

# Patient & Family Partner Program 2022 Annual Report



**Stanford**  
MEDICINE

Health Care

# Table of Contents

1	Patient & Family Engagement
2	Patient & Family Advisory Councils
3	Adult Congenital Heart Disease
4	Cancer Center, Palo Alto
5	Cancer Center, South Bay
7	Cystic Fibrosis
8	Disabilities
10	Emergency Department (ED)
11	Founding
13	Heart Transplant
15	Lung & Heart-Lung Transplant
16	Stanford Adolescent and Young Adult Cancer
18	Thank You

# Patient & Family Partner Program 2022

**118** Patient & Family Partners

**11** Active Patient & Family Advisory Councils

**2,500**  
Volunteer Hours

Composition of Patient & Family Partners

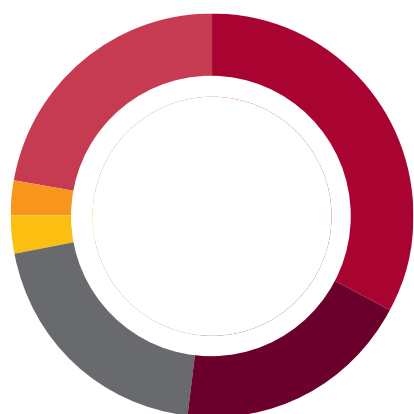


**25%** Caregivers

**75%** Patients

## Types of Engagement

Outside of Patient & Family Advisory Councils



- Consulting (33%)
- Workgroups (22%)
- Improvement Events (20%)
- Speaking Opportunities (19%)
- Committees (3%)
- Focus Groups (3%)

**60+**  
Departments & Services Requesting Patient & Family Partners

# Patient & Family Engagement

In addition to Patient & Family Advisory Councils, Patient & Family Partners volunteer as advisors on committees, speakers, and consultants. They participate in focus groups, improvement projects, and workgroups. The program received over 60 requests in 2022 for patient and family engagement in projects highlighted throughout this annual report.

# 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 Health Care.

# Adult Congenital Heart Disease

## Patient & Family Advisory Council



### ACCOMPLISHMENTS

- Continued to provide peer-to-peer support to existing adult congenital heart disease (ACHD) patient mentees, including solid organ transplant recipients.
- Increased percentage of ACHD program patients registered for MyHealth from 67% to 75%.
- With the help of the ACHD program's Administrative Assistant, Natalie La Mariana, PFAC Facebook social media followers grew 70% - from about 377 to 554 followers.
- Continued collaboration with Adult Congenital Heart Association to host quarterly "ACHD Conversations" that support patients and caregivers impacted by adult congenital heart disease. PFAC members presented content on the following topics:
  - Using yoga as a form of exercise and stress management
  - How to optimize patient-provider communication
  - Balancing family with congenital heart disease
- Reunited for our first two in-person ACHD PFAC meetings since February 2020
- Received increased interest in PFAC recruitment following CHD Conversations.

### 2023 GOALS

- Continue new member recruitment
- Developed three SMART goals to have a successful upcoming year in 2023!
  - Continue hosting ACHD Conversations bi-annually.
  - Recruit four new PFAC members for the Council.
  - Support the annual ACHA fundraising event. Utilize the event as an opportunity to engage the CHA community and recruit new members.

### Year Established

2017

### Patient & Family Chair

Vacant

### Co-Staff Advisors

Kristina Fontecha, RN

*Nurse Coordinator*

Maria Tirador-Carter

*Administrative Coordinator*

### Members

#### Patient & Family Partners

Ryan Dillard

Daniah Khan

Courtney Merhab

Uduak Osom

# Cancer Center, Palo Alto

## Patient & Family Advisory Council

### ACCOMPLISHMENTS

Contributed to Cancer Center projects, participating in various roles including:

- Cancer Survivorship Program
- Advanced Practice initiatives
- Preventive Genomics Program
- Taylor Design 300P Radiology Imaging department redesign focus group
- Storytelling Workshop (Collaborated with Cancer Center South Bay)

