Stanford MEDICINE
Health Care

2025

Annual Report

Patient & Family Partner Program

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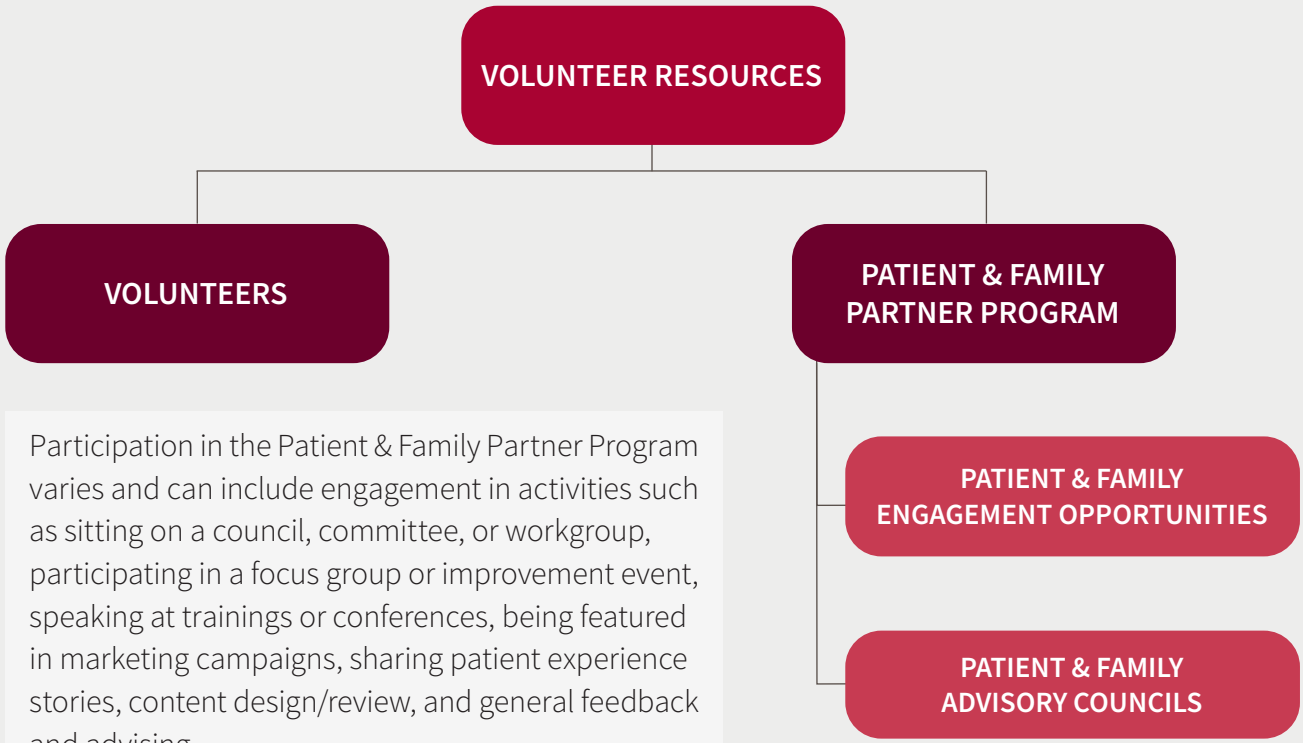
Stanford Adolescent Young Adult Cancer 27

Thank You 29

About Us

Stanford Health Care's Patient & Family Partner Program is comprised of volunteers who advise, consult, speak, and participate in hundreds of patient experience improvement and marketing engagements each year.

The goal of the Patient & Family Partner Program is to bring the patient and family voice into design and improvement work aimed at improving patient care.



Participation in the Patient & Family Partner Program varies and can include engagement in activities such as sitting on a council, committee, or workgroup, participating in a focus group or improvement event, speaking at trainings or conferences, being featured in marketing campaigns, sharing patient experience stories, content design/review, and general feedback and advising.

This report highlights the work of the Patient & Family Advisory Councils.

Patient & Family Advisory Councils provide a forum for ongoing partnerships among patients, families, staff, and physicians. The chair of each Patient & Family Advisory Councils is a patient and family partner who co-leads the council with a staff member or clinical advisor. The chair and staff advisor of each Patient & Family Advisory Council are part of the Patient & Family Partner Program Board which meets quarterly to share best practices and provide governance to the program.

