



# Introduction

Lived experience: NICU mom, NICU family. Family Advisory Council 2008-12



**THE LIGHTHOUSE**  
A glowing light through your NICU journey

**THE NEONATAL INTENSIVE CARE UNIT - PARENT ADVISORY COUNCIL NEWSLETTER**  
**THE LIGHTHOUSE**  
A glowing light through your NICU journey

**Baptist NICU Parent Advisory Council**  
**Neonatal Nurses Annual Conference**

**MEET THE NICU MEDICAL WARD MANAGERS**

**WHO'S WHO IN THE NICU**

**PSYCHOLOGICAL SUPPORT**

**INTERVIEW with YANI PASCUAL, 2009 NICU NURSE OF THE YEAR**

**THE BEST THING I CAN DO TO SUPPORT MY NICU JOURNEY**

**IF YOU HAD TO LIVE IN A NICU ROOM, WHAT WOULD THAT BE?**

**YOUR INTERACTION WITH NICU PROVIDERS**

**EMG Parents speak at NEONATAL Conference**



WHAT ARE PFACs?

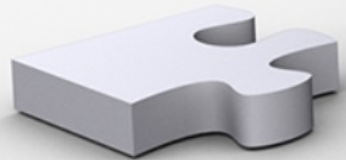
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# Creating, sustaining and growing PFACs in NICU

Lelis Vernon - S.Q.I.L

# Definition

A patient and family advisory council (PFAC) is an organization of current and former patients, family members and caregivers that works together to advance best practices at a hospital or healthcare organization.

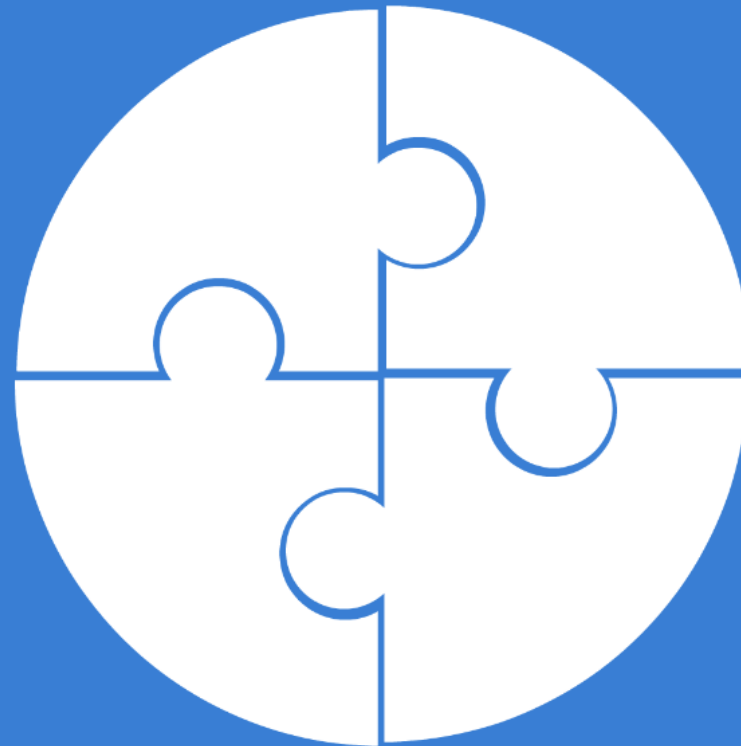
# The functions of PFACs

## Advising

Council members advise on projects, policies, and change initiatives presented by hospital staff.

## Sustaining FCC in the NICU

Scalable/ Self sustaining provision of family voices to council



## Implementing

Council members identify and implement agreed-upon projects.

## Hybrid: A/I

Council members advise on projects, policies, and change initiatives and implement Council-based projects

# The values of PFACs

- Promote and sustain Patient- and Family-Centered Care pillars
- Patients and Families are essential allies for quality and safety
- Qualitative real-time feedback
- Provision of perspectives that differ from internal staff perspectives;
- Incorporation of the family experience into all aspects of health care operations;
- Creation of a venue to “walk the talk” of mission statements (i.e., “patients and families at the center of care);
- Aid in the development of effective patient safety and quality initiatives;
- Creation of efficiencies in which FAC input identified “right-fit” policies and practices for patients and families.