PFAC Development Initiatives

- Active membership in Cancer Quality Council and SQIMM subgroup projects
- Maintained current roster with active participation and attendance

### 2023 GOALS

#### Department

- Active membership participation in Cancer Quality Council
- SQIMM improvement and initiative project opportunities

#### Community

- Stanford Medicine Health Matters 2023 – event booth representation (partner with Cancer Center South Bay and Cancer Center East Bay PFACs)
- Explore Patient Financial workflow

#### Patient & Family Advisory Council Goals

- Development of Palo Alto Cancer Center PFAC charter
- Collaboration and initiative sharing with Cancer Center PFAC's in the South Bay and East Bay

### Year Established

2012

### Patient & Family Chair

Tom Guntly

### Staff Advisor

Emily Nazerali, RN

*Patient Care Manager*

### Members

#### Patient & Family Partners

Leo Chang

Chuck Comey

Adriana Faiman

Kristin Gananian

Frank Gemignani

Kari Lam

Julie Martinez

Tom Neukranz

Jackie Osborne

Donna Spagna

Tom Tish

#### Staff/Physicians:

Maria Gonzalez

Donna Healy

# Cancer Center, South Bay

## Patient & Family Advisory Council



### ACCOMPLISHMENTS

- Participated in all Cancer Center South Bay (CCSB) new hire interviews.
- Worked with Dr. Cabebe to develop a CCSB patient resource guide.
- Developed a leadership succession plan for future PFAC chairs.
- Updated group roster with photos and contact information.
- Participated in the nurse navigation workgroup, badge retention initiative, and the HealthStream update workgroup.

### 2023 GOALS

#### Group Goals

- Sustain participation of 12-15 members with a collective diversity of caregivers, past patients, and nurse resources through huddles and caregiver workshops.
- Promote partnership with PFAC physicians and nurses to expand advisory council membership.
- Participate in Health Matters.
- Mentor all new PFAC members  
Operationalize a buddy/mentor for all new members
- Implement an onboarding program for new PFAC members like that of the CCSB program.

#### Year Established

2013

#### Patient & Family Chair

Jennifer Geranen

#### Staff Advisors

Traci Clark

*Nurse Coordinator*

Katie Smith

*Manager – Volunteer Resources, Patient & Family Partner Program*

#### Members

##### Patient & Family Partners

Gay Crawford (Emeritus)

Mary Lou De Natale

Cherry Fairchild

Jayne Goldberg

Nazila Malekpour

Wei Li

Rose Simmons

##### Staff/Physicians:

Cam Tu Bui

Sandra Erickson

Ginny Kroening

Danielle Lembke

Haley Maness



# Cancer Center, South Bay cont.

## Patient & Family Advisory Council

### Facility Support Goals

- Participate in work groups that focus on access to Stanford Health Care
  - Healthstream
  - Nurse Navigation
  - Anything new to arise from center goals
- 2585 participation with the expansion of SHC
- 100% participation in CCSB staff interviews

### Community Oriented Goals

- Complete reference handout
- Participate in Health Matters, collaborating with Palo Alto PFAC to plan and work at event
- Education Series
  - Formulate a quarterly seminar series possibly highlighting clinical trials.
  - Possible coordination with ACS and Cancer Care Point

# Cystic Fibrosis

## Patient & Family Advisory Council

### ACCOMPLISHMENTS

- Successful re-launch of PFAC after the COVID hiatus.
- Mentored pediatric cystic fibrosis patients transitioning to care on the adult side. PFAC completed Peer2Peer mentoring training with Michael Thomas. Mentoring is ready to go live.
- Collaborated with cystic fibrosis clinical team on a quality improvement project that focused on advance care planning in the clinic.
- Participated in Cystic Fibrosis Education Day
  - Kate Powell was a guest speaker whose topic covered pregnancy and cystic fibrosis
  - Will Harvey and Shawn Taylor presented work done by PFAC
- Provided input to cystic fibrosis clinical team on how to improve home spirometer adherence.