2025 Patient & Family Partner Program

Year at a Glance

3,400
Volunteer Hours

106
Patient & Family Partners

9
Active Patient & Family Advisory Councils

Composition of Patient & Family Partners

72% Patients

28% Caregivers

Departments Requested Support

25+

Types of Engagement

Outside of Patient & Family Advisory Councils

- Consulting **41%**
- Improvement Activities **30%**
- Speaking Engagements **23%**
- Focus Groups, Workgroups, Committees **6%**

Adult Congenital Heart Disease

ABOUT US

The Adult Congenital Heart Disease Patient & Family Advisory Council (PFAC) aims to improve patient care and outcomes by identifying barriers, collaborating with departmental and hospital staff, and implementing new methods and programs to support the 3,000+ patients and families cared for by Stanford Medicine's Adult Congenital Heart Program.

Established: 2017

Chairperson:
Nicholas Farr

Staff Advisors:
Kristina Fontecha, RN
Nurse Coordinator

Lissette Tunchez
Cardiovascular Coordinator

Members:
Patient & Family Partners
Michael Barbe
Daniah Khan
Courtney Merhab
Aaron Hughes
Kali Schlieman

2025 Key Accomplishments

Recruiting

In 2025, the PFAC recruited two new members, including onboarding one member as a new volunteer to the Patient & Family Partner Program. This achieved half of our 2024 recruitment goal.

Back to Basics: Health Informaton Management



In July 2025, the PFAC hosted Back to Basics: Health Information Management, a program focused on adolescent and young adult patients and their families. It explored various paths for navigating the transition from pediatric to adult care and encouraged patients to become advocates for their own health.

Speakers included Anitra Romfh, MD from the Adolescent and Young Adult Transition Clinic; Kristina Marie Fontecha-Gregory, RN and PFAC Co-Staff Advisor; and a panel of patients, clinicians, and families with experience transitioning to adult congenital heart disease care.

2026 Goals

Adult Congenital Heart Association: Heart to Heart Regional Conference

In 2026, the PFAC is excited to collaborate with the Adult Congenital Heart Program at Stanford Medicine at the 2026 Heart to Heart Regional Conference. The goal of the event is to foster connection, community, and fellowship with ACHD patients throughout the Bay Area. The event will be held in the spring and will feature speakers from the PFAC and Stanford Medicine clinicians.

Recruiting

Recruitment remains a priority for the PFAC, with a goal of 10-12 staff and volunteer members.

Cancer Center

ABOUT US

The Stanford Medicine Cancer Center Patient & Family Advisory Council (PFAC) is made up of patients and caregivers who aim to improve the patient experience. Since its merger in the Fall of 2024, PFAC members have supported South Bay, Palo Alto, and East Bay Cancer Centers by bringing the patient and family voice to ongoing projects.

Established: 2012

Chairpersons:
Jennifer Geranen
Jan Hufnagl

Staff Advisors:
Traci Clark, RN
Clinical Nurse

Paulina Eulloqui-Flores
Manager, Clinical Operations

Linda Cobb
Event Manager, Cancer Destination Service Line

Members:
Patient & Family Partners
Mary Lou De Natale
Adriana Faiman
Kristin Gananian
Frank Gemignani
Jayne Goldberg
Tom Guntly
Wei Li
Julie Martinez
Jim Rowe
Rose Simmons
Srdjan Stakic
Chiquita Tuttle
Diane Tran
Gay Crawford – Emeritus Member

Staff/Physicians
Elwyn Cabebe, MD

2025 Key Accomplishments

In 2025, the PFAC remained focused on raising awareness of the great resources offered at Stanford Health Care and continued to educate patients and expand its reach throughout the local community through hosted events.

Survivorship: Continue to Get the Care You Need

Led by Dr. Lidia Schapira and Dr. Jennifer Kim, the seminar featured the Stanford Health Library, American Cancer Society, Pink Ribbon Good, CancerCare Point, and the YMCA, who shared resources and attended the events to answer questions.

Tri-Valley Breast Cancer Symposium

In October 2025, the PFAC collaborated with Stanford Health Wellness Classes, Culinary Angels, and the HERS Breast Cancer Foundation. Topics included Life After Breast Cancer, Surgical Innovations, and Empowering Treatment Options.



At the request of Cancer Center South Bay leadership, PFAC members participated in the following workgroups throughout 2025:



- **The Stanford Health Care Financial Literacy Webinar**
  Helped cancer patients understand and navigate their insurance coverage.
- **Health Matters**
  Raise awareness of the PFAC role
- **Hope Walk**
  A fundraising event supporting Cancer Support Community San Francisco Bay Area
- **Cancer Center South Bay's 10-year Anniversary**
  PFAC members provided infusion patients with fans as a gift to honor the opening of this Cancer Center
- **Phone Tree Optimization**
  A phone tree optimization project to simplify communication with our patients.
- **Staff Interviews**
  PFAC members continued to participate in staff interviews for the South Bay Cancer Center.

