

# Strengthening the Future of PFACs and PFAs: Learnings from a National Study of PFACs in Children's Hospitals

December 14, 2021  
Chat Log with Live Links

## **Quick Links:**

- Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals: <https://nyshealthfoundation.org/wp-content/uploads/2018/06/strategically-advancing-patient-and-family-advisory-councils.pdf>
- Key Learnings for Strengthening Partnerships: Recommendations from a National Study of Patient and Family Advisory Councils in U.S. Children's Hospitals: <https://www.ipfcc.org/bestpractices/patient-and-family-advisory-programs/study-pfac-childrens-hospitals.html>
- PFCC.Connect: <https://pfcc.connect.ipfcc.org/home>
- Family Voices Family Engagement in Systems Toolkit: <https://familyvoices.org/familyengagementtoolkit/>

Bev Johnson: Welcome everyone. We are thrilled you are here. Please introduce yourself and tell us where you are from.

Erin Sturgeon: Erin Sturgeon, Brigham and Women's Hospital - Boston

Rose Tandeta: Rose Tandeta, Child Life Specialist, UCSF Benioff Children's Hospital Oakland

Beth Jackson: Beth Jackson - Tufts Medical Center in Boston

Teresa Prouty: Teresa Prouty, Family Partnership Coordinator, Dayton Children's Hospital-Ohio

Maria Alaniz: Maria Alaniz

Michelle Fritsch: Michelle Fritsch, Texas Children's Hospital in Houston Texas

Jennifer Manciel: Jen Manciel, Beaumont Hospital Grosse Pointe

Leslie Louie: Leslie Louie from Ronald McDonald House BC & Yukon

Trisha MacLeod: Trisha MacLeod- Canadian Forces Health Services (military healthcare) Petawawa!

Sandi Rippe: Sandi Rippe. Hi from Syracuse Nebraska

Maria Alaniz: Maria Alaniz Brigham and Women's Faulkner Hospital

Tricia Campero: Tricia Campero, Parent and Volunteer, Co-Chair UMass Memorial Health Children's Medical Center PFAC

Emily Iske: Emily Iske, social worker at Syracuse Area Health in Nebraska.

Ricker: Sophie Moeller - Ronald McDonald House - Reno, NV

Marie Abraham: Welcome everyone!

Ben Yeager: Ben Yeager from Ronald McDonald House Charities of Central Texas  
Paula Haraldson: Paula Haraldson from Ronald McDonald House in Rochester, MN

Kerri Machut: Kerri Machut, Ann & Robert H. Lurie Children's Hospital of Chicago

Sarah Barry: I am Sarah Barry, Patient Advocate and Patient Experience Coordinator at Maury Regional Health in Columbia, TN

Kelly Loyd: Kelly Loyd, Medical University of South Carolina, Charleston, SC

Rachael Smock: Kaitlin Knapp - Peyton Manning Children's Hospital (Indianapolis, IN)

Luis Morales: Luis Morales from Childrens Hospital Los Angeles

Cassandra Kemp: Good afternoon! Cassandra Kemp, AdventHealth located in Central Florida

Sharon Cross: Sharon Cross, Ohio State University Wexner Medical Center - Columbus OH

Jessica Stultz: Good morning! Jessica Stultz, Missouri Hospital Association

Bob Strain: Bob, Patient Partner, from the recently flooded Fraser Valley of BC!

Mark Newsom: Mark Newsom, Anchorage, Alaska

Nicole Poplawski: Nicole Poplawski, Ronald McDonald House Central New York

Nicole Apostle: Hello! Nicole Apostle, Patient Experience Specialist at Baystate Wing Hospital in Massachusetts. Happy to be here.

Erica Davis: Erica T. Davis from Ronald McDonald House of Delaware

Jami Brown (she/her/hers) BCPSQC: Hello everyone! Jami Brown - BC Patient Safety & Quality Council, British Columbia, Canada

Grenetta Jones: Neechie Jones-Forrest General Hospital, Hattiesburg MS

Becky George: Becky George, PFAC co-chair, Baystate Franklin Medical Center, Greenfield, Mass

Theresa Floyd-Maas: Theresa Floyd-Maas - Ronald McDonald House in Evansville, IN

Alexandra Zacks: Alexandra Zacks - Beaumont Hospital in Metro Detroit

Anna Albritton: Anna Albritton--Children's Healthcare of Atlanta in Atl, GA

Heather Nino de Guzman: Heather Nino de Guzman is from Brigham and Women's Hospital Department of Pediatric Newborn Medicine and NICU

Lorna Blodgett: Lorna Blodgett, Joint Base Mcguire Dix Lakehurst

Elizabeth Wallace: Elizabeth Wallace from RMHC CTX!