### 2023 GOALS

#### PFAC

Engage and solicit feedback from the greater Stanford Health Care adult cystic fibrosis community to inform PFAC's work.

#### Community (SHC cystic fibrosis patients)

Mentor pediatric cystic fibrosis patients through transition to adult care.

#### Department (cystic fibrosis team)

Participate in cystic fibrosis team's quality improvement work around advanced care planning.

### Year Established

2009

### Patient & Family Chair

Anna Powell

### Staff Advisor

Kate Yablonsky, LCSW

### Members

#### Patient & Family Partners

Will Harvey

Angela Nida

Jacob Parrish

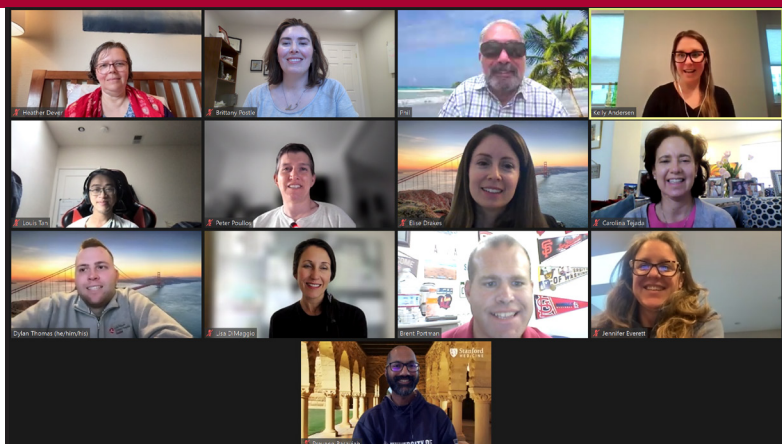
Anna Powell

Kate Powell

Shawn Taylor

# Disabilities

## Patient & Family Advisory Council



### ACCOMPLISHMENTS

- Ran Voices of Disabilities, a long-term project with the assistance of StoryCorps and the Stanford Health Library.
  - Conducted two SHC StoryCorps interviews with Disabilities PFAC patients and their medical providers.
  - Launched the website.
  - Hosted Art Night at Stanford Health Libraries for patients to participate in self-expression in various mediums (paint, crayons, digital art, and written/spoken word).
  - Created an online art gallery to showcase patient artwork.
- Worked with the Patient Experience department to make HealthStream more accessible.
- Partnered with the Emergency Department PFAC
  - Shared personal ED experiences and the pitfalls someone with various disabilities might have.
  - Brainstormed suggestions for improved physical accessibility and ED staff interactions.
- Presented both personal experiences and the Voices with Disabilities project at C-I-CARE Monthly Management Rounds.
- Collaborated on a variety of topics presented by guests who attended Disabilities PFAC meetings:
  - Palo Alto Cancer PFAC (Chair, Tom Guntly)
  - We Ask Because We Care (Jacqueline Liu)
  - Disability Ethics (Holly Tabor)
  - Planning Design and Construction - construction plan for 300P

### Year Established

2021

### Patient & Family Chair

Brittany Postle

### Staff Advisors

Kelly Andersen

*Program Manager, Revenue  
Cycle Workflow Audit*

Peter Poullos, MD

*Clinical Associate*

*Professor of Radiology and  
Gastroenterology*

*Founder and Co-Chair of the  
Stanford Medicine Abilities*

*Coalition*

### Members

#### Patient & Family Partners

Ezio Alviti

Praveen Basaviah

Heather Dever

Lisa Merritt-Dimaggio

Elise Drakes

Jennifer Everett

Philip Georgy

Brent Portman

Louis Tan

Carolina Tejada

Dylan Thomas

#### Staff

Anna Dapelo-Garcia

Jody Greenhalgh

Grace Hsu

Shelby Stewart

Jackie Stiasny

# Disabilities cont.

## Patient & Family Advisory Council

### 2023 GOALS

- Continue to share our stories and expand the Voices of Disabilities website.
- Create a workflow to escalate disability concerns in a timely manner.
- Work with management to better enable and equip staff to care for patients with all types of disabilities.
- Proper repair and management of onsite wheelchairs (wheelchair bolting).