2026 Goals

- To continue to focus on patient care and education with a goal of providing a seminar in another language
- Raise awareness of what it means to become a PFAC member
- Support all workgroups that bring better access to Stanford Health Care.

Cystic Fibrosis

ABOUT US

The Adult Cystic Fibrosis Patient & Family Advisory Council (PFAC) serves as a bridge between the patient community and the clinic. Drawing on their expertise in living with and managing a highly complex chronic disease, the PFAC aims to identify and address challenges to a high-quality patient/family partnership with the provider. They aim to represent fellow patients and loved ones as cystic fibrosis standards evolve in the era of highly effective modulators.

Established: 2009

Chairperson:
Angela N.

Staff Advisor:
Kate Yablonsky
Licensed Clinical Social Worker

Members:

Patient & Family Partners
Rebekah D.-M.
Laura J.
Michelle L.
Angela N.
Anna P.
Jacob P.
Kate P.
Abhijit T.
Shawn T.
Will T.

Staff Partners
Cristal Willis

2025 Key Accomplishments

Recruitment

Recruited two new caregivers to increase representation of the loved ones' experience – adding another parent of a cystic fibrosis patient, and the PFACs first spouse!

Presentations at C-I-CARE Management Rounds

- The PFAC Chair shared an exemplary experience she had with an inpatient respiratory therapist. In sharing her story, Angela used the patient voice to demonstrate the power of Stanford Health Care's values.
- Another PFAC member shared the group's experience in co-production of goals between patients and medical teams. He discussed how the PFAC contributed to a realistic, patient-friendly structure for the center's advanced care planning quality improvement initiative.

Quality Improvement Work

- The PFAC played an active role in helping the Adult Cystic Fibrosis Center, the general medicine teams, and cystic fibrosis patients adapt to a new model of inpatient care. PFAC members conducted interviews with recently admitted patients to identify what is going well and areas for improvement. Patient feedback has been incorporated into quality improvement efforts around this ever-evolving care model.
- Provided valuable input on quality improvement efforts in the Cystic Fibrosis clinic around collaboration with endocrine and increasing compliance with the annual oral glucose tolerance test requirement.

2026 Goals

PFAC Goals

Increase knowledge, awareness, and outreach around topics related to PwCF without access to CFTR modulators

Community Goals

Empower the Stanford Health Care cystic fibrosis community with more information on aging with the disease (like retirement planning and navigating the larger healthcare system) and disaster preparedness

Department Goal

Host a virtual town hall for the Stanford Health Care cystic fibrosis community

Disabilities

ABOUT US

The mission of the Disabilities Patient & Family Advisory Council (PFAC) is to increase awareness and foster a culture of disability inclusion at Stanford Health Care.

Composed of patients and Stanford Health Care staff, the PFAC was created to highlight the experiences of patients with complex intersecting life experiences in disability, race, gender, sexuality, and all-around diversity - perspectives that have been traditionally overlooked in medicine.

The PFAC works to make equity actionable and healthcare an accessible, dignified, and equal experience for all who come to Stanford Health Care. The PFAC seeks to be the driving force behind these future conversations and contributes to projects that emphasize equity and the human experience in healthcare.

Established: 2021

Chairperson:
Dylan Thomas

Staff Advisor:
Kelly Andersen
Program Manager, Revenue Cycle Workflow Audit

Members:

Patient & Family Partners
Ezio Alviti
PG
Anne Mason
Brent P.
Louis Tan
Carolina Tejada

Staff/Physicians
Jody Greenhalgh, OTR
Jacqueline Stiasny

2025 Key Accomplishments

Disabilities Walk

The PFAC met to discuss the findings of the disability walk that was done in 2024. They decided to focus on Transportation since it was the department most directly connected to the improvements outlined in the assessment.

In June, the PFAC met with Transportation to highlight findings from the disability walk. Together, they worked to come up with improvements that would for both parties and be realistic to implement. Some of the key improvements included:

- Replace the thin wire near the entrance of 500 Pasteur Drive with something like a velvet rope – making it easier for those with visual impairments to avoid entering the traffic area and know where to stand while waiting for the golf cart.
- During the disability walk, one of the elevators was not working, resulting in long wait times. The PFAC expressed concern and looked for a solution should it happen again. Transportation is committed to having service golf cart drivers proactively circle the levels to minimize wait times.