Shannon Sacks: Shannon Sacks - Ronald McDonald House of Greater Las Vegas

Kamil Cak: Kamil Cak, PXO, Children's Hospital of The King's Daughters, Norfolk, VA

Heidi Shannon: Heidi Shannon, M Health Fairview, MN

Tina Ledo: Tina Ledo - Ronald McDonald House Charities of New England

Jennifer Johns: Hello from Jennifer Johns, Ronald McDonald House of Fort Worth!

Irma Dadic: Good afternoon! Irma Dadic, PX Project Lead, Patient Experience, Yale New Haven Health, CT

Rhonda Jordan: Rhonda Jordan from Beaumont Dearborn, Michigan

Tandrea Hilliard-Boone: Tandrea Hilliard-Boone, American Institutes for Research, Morrisville, NC

Veronica Biver: Veronica Biver - Ronald McDonald House Charities St. Louis MO

Lisa MacVarish Pizzi: Lisa MacVarish Pizzi, Advisor/Advocate from Boston, MA Brigham

Barbara Burke: Barbara Burke, Ann & Robert H. Lurie Children's Hospital of Chicago

Laura Winterstein: Laura Winterstein, Patient and Family Partner Programs Coordinator, M Health Fairview, Minneapolis MN

Mariel Spengler: Mariel Spengler - Lucile Packard Children's Hospital, Stanford

Richard Sider: Rich Sider from Smilow Cancer Hospital PFAC, New Haven Connecticut

Tania Lambert: Tania Lambert - West TN Healthcare Jackson, TN

Matthew Coffey: Matthew Coffey, Ronald McDonald House Cincinnati

Diana Copeland: Hello! RMHC of Oregon and SW Washington

Donna Rubenstein: Hi everyone , Donna Rubenstein , PFA Nova Scotia, Canada

Cleary Williams: Cleary Williams - RMHC Global, Chicago

amy mclean: Amy McLean, Mercy St Louis/Mercy Kids, NICU Family Support Nurse Manager

Mary Ellen Pappas: Mary Ellen Pappas YNHHS New Haven CT

Dawn Gilbert: Jill Stephens - Memorial Health System, Gulfport, MS

Anne Bosc: Anne Bosc Phd student in nursing from Ulaval university

Angela Miney: Angela Miney, Family Partner, University of Florida and Florida Family Leader Network ([floridaleaders.org](http://floridaleaders.org))

Rikki Ricker: Rikki Ricker, Executive Director RMHC Northern NV

Pat O'Hanlon: Good to see everyone! Shanette and Pat joining from Children's Specialized Hospital in NJ and were' family advisors (Family Faculty).

Linda Sample: Linda Sample, Empowered Healthcare

Amanda Gerard: Amanda Gerard, Texas Children's Hospital

Asia Hayes: Asia Hayes, Director of Programs - RMHC Northwest Florida

Angela Henderson: Angela Henderson, Ronald McDonald House Cincinnati

April Clark: Hi All! April Clark, Director of Family and Volunteer Services - RMHC Atlanta

Susan Orozco: Susan Orozco Church Health Memphis, TN

Susan Colburn: Susan Colburn, Family Leader at the CYSHCN Program in Alabama

Stacey Laho: Stacey Laho Ronald McDonald House Charities Ann Arbor

Alyson McCarthy: Greetings from Alyson at RMHC Las Vegas!!!!

Carol Cestaro: Good afternoon. Carol Cestaro, Yale New Haven Hospital, Psychiatry & Behavioral Health, New Haven, CT.

Sue Mead: Sue Mead, Parent Advisor on Staff, Johns Hopkins Children's Center, Baltimore MD

Karen Beattie: Karen Beattie, Family Advisor at McMaster Children's Hospital in Hamilton, Ontario, Canada

Anita Bilden: Hello! Anita Bilden, PX Consultant, Gillette Children's Hospital, St. Paul, MN

Michele King: Hello from Michele King Golisano Children's Hospital of Southwest Florida

Jeffrey Stec: Good Morning Jeff Stec from Madonna Rehabilitation Hospitals

Hena Bajaj: Hena Bajaj, New Jersey Hospital Association

Lori Albers: Hello, Lori Albers from Children's Wisconsin

Courtney Nataraj: Hi from Courtney Nataraj PFA NewYork-Presbyterian Komansky Children's Hospital

Janet Cross: Janet Cross, Monroe Carell Jr. Children's Hospital at Vanderbilt in Nashville, Tennessee

Emily Whitacre: Hello from Emily at Ronald McDonald House Charities Northeast Indiana

Emily Andrews: Hello! Emily Andrews, Program Manager of the Ronald McDonald House in Spokane, Washington

Andrea Kennedy-Tull: Andrea Kennedy-Tull Director of Patient Experience and Operations, Harris Health System, Houston, TX