# Emergency Department (ED)

## Patient & Family Advisory Council



### Year Established

2016

### Patient & Family Chair

Cathy Castillo

### Clinical Advisor

Brett Cohen, MD  
*Emergency Medicine  
Attending*

### Staff Advisor

Jean Reyes, RN, BSN, MBA  
*Patient Care Manager,  
Emergency Services*

### Members

#### Patient & Family Partners

Julie Craven  
Vaishali Dixit  
Alka Jayakar  
Brent Portman  
Ting Pun  
Kelvin Yu

#### Staff

Seth Cohen

### ACCOMPLISHMENTS

- A significant focus in 2022 was centered around improvements for patients and families in the Emergency Department via MyHealth.
  - Working with the MyHealth team, provided ongoing user feedback.
  - Brainstormed ideas for improvement and new features.
  - Recommended that patient-centered changes be elevated on the MyHealth priority list.
- Patient and caregiver members contributed to the Precision Emergency Medicine Project headed by Dr. Mike Gisondi, where their input was included in a presentation he gave at a conference in May.
- Welcomed Dr. Brett Cohen as the PFAC's new physician advisor and added a new PFAC member.
- Two PFAC members collaborated with Volunteer Resources leadership to update the HealthStream training required annually for all volunteers.
- One member served on the project committee for the Emergency Department's geriatric project.

### 2023 GOALS

- Continue supporting Emergency Department's geriatric project.
- Support efforts to increase patient and caregiver access to MyHealth.
- Work with the ED staff to improve the patient experience for patients admitted to the hospital.

# Founding

## Patient & Family Advisory Council



### ACCOMPLISHMENTS

- Provided feedback to the MyHealth team on how to improve transparency and the patient experience by displaying more meaningful content around patient progress and discharge goals.
- Created PFAC workgroups to lead and carry out goals.
- Invited speakers from the SHC Caregiver Program and Age Friendly Governance Council to learn more about the work happening to support caregivers across the organization.
- Informed the Patient Journey Optimization team on how SHC can improve the pre-visit experience for patients.
- Recruited patients for research opportunities.
- Supported the Planning, Design, and Construction team on updates to the room templates, a specific initiative focused on inpatient rooms and inpatient toilets for upcoming specialty hospitals.
- Provided feedback on how SHC can improve the video visit experience for patients.
- Added one new member to the PFAC.
- Reviewed and updated the Founding PFAC webpage to reflect the current vision.
- The PFAC chair shared her patient story with staff at a Monthly Managers Meeting.
- Two PFAC members contributed to a paper titled “Re-envisioning community genetics: community empowerment in preventive genomics”, which was published in the Journal of Community Genetics.
- Collaborated with the Lung & Heart-Lung Transplant PFAC to share best practices for hosting a virtual patient education event.

### Year Established

2009

### Patient & Family Chair

Annamaria Smitherman

### Staff Advisor

Katie Smith  
*Manager, Volunteer Resources and the Patient & Family Partner Program*

### Members

#### Patient & Family Partners

Mukund Acharya  
Praveen Basaviah  
Kimberley Cashin  
Elise Drakes  
Lynn Fraher  
Tom Guntly  
Michael Moore  
Jayant Phadke, MD  
Ting Pun  
Louise Ryoo  
Shahin Shabahang

### Staff

Reina Loyola

# Founding cont.

## Patient & Family Advisory Council

### 2023 GOALS

#### PFAC

Apply for a PFAC mini-grant to fund training on how to become an effective PFAC contributor and/or offer meaningful feedback.

#### Community

Continue to prioritize the patient experience, ongoing research into caregiver support, and pursue relationships with units that currently do not have a dedicated PFAC.

#### Department

Be accessible to offer feedback across all SHC departments - especially nursing, and supporting program leadership as they rebrand the PFAC teams.

