



IPFCC Webinar

October 29, 2020
12 - 1 PM ET


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Patient- and Family-Centered Care and Pediatric Partnerships during
COVID-19: Moving Forward with New Learnings and Strategies

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Helpful Tips:



- To download handouts – see link in chat
- All participants will be muted upon entering
- Please do **not** use the Q&A function for questions, enter all questions into the **chat box**
- If there are technical difficulties due to the high volume of Zoom usage, we will record and post this webinar within 24 hours to IPFCC's website.

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**Patient- and Family-Centered Care and
Pediatric Partnerships During COVID-19**

Funded by:



Lucile Packard Foundation
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In our time together . . .

- ◆ Discuss how PFCC, including its emphasis on partnerships, can continue to be the framework for providing care to children, youth, and their families during COVID-19
- ◆ Share the new learnings and strategies of pediatric hospitals in adapting services **thru partnerships** to meet the needs of children and their families, related to:
 1. Role of PFACs and PFAs;
 2. Telehealth;
 3. Mental health;
 4. Family presence; and
 5. Diversity and inclusion.



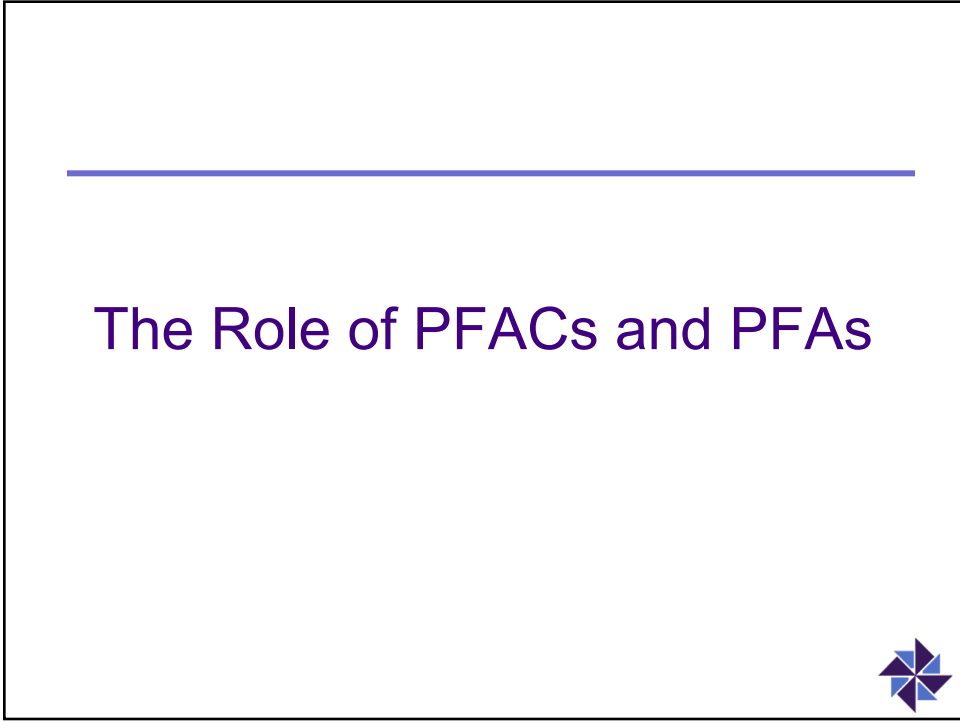
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Patient- and Family-Centered Care Core Concepts

- ◆ People are treated with **dignity and respect**.
- ◆ Health care providers communicate and share complete and unbiased **information** with patients and families in ways that are affirming and useful.
- ◆ Patients and families are encouraged and supported in **participating in care and decision-making** at the level they choose.
- ◆ **Collaboration** among patients, families, and providers occurs in policy and program development, QI and safety, professional education, and research as well as in the delivery of care.



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Patient Family Advisory Councils

Family Advisory Board

- Tracheostom y PFAC
- Teen Boards: TAB HOT KIDS KC
- El Consejo de Familias Latinas/Hispanas
- Beacon PFAC
- Cardiac PFAC
- CF PFAC
- Eating Disorders Center PFAC
- Food Allergy PFAC
- IBD PFAC
- Kansas PFAC
- Mental Health PFAC
- NICU PFAC
- PFAC Alumni
- Rare PFAC
- Spinal Differences PFAC

Children's Mercy
LOVE WILL.