The Disabilities PFAC performed another disability walk in November 2025. The areas of focus were the artium and cafeteria located at 500 Pasteur Drive. These specific locations were toured to identify any issues that may be detrimental to patients and visitors with disabilities.

MyHealth

MyHealth developers and project managers regularly attend PFAC meetings throughout the year to gather general feedback and test features they haven't released yet. This year, much of the focus was on the wayfinding feature and on making it easier to use for people with visual impairments. The PFAC also helped with the app's general navigation, making it easier for those with various disabilities.

Patient Relations Concern Form

Sarah Foad, Director of Patient Relations, presented the complaint/grievance process at Stanford Health Care. In the presentation, Sarah covered what was classified as a complaint vs a grievance and the different paths of action required for each. The PFAC expressed interest in integrating the process into MyHealth - to make it easier for someone to file a complaint/grievance. Although Sarah agreed that this enhancement to MyHealth was a good suggestion, it is not allowed at this time due to privacy concerns and the risk of retaliation.

2026 Goals

Perform two (2) disability walks during the 2026 calendar year, and share findings with areas to help improve the patient and family experience at SHC.

Partner with the MyHealth team to continue to improve accessibility to the MyHealth platform.

Emergency Department

ABOUT US

The mission of the Emergency Department Patient & Family Advisory Council (PFAC) is to provide firsthand experience and insights and serve as the voice of patients, loved ones, and caregivers in organization-wide programs and standard work in the Emergency Department. The PFAC works to improve the Stanford Health Care experience by emphasizing patient-centered care.

Established: 2016

Chairpersons:
Cathy Castillo
Dylan Thomas

Staff Advisor:
Jean Reyes
Patient Care Manager, MBA, MSN, RN

Members:

Patient & Family Partners
Julie Anna Craven
Natasha Humphries
Jheannelle Johnson
Brent P.
Ting Pun
Srdjan Stakic

Staff/Physicians
Dheeraj Duggineni, MD, MBA
Matthew Lim
Stefanie Sebok-Syer, PhD
Andrew Stromberg, MD

2025 Accomplishments

Over the course of the year, the PFAC focused heavily on improving the patient experience, communication, and operational efficiency within the Emergency Department. Early discussions centered on caregiver and patient surveys, MyHealth integration, patient tracking, and reducing delays. This included addressing staffing shortages, expanding imaging capacity by adding CT scanners, reinforcing masking and security measures, and monitoring how the length of stay impacted the patient experience in the Emergency Department.

Overall, the year reflected a sustained effort to improve transparency, patient-centered care, communication, and safety within the Emergency Department.

Plain Language Questions

Patient & Family Advisory Council members helped develop a comprehensive list of plain-language questions patients should ask before discharge, with the goal of empowering patients and caregivers to better understand diagnoses, medications, follow-up care, and warning signs. A formal paper that summarizes the project findings is pending.

Caregiver Inclusion

Emphasizing caregiver inclusion in physician discussions, the PFAC explored FAQ handouts and digital resources for patients and discussed leveraging AI tools to support patient education and communication.

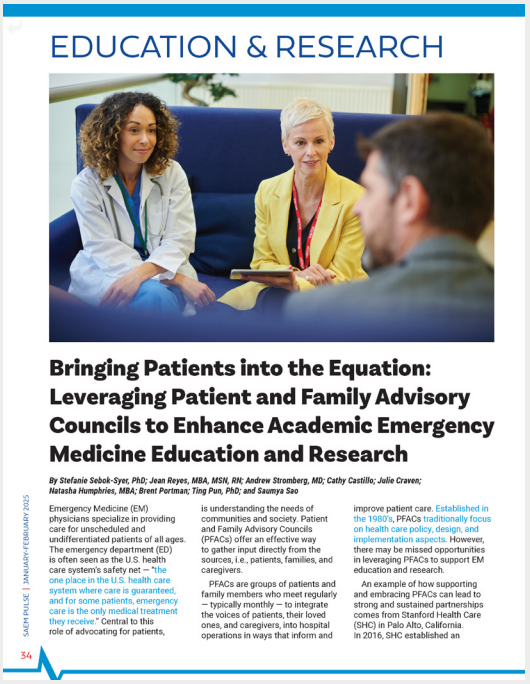
Addressing Safety, Equity, and Community Health

The PFAC addressed broader safety, equity, and community health initiatives. Topics included:

- Protecting immunocompromised and geriatric patients through masking protocols, isolated waiting areas, and possible identification systems
- Geriatric patient rounding
- Complaint processes and patient grievance resolution metrics
- Homelessness classification
- Research and innovation, including a hospital wastewater surveillance project for outbreak detection
- The growing role of AI in healthcare, including its benefits, risks, and impact on patient-physician trust
- Encouraging greater in-person participation, collaboration with hospital leadership, and stronger partnerships with programs focused on age-friendly care, diversity, and patient advocacy

Age-Friendly / Geriatric Care

- Members played a pivotal role in achieving ED Geriatric Level 1 accreditation, providing essential patient and family centered insights throughout the process.
- A PFAC member serves on the Age-Friendly Governance and Geriatric ED steering committees, ensuring the patient voice informs governance and strategy.
- PFAC members also offer ongoing feedback to the age-friendly volunteer program to strengthen geriatric care.



