



Patient & Family Partner Program



FY2018 Annual Report



Stanford
HEALTH CARE

Welcome Letter

As we reflect on FY18, we have been amazed by the culture shift at Stanford Health Care in how we engage our patient & family partners, not as advisors but as true collaborators earlier on in the planning stages of improvement. The Patient & Family voice has not only seen its relevance in improving the Patient Experience, but also Quality, Cost and Efficiency, and Employee and Physician Engagement and Wellness. This past year was also a big milestone for patient & family engagement in medical school education and digital health design, which will be highlighted in this report.

Many of our Patient & Family Partners travel far and take time from their busy schedules to join us for meetings, phone calls, and to email us feedback. We want to express our gratitude for all your continued dedication and support for the mission of Stanford Health Care. Your willingness to partner with us and bring insights from your experience is invaluable to us. Our job in Patient Experience is to make sure we are bringing the patient and family voice to the work we do.

As we start a new year in FY19, we are excited about the continued engagement of our Patient & Family Partners in activating the new hospital, raising the bar in hospital quality and patient safety, and redesigning the patient & family experience. Whether you are a patient & family partner who volunteers your time, or a manager who requests patient & family partners on your projects, you are part of this tremendous culture shift in engaging patients and families in improving care.



Alpa Vyas
Vice President, Patient Experience



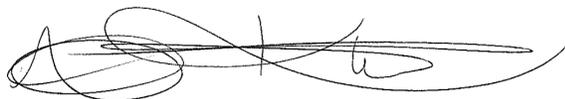
Mysti Smith-Bentley
Administrative Director, Service Excellence



Bryanna Gallaway
Director, Service Excellence



Mary Song
Manager, Volunteer Resources and the
Patient & Family Partner Program Manager



Addie Klein
Program Coordinator, Volunteer Resources



Katie Smith
Program Coordinator, Volunteer Resources

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Patient & Family Partner Program FY2018

120 Patient & Family Partners

12 Active Patient & Family Advisory Councils

4,000+

Volunteer Hours

Composition of Patient & Family Partners

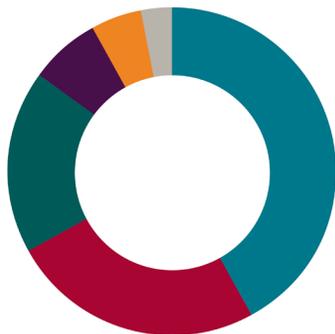


18% CAREGIVERS

82% PATIENTS

Types of Engagement

Outside of Patient & Family Advisory Councils



■ Workgroups / Projects (42%)

■ Speaker / Faculty (25%)

■ Consulting (18%)

■ Committees (7%)

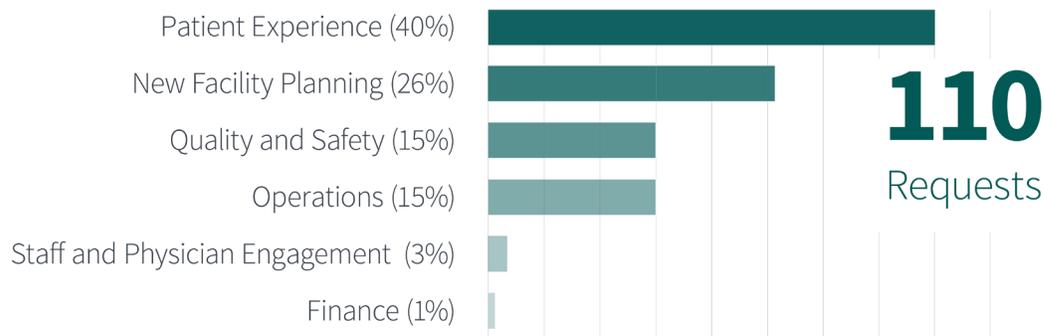
■ Improvement Events (5%)

■ Focus Groups (3%)

50+ Depts.

& Services Requesting Patient & Family Partners

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 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 110 requests in 2018 for patient & family engagement in these categories, which are highlighted in this section.



Patient & Family Engagement

Every week, the Patient & Family Partner Program receives several requests throughout Stanford Health Care, Stanford University, and Stanford School of Medicine for patient & family partner engagement. While these requests vary in terms of time commitment and how our Patient & Family Partners are engaged, all requests have the goal of bringing patient and family voice into various design and improvement work to improve patient care. Many Patient & Family Partners are members on a Patient & Family Advisory Council, as well as participants in these additional examples of Patient & Family Engagement.

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

Examples of Committees with Patient & Family Partners:

- Shared Leadership Councils
- Patient Experience Action Team
- Patient Education Committee
- 500 Pasteur (New Hospital) Planning Committees
- Quality Improvement, Patient Safety, and Clinical Effectiveness Committee (QIPSEC)

CONSULTANTS When Patients & Families cannot participate in recurring project meetings, they serve as consultants to the project leaders by phone, email, or by attending several key meetings.

Examples of Patient & Family Partners as Consultants:

- Patient Financial Services Phone Tree
- Population Health and Chronic Disease Management
- C-I-CARE Message of the Month
- Building Clinical Pathways around Falls
- Urinary Tract Infection Prevention
- Ambulatory Treatment Infusion Center (ATIC) closure communication letter to patients
- MyHealth Patient Portal Redesign (please see page 10 for more information)

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

Examples of Focus Groups with Patient & Family Partners:

- Communication around Opioid Shortage
- Patient Experience in the Chemotherapy Infusion Treatment Area
- Transitions of Care Project ACHIEVE Site Visit
- Precision Health in Primary Care

IMPROVEMENT EVENTS Patient & Family Partners (PFPs) participate in multi-disciplinary improvement events, ranging from a half-day to 5 days, to problem-solve, design, and pilot solutions together.

Examples of Improvement Events with Patient & Family Partners:

- Trauma Patient Experience
- C-I-CARE Compass Design
- Day in the Life Dress Rehearsals for Redwood City Pavilion D
- Designing communication tool between providers and patients/families in the ED lobby
- Patient Guided Journey (please go to page 14 for more information)

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. As Faculty, Patient & Family Partners not only co-develop content and curriculum, but also co-instruct the trainings.