Meanwhile, at today's meeting on feline healthcare...





# Characteristics of PFACs

Venue	Hospital-Wide	Unit-Based		
Authority	Parents Advise Multiple Perspectives	Parents Vote Recommendation	Members Vote Input Binding	Staff/Parents Vote Input Binding
Membership	Parent of a Current Patient	Parent of a Chronically Ill Child	Advisors Only	Advisors and Staff Members
Training	Hospital Orientation	One Time FAC Orientation	Monthly Training FAC Debrief	Tiered Advisory/ Leadership Training

# Challenges

- Budgeting, creating a niche for family leader
- Aligning family and administration expectations regarding function, scope, and authority;
- Sustaining family and provider interest in the work;
- Balancing staff and family input;
- Assuring equal voice among family participants;
- Assuring FAC engagement in meaningful work;
- Accommodating to the slow process of change in health care settings;
- Marketing the FAC within the unit



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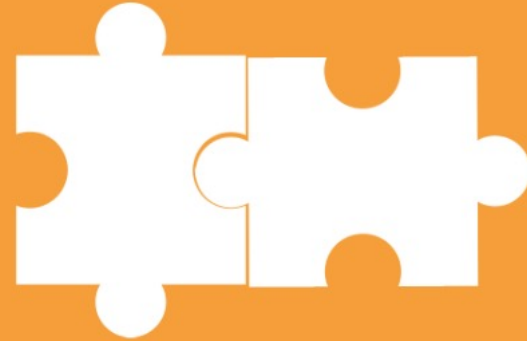
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# Get ready!

## Clinical

- Inform leadership of need for PFAC (bring the evidence! show the numbers!)
- Inform unit of PFAC formation
- Designate staff liaison
- Venue (NICU grads included?)
- Secondary liaison
- Media and tech tools
- 



## Family

- Identify/ welcome family
- Clear Family Partner (FP) with volunteer department
- Receive education/training (Unit based)
- Receive education/ training (FP role)
- Hold "onboarding" meeting
- Feedback
- Meet with leadership/staff



# Where are the FPs?

Brochures (advertise)  
Interviews (**EBCD?**)  
Focus Groups  
Feedback  
Customer-Facing Employees  
NICU Reunions

Surveys  
Phone calls  
Reviews



# Who are the FPs?

Families who had a NICU experience

- Are coping well with their NICU experience
- Are able to leave their NICU grad to attend meetings
- Are willing to talk about their experiences and can effectively share insights and information
- Demonstrate a passion for improving health care for others
- Have the ability to listen well, respect the perspectives of others, interact with many different kinds of people, and work in partnership
- Enjoy working with others, show a positive outlook on life, and bring a sense of humor
- Represent a broad cross-section of your hospital's population