# Heart Transplant

## Patient & Family Advisory Council



### ACCOMPLISHMENTS

- Planned and executed the 2nd and 3rd annual virtual symposiums, temporarily replacing the annual in-person Symposium, Reunion, & Celebration event that was canceled during the pandemic. Virtual breakout rooms featured social gatherings and a very popular cooking demonstration.
- Published and distributed a semi-annual heart transplant newsletter in English and Spanish concentrating on the 2022 theme of Empowerment.
- Continued to promote the Peer2Peer Mentor Program, naming a formal liaison from the PFAC to work with the P2P director and social workers.
- Recruited two new PFAC members.
- Continued to raise awareness about lifecycle care and wellness among the heart transplant community through the newsletter and symposium.
- Presented a PFAC certificate of recognition to the Hoover Infusion Center team for going for going above and beyond administering Evusheld.
- To build community spirit, organized the first 30-day virtual fitness program, in April 2022.
- Created fitness challenge fliers with instructions in English and Spanish.
- Continued to keep patients informed on the latest COVID19 news via email updates.

To access all of the available resources mentioned above, scan the QR code to visit the Heart Transplant PFAC [webpage](#).

### Year Established

2011

### Patient & Family Chair

Michael Vollstedt

### Staff Advisor

Helen Luikart  
*Research Nurse Manager,  
Heart Transplant*

Gabriela Oro  
*Nurse Practitioner  
Heart Transplant*

### Members

#### Patient & Family Partners

Jordan Ackernelcht  
Srilatha Davuluri  
Subu Davuluri  
Les Denend, Emeritus  
Janine Elliott  
Eric Gries  
Anna Jelks  
Alyse Ornelas  
Becky Pomerleau  
Tom Pugh  
Susan Roberts  
Carolina Tejada

#### Staff/Physicians

Shirin Jimenez, MD  
*Associate Professor,  
Cardiology*





# Heart Transplant cont.

## Patient & Family Advisory Council

### 2023 GOALS

Focusing on the 2023 theme “Overcoming Obstacles”, the Heart Transplant PFAC’s strategic goals and tactics include:

#### Advocate

- To raise awareness about lifecycle care and wellness among heart transplants.
- Continue to recruit new patient and/or caregiver PFAC members targeting 1-2 per year.
- Be available to assist in clinic decisions by providing patient perspective.

#### Educate/Inform

- Plan and execute one virtual symposium.
- Publish and distribute the semi-annual heart transplant newsletter to approximately 500 recipients.
- Continue to offer the PFAC newsletter in both English and Spanish
- Email community educational information (i.e. COVID-19)

#### Build Community

- Further develop and promote the Peer2Peer Program by working with Michael Thomas, LCSW Program Manager, and Stanford licensed clinical social workers assigned to heart transplant patients
- Present PFAC certificates of recognition to Stanford healthcare workers as appropriate (target 1-2 per year)
- Build community spirit by doing a 30-day virtual exercise challenge.
- Collect and share inspirational stories from our heart transplant community for publication in the Heart Transplant newsletter.

#### Administrative Tasks

- Create and obtain budget approval for Heart Transplant PFAC initiatives.
- Ensure periodic follow-up regarding tracking potential PFAC-specific donations received by the Stanford University Office of Development.

# Lung & Heart-Lung Transplant

## Patient & Family Advisory Council



### ACCOMPLISHMENTS

- Held two virtual town hall meetings
- Wrote six patient stories and distributed them via MyHealth
  - Experiencing the “Joy of Having a Pet” Post-Transplant
  - Managing Medications
  - My Transplant Story (*as told by a double lung recipient*)
  - The Lung & Heart-Lung Transplant PFAC Third Virtual Town Hall
  - Post-Transplant/Post-Vaccine!
  - Living with Skin Cancer
- Provided three written success stories to patients in Unit M6. Each story features a series of questions answered by a current PFAC member. Topics included:
  - What was the pathway to the SHC Lung Transplant program like?
  - Testing, conditioning, exercise, etc.?
  - Details about surgical date (feelings, emotions, support)
  - Results
  - What is the biggest aspect of care that nurses made a difference with during your inpatient stay?
- Implemented PFAC-related improvements to Clinic Bulletin Board

