

Massachusetts PFAC Spring Forum







- Presentation: Engaging with Leadership
 - Monique Manna and Michael Gustafson
- Presentation: Diversifying PFAC membership
 - Pam Dardess
- Breakout discussion sessions
- Wrap up and next steps

Monique Manna UMass Memorial Medical Center PFAC

Betsy Lehman Spring Forum 2024:

Creating Connections To Strengthen The Impact Of Patient and Family Advisory Councils

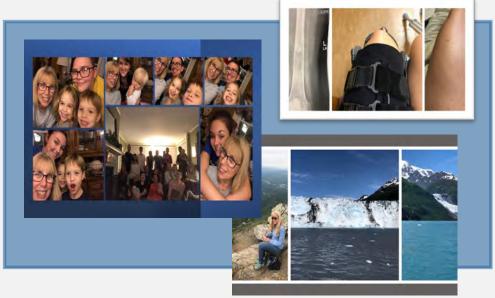
5.30.2024





INTRODUCTION ... PASSIONATE ABOUT GIVING BACK





- Mother of six, grandmother of five
- Diagnosed with osteosarcoma (bone cancer) in October 2020
- Tumor grown out of left femur, amputation above knee January 2021
- Inpatient on 8E, oncology floor, for one month, three days
- Developed a special relationship with nurse Kathy always there for Monique
- Stay and treatment by all at UMass Memorial Medical Center were wonderful, truly felt treated as a whole person
- Medical Center PFAC member since 2021

BACKGROUND ·

- One of eight PFACs at the Medical Center (flagship PFAC with PFAs representing inpatient/outpatient population).
- Learned about PFAC at a medical appointment from PFAC screensaver campaign running on desktops/screens in July 2021.
- Submitted application on UMass Memorial Health website and completed onboarding process.
- Monique shares her story in the Patient Experience 'Gratitude Video' produced by PX team for Patient Experience Week 2022.
- During Covid, a remote-only membership was created conducive for Monique to remain involved in PFAC.
- Moved to Kansas in 2022 but was able to remain on PFAC as a remote member because her care is still overseen at UMMMC.





PFAC REPRESENTATION AT UMMMC

- Patient Care Assessment Committee
- Readmissions Committee
- PFAC Members on Patient/Family Experience Committees
- ED Boarders Focus Group
- Diversity, Equity, Inclusion, Belonging (DEIB) Committee
- Schwartz Rounds Planning Committee



PFAC ENGAGEMENT – KEY INITIATVES

New Inpatient Building:

- Determination of Need (DON) endorsement from PFAC
- Testimony at public hearing
- Facility tours ideas incorporated to facilities planning/design
- Food Services: At Your Request Dining,
 Patient Simulation Event
- Care Partners Program Development:
 Care Partners Discovery Process
- ED Patient Experience Improvement Initiative: Improving the Waiting Room Experience at the University Campus ED





TESTIMONIALS: PFAC's POSITIVE IMPACT

What leaders are saying...

"Ambulatory has been privileged to have an opportunity to partner with our PFAC group who has provided powerful patient perspectives as we launch critical work intended to provide exceptional experience."

Dianna Caffarena, Senior VP, Ambulatory Care

. . . .

"Having PFAC involved with the Food & Nutrition Department has been a tremendous asset. The voice of patients and their families has helped us diversify our pediatric menu and bring in additional vegetarian items to help better serve our patients. The work that PFAC does continues to drive our department toward our goal of exceptional patient experience."

Brendan Parker, Patient Experience Manager, Nutrition and Food Services

What PFAC members are saying...

"In the four years I've been a member we've established ourselves as a legitimate voice for the patient. We now have members who serve on influential committees like the Patient Care Assessment Committee and other high-level committees. I am proud of the work we are doing!"

Kathy Buchanan Medical Center PFAC Member



THANK YOU!



