patient satisfaction
- Proposed a project to improve specific aspects of patients' experiences to Division leadership

### 2017 PROPOSED GOALS

- Integrate feedback from Division leadership about project to improve patients' experiences, and resubmit proposal for approval in early 2017
- Implement project and track outcomes to assess efficacy of intervention
- Expand Council membership

### Year Established

2016

### Patient & Family Chair

Kristina Breen

### Staff Advisor

Ravi Prasad, PhD  
*Associate Chief,  
Division of Pain Medicine*

### Number of Members

6 Patient Partners  
1 Community  
Representative  
1 Staff  
2 Clinicians

# Stanford Coordinated Care (SCC)

## Patient & Family Advisory Council

### 2016 KEY ACCOMPLISHMENTS

- Council membership was impacted by multiple Clinic and PFAC transitions
- Collaborating with staff, developed method to reengage inactive Care Support program patients and implemented a Graduation process
- Identified vendor to consistently fulfill SCC patient and staff needs
- Provided feedback about SCC's efforts to regularly administer Clinic's annual patient health assessments; as a result, patients receive personal data to track their responses over time
- Described benefits and responsibilities of SCC patients for New Patient Packet
- Chair participated as a patient in improvement events, including:
  - Design of SHC Emergency Department waiting room
  - Patient navigation through Design for Health Program
  - National Partnership for Women and Families discussions
  - Interviews related to Ambulatory Pharmacy services
  - Engaging patients and family members in research training

### 2017 PROPOSED GOALS

- Recruit 8 members that represent diverse patient populations (current employees and adult dependents) of SHC and Stanford University, each with a complex and/or chronic health condition
- Create a needs assessment survey for SCC patients to identify improvements and/or patient services that SCC can implement

### Year Established

2011

### Patient & Family Chair

Sheryl Michelson

### Staff Advisor

Coleen Travers  
*Licensed Clinical Social  
Worker (LCSW), Stanford  
Coordinated Care*

### Number of Members

5 Patient Partners  
1 Caregiver  
4 Staff

## Patient & Family Engagement

In addition to Patient & Family Advisory Councils, Patient & Family Partners volunteer as advisors and speakers on committees, consultants, focus groups, improvement events, speakers & faculty, and workgroups. The program received 145 requests in 2016, a 40% increase from 2015, for patient and family engagement in these categories, which are highlighted in this section.



“Asks questions or points out issues that the other committee members may not see.”

# Committees

Patient & Family Partners (PFPs) meet monthly with other committee members consisting of multidisciplinary staff and leadership to inform key planning and decision-making. Committee membership is continual.

## QUALITY, PATIENT SAFETY, AND CLINICAL EFFECTIVENESS COMMITTEE

The Quality, Patient Safety and Effectiveness Committee (QPSEC) oversees the quality and safety of patient care at SHC. The committee, which includes representatives from all hospital departments and clinical service lines and one Patient Family Partner (PFP), meets monthly to review the quality dashboard and to review and approve all policies that involve direct patient care. Specific focus areas included sepsis mortality, re-admissions, inpatient discharge-by-noon, new outpatient access and improving wait times in the Emergency Department.

Representing patients' and family members' views on all topics discussed, the PFP on the committee describes the role in this way: "At each meeting, I continue to learn about new efforts within departments or service lines in this context, and am pleased by the willingness of committee members to listen to my perspective as the PFP member on the committee whenever I have a comment to offer or question to ask."

Dr. Joseph Hopkins, Senior Medical Director for Quality, points out, "the Patient & Family Partner often asks questions or points out issues that the other committee members may not see,"

## HEART FAILURE READMISSION COMMITTEE

Medical centers are increasingly challenged to provide cost-effective services that meet patient needs, facilitate care transitions across the continuum and support patient self-management. Such patient-centered care is distinguished by attention to those factors that patients and family members identify as important, staying aware of procedures that might be onerous or burdensome for patients and family members, and following practices that encourage patient adherence and reduce readmissions. The committee also reviews updated quantitative and qualitative data for readmission rates, which they compare to target goals; improvements have resulted in 55% improvement in 30-day readmissions from baseline.