EDUCATION & RESEARCH

Bringing Patients into the Equation: Leveraging Patient and Family Advisory Councils to Enhance Academic Emergency Medicine Education and Research

By Stefanie Sebok-Syer, PhD; Jean Reyes, MBA, MSN, RN; Andrew Stromberg, MD; Cathy Castillo; Julie Craven; Natasha Humphries, MBA; Brent Portman; Ting Pun, PhD; and Saumya Sao

Emergency Medicine (EM) physicians specialize in providing care for unscheduled and undifferentiated patients of all ages. The emergency department (ED) is often seen as the U.S. health care system's safety net — "the one place in the U.S. health care system where care is guaranteed, and for some patients, emergency care is the only medical treatment they receive." Central to this role of advocating for patients, is understanding the needs of communities and society. Patient and Family Advisory Councils (PFACs) offer an effective way to gather input directly from the sources, i.e., patients, families, and caregivers.

PFACs are groups of patients and family members who meet regularly — typically monthly — to integrate the voices of patients, their loved ones, and caregivers, into hospital operations in ways that inform and improve patient care. Established in the 1980's, PFACs traditionally focus on health care policy, design, and implementation aspects. However, there may be missed opportunities in leveraging PFACs to support EM education and research.

An example of how supporting and embracing PFACs can lead to strong and sustained partnerships comes from Stanford Health Care (SHC) in Palo Alto, California. In 2016, SHC established an

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Published Article

The PFAC published an article in the Society of Academic Emergency Medicine, entitled, "Bringing Patients into the Equation: Leveraging Patient and Family Advisory Councils to Advance Academic Emergency Medicine Education and Research".

Staff Recognition

Throughout the year, PFAC members remained involved in recognition and volunteer initiatives, including the Orchid Award program.



2025 Orchid Award recipient Amber Gill shown with Emergency Department staff and PFAC members

2026 Goals

Increasing awareness of the PFAC among hospital staff and the community remains an important goal.

- Look for opportunities to speak at Management Rounds and other hospital forums to help staff better understand the PFAC's role and encourage greater collaboration.
- Expand community awareness to strengthen patient and family engagement.

Collaborate with other PFACs on issues that affect patients and caregivers across departments. Share experiences, ideas, and best practices with other councils to improve communication and address common concerns more effectively.

Find ways to improve caregiver support and recognize the important role they play in patient care and recovery. Discussions to include finding ways to improve access to resources, communication, and services that help caregivers feel more informed, supported, and included in the care process.

Prioritize walk-in clinics by discussing concerns related to patient experience, access, and operational challenges, and express interest in exploring ways to improve efficiency, communication, and overall care within the clinic setting.

Founding Patient & Family Advisory Council

ABOUT US

The Founding Patient & Family Advisory Council (PFAC) aims to provide insight and recommendations regarding the patient and caregiver experience at Stanford Health Care. The PFAC provides a forum for patients and their families to have their voices heard and be represented in the design and improvement of patient care.



Established: 2009

Chairperson:
Annamaria Smitherman

Staff Advisor:
Katie Smith
Manager, Volunteer Resources and the Patient & Family Partner Program

Members:
Patient & Family Partners
Mukund Acharya
Kimberley Cashin
Lynn Fraher
Reina Loyola
Michael Moore
Camilla Olson
Jayant Phadke
Ting Pun
Louise Ryoo
Shahin Shabahang

2025 Key Accomplishments

Caregiver Improvement Work



In 2025, the Founding PFAC applied and was accepted to participate in the Stanford Medicine Realizing Improvement through Team Empowerment (RITE) program. RITE is for project teams interested in addressing a complex problem with a multidisciplinary team while simultaneously learning improvement methodology. RITE project teams are normally comprised of Stanford Medicine staff. This project is the first to be led by patients and family caregivers, in partnership with staff. The team looked at identifying and documenting family caregivers to ensure they can be screened for strain and, ultimately, provided the resources they need to care for their loved ones at home. The team piloted the identification and documentation process on one unit in 2025 and looks forward to expanding the work in 2026.