Examples of Patient & Family Partners as Speakers/Faculty:

- Medical School Elective (please see page 12 for more details)
- Nursing Education/Continuous Education Professional Development
- C-I-CARE Bootcamp trainings for Patient Access Services
- Stanford University Medical Center Clinical Quality Summit
- UnitedHealth Group Executive Design Thinking Trainings
- Stanford Storybank

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

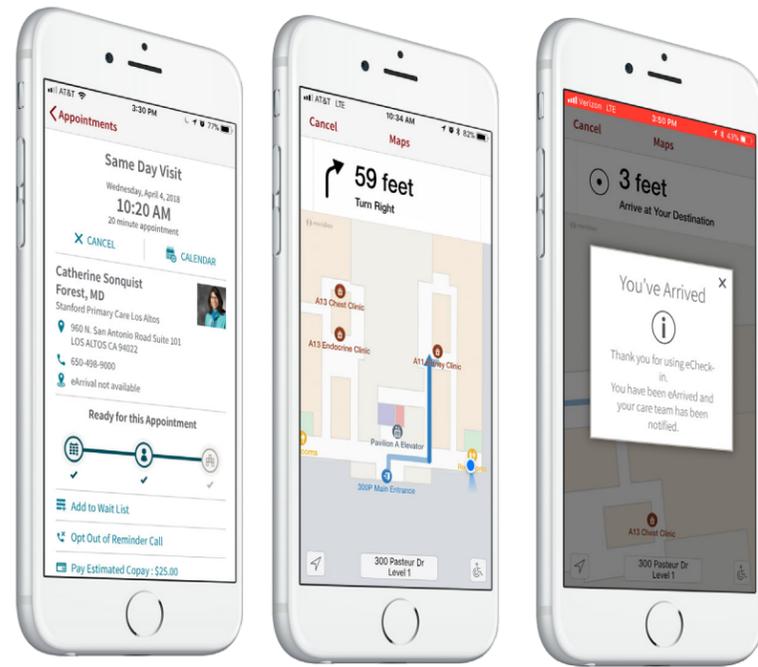
WORKGROUPS / PROJECTS

Patient & Family Partners (PFPs) participate in workgroups or projects as part of multidisciplinary teams during the planning, implementation and evaluation of improvement projects. Workgroup meetings have recurrences varying from biweekly to monthly, and have end-dates based on the scope and timeline of the work.

Examples of Patient & Family Partners in Workgroups/Projects:

- Improving survival outcomes for lung transplant patients
- SMART Patients Online Peer 2 Peer Mentoring for Patients and Families
- Conversations around Serious Illness
- Integrating Behavioral Health into Primary Care
- Improving access in outpatient Neurology
- Reducing time from ED to Medicine admissions
- 500 Pasteur (New Hospital) Retail Program





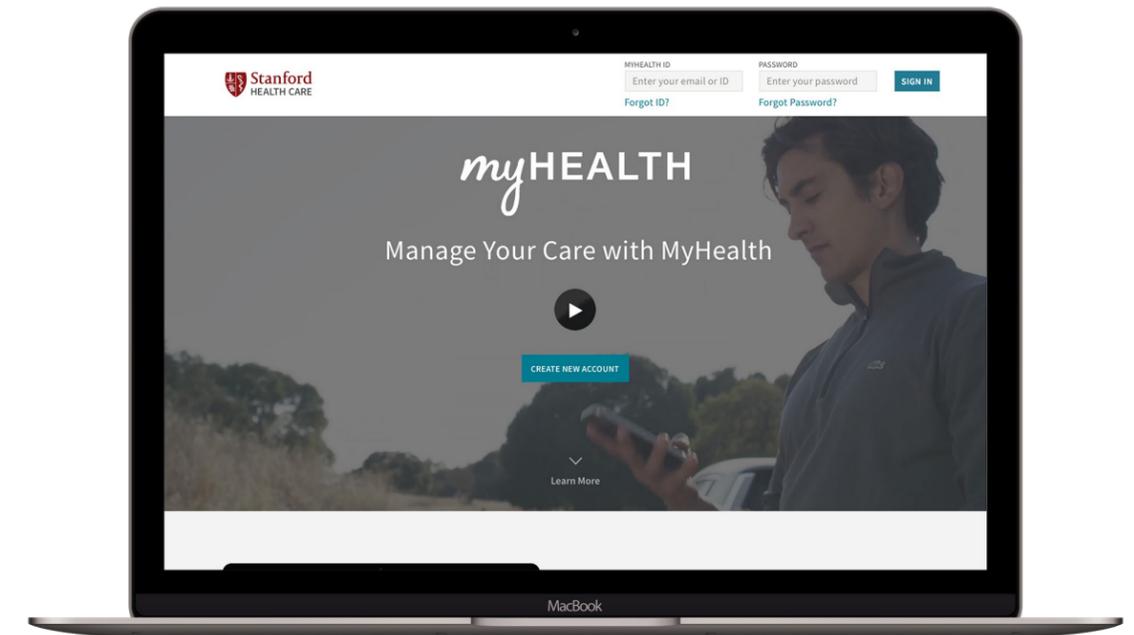
MyHealth Patient Portal

MyHealth is a secure portal where patients can view parts of their medical record, manage prescriptions, make appointments, and even conduct video visits from the computer or phone. The MyHealth Design team had the pleasure of working with over 30 Patient & family partners on a variety of MyHealth Patient Portal initiatives and enhancements. The patient and family volunteers contributed through one-hour interviews, design workshops, and usability testing sessions where they could interact with new features and provide valuable feedback.

The Patient & Family Partners' time and input resulted in the following improvements:

- **MyHealth Home Page** – ADA usability enhancements now make navigation and log in much easier for our elderly patients as well as patients with disabilities.
- **Mobile Scheduling** – Improved mobile scheduling workflow for easier Appointment Scheduling, eCheck-In, a Wait List option and turn-by-turn directions at the hospital and select clinics.
- **Patient Education** – Launched a digital experience for educational content within MyHealth. Patients can now read articles, watch videos and ask their doctors questions about their upcoming procedures.
- **Medicine X** – Led a workshop at the largest academic medical conference in the world, with Patient & Family Partner, Elizabeth Pirrotta, to share how MyHealth design team partner with patients to design features in MyHealth.