Partnering with patients from the outset, the Heart Failure Readmission Committee redesigned care for heart failure patients, which reduced re-hospitalizations and improved patient experiences. Patient & Family Partners participated in revising patient and family member education materials. Their participation in week-long Rapid Process Improvement Workshops, which was focused on medication safety, resulted in improved medication lists for patients when they are being discharged. Their opinions were crucial to Cardiovascular Health value-stream mapping, as is their ongoing participation in SHC-hosted monthly meetings with community partners (i.e., clinical, subacute and home health facilities). Additionally, two HIPAA-trained patient volunteers perform structured patient interviews to better understand inpatient experiences.

## ADDITIONAL EXAMPLES

- Shared Leadership Councils (Patient Education, Magnet, Quality, and Coordinating Council)
- Orthopedic Unit Shared Leadership Council
- Patient Experience Action Team
- Patient Education Committee



## Consultants

Outside of workgroup meetings, Patient & Family Partners (PFPs) serve as consultants to the leadership of specific initiatives.

### THE PATIENT PLAN “A GUIDED JOURNEY”

The Product & Service Integration (PSI) Team at SHC is designing the Patient Plan, a Guided Journey, to help patients and family members prepare for the before, during and after aspects of their healthcare interactions, specifically related to hospitalizations. Partnering with Digital Solutions and the Health Education team, PSI is building a technology platform to facilitate a uniquely accommodating and supportive patient experience. SHC projects that the initial version of the Guided Journey will be implemented when the new hospital opens at 500 Pasteur.

Sixty patients and family members on inpatient units, in the pre-anesthesia and ambulatory care clinics, and in ambulatory surgery areas, informed the initial research. More than 30 PFPs worked in smaller design work sessions, including planned and urgent arrival, parking, departure, procedure scheduling, inpatient stay, and discharge readiness and planning. PFP’s observations have helped ensure that products and services are desirable, usable and feasible. For example, a family member helped design more humane care when they described the challenges of managing the range of demands related to a patient’s care.

Hospitalized patients, family members and PFPs continue to be involved in the work, from product design through testing, providing unique and valuable perspectives of the healthcare system and an academic medical center setting.

“ Provided encouragement that the new model would meet patients’ needs. ”