# Our FPQC family team









# Family Partners by the numbers



Volunteers

**55%**



>5 years

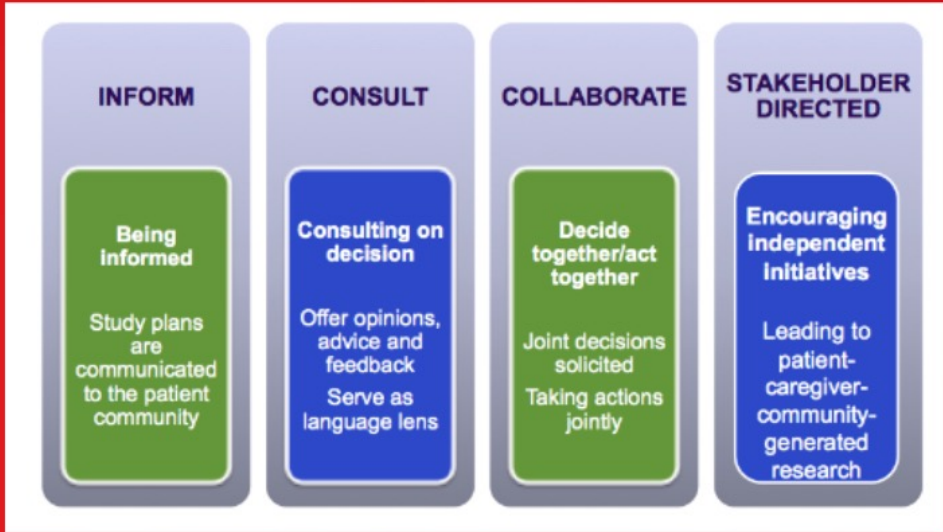
**75%**

Variations in:

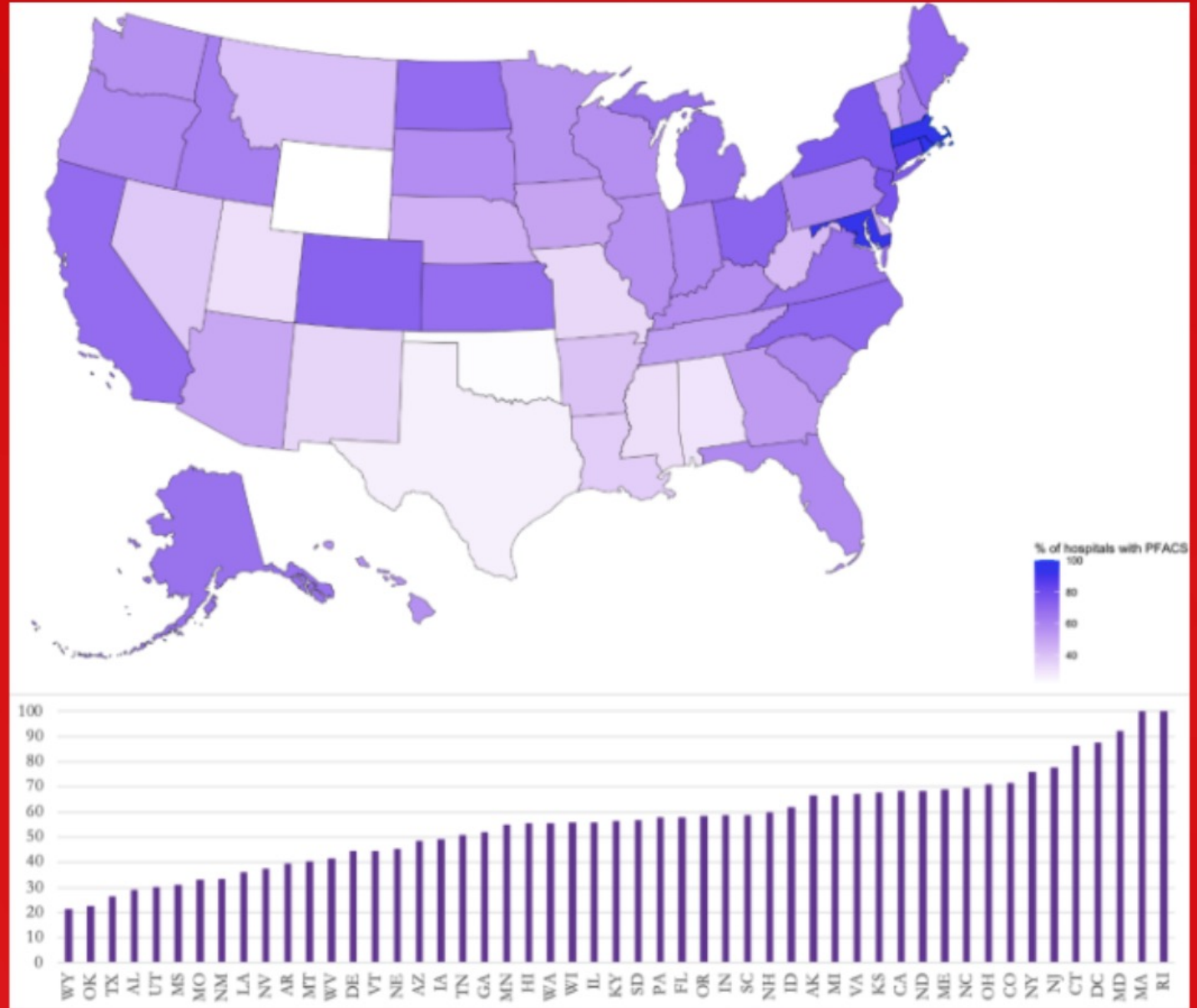
- LOS
- Outcome
- Time lapse after d/c

Sustainability and Scalability:

- Engagement of community groups (post pandemic)
- "Virtual" expansion
- "Back to the Future" effect of COVID



## PCORI



# Compensation



## VOLUNTEER

Hospital PFAC Membership  
(May include expense reimbursement)

**\$15/hour**

Select Hospital PFA Committee

**\$20-50/hour**

Working Groups and  
Webinars for Hospitals

**\$100-300 Gift Card**

Webinars, Workshops,  
Patient Panels

**\$175/hour**

Research Project Teams

**\$1,800 Stipend**

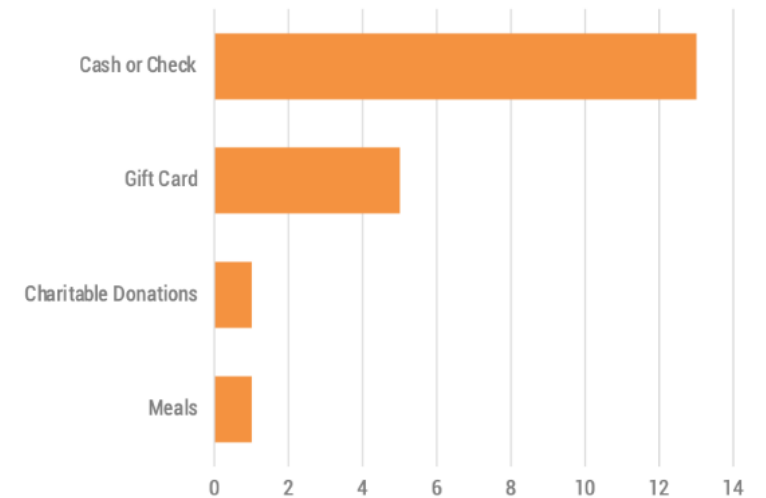
Measure Development Teams,  
Consulting Interviews, Focus Groups

**\$250/hour**

Co-Investigator Roles

## Compensation Preferences

65% of PFAnetwork members preferred cash or check compensation for Advisory efforts. Gift cards, food, and donations were also preferred.





# IPFCC survey 2021

## PFAC Prevalence

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

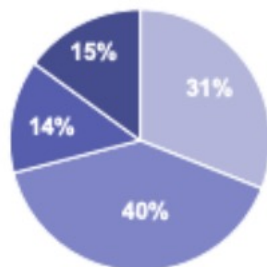
88%

Hospitals with at least one PFAC

8%

Hospitals with a PFAC in development

Many hospitals have multiple PFACs



- 1 PFAC
- 2-4 PFACs
- 4-5 PFACs
- 6+ PFACs

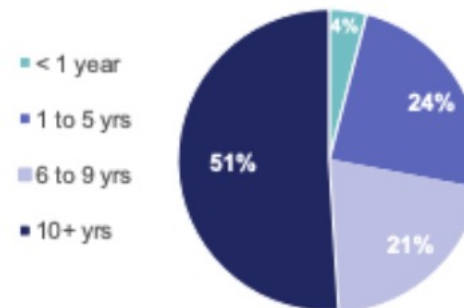


## PFAC History

Many children's hospitals have a long history with PFACs

In interviews, specific influential leaders often cited as forces behind PFAC development