“ The more we know about our patients and families, the more we understand their full stories; about who they are; and not just the conditions they manage. ”



DESIGN PROCESS Patient involvement is an integral part of the design process. This design team has made it a requirement for all their design work to incorporate patient and families input. Impact is evidenced by the continued growth of MyHealth's user base through positive reviews on the App store and Google play, and in MyHealth's usage analytics. This team is looking for more ways to partner with Patient & Family Partners and the Patient & Family Advisory Councils to continually improve as Stanford Health Care strives to deliver a premium patient centered experience. Each discussion leads to learning about patients' and families' unique challenges and successes that will help the organizational partner with them to achieve their health goals.



Medical School Elective

Through a collaboration between PFPP and Stanford School of Medicine, Patient & Family Partners (PFPs) inform the perspectives of future physicians and physician assistants through their involvement in medical education, from recruitment through to residency. Patient and Family Partners are not only participating as speakers, but as educators and curriculum co-designers. Two examples of this innovative partnership are “Walk with Me” and “What Patients and Families Want You to Know About Being Their Doctor”.

**WALK WITH ME:
A PATIENT AND
FAMILY ENGAGED
EXPLORATION OF
HEALTH AND THE
HEALTH CARE SYSTEM**

Students enrolled in the “Walk With Me” course enroll for 1 -3 quarters. In addition to a monthly workshop, centered around a health systems science topic, students are paired with a patient partner who may be a patient, caregiver, or both. 23 Patient & Family Partners participated in the course in this inaugural year.

Together, the student and patient partner explore health and the health care system. The result is shaped by each pair’s unique life experiences, guided by a set of learning objectives and reflections. The overall goal of the course is to prepare students for a future role as change agents within the healthcare system, by giving them opportunities to appreciate the patient and caregiver perspective, and later identify and explore ways to overcome traditional barriers to patient-centered care.

“ This was the most important and meaningful weekly class of my first semester in medical school and I truly believe it should be a required component of the curriculum for every first-year medical student at Stanford. – Medical Student ”

**WHAT PATIENTS
AND FAMILIES WANT
YOU TO KNOW
ABOUT BEING THEIR
DOCTOR**

“What Patients & Families Want You to Know About Being Their Doctor” is an innovative nine-week elective for first and second year Stanford medical students piloted in Fall 2017. Four Patient and Family Partners co-designed content and co-taught the course. Perspectives of other patients and caregivers, guest physicians, and other members of the inter-professional team were also included in the weekly sessions. Topics included the essential role of the caregiver, treating the whole patient, and what compassion means to patients. 100% of students evaluated the course as relevant, and 90% of the students evaluated the course as extremely or very relevant. The course is now integrated into the Stanford Healthcare Innovations and Experiential Learning Directive program.

**ADDITIONAL
ENGAGEMENT WITH
THE SCHOOL OF
MEDICINE**

In addition to the above two courses, below is a summary of ways patients, families, and caregivers are engaging in medical education within the School of Medicine:

- Multiple Mini Interviews (MMI) admissions interviews
- Guest patient in a clinical skills session of the Practice of Medicine (doctoring) course for first and second year medical students and physician assistant students.
- Guest patient in clerkship sessions (3rd and 4th year clinical students)
- Speakers in courses across the 4 years of medical school: basic science, doctoring, and clerkships (3rd and 4th year)
- Participate in student research and quality improvement projects
- Review MD curriculum for opportunities to further highlight the patient and family perspectives.



The Patient Guided Journey

Patient Experience's Health Education team, in partnership with Digital Solutions, is designing the Patient Guided Journey, a technology that creates a supportive experience to enhance the partnership between patient and care team through seamless interaction and education during major milestones of their hospital stay.

PATIENT & FAMILY ENGAGEMENT

More than sixty patients and family members on inpatient units and clinics have informed the initial research that led the team to create the design and experience principles for the product. Ongoing Patient & Family Partner engagement with multiple conceptual and interactive digital prototypes have resulted in deeper learnings to improve the Patient Guided Journey experience.

Engagements to date include:

- Testing interactive prototypes with 25 patients and family members on units
- Providing the Founding Patient & Family Advisory Council a demo
- Facilitated focus group sessions with more than 40 Patient & Family partners.
- Assessed the usability and effectiveness of Patient Guided Journey features through 15 one-on-one interviews.

Hospitalized patients, family members, and Patient & Family Partners will continue to be involved in the work to lend their unique perspectives of our complex healthcare and academic medical center setting. SHC projects that the initial version of the Patient Guided Journey will be implemented when the new hospital opens at 500 Pasteur.

Patient & Family Advisory Councils

Patient & Family Advisory Councils (PFACs) provide a forum for ongoing partnerships among patients, families, staff, and physicians. 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. In this section, we have included the Year in Review for the PFACs that have made submissions for this annual report, but all PFACs have made tremendous impact at Stanford.

Adolescent Young Adult Cancer

Patient & Family Advisory Council



2017-2018 KEY TOPICS / ACCOMPLISHMENTS

- Held This is Life advocacy and survivorship conference in conjunction with Project Koru, 2017 and 2018.
- Held Adolescent and Young Adult networking event in Santa Cruz August, 2018.
- Collaborated with St. Baldrick's Foundation volunteers for 2018 Silicon Valley Tech Conquers Cancer fundraiser and provided a patient speaker.
- Partnered with Smart Patients to provide patient education for AYAs.
- Pam Simon and Gary Dahl, MD co-authored a study on Fitbits and iPad wearable technology that was published in June, 2018.
- Added 10 AYA peer-to-peer mentors.
- Added 3 new patients who recently completed treatment to better represent that population.
- Added a new sibling to PFAC.
- Added eight new volunteers to the PFAC, including a new sibling and 3 new patients who recently completed treatment to better present that population.
- Pam Simon provided fertility consultations to nearly 100% of the patients in the program.
- The age range for fertility consultations was eliminated—there is now no minimum or maximum age.
- Added more disease types to referral process.