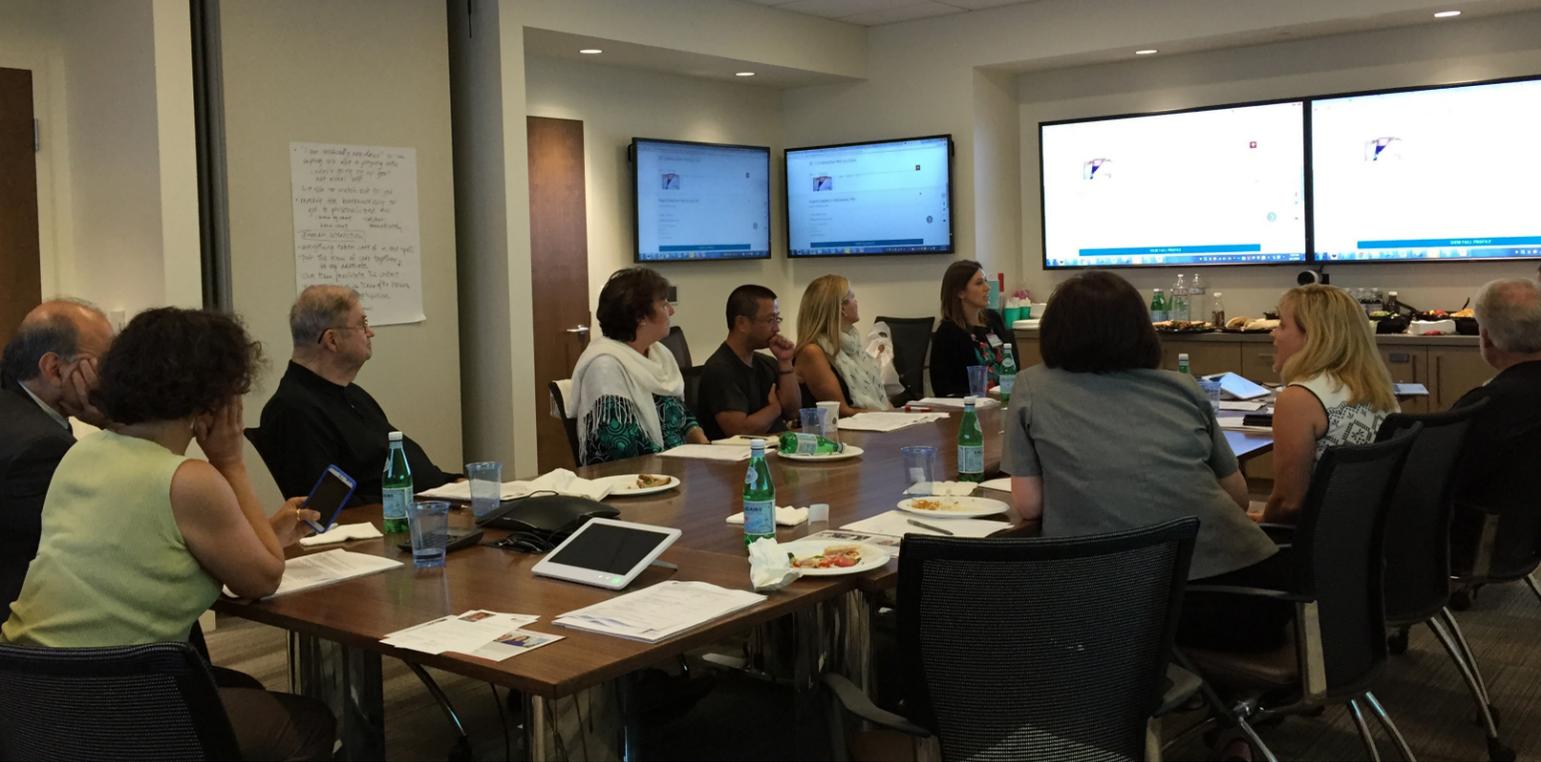
### PRIMARY CARE REDESIGN

Three Patient & Family Partners (PFPs) participated in a 4-day retreat that introduced staff to a new Primary Care 2.0 model and resulted in transformational change that uses a team-based approach to extended clinic visits with patient, care coordinators and providers.

PFPs participated in discussions about the workflow and nuts and bolts of clinic visits. The PFPs offered valuable insights into the processes, and they were particularly instrumental during role plays, teasing out hopes, concerns and fears that patients bring to clinic visits, raising questions and concerns that motivated the clinic to revise workflows. They also provided encouragement that the new model would meet patients’ needs.

### ADDITIONAL EXAMPLES

- Stroke Patient Education
- Breast Cancer Patient Education
- Welcome Amenity Kits Development
- Emeryville Outpatient Center Dress Rehearsal Planning
- Informed Consent Form Review
- MyHealth Design Session Participation
- Senior Care Interviews
- “What Matters Most” Letter Feedback
- Blood Product Administration Safety Interviews
- Inbound Phone Calls Policy Feedback



# Focus Groups

Groups of 5 to 8 Patient & Family Partners (PFPs) provide dialogue and ideas about specific topics during one-time meetings, typically lasting for 2 hours.

## OUTPATIENT SPECIALTY PHARMACY FOCUS GROUP

Insights offered by 7 Patient & Family Partners (PFPs) were invaluable to the design of the SHC pharmacy service that will open in 2017. Participating in two focus group, the PFPs assessed how patients and family members currently use pharmacy services and the attributes, including the layout, of an ideal pharmacy service. They generated patient-centered themes linked to connection, cost, privacy, ambiance, operational efficiency, technology and education.

Key learnings included the patient's need to have a personal relationship with pharmacy staff and to have service provided in a calm and private environment, as well as being able to purchase medications at low out-of-pocket prices. The PFPs offered that ideal pharmacy service would include sufficient in-stock medication and supportive care supplies to facilitate one-stop shopping experiences, integrate with MyHealth for refills, have 90-day supplies available for mail order medications, price-match, have expanded hours for meds to beds, and have compounding capabilities and drug waste services.

The Outpatient Specialty Pharmacy team will continue to work with PFPs to solicit feedback about marketing and educational materials.

“Further integrate patient and family voices into the design.”