Quinn Franklin: Quinn Franklin, Cancer and Hematology, Texas Children's Hospital (Houston, TX)

heather ufberg: Heather Ufberg, from St. Mary's Health Care System for Children

Richard Metz: dick Metz from YNHH is on the chat

Joanne Ganton: Hello from Calgary Alberta Canada - Alberta Health Services Primary Health Care

Quinlan Davis: Good Afternoon! Quinlan Davis from Michigan Medicine (Ann Arbor, MI)

Ellen Cruze: Ellen Cruze, Children's Hospital Colorado

pamela brewer: Good morning - Pamela Brewer from Dignity Health in Las Vegas, NV

Laura Klein: Hello from Surrey British Columbia - Fraser Health Authority

Kathryn Carter: Hello! Brittany Barnett from St. Jude Children's Research Hospital, Memphis, TN

Deborah Dokken: <https://nyshealthfoundation.org/wp-content/uploads/2018/06/strategically-advancing-patient-and-family-advisory-councils.pdf>

Desiree Collins Bradley: Desiree Collins Bradley, Texas Childrens Hospital, Houston, TX

Laurie Hines: good morning, from Missouri Kidney Program, proud of DeeJo Miller on your panel!

DeeJo Miller: Hi Laurie! It's great to see you here!

Dick Trub: Dick Trub, Maine Medical Center, Portland,Maine

Emily Lawler: Emily Lawler, Ronald McDonald House Central Alabama

Bhupinder Nahal: Hi, this is such a great presentation. I have a newly formed PFAC so this information is so helpful. Unfortunately I need to hop off in 10 minutes to get onto another call. Are you able to share these slides with us?

Marie Abraham: The recording will be available on our website with any handouts within a few days of this webinar.

Lindsay Hartman: Thank you!

Bev Johnson: There will be a recording posted by tomorrow. And this new resource Deborah is describing will be available on the website.

Cecilia Hernandez: This is great. Thank you.

Linda Starnes: Thanks so much — this is such a timely resource! Linda Starnes, FL DOH Title V

Angela Miney: Hi Linda Starnes 😊

Cassandra Kemp: Very grateful for this resource!

Bev Johnson: Great to have the interest and commitment of Title V. You are so important in each of the states.

Teresa Prouty: Looking forward to it!

Irma Dadic: Fantastic! Thanks so much for all of this work and for sharing it with us

Patrice Mayo: Patrice Mayo, Tennessee Hospital Association

Marie Abraham: You can find that resource on our website at:

<https://www.ipfcc.org/bestpractices/patient-and-family-advisory-programs/study-pfac-childrens-hospitals.html>

Bev Johnson: Patrice, welcome. I hope everyone on the call will share information with their statewide hospital association. And in Canada, with your health authorities.

Linda Starnes: Hi back to you @Angela Miney of the FL UF-PPC and our FL Family Leaders Network (yes, I'm organization name dropping ;)!

Patrice Mayo: Absolutely!

Angela Miney: I will be sharing this widely to family leaders and organizations in Florida, and to the Maternal and Child Health Bureau Pediatric Pulmonary Centers nationally

Edward (Ed) Schor: I'm unable to find the "Key Learnings": document on the IPFCC website.

Linda Starnes: Thank you @Bev Johnson ... I already have two upcoming meetings to share this newest information / resource through our Title V work here, as well as with the University of Miami's UCEDD/LEND advisory committee of which I'm a part.

Marie Abraham: Here is the direct link to the Key Learnings:

[https://www.ipfcc.org/resources/IPFCC\\_Key\\_Learnings.pdf](https://www.ipfcc.org/resources/IPFCC_Key_Learnings.pdf)

Bev Johnson: Hi, Ed. SO glad you are here. Your leadership was key to launching this important work.

Heidi Shannon: Can we get some examples of training/ continuing education that folks are doing for their PFAs beyond orientation. Thanks!

Pam Dardess: Heidi, our panelists may have some info to share, and we will also be sure to look at questions after the webinar and provide additional info

Tricia Campero: Are there resources where PFAC's around the country can communicate with each other to share recruitment ideas and other ideas so support their hospital?

Irma Dadic: Thanks Pam! The info for the additional training/continuing edu would be helpful. I would also appreciate any information you have gathered of successful mentoring programs

Becky George: Could you give examples of best practices to engage staff in suggesting community members to be involved in PFAC's. and ideas about great recruiting tools?

Pam Dardess: Thanks, Irma — we'll be sure to capture that request!

Marie Abraham: IPFCC hosts the PFCC.Connect online learning community (free) where people share resources, post questions, and communicate with each other. If you are not a member, you can join here: <https://pfcc.connect.ipfcc.org/home>

Irma Dadic: Thank you Pam!

Tricia Campero: Thank you!

Sandra Holdsworth: What tools do you use to measure impact?