Year Established

2015

Patient & Family Chair

Jasan Zimmerman

Staff Advisor

Pam Simon

Program Manager/Nurse

Practitioner, Stanford

Adolescent Young Adult

Cancer Program

2017-2018 Members

Patient & Family Partners

Nick Clark

Lara Farhat

Kevin Frandsen

Fiona Gutierrez-Dewar

Monica Hennings

Will Kodash

Kristien Karmarker

Myndi McDonald

Erik Muller

Vy Nguyen

Koji Oka

Nicole Porto

Ranjit Steiner

Staff & Physicians

Gary Dahl

Morgan Gross

Anne Heideck

Linda Jordan

Jake Lore

Shionda Nickerson

Maureen O'Hara

- Pam Simon was on the program committee for the AYA Global Congress and spoke at the conference.
- Michaela Liedtke attended the AYA Global Congress and SAYAC presented posters.
- Volunteer Casey Walsh, PhD, worked with the PFAC to complete her dissertation research with SAYAC patients.
 - Achieved 2018 goal to disseminate her results about social functioning to patients just off therapy and into survivorship.
- Sent six patients to CancerCon with the support of the 19 for Life foundation.
- Shared patient experiences with 19 for Life.
- Connected with Lucile Packard Children's Hospital Stanford ambassadors to plan future AYA-focused events.
- Pam Simon and Jasan Zimmerman were interviewed for a Conquer magazine article about long-term survivorship.
- Held a symposium for Stanford health care professionals led by Triage Cancer.
- Added an AYA resource section to the Stanford Cancer Center Resource Center with guidance from our patients and the Cancer Center Health Librarian, Gillian Kumagai.
- Pam Simon finished a masters certificate course at Coventry University called Adolescent and Young Adult Cancer Care, sponsored by Teen Cancer America.
- Disseminated a relationship study led by a Stanford urology fellow to our patients.
- Held an honorary Stanford School of Medicine graduation ceremony for an AYA patient.

FY19 PROPOSED GOALS

- Continue adding AYA peer mentors and expand their scope of involvement with the program.
- Continue to 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.
- Continue Smart Patients partnership.
- Increase recognition of SAYAC locally, regionally, and nationally.
- Attend CancerCon with 19 for Life as an exhibitor.

Adult Congenital Heart Program

Patient & Family Advisory Council



2017-2018 KEY TOPICS / ACCOMPLISHMENTS

- Developed a structure for PFAC remote video meetings with rotating physician involvement.
- Established PFAC Goals and action items.
- Invited guest speakers to inspire direction for goals and action items.
- Shared stories amongst PFAC members to build team cohesiveness.
- Held quarterly physician education sessions to help educate PFAC members.
- Created PFAC Facebook page to help keep current and prospective patients updated on clinic events and news.
- Discussed peer-to-peer program and identified potential peer-to-peer trainees.
- Reviewed patient educational materials.
- Toured the new Stanford Children's Hospital.

FY19 PROPOSED GOALS

- Initiate Adult Congenital Heart peer-to-peer program.
- Plan Adult Congenital Heart patient and family celebration for Summer 2019.
- Increase MyHealth adoption by 25%.
- Create online educational portal for patients and families on Stanford website.
- Expand educational materials and resources for caregivers.
- Recruit new PFAC members.

Year Established

2017

Patient & Family Chair

Linda Jenkins

Staff Advisor

Christy Sillman, RN, MSN
*Nurse Coordinator, Adult
Congenital Cardiology*

2017-2018 Members

Patient & Family Partners

Alice Georgitso
Michael Jaynes
Tim Jenkins
Daniah Khan
Barbara Stone
Brooke Stone

Staff & Physicians

Dr. Christiane Haeffele
Dr. George Lui
Dr. Ian Rogers
Dr. Anitra Romfh
Maria Tirador

Cancer Center

Patient & Family Advisory Council



2017-2018 KEY TOPICS / ACCOMPLISHMENTS

- Partnered with staff on 3 principal initiatives:
 - **Cancer Care Navigator Design, Phases 2 & 3**—Informed Cancer Care Navigator role, requirements, design and process flow; served as voice of customer; assisted with adoption and communication of role.
 - **Patient & Family Education**— Contributed to New Patient & Family Resource Guide implementation.
 - **Patient Reported Outcomes Design and Implementation** – Partnered in design sessions, survey development, and patient and team focused workflows for pilot in Head and Neck Cancer Care program.
- Contributed to other Cancer Center projects, including:
 - **Staff Interviews**— Participated in Patient Coordinator panel interviews.
 - **GI Navigation** – Provided feedback on personalized patient portfolios.
 - **Transformation Workshop** –Informed on delays and waits.
 - **Job Descriptions** — Developed Patient & Family Partner volunteer and Chairperson job descriptions.
 - **Transformation Evaluation**—Provided design and approach for transformation initiatives.
 - **Peer-to-Peer Program**—Piloted program within Cancer service line.
 - **UnitedHealth Group** - Joined the Stanford Graduate School of Business as panelists speaking to designing future care navigation strategies for patients and family members.

Year Established

2012

Patient & Family Chair

Tom Neukranz

Staff Advisor

Deepti Randhava, *Director Cancer Patient Engagement & PathWell Programs*

2017-2018 Members

Patient & Family Partners

Bev Anderson
Bonnie Willdorf
Judy Chang
Leo Chang
Frank Gemignani
Julie Martinez
Meryl Selig

Staff/Physicians:

Esther Chyan
Patricia Falconer
Donna Healy
Beverly Mitchell, MD
Kavitha Ramchandran
Eben Rosenthal, MD
Lidia Schapira, MD
Sri Seshadri
Darla Watanabe

FY19 PROPOSED GOALS

Support Cancer leadership in successfully achieving FY19 initiatives related to Patient Experience; Operational Excellence; Quality; Financial Strength; and Strategy.

Potential projects include:

- **Fiscal** - Clarify processes for non-contracted insurance authorizations, and for setting better and clearer patient and family expectations .
- **Patient Reported Outcomes** - Help craft language that engages patients, families, and caregivers on the value of patient reported outcomes and surveys.
- **StoryCorps** - Serve as a conduit for recruiting patient and family volunteers to share stories.