Years PFAC has been in existence

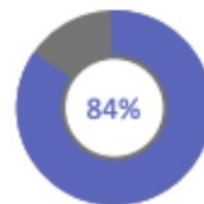


## PFAC Adaptations Due to COVID-19



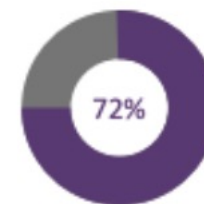
Meeting virtually

86% of PFACs had met at least once since March 2020



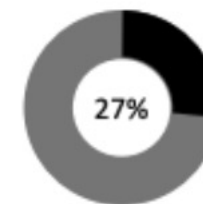
Meeting frequency

84% of PFACs anticipated meeting as frequently as before the pandemic



Meeting attendance

72% of PFACs reported attendance at meetings was the same as or better than before the pandemic



PFA involvement in COVID committees

27% of hospitals involved PFAs on pandemic planning and response committees



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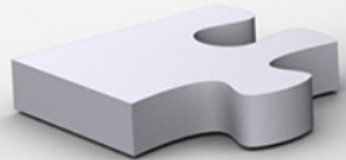
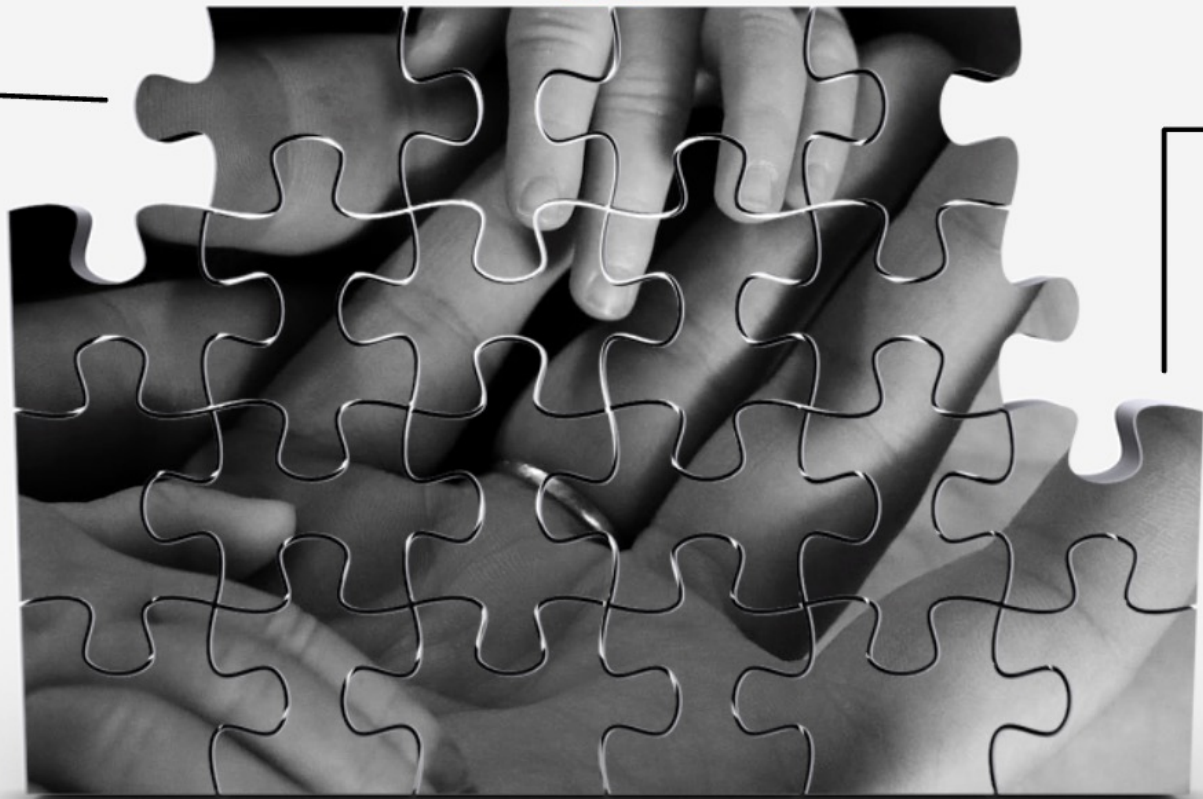
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# Thank you!



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