Engagement with Leadership

Over the past year, the Founding PFAC partnered with organizational leaders to advance patient-centered care. First, the council collaborated with the Chief Patient Experience Officer to advocate for additional caregiver support at the hospital, underscoring the impact that caregivers have on ensuring positive patient outcomes. Next, they worked with the Chief Health Equity Officer to provide feedback on the organization's new health equity pillars, which are helping to shape strategies that ensure care is equitable and responsive to diverse patient needs.

Other Accomplishments

- PFAC members provided feedback on an interactive radiology report tool. Using the tool, members reviewed sample radiology reports and validated a rubric for AI-generated, more patient-friendly reports. The project aimed to improve how SHC radiologists and AI systems communicate medical information to patients.
- The PFAC supported the process of selecting the name for Stanford Health Care at Home, a program designed to deliver virtual at-home care to patients in their transition to home.
- In collaboration with the Marketing team, the PFAC tested and provided feedback during the redesign of the Stanford Health Care website.



- Two new members were recruited to join the council.
- The PFAC solicited input from the Social Work team on how the organization could provide better support to family caregivers.

2026 Goals

In 2026, the Founding PFAC plans to launch “Phase 2” of the work started in the RITE Project, focusing on how caregivers will be screened and supported now that they are consistently identified and documented.

The PFAC will host in-person events for caregivers, offering resources and a forum to connect with peers.

Finally, the PFAC will explore local housing resources available to caregivers, and develop a plan for promoting these resources to caregivers whose loved ones will be admitted to the hospital.

Heart Transplant

ABOUT US

The Heart Transplant Patient & Family Advisory Council (PFAC) seeks to enhance the patient care experience by ensuring that the voices of patients and families are represented. The PFAC is committed to providing support and guidance to Stanford Health Care's Heart Transplant Program, its patients, and their families.

Established: 2011

Chairperson:
Linda Karr

Staff Advisors:
Nichole Côté, MSN, RN
Helen I. Luikart, RN, MSN
Gabriela Oro, NP

Members:
Patient & Family Partners
Janine Elliott
Stephen Goddard
Eric Gries
Alyse Hayashi
Lilian Lam
Lovester Law
Susan Roberts
Carolina Tejada
Michael Vollstedt
Jake White

2025 Accomplishments

Heart Transplant Virtual Symposium

The PFAC hosted a virtual symposium in October 2025. The topics included an inspirational speaker, Reverend Floyd Thompkins, who spoke about “Surviving Certainty of Uncertainty,” and a mental health speaker, Alyssa Vela, PhD, Cardiac Behavioral Medicine, Northwestern. Dr. Vela gave a talk on “The Heart of the Matter: Why Mental Health Matters Before and After Transplant“.

The symposium highlight was a patient-caregiver panel that shared their reflections on challenges and rewards at different time points post-transplant (short-, medium-, and long-term).

Feedback from the event was extremely positive. Dr. Vela’s topic was very relevant and important for the heart transplant community, and the Reverend Thompskin’s prayer was heartfelt. The patient-caregiver panel was well-received, and the audience loved hearing from multiple perspectives.

Recognizing Outstanding Service

At the July meeting, in a moving ceremony, the PFAC presented Stanford Hospital’s Cardiology Unit (J7) with a “Certificate of Recognition” for exceptionally positive patient feedback. The J7 team provides excellent, highly specialized care to new heart transplant recipients and very ill patients awaiting the opportunity of a new heart. The result of this amazing surgery is successful in most cases. Yet, occasionally the team must navigate through great challenges and distressing outcomes with patients, families, and themselves.



Produced Two Newsletters

Twice a year, the PFAC creates and publishes a newsletter for the heart transplant community. The newsletter comprises articles from expert contributors on relevant topics. Many PFAC members contribute to making it informative and entertaining to the readers.

The 2025 theme was gratitude, which gave the newsletters a specific focus and direction. Features such as pharmacists' advice, healthy recipes, patients' kids' perspective, caregiver/patient spotlight, and travel adventures were included, to name a few.

The final collaborative newsletters were printed and delivered electronically and by mail. It is also translated into Spanish to reach our Spanish-speaking community.

2026 Goals

The overarching goals of the PFAC are to advocate, educate, and build community for the Stanford Medicine heart transplant community.

In 2026, the PFAC will focus on the theme of Longevity. For those living with a transplant, longevity has a deeply personal dimension. As we mark milestones of five, ten, or more years post-transplant, it's natural to reflect on long-term health and quality of life. Some patients may feel uncertainty or concern about the future. The PFAC will continue sharing helpful information and perspectives on these topics throughout the year.