Cancer Center South Bay

Patient & Family Advisory Council



2017-2018 KEY TOPICS / ACCOMPLISHMENTS

- Adopted a mission statement.
- Created a mentorship program for members.
- PFAC Chair interviewed each council member to assess areas of interest and engagement.
- Participated in team building and goal setting exercises.
- Recruited and onboarded 5 new members.
- Participated in 100% of 75 staff interviews at the Cancer Center South Bay (CCSB).
- Participated in building-wide Guiding Principles renewal program.
- Advised on locator badge retention program.
- Toured and advised on operating suite space planning.
- Discussed medical oncology clinic restructure plans.
- Advised on implementation of infusion gatekeeper role.
- Chose infusion suite privacy screens.
- Discussed laboratory space planning and operational changes.
- Participated in Cancer Network - Valley Medical Oncology to CCSB integration.
- Participated in planning for Cancer Network - Redwood City implementation.

Year Established

2013

Patient & Family Chair

Rose Simmons

Vice Chair

Linda Toeniskoetter

Staff Advisors

Sara Malm

*Clinical Operations
Manager*

Nancy Dickenson

*Patient Experience
Manager/Librarian*

- Advised Radiation Therapy on improvements regarding staff concern for patient emotional needs.
- Advised on several clinical nursing improvement projects.
- Consulted on nutrition programs, including new patient class and telephone consultation.
- Shared and recorded audio stories through StoryCorps program.
- Provided yoga for staff support.
- Participated in C-I-CARE Patient Experience Week open house at the CCSB.
- Attended and presented poster at Institute of Patient- and Family-Centered Care conference in Baltimore, MD.
- Published case study in Beryl Institute newsletter.
- Participated in Sutter Health Patient and Family advisory development meeting.
- Participated in United Healthcare focus group.

FY19 PROPOSED GOALS

- Implement peer-to-peer program at CCSB, in collaboration with Social Work.
- Continue involvement in staff improvement projects.
- Develop caregiver resource network.
- Recruit new members, increase diversity, and expand into community.
- Participate in 100% of new CCSB employee interviews.

2017-2018 Members

Patient & Family Partners

Donna Adam
Gay Crawford
Jayne Goldberg
Mary Lou De Natale
Margot Provost
Mariam Ford
Michael Furze
Nazila Malekpour
Bev Quinby
Suzanne Rivers
Peggy Tuite
Nancy Zillman

Staff/Physicians:

Patty Falconer
Nicole Fontana
Ginny Kroening
Sarah Lange
Shiva Modarresi
Patrick Swift, MD
Catherine Terrell
Darla Watanabe

Cystic Fibrosis

Patient & Family Advisory Council

2017-2018 KEY TOPICS / ACCOMPLISHMENTS

- Completed a pilot research study on the perceived benefits of Cystic Fibrosis (CF) patients monitoring their FEV1 scores at home to better manage their healthcare needs. This was the first step in a larger project with a goal of supporting virtual clinic visits to improve the healthcare of CF patients.
- Produced information on masks for lung disease to provide patients with a better understanding of the various types of masks and when they should be used.
- Worked with national Cystic Fibrosis Foundation (CFF) organization in the development of new and exciting projects to improve CF healthcare for patients across the US.
- Worked with the MyHealth development group to continue improvement of the patient portal.
- Paired patients with medical students to provide valuable insight to the patient's view of healthcare.
- Contributed information for the Stanford Facebook page for CF patients.

FY19 PROPOSED GOALS

- In honor of 2 beloved council members lost last year, investigate the possibility of getting a piece of art in the new Stanford Hospital dedicated to patients lost due to CF.
- Plan and execute subsequent steps based on initial research study on FEV1 home measurement.
- Ramp up of the CF Encounters project, focused on alignment with the Service Excellence department to help capture the patient voice.
- Support national projects managed by the CFF with focus on project participation and the elevation of the voice of the patient.
- Investigate methods to include more CF patients in the activities being led by the council.

Year Established

2009

Patient & Family Chair

Brian Eddy

Staff Advisor

Colleen Dunn

*Clinical Research
Coordinator, CF Center at
Stanford Hospital*

2017-2018 Members

Patient & Family Partners

Jay Archibald

Amy Baugh

Aimee Braddock

Linda Burks

Brian Eddy

Elyse Goldberg

Ed Kinney

Abby Lewis

Larissa Marocco

Angel Mammino

Shawn Taylor

Emergency Department (ED)

Patient & Family Advisory Council



2017-2018 KEY TOPICS / ACCOMPLISHMENTS

- Designed and implemented the Primary Patient Support project for the Emergency Department (ED). Project enables primary support person to stay with patient during rooming so that they can provide critical information on patient if the patient is unable to do so - potentially improving patient care in the ED.
- Presented Primary Patient Support project at the Institute of Patient- and Family-Centered Care conference in June 2018 in Baltimore, MD.
- Recommended and implemented changes to the ED lobby PowerPoint presentation.
- Brainstormed and made recommendations on the Real Time Locating Tracking System for the new Stanford Hospital (500 Pasteur Drive).
- Provided feedback on the After ED Visit cards and Press Ganey Patient Satisfaction surveys.
- Observed the ED and provided feedback on caregiver involvement with triage and rooming patients.
- Provided feedback and suggestions to decrease perceived wait time before seeing an doctor.
- Participated in Strengthening the Caregiver Relationship workshop - focusing on the ED.
- Provided feedback and regarding ED call-backs.
- Provided feedback to the Office of Medical Development about seeking donations from Stanford patients.