## NEUROENDOCRINE TUMORS FOCUS GROUP

SHC recently launched the Neuroendocrine Tumors (NETs) Program to provide comprehensive care for NETs patients and family members. A focus group made up of 4 patients and 2 caregivers discussed perspectives to improve patients' and family members' experiences and to better meet needs related to the NETs Clinical Program and the NETs Survivorship Clinic. Needs that participants raised include:

- A SHC website for NETs patients and health care providers that is credible, up-to-date and easily accessed: The NETs program is developing a website of qualified NETs information, and plans to further integrate patient and family voices into the design.
- An array of support services for NETs family members: In addition to developing support services that will be available through the NETs Survivorship Clinic, the clinic has initiated conversations with nursing and social work to determine how the clinic can better support NETs family members.
- The option for telehealth visits, to increase patient access to NETs Survivorship, particularly for patients coming from greater distances: The NETs program team is meeting with providers of a pilot program already utilizing telehealth visits, and is considering piloting this option for NETs patients when insurance coverage is better understood.

## ADDITIONAL EXAMPLES

- Defining Patient- and Family-centered Primary Care and Population Health
- Understanding the experiences of Oncology and Transplant Patients and Caregivers residing at Welch Rd Apartments
- Understanding the needs of Older Patients with Cancer



# Improvement Events

Patient & Family Partners (PFPs) participate in continuous improvement events that provide multidisciplinary teams with dedicated time, ranging from a half-day to 5 days, to problem-solve and design solutions together. Workshops over 3 days also include dedicated time to pilot ideas.

## DIGESTIVE HEALTH FUTURE STATE MAPPING IMPROVEMENT EVENT

Digestive Health hosted a 2-day Improvement Event to reach alignment on current-state processes for pre-visit care coordination in the Gastroenterology and Liver clinics. With PFPs' input, the team identified stakeholder barriers and pain points in current processes, and they designed an ideal future-state process for pre-visit care coordination. Because of the event, the clinical team is also developing pre-visit care coordination guidelines for new patient and return patient visits, as well as standard work for each sub-specialty.

Performance Improvement Consultant in the workshop commented: "Having a patient partner in the event brings the whole group back to true north, which, for us, is to have a world class patient-centered digestive health center. Clinicians and staff, who do the work every day, would get very focused on the technical details of a process. When our Patient & Family partner spoke, she elevated the group by implicitly reminding them of the person on the other end of those technical details and what matters to them. It was like a reset button. It would not have been a finished product without her participation."

“Pushed us to think outside the box.”

## C-I-CARE MANAGEMENT ROUNDING REDESIGN IMPROVEMENT EVENT

Service Excellence facilitated a one-day C-I-CARE Management Rounding Redesign improvement event to redefine the purpose and mission of C-I-CARE rounds, to maximize the rounding experience for leadership, staff, and patients and family members, and to determine how to best prepare everyone for the rounding experience. In preparation for the improvement event, Service Excellence interviewed 46 SHC leaders about their rounding experiences,

The Design Thinking event included 30 diverse participants, including 3 PFPs, and surfaced 70 new ideas to improve rounding. The PFPs demonstrated considerable empathy for staff and leaders, helping all participants focus on the goals of rounding and raising the comfort-level of any leaders who had had little or no rounding experience. In the words of Bryanna Gallaway, Director of Service Excellence, "The PFPs pushed us to think outside the box and share their perspectives on how it feels to be rounded on and what story or information they would really value the opportunity to share with SHC leadership."

Since the event, many of the ideas raised have been piloted, including revisions to the rounding form and field trips, bringing leaders from off-site campuses to the hospital for direct patient interactions.

## ADDITIONAL EXAMPLES

- 500 Pasteur New Hospital Planning
- Emergency Department Simulations
- Neurosurgery Spine Improvement Event
- Patient & Family Partner Program Orientation Redesign



## Speakers & Faculty

Patient & Family Partners (PFPs) teach and motivate staff, physicians and leaders by telling their personal healthcare stories and by training staff and physicians about Patient- and Family-centered Care.