SMART Goals:

- Build Community
  Host an in-person heart transplant reunion with medical and patient speakers, and an opportunity to network with up to 300 heart transplant patients and family members on October 6, 2026.
- Educate
  Create, design, and publish two professional-quality color newsletters in English and Spanish. Distributed in March and November 2026 by email and hard copy.
- Advocate for Patients and Caregivers
  Collaborate with Stanford Health Care nursing staff to review and update the Heart Transplant Patient Manual by December 2026.

Other Interest Areas:

- Host a PFAC meet and greet for all transplant community participants at the My Heart Counts 5k Walk/Fun Run at Stanford on May 3, 2026
- Provide more mental health awareness for patients/ caregivers through speakers or articles
- Provide support for caregivers through the Caregiver Coaching Program



Lung & Heart-Lung Transplant

ABOUT US

The Lung & Heart-Lung Transplant Patient & Family Advisory Council (PFAC) serves as the voice of patients and families, and works in partnership with the transplant medical staff to continually improve the patient experience in the Stanford Lung and Heart-Lung Transplant Program. The Lung & Heart-Lung Transplant PFAC seeks to ensure that the patient and family perspective is represented in all discussions with the healthcare team through a variety of initiatives.

Established: 2018

Co-Chairs:
Elyse Elconin-Goldberg

Staff Advisor:
Kelly Teeter
Physician Assistant

Members:

Patient & Family Partners
Claire Herriot
Jennifer Julian
Dan Lagasse
Michelle Smith

Staff/Physicians
Maia (Eileen) Bucoy-Duque
Program Manager

Claire Reichle
Nurse Coordinator
Post Lung & Heart Lung Transplant

Key Accomplishments

Newsletter

The PFAC compiled two informational newsletters for its patient community. These newsletters were distributed through MyHealth to post-transplant patients, families, and caregivers. The Summer newsletter highlighted the importance of maintaining mental health after transplant, a theme that resonates not only with patients but also with caregivers and family members throughout the transplant journey. Articles included:

- The Power of the Caregiver – recognizing and supporting those who give so much
- Pharmacy Corner – featuring an in-depth look at Nicotinamide and its role in reducing the incidence of skin cancer
- Managing Stress Eating Post-Transplant – practical advice and insights
- Traveling After Transplant – a helpful guide for planning safe and enjoyable trips
- A Patient Perspective by Robert Duffy – an inspiring and personal reflection

The Winter newsletter included articles on Vaccines to Protect Against Lung Infections, Pain Management for Patients, Collaborating with Transplant Team for Treatment of Common Cold Viruses, Comfort Foods for the Winter, and a Patient Perspective by Dan Lagasse.



The Stanford Lung & Heart-Lung Transplant PFAC

NEWSLETTER

Summer 2025

PFAC Opportunities

Dear Patients, Caregivers and Families of the Lung and Heart-Lung Transplant Community,

Summer is upon us, and with it comes new opportunities to learn, connect, and contribute to the thriving transplant community at Stanford. Since our last newsletter, we have continued to expand our support efforts to educate and inform the Lung and Heart-Lung Transplant Community through our newsletters and Virtual Education Symposium.

One highlight this past year was our **Virtual Education Symposium**. This insightful event focused on addressing chronic and acute rejection, as well as medical intervention for viral and bacterial infections in immunocompromised patients. Bringing together expert speakers and interactive discussions, the symposium provided critical information for patients and caregivers navigating the complexities of post-transplant care. Links to the Recording of this Virtual Education Symposium and our past events are available on the Volunteer Services Website: : https://stanfordhealthcare.org/for-patients-visitors/patient-advisory-councils-1/lung-transplant-pac.html

As we look ahead, we invite you to **join us in shaping the future of our transplant community**. The Advisory Council is actively seeking volunteers—enthusiastic patients and devoted caregivers who are passionate about improving the transplant experience for all. Whether you're interested in sharing your story, assisting with outreach, or contributing your ideas to new initiatives, we welcome your involvement with open arms.

Together, we can create a stronger, more supportive transplant community. Thank you for being part of this journey, and we look forward to growing and learning together.