Year Established

2016

Patient & Family Chair

Vanessa Deen Johnson

Clinical Advisors

Viveta Lobo, MD
Clinical Assistant Professor,
Associate Director,
Emergency Ultrasound
Program

Jason Francis, RN (2017)
BSN, CEN, CCRN
Assistant Patient
Care Manager
Emergency Services

Jean Reyes, RN (2018)
MSN, MBA
Assistant Patient
Care Manager
Emergency Services

2017-2018 Members Patient & Family Partners

Gary Bronstein
Jean Bronstein
Cathy Castillo
Julie Craven
Francie Green
Elizabeth Pirrota
Kelvin Yu

Staff:

Patrice Callagy
Elizabeth Halligan

FY19 PROPOSED GOALS

- Improving Patient Experience Likelihood to Recommend
- Increasing visibility and importance of role of Caregiver in the ED
- Reducing time for Door-to-Disposition for non-FAST track patients
- Update results of Primary Patient Support project
- Assessing and improving ED care of patients waiting to be admitted
- Reducing wait time for Neurology consults

Founding

Patient & Family Advisory Council



2017-2018 KEY TOPICS / ACCOMPLISHMENTS

- Partnered with Stanford School of Medicine “Walk with Me” to pilot patient/family and medical student matching longitudinal course.
- Provided feedback on Open Notes to plan for implementation in specialty clinics
- Partnered with Patient Care Services and Supply Chain to eliminate SHC embroidery on hospital pillows, created over \$25,000 in cost savings.
- Provided feedback to Patient Unit F3 nursing on bedside shift-to-shift report pilot.
- Participated in Patient Financial Services survey to improve the patient and caregiver experience.
- Provided input to Project for Planning Spaces for use of public spaces around hospital.
- Piloted StoryCorp for Stanford Storybank and supported facilitator training.
- Invited CEO of Beryl Institute to a Founding PFAC meeting.
- Provided input to Primary Care’s Population Health/Healthy Planet improvement work.
- Provided input to Zoom Caffé management on enhancing patient experience in our off-site cafés.
- Provided feedback to Medical Center Development on how to improve patient appeals process.
- Provided input on amenities, services, and vendors connected to 300 Pasteur and 500 Pasteur.

Year Established

2009

Patient & Family Chair

Lynn Fraher

Staff Advisor

Mary Song

Manager, Volunteer Resources and the Patient & Family Partner Program

2017-2018 Members

Patient & Family Partners

Mukund Acharya

Kim Cashin

Leilani Graham

Jennifer Julian

Michael Moore

Shahin Shabahang

Christine Stamper

Staff/Physicians:

Elisa Drakes

Bryanna Gallaway

Reina Loyola

Katie Stephens

- Represented the community voice in the Strategic Plan for Integration of Stanford Health Care, Stanford Children’s Hospital, and the Stanford School of Medicine.
- Provided patient and family input on technology and design, including tablets usage; discharge planning technology for new hospital; and the MyHealth patient portal.
- Invited guest presenters from Nursing Excellence, the Risk Authority, Guided Journey Design Team, Aging Adult Services, 500 Pasteur Patient Experience Committees, and Sutter Health’s Patient & Family Advisory Councils to council meetings.

FY19 PROPOSED GOALS

- Support Service Excellence leadership in addressing key challenges in patient experience.
- Support quality and patient safety initiatives throughout the hospital and in clinics.
- Provide feedback to workgroups focused on cost savings.
- Further develop partnerships with the School of Medicine.
- Support planning and activation for new Stanford Hospital (500 Pasteur Drive) and 300 Pasteur Drive redesign.

Heart Transplant

Patient & Family Advisory Council



2017-2018 KEY TOPICS / ACCOMPLISHMENTS

- Completed a significant expansion and update of the Heart Transplant Patient Handbook, including new caregiver/family member section.
- Executed 5th annual Heart Transplant Symposium, Reunion, and Celebration on March 23, 2017. Event was attended by approximately 325 heart transplant recipients, family members, and Stanford health care providers.
- Executed 6th annual Heart Transplant Symposium, Reunion, and Celebration on March 29, 2018. Event was attended by approximately 350 heart transplant recipients, family members, and current and former Stanford health care providers.
- Planned and presented the Heart of Gold celebration - honoring the 50th anniversary of the first U.S. heart transplant by Dr. Norman Shumway at Stanford.
- Published three semi-annual heart transplant newsletters to inform, educate, and encourage the heart transplant community. Newsletters were distributed to approximately 400 patients via U.S. mail and email.
- Five Peer 2 Peer mentors were invited to a PFAC meeting, promoting communication between mentors and PFAC members, as well as offering potential for PFAC recruiting.
- Added five new PFAC members, successfully increasing the team to a total of 12 people.
- Supported the October 2017 launch of Smart Patients, an online peer-to-peer mentoring program for the heart transplant community. Several PFAC members engaged with the program.

Year Established

2011

Patient & Family Chair

Susan Roberts

Staff Advisor

Helen Luikart

*Research Nurse Manager,
Heart Transplant*

2017-2018 Members

Patient & Family Partners

Ryan Comerford

Les Denend

Eric Gries

Anna Jelks

Lyn Kagihara

Lovester Law

Becky Pomerleau

Susan Roberts

Carolina Tejada

Michael Vollstedt

Staff/Physicians:

Morgan Gross, LCSW

Anne Heideck, LCSW

Jose Maldonado, MD

- In March 2018 created and presented a service award to recognize the Cath Lab **receptionist** (not an SHC title) for his efficient and caring service to heart transplant patients.
- Individual PFAC members continued to be actively involved in the following areas:
 - **Peer 2 Peer Program** - 8 volunteers trained as Peer 2 Peer mentors.
 - **Stanford Heart Transplant Quality Council** - monthly attendance.
 - **Donor Network West** - organ donation-related talks, fundraiser walks, etc.
 - **American Heart Association** - various events.
 - **Same Day Feedback** - engaging the voices of Spanish speaking patients to improve their hospital experience.
 - **Stanford School of Medicine** - Collaborated with programs such as Walk with Me.
 - **New Stanford Hospital** - various committees
 - **Spontaneous Coronary Artery Dissection** - 1st annual Survivor Retreat co-hosted by Stanford and the SCAD Alliance.