### **CARRYING THE LOAD: STRENGTHENING THE FAMILY/ CAREGIVER/PATIENT RELATIONSHIP WORKSHOP**

A day-long workshop for Emergency Department clinicians and staff and ED Patient & Family Advisory Council (PFAC) members, focused on the family member's role and ways in which illness effects the relationship between the patient and their family member, emphasizing the effect relationship has on patients and on health outcomes. The workshop faculty included a PFP, a subject matter expert, and the Patient Experience Administrative Director, who collaborated on the workshop design which, in part, was based on the book, *In Sickness As In Health: Helping Couples Cope with the Complexities of Illness* (Roundtree Press 2013).

The idea of supporting a patient and their family member as a unit resonated with participants, who appreciated learning techniques to do so. ED PFAC member participants noted that the workshop was a strong reminder for providers that family members can help improve patients' health outcomes, and they recommended incorporating the approach into patients' care plans. One ED PFAC member reflected, "This workshop was important to me to see the prospective of all the nurses, patients, caregivers and staff on how to change the ways we look at problems."

“Change the ways we look at problems.”

### **PATIENT SPEAKER FOR FOOD SERVICES WORKSHOP**

Food Services and Housekeeping staff (e.g., food service workers, cooks and dietetic assistants) and leadership are sometimes challenged to recognize the impact they have on patient care. One PFP changed that when he spent 2 days speaking to staff on every shift in both departments of over 150 employees. He shared his experiences about the profound effect that their interactions had on his care and recovery. Manager of Housekeeping says the patient speaker “was very impactful when he talked about his stay here at Stanford. He was very detailed in his response to how the housekeepers engaged patients and the little things they did to lighten up his day in such a dark time.”

### **ADDITIONAL EXAMPLES**

- Palliative Care Always Online Course
- C-I-CARE Videos
- Patient Access Services C-I-CARE Trainings
- Pharmacy Technician Staff Meeting
- Stanford Youth Medical Science Program Training on Communication
- New Hospital Sneak Peek Donor Event
- C2 Trauma Unit Staff Retreat
- E1 Bone Marrow Transplant Unit Staff Retreat
- C-I-CARE Champions Celebration
- Primary Care 2.0 Video



# Workgroups

Patient & Family Partners (PFPs) participate in workgroups as part of multidisciplinary teams during the planning, implementation and evaluation of improvement projects. Workgroup end-dates are based on the scope and timeline of the work.

## ADVANCED CARE PLANNING WORKGROUP

A PFP reviewed and provided feedback for a multidisciplinary workgroup that was tasked with creating a What Matters Most Letter for all Blood and Marrow Transplant patients to complete, as outpatients, early in their experiences at SHC. The objective included developing educational materials, establishing roles, writing standard work and training relevant staff. The PFP's insights affirmed the concept of asking patients to complete the document and helped to shape scripting and to identify when the letter might be offered to patients.

Since the workgroup, the SHC What Matters Most Letter and information about advanced care planning has been included in materials that a patient receives when they are initially evaluated for a transplant; Social Workers use the scripts to encourage patients to complete advanced care planning and the What Matters Most Letter prior to their transplants.

“ Insights on how patients feel in this hospital setting. ”

## REDUCING CLINIC RESPONSE TIME VIA MYHEALTH AND PHONE WORKGROUP

At the end of a clinic appointment, patients and family members typically need to receive a variety of information about follow-up appointments and medications, and healthcare teams need to complete a variety of steps.

As part of a several-months-long Realizing Improvement Through Team Empowerment cohort to improve response time to patient's phone calls, a PFP spent many hours working with a multidisciplinary team from SHC's Dermatology and Byers Eye Institute clinics. The Director of Clinical Operations recalls, "Our Patient & Family Partner added valuable information, including insights on how patients feel in this hospital setting. The team created standard workflows to respond to and resolve these out of clinic patient needs in a timely fashion. As a result of this workgroup's project, the average turnaround time to resolve these phone calls was reduced from 3 days average to less than 2 days."

## ADDITIONAL EXAMPLES

- Palliative Care
- Population Health
- Lab Wait Time Improvement
- Cisco Clinic Quality
- Santa Clara Primary Care Diabetes Quality
- Virtual Art Exhibit
- 500 Pasteur Workflow Approval
- 500 Pasteur New Hospital Amenities
- 500 Pasteur New Hospital Patient Belongings
- 500 Pasteur New Hospital Tour Program

# Thank You

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