Linda Starnes: One of the diversity areas for membership, and for involvement in QI initiative within a health care systems, is the desire for representation of those with specific health condition, i.e. HIV/AIDS, mental health conditions, etc. However, due to stigma and reluctance to disclose, it is difficult to recruit and include those members. Any suggestion as to how to build trust and comfort on inviting and including Patient/Family Advisors with specific conditions such as these?

Laurie Hines: love the idea of PFAs being links to, highway for, educators to staff...thus creating new advocates/advisors.

Linda Starnes: @Tricia Campero — Totally agree with @Marie Abraham on PFCCpartners, and their connected PFAnetwork.

Sandra Holdsworth: When working with underserved & underrepresented individuals, I think instead of looking to individuals to represent that you partner with the community groups representing them.

Richard Sider: Staff champions are clearly important to the process of gaining and improving advisor participation in committees, redesign teams, and quality improvement teams. What are the best ways that PFAC organizations have found to find and develop those champions?

Irma Dadic: Love what you shared Donna! What advice would you share about hardwiring the partnership with teams outside of PFACs?



Pam Dardess: Sandra, that is a really important point — developing those relationships is critical

Desiree Collins Bradley: It is very important to be intentional when recruiting diverse populations. The messenger and the message is a key component.

From Desiree Collins Bradley: Very good points. Trusted messengers

Pam Dardess: Thanks for noting this, Desiree - it's important to make sure that we're being intentional and respectful in this process

Rhonda Cady: A knowledge translation team that I lead, which includes parent advisors, had the opportunity to assess our team's level of family engagement using the FESAT. FESAT is Family Engagement in Systems Assessment Tool. I was eye-opening and extremely useful. Giving a shout-out to this tool as not sure this work will touch on tools for assessment piece:)

Lori Albers: Excellent insight

Mark Newsom: I think you are looking for the different lenses that health care is seen through. What does it look like for the different populations

Rhonda Cady: FESAT developed by Family Voices. I'll post the link next

Ian Todd: What specific techniques have worked for children's hospitals to recruit new mothers who have limited time?

Rhonda Cady: <https://familyvoices.org/familyengagementtoolkit/>

Irma Dadic: To recruit diverse advisors - We evaluated each PFAC and set goals for each. We then partnered with our Community and Gov relations department to connect us with leaders in our community that could help us expand our reach

Richard Sider: What are the best ways that PFAC organizations have found to educate and encourage staff members on the advantages of having PFAC/advisor participation in all teams addressing patient-facing activities and changes?

Bev Johnson: Ian, it has been always been challenging to recruit mothers and fathers who have a new baby. I think our new comfort in using technology and virtual meetings may work better for this population. Much more time efficient. And you can participate with a babe in arms! Have you offered the opportunity to participate virtually... even a hybrid model with some in-person time.

Marie Abraham: Community members have also told us that getting out into the community is an important approach to connecting and recruiting. With COVID-19, many community health

events are offered online or as safe in-person events. Reach out to the organizations leading those.

Teresa Prouty: I would love to hear how onboarding barriers are being adjusted to make it easier for our more hesitant voices to be heard

Marie Abraham: IPFCC hosts the PFCC.Connect online learning community (free) where people share resources, post questions, and communicate with each other. If you are not a member, you can join here: <https://pfcc.connect.ipfcc.org/home>

Edward (Ed) Schor: PFACs leaders can work with their hospital's development offices.

Marie Abraham: Thank you for the great session.

Pat O'Hanlon: Thank you so much! Great webinar!!

Donna Rubenstein: Thanks for sharing, excellent presentation and discussion. Encouraging to hear how far we have come -and where we are going!

Irma Dadic: Great session! Thank you so much for sharing this information with all of us.

Tricia Campero: This was a wonderful session and I learned a lot. Looking forward to talking to our PFAC about this meeting and connecting with other PFACs around the country. Thank you!

Joanne Ganton: Thank you for sharing this new resource - I can't wait to share it with our engagement teams!

Lori Albers: Thank you all. This was a great session.

karen anderson: thank you for the wonderful talk.

Alisa Powell: Great job, thanks!

Richard Sider: Excellent presentation and insights. Thank you.

Leslie Louie: Thank you!

Linda Sample: Thank you so much for this webinar and sharing so many great resources!

Beverly Guttman: Great session. And thank you to whomever for mentioning the FASET resources. They look wonderful!

Tonio Axisa: Thanks for a great session.

Jessica Slayback: Thank you!

Patricia Follano: Thankyou!

Erin Sturgeon: Thank you

April Clark: Thank you!

Alex Zavala: Great session!

Desiree Collins Bradley: great session

Mary Minniti: Great job!

From Darlene Didham: Very helpful presentation/discussions. Thank you

From heather ufberg: thanks!