FY19 PROPOSED GOALS

- Plan and execute seventh annual Heart Transplant Symposium, Reunion, and Celebration (March 2019) to build community and provide education and encouragement. Expected attendance: 350 people
- Publish and distribute semi-annual heart transplant newsletters (approximately 400).
- Update Heart Transplant patient manual.
- Create and obtain an approved budget for Heart Transplant PFAC initiatives.
- Continue to promote the Peer 2 Peer mentor program.
- Continue successful PFAC recruiting with a goal of adding a minimum of one new member.
- Escalate concerns regarding patient/family temporary housing to leadership.
- Develop a mechanism or process to capture patient feedback, and identify areas for improvement.
- Present PFAC Certificates of Recognition.
- Enhance Heart Transplant website.

Lung Transplant

Patient & Family Advisory Council



2018 KEY TOPICS / ACCOMPLISHMENTS

- Launched PFAC in February 2018.
- Provided feedback on letter sent to patients regarding Lung Transplant staffing changes.
- Reviewed clinic patient satisfaction data and key clinic challenges affecting the patient experience.
- Partnered with the Peer 2 Peer mentoring program to increase access and referrals for lung transplant patients.
- Provided feedback on the Lung Transplant's Realizing Improvement Through Team Empowerment (RITE) - project focused on reducing length of stay for lung transplant hospitalization.
- PFAC partner participated Lung Transplant Length of Stay RITE project workgroup.
- Discussed ways to transition lung transplant patients' general medical care back to primary care after transplant .

FY19 PROPOSED GOALS

- Discuss improvement ideas and results to improve clinic wait times.
- Continue to monitor the patient satisfaction survey metric.
- Plan lung transplant education and reunion.
- Improve patient education for lung transplant patients and caregivers.
- Create a communication tool to connect the PFAC, Lung Transplant Program, and all lung transplant patients.

Year Established

2018

Patient & Family Chairs

Elyse Elconin-Goldberg
Luanne McKinnon

Staff Advisor

Kelsey Winnike
*Social Worker, Social Work
and Case Management
Department*

2017-2018 Members

Patient & Family Partners

Jill Cooper
Robert Duffy
Heidi Geyer
Elyse Elconin-Goldberg
Jennifer Julian
Gerardine Hernandez
Luanne McKinnon
Mari Matsumura
Marjorie Young

Staff/Physicians:

Laveena Chhatwani, MD
Jason Francis
Kelly Johnson
Claire Reichle
Jared Roberts
Michelle Stroebe
Megan Webb

Neuroscience

Patient & Family Advisory Council



2017-2018 KEY TOPICS / ACCOMPLISHMENTS

- Collaborated with clinic administration to install automatic push button accessible doors in the first floor bathrooms at the Stanford Neuroscience Health Center.
- Provided feedback to staff in clinical departments including Multiple Sclerosis, Headache, Orthopedics, Stroke and Traumatic Brain Injury.
- Met with hospital departments such as Parking Services and Pastoral Care to learn about their services and provided suggestions to improve patient care and satisfaction.
- Provided feedback regarding Press Ganey patient satisfaction surveying process.
- Provided feedback to the Neuroscience Supportive Care Program - which provides over 30 services to 7,272 people.
- Supported procedures 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 PFAC member development and growth by encouraging members to remain engaged in a variety of activities and improvement projects.
- Achieved goal of adding two staff members. Also added one caregiver.
- Provided operational feedback on the patient check-in process and patient tracking while in clinic. Feedback lead to improvements.
- Explored advancements in new diagnostic equipment and technology.

Year Established

2013

Patient & Family Chair

Jody Yarborough

Staff Advisor

Dana Gonzales
*Clinic Manager,
Neurosurgery Clinic*

Jacque Keeling
*Assistant Director,
Clinic Operations*

2017-2018 Members

Patient & Family Partners

Lauren Cotter
Jinny Fruin
Martha Gardner
Kevin Giberson
Cheryl Hewitt
Paula Holwell
Scott McLaggan
Ting Pun
Nancy Stohn
Ginger Tanner
Jody Yarborough
Armando Ybarra

Staff:

Cynthia Cabatan
TC Cowles

- Mentored new medical students through participation in newly established "Walk With Me" School of Medicine curriculum.

FY19 PROPOSED GOALS

- Review patient access data and offer 2 improvement activities to improve access.
- Review patient access and satisfaction data, and offer 2 improvement ideas to improve patient satisfaction.
- Actively help Neuroscience Supportive Care Program by offering feedback and program participation.
- Host one subspecialty speaker at each PFAC meeting with an emphasis on how PFAC can support clinicians.
- Draft a PFAC mission statement.

Pain Management Center

Patient & Family Advisory Council



2017-2018 KEY TOPICS / ACCOMPLISHMENTS

- Reviewed data on top reasons for clinic cancellations to support clinic workflow and to improve patients' access into clinics, while brainstorming challenges and solutions
- Implemented multi-faceted campaign to encourage patients to provide at least 72 hours advance notice when cancelling appointments. Appointment cancellations adversely impact patient access into clinic, and the overwhelming majority of cancellations occur within 24 hours of the scheduled appointment time.
- Discussed different opportunities for patients and families in clinic to provide real time feedback, including PFAC members' role in engaging patients and families in completing the surveys
- Reviewed Pain Clinic Patient Satisfaction Survey data
- Identified several key areas of opportunity for the Pain Center to improve patient experiences, including MyHealth documentation, providing list of education programs offered, and helping patients prepare for clinic appointments
- Reviewed call volume data to see if any questions could be answered in advance. Proposed solutions around scripting for physicians and check out staff to reduce call volume.
- Implemented ideas to share PFAC's appreciation to all Pain Service staff and providers

Year Established

2016

Patient & Family Chair

Kristina Breen

Clinical Advisor

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

2017-2018 Members

Patient & Family Partners

Suzan Carrico
Penney Cowan
Nancy Cytron
Ron Forsythe
Wendy Holthaus
Julisa Voinche

Staff/Physicians:

Ranjini Reddy-Deo
Scott Pritzlaff, MD
Esteban Valenzuela

FY19 PROPOSED GOALS

- Review previously brainstormed areas of opportunity to improve the patient experience and create project goals for PFAC to support - focusing on:
 - Preparing patients for clinic
 - Contact Center communication
 - Sharing list of resources for patients
 - MyHealth documentation
- Integrate feedback from division leadership and staff about project to improve patient experiences.
- Expand council membership.