Warm regards,

Stanford Lung and Heart-Lung Transplant Patient and Family Advisory Council
DL-LungPFAC@stanfordhealthcare.org

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PFAC Volunteers

Chair :
Elyse Elconin Goldberg

Secretary :
Robert Duffy

Members:
Claire Herriot
Jen Julian
Dan Lagasse
Michelle Smith

PFAC Medical Staff

Maia (Eileen)Bucoy-Duque, RN,CNL, MSN
Adult Lung & Heart-Lung Transplant Program Manager

Kelly Teeter, PA-C, MPH
Post-transplant Physician Assistant

Claire Reichle, BSN, RN
Post-transplant Nurse Coordinator

Community Event

On Friday, October 24, 2025, the PFAC held its first Lung and Heart-Lung Transplant Community Gathering for patients, families, caregivers, and medical providers at Stanford Hospital. It was a huge success! It was a time for patients to see other individuals that they knew, and to make new friends. Each guest who attended received a special gift, "Celebrating Lung Transplant" keychains made by PFAC member Michelle Smith and her husband.



2026 Goals

Newsletters

In 2026, the PFAC plans to produce two newsletters for patients, families and caregivers with the themes of Living with Cancer Post Transplant (Winter Edition) and Elements That Impact Mental Health Post Transplant (Summer Edition).

Virtual Education Symposium

The PFAC is planning its 5th Virtual Education Symposium in May 2026, which will focus on GI issues post-transplant.

Community Gathering

They are also looking forward to hosting their second Community Gathering this Fall with lung and heart-lung transplant patients, families, and caregivers at the Stanford Hospital.



Stanford Adolescent Young Adult Cancer

ABOUT US

The Stanford Adolescent & Young Adult Cancer Patient & Family Advisory Council (PFAC) represents the voices of the adolescent and young adult cancer patients and survivors treated at Stanford Medicine, along with their caregivers and family members. The PFAC's goal is to create an Adolescent and Young Adult (AYA) community within Stanford Medicine to help the staff and faculty better understand the unique needs of this cancer population, and through this work, improve the care experience for AYAs and their loved ones at diagnosis, during treatment, and throughout survivorship.

Established: 2019

Chairperson:
Jasan Zimmerman

Staff Advisor:
Pam Simon
SAYAC Program Manager

Members:

Patient & Family Partners
Vivek Chotai
Fiona Gutierrez-Dewar
Harry Forbeck
Monica Hennings
Matt Hunt
Myshka Javier
Kristien Karmarkar
Ryan Lee
Maureen O'Hara
Kim Wong
Sun Wee (Sunny) Yun

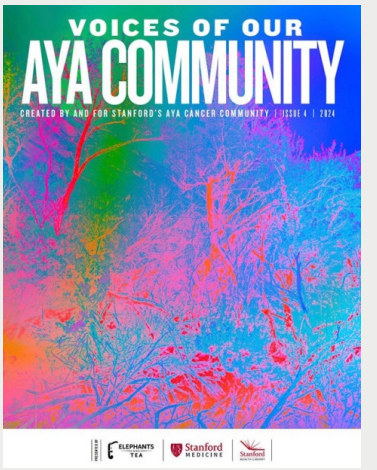
Staff/Physicians
Catherine Benedict
Bobbie Davis
Jax Huerta
Young Kim-Parker
Stephanie Smith, MD
Deanna Beyer
Gary Dahl, MD

Key Accomplishments

Storytelling

The PFAC continues to partner with the Stanford Health Library and Elephants & Tea to host storytelling events, one of which was held via Zoom in April 2025. This year, they have created the fifth Stanford Medicine AYA magazines that will be published soon.

To access past issues, click here.



Walk with Me

PFAC members presented their AYA experiences to students enrolled in the class Walk with Me at the Stanford School of Medicine. Examples of AYA experiences shared included: pediatric to adult care; transitioning from one geographic area to another; and transitioning from one therapy to survivorship. The shared stories gave medical students valuable insight and education regarding transitions of care.

CancerCon

In August, several PFAC members and twelve Stanford Health Care AYA patients attended Stupid Cancer's annual CancerCon in Washington, DC. At the conference, they met with other AYA delegations from programs across the country and held discussions on AYA advocacy.

AYA Research

Dr. Stephanie Smith, a pediatric oncologist at Stanford Medicine Children's Health, regularly attends PFAC meetings to gather feedback from members for her research on working with AYAs.

Community Event

Several members of the PFAC attended the 19 for Life Bocce Ball Tournament. 19 for Life is a foundation that donates to the Stanford Adolescent & Young Adult program to support ongoing AYA community efforts.



Thank You

Stanford Health Care would like to extend our sincere gratitude to the members of the Patient & Family Partner Program for their dedication to improving the experience of our patients and family members. We also thank the Patient & Family Advisory chairs and staff advisors for their support and leadership of the advisory councils.



Contact Us

650-723-7424

VolunteerResources@stanfordhealthcare.org

www.StanfordHealthCare.org/Volunteer