### 2023 GOALS

- Host 2 virtual town hall meetings
- Produce and distribute a PFAC newsletter
- Continue PFAC-related improvements to Clinic Bulletin Board
- Provide feedback on the upcoming redesign of the transplant clinic

### Year Established

2018

### Patient & Family Co-Chairs

Elyse Elconin-Goldberg

Robert Duffy

### Staff Advisor

Julia Viger, RN

Manager, Transplant

Program

### Members

#### Patient & Family Partners

Geri Hernandez

Claire Herriot

Jennifer Julian

Michelle Smith

#### Staff

Claire Reichle

Nurse Coordinator, Post Lung  
& Heart Lung Transplant

# Stanford Adolescent and Young Adult Cancer Patient & Family Advisory Council



## Year Established

2019

## Patient & Family Chair

Janan Zimmerman

## Staff Advisor

Pam Simon

*SAYAC Program Manager*

## Members

### Patient & Family Partners

Antonio Clegg-Gonzalez

Lara Farhat

Harry Forbeck

Monica Hennings

Ella Holsinger

Kendra Jackson

Kristien Karmarkar

David Llano

Maureen O'Hara

Anika Singh

Lydia Tam

### Staff

Catherine Benedict

Gary Dahl

Fiona Gutierrez-Dewar

Tania Haake

Alexander Jin

Young Kim-Parker

Stephanie Smith

## ACCOMPLISHMENTS

- The SAYAC Squad continued publishing content on Instagram (@AYA\_Stanford)
  - The SAYAC Squad creates and posts their own videos and stories to welcome and inform the larger SAYAC community
  - The Instagram page has nearly 800 followers locally and nationally
- Hosted three online events during FY22
  - Collaborated twice with the national organization Elephants & Tea Collected stories and artwork from participants that were published in a magazine for the SAYAC community and newly diagnosed AYA patients
  - In collaboration with the non-profit organization b-present, hosted an online game night
- Presented researched information about AYA lounges found at other medical facilities, and successfully advocated for an AYA lounge in the new cancer hospital. The new AYA lounge will be designed with input from the PFAC members.
- Helped launch a new clinic in the Hematology clinic for adult survivors of childhood leukemia. The GREAT (Getting Regular Examinations After Treatment) Survivorship Clinic helps adults who survived leukemia as children or teens transition to adult care.
- Hosted a live Instagram AYA program with AYA PFAC members Pam Simon and Stephanie Smith, MD.
- Participated in the Walk with Me class offered to Stanford Medicine students in partnership with the Stanford Patient and Family Engaged Medical Education program.
  - One-on-one partnership with first year medical and physician assistant students
  - Participated in a lecture on transitions of care where PFAC members shared their experiences transitioning from pediatric to adult care; transitioning from one geographic area to another; transitioning from active care to survivorship care; and other transitions. The lecture went so well that the PFAC was asked to present again in FY2023

# SAYAC cont.

## Patient & Family Advisory Council

### 2023 GOALS

- Increase education of medical staff (nurses, social workers, medical students, physicians) and partnerships between AYAs and medical staff
- Increase the number of volunteers for the SAYAC program with an emphasis on seeing patients who have been newly diagnosed
- Create an AYA cart filled with art supplies, magazines, games, and other projects for volunteers to share with patients
- Offer online events for AYAs in the community to meet and share information
- Strengthen ties with local foundations that are interested in supporting AYAs
- Continue to partner with Elephants & Tea to offer AYA virtual journaling events and publish additional Stanford AYA magazines
- Hire a paid AYA intern to better establish the AYA voice in the program

# Thank You

Stanford Health Care would like to thank our Patient & Family Partners for their time and dedication to improving care for our patients and families. We'd also like to thank our PFAC Chairs for co-leading our Patient & Family Advisory Councils. In addition to our Patient & Family Partners, we appreciate the support and growing requests for Patient & Family engagement from Stanford Health Care and the community.