Stanford Health Care ValleyCare

Patient & Family Advisory Council



2017-2018 KEY TOPICS / ACCOMPLISHMENTS

- Corrected wayfinding error and suggested other edits on marketing material that Livermore Skilled Nursing Director brought for review.
- Focused on improving patient experience by better understanding how staff inform patients about delays, and helped initiate improvements to keep patients updated about wait times in the clinic by reducing communication gaps.
- Shadowed patients from registration to discharge and recorded 12 hours of observations - focusing on patient wait-times and staff processes at the Dublin and Livermore Urgent Care Centers.
- Conducted 14 staff and patient interviews at both urgent care centers.
- Co-facilitated 7 trainings, shared findings, and brainstormed possible solutions with Patient Experience managers and Urgent Care frontline staff to resolve ways to communicate meaningful information to patients.
- Recommended that Urgent Care staff calibrate patient expectations of wait-times starting at Front Desk registration, followed by medical staff updates every ten to fifteen minutes once patient is escorted to exam room
- Recommended hospital administration's directive that Quiet Champions schedule routine debriefings with their managers to update them on Quiet Governance Committee issues, ultimately encouraging the managers to be informed advocates of the Quiet Campaign.
- Staffed tables at Pleasanton and Livermore hospitals for a total of 21 hours over a week to encourage patients to enroll in MyHealth portal.

Year Established

2017

Patient & Family Chairs

Leslie Patterson
Mary Ellen Huey

Staff Advisor

Tracey Lewis Taylor
*Chief Operating Officer,
Stanford Health Care,
ValleyCare*

2017-2018 Members

Patient & Family Partners

Lauren Cotter
Kirstin Litz
Judy Chang Otani
Bob Nebozuk

Staff/Physicians:

Amanda Felix
Gina Teeples
Krystal Tsui
John Yee, MD

- Created informative handout tailored to the Stanford Health Care ValleyCare PFAC for staff physicians to use as a guideline to identify and recommend prospective recruits to our Advisory Council
- Participated at different levels in six areas: Signage, Quiet Governance, Urgent Care, My Health, Patient Experience and Skilled Nursing

FY19 PROPOSED GOALS

- Create mutual understanding between SHCVC staff and PFAC by inviting targeted physicians and other staff to speak to us about clinical and patient issues that impact community and hospital
- Expand PFAC by one to two new members by August 1, 2019
- Support new, primary stroke center where needed—e.g., simulating stroke patients for SHCVC team-training; delivering community-based program to educate retirement communities about stroke center

Thank You

Stanford Health Care would like to thank the following Patient & Family Partners for their time and dedication volunteering to improve care for our patients and families. We'd also like to thank our Patient & Family Chairs (*) for co-leading our Patient & Family Advisory Councils. In addition to everyone mentioned below, we appreciate the support and growing requests for Patient & Family engagement from Stanford Health Care and the community.

We look forward to what we can accomplish together in FY2019!

Abby Lewis	Brooke Stone	Francie Green
Aimee Braddock	Carolina Tejada	Frank Gemignani
Alice Georgitso	Carolyn Schwartzbord	Gary Bronstein
Alka Jayakar	Catherine Enciso	Gay Crawford
Amy Baugh	Cathy Castillo	Gerardine Hernandez
Andrew Oman	Charlene Setlow	Ginger Tanner
Angel Mammino	Cheryl Hewitt	Hazen Kazaks
Anna Jelks	Christine Stamper	Heidi Geyer
Armando Ybarra	Daniah Khan	Jacob Fraker
Barb Kivowitz	David Smith	Jasan Zimmerman*
Barb Stone	Donna Harris Adam	Jay Archibald
Becky Pomerleau	Ed Kinney	Jayne Goldberg
Bev Anderson	Elizabeth Pirrotta	Jean Bronstein
Bev Quinby	Elyse Elconin-Goldberg*	Jeff Lulenski
Bob Nebozuk	Eric Gries	Jennifer Geranen
Bonnie Willdorf	Erik Muller	Jennifer Judas
Brian Eddy*	Fiona Gutierrez-Dewar	Jennifer Julian

Jill Cooper	Laurie Talevich	Meryl Selig	Rich Valdes
Jinny Fruin	Leilani Graham	Michael Furze	Robert Duffy
Joan Scott	Leo Chang	Michael Jaynes	Robin Beresford
Joanne Koltnow	Leslie Denend	Michael Moore	Ron Forsythe
Jody Yarborough*	Leslie Patterson*	Michael Vollstedt	Rose Simmons*
John Au	Linda Burks	Mila Wright	Ryan Comerford
Judy Chang	Linda Jenkins*	Monica Hennings	Scott McLaggan
Julie Craven	Linda Knepper	Mukund Acharya	Shahin Shabahang*
Julie Martinez	Linda Toeniskoetter*	Myndi McDonald	Shawn Taylor
Julisa Voinche	Linda Umbach	Nancy Cytron	Sheryl Michelson
Kelvin Yu	Lizzy Craze	Nancy Stohn	Susan Roberts*
Kevin Frandsen	Lovester Law	Nancy Zillman	Suzan Carrico
Kevin Giberson	Luanne McKinnon*	Nazila Malekpour	Suzanne Rivers
Kim Cashin	Lyn Kagihara	Nicholas Clark	Thomas Neukranz*
Kirstin Litz	Lynn Fraher*	Nicole Porto	Tim Jenkins
Koji Oka	Manuel Abad	Olivia Davis	Ting Pun
Kristen Terlizzi	Margot Provost	Patti Plummer	Vanessa Johnson*
Kristien Karmarkar	Mari Matsumura	Paula Holwell	Viveta Lobo
Kristina Breen*	Mariam Ford	Peggy Tuite	Vy Nguyen
Lara Farhat	Marjorie Young	Pei-Pei Yow	Wendy Holthaus
Larissa Marocco	Martha Gardner	Penney Cowan	William Kadash
Laura Jammal	Marty Howard	Ranjit Steiner	
Lauren Briskin	Mary Ellen Huey*	Reina Loyola	
Lauren Cotter*	Mary Lou Denatale	Renee Loth Cali	