More Than Checking a Box: Diversifying PFAC Membership

May 30, 2024

5:00 - 6:30 pm ET

Pam Dardess, MPH

Vice President, Strategic Initiatives & Operations

Institute for Patient- and Family-Centered Care (IPFCC) www.ipfcc.org

pdardess@ipfcc.org



Our Time Together

- Share learnings from a national survey of children's hospital PFACs that relate to diversity, equity, and inclusion
- Discuss opportunities for action to improve PFAC diversity and inclusion

Support for this work provided by:

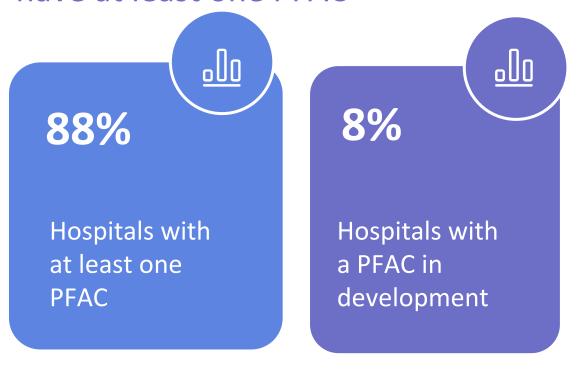


Children's Health

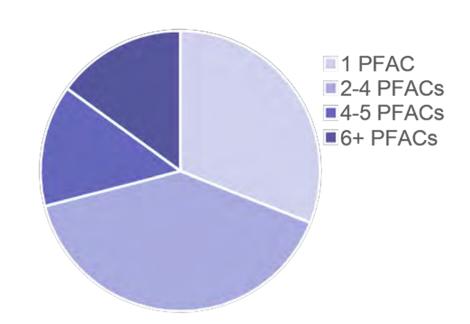


PFACs Are an Important Part of Partnership

The majority of children's hospitals have at least one PFAC



Many hospitals have multiple PFACs



Results from a national survey of U.S. children's hospitals



PFAC Diversity is a Challenge

62% of respondents identified "difficulty recruiting or retaining PFAs who reflect the diversity of the patient/family population served" as one of their 3 most significant challenges.

"The councils don't reflect the membership of the hospital's patient and family population. We've been aware of that for a while. They don't."

Hospital interview participant



PFAs Often Are Not Connected to DEI Work

Only 27% of respondents integrated PFAs into committees working on diversity, equity, and inclusion (DEI).

"The bottom line is we have so much work to do. And if we can't utilize our patients to help us do it, where are we going?"

Hospital interview participant



Importance of PFAC DEI

"When we fail to reflect the diversity and backgrounds and perspectives of patients and families in our group of advisors, we're missing those viewpoints.

And those are the same marginalized communities and populations that are often disproportionately affected by health disparities. So **this is an important part of closing equity gaps**, making sure that we are engaging with patients and families from marginalized communities.

It's about outcomes and potentially continuing to cause harm and continuing to traumatize people because we're not aware of their experiences. We're not giving them space to voice what's happened and what's influenced how they've moved through healthcare in the past."

-PFAC Coordinator



Identifying Opportunities to Advance PFAC DEI











Literature Review

Review of articles, resources, documents, tools, from peer-reviewed and grey literature



18 virtual interviews with participants from children's hospitals, other child-focused health and social service organizations

Focus Groups

4 virtual, 60-minute focus groups with PFAs from underrepresented populations

Dissemination

Key learnings, webinar, manuscripts



Framing the Opportunities for Action

- Articulate clear goals for progress
- Learn about barriers from communities and populations that have historically been excluded
- Act intentionally to address barriers and achieve goals





Work Differently, Not Harder

- Think outside the box of how things have been done – same processes = same results
- Look to other fields for ideas, particularly community
 engagement, community-based participatory research





Opportunities for Action: Data and Goals

Define Goals for PFAC Diversity, Equity, and Inclusion

- Obtain data to understand the diversity needed on the PFAC
- Develop goals and plans for PFA diversity and inclusion
- Create connections between the PFAC and hospital DEI work



Recruit to Increase PFA Diversity

2

- Increase PFAC visibility and make PFA diversity a shared goal of the institution
- Build authentic relationships between the hospital and community
- Identify and address barriers in the PFA recruitment and application process
- Develop recruitment materials that promote diversity and inclusion



3

Explore and Use Structures that Facilitate PFA Participation

- Offer varied options for PFA participation
- Explore opportunities for specialty PFACs
- Develop approaches to meet community needs



Support Inclusive and Equitable Practices

4

- Identify and address barriers that prevent full participation from PFAs
- Develop and implement guidelines for inclusion
- Provide training related to DEI practices for staff and PFAs
- Create opportunities for relationship-building



Partner with PFACs in Hospital DEI Initiatives

5

- Engage PFAs as partners on all DEI projects, workgroups, and committees
- Actively seek input from historically marginalized patients and families
- Share DEI data and brainstorm opportunities to eliminate inequities



Sustain PFAC Progress

- Provide opportunities for meaningful participation and feedback about results
- Conduct formal and informal assessments of the PFAC
- Increase diversity in PFAC leadership



Learn More

Key Learnings for Strengthening Partnership: Recommendations from a National Study of Children's Hospital PFACs



Strengthening the Diversity and Role of PFACs: Opportunities for Action



Dardess P, Dokken DL, Unaka NI, Casillas CA, Rouse L, Patel U, Rodriguez LR, Beck AF. Diversity, Equity, and Inclusion in Patient and Family Advisory Councils: Advancing Best Practice in Children's Hospitals. J Pediatr Health Care. 2024 Mar-Apr;38(2):184-193.



Free Resources on IPFCC's website



And – join our PFCC.Connect community at https://pfcc.connect.ipfcc.org/home



Advancing PFAC DEI Learning (and Practice) Community

For hospitals that have goals related to any aspect of advancing PFAC DEI.

Hospitals will get access to a comprehensive Toolkit, educational events, and TA.

Contact Pam Dardess (pdardess@ipfcc.org)

if you are interested in being notified when applications are open (late summer 2024)





Discussion rooms



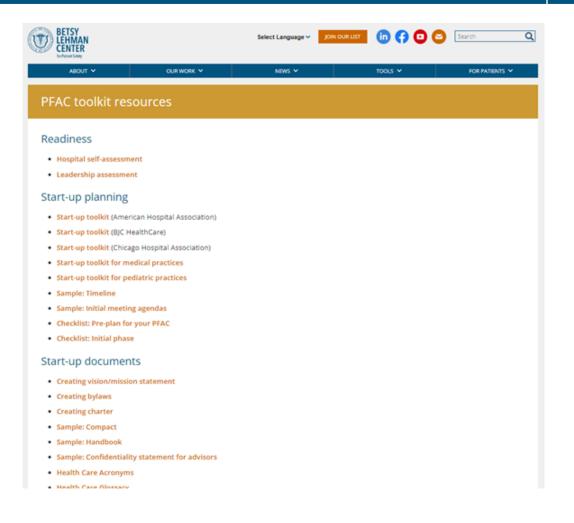
1. Engaging with leadership

2. Diversifying PFAC membership

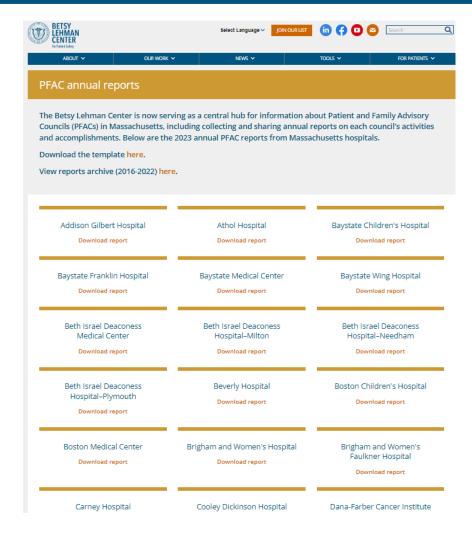
BetsyLehmanCenterMA.gov



Toolkit & resources



Annual reports



Our advisory committee

Penny Blaisdell	Health Care SOS
Kathy Campanirio	Southcoast Health
Marcie Dyer	C3 ACO
Pat Noga	Massachusetts Health & Hospital Association
Yinka Oluwole	Southcoast Health
Pooja Phaltankar	Dept. of Public Health/Bureau of Safety & Quality
Tony Scibelli	Cooley Dickinson
Cynthia Suopis	Cooley Dickinson
Glenda Thomas	Beth Israel Deaconess Medical Center
Nicola Truppin	Health Navigator Partners
Deb Wachenheim	OpenNotes

Thank you!

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