2019 ANNUAL REPORT

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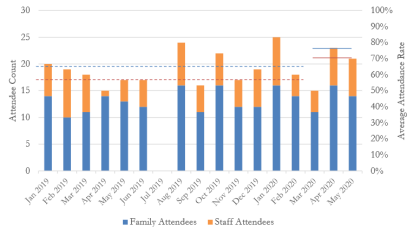
Moving 18 PFACs to a Virtual Platform

5 Tips for Hosting a Successful Virtual PFAC Meeting

1. Use the Children’s Mercy Guidelines to set up a Microsoft Teams meeting
 - Video created and distributed that included step by step instructions
2. Email agenda with Teams log in directions
 - Templates for agendas and email instructions provided
3. Assign virtual meeting roles
 - Roles and descriptions
4. Meeting logistics and online etiquette
5. Email the meeting minutes to PFAC members within one week



TeleBoard: The move to a virtual family advisory board



	In-Person	Virtual	p-value
Family	64.3%	75.0%	0.20
Staff	56.2%	70.0%	0.38

We found no statistically significant difference in attendance between virtual and in-person meetings.

Beyond attendance, engagement was also high during the virtual meetings and input was gathered from a substantial portion of the family attendees.

Type of Contribution	Contributors			
	April N = 17		May N = 16	
	n	(%)	n	(%)
New Ideas	7	(41.2)	9	(56.3)
Verbal	17	(100)	8	(50.0)
Chat Box	12	(70.6)	14	(87.5)
Affirmation	3	(17.6)	14	(87.5)

Moving forward, a virtual meeting option may improve the ability to recruit historically under-represented voices from our patient base.

Chadwick, Sheryl; Miller, DeeJo; Taff, Kathryn; and Montalbano, Amanda (2020) "TeleBoard: The move to a virtual family advisory board," Patient Experience Journal : Vol. 7 : Iss. 2 , Article 17. DOI: 10.35680/2372-0247.1472



 **Children's Hospital of Philadelphia** **PFAC/PFA Role with Marketing**

- ◆ Development of website resources is a collaborative effort, involving PFAs, staff, and Marketing.
 - ◆ The Family Advisor Council (FAC) had a significant role in developing the messaging for the section of the website: “Is It Safe to Come to CHOP?”
 - ◆ Handouts were first created – and then the material was adapted for the website.
- ◆ A variety of COVID topics from “Video Visit Support” to “Coping with Uncertainty” were developed. A FAC member is featured in the video.

www.chop.edu/video/what-expect-when-you-come-chop-pandemic-edition



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 **Children's Hospital of Philadelphia**

YOU MIGHT ALSO LIKE



Don't Delay Care for a Sick Child



What to Expect at the Hospital and ED During COVID-19



Getting Your Child to Wear a Face Mask

www.chop.edu/video/what-expect-when-you-come-chop-pandemic-edition



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“Since COVID, the partnership between the patient and family experience team and its family partner program and the Marketing team grew as the importance of sharing messaging that made families feel safe and supported was elevated with COVID. CHOP teams recognized the expertise of family partners in helping craft the messages.”

Brooke Rothman, Patient and Family Experience Manager (Interview 10/20/20)



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Inspiring Words from PFCC Leaders in the Field



“COVID created positive awareness at the leadership level of the value of partnering with patients and families at this time.”



“PFAs marched forward ever more strongly. All members were 100% in!”



“We never missed a beat!”



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Roles for PFACs and PFAs

- ◆ Serving on COVID-19 planning, implementation, and evaluation teams
- ◆ Meeting with regularly with key staff from the Emergency Operations Committee
- ◆ Working with Communications/Marketing on new content for websites and other communications about COVID-19 for the various communities served
- ◆ Participating as patient and family faculty and co-designers of training for new roles for front-line staff and administrative leaders
- ◆ Partnering in evaluation and research about impact of changes and initiatives related to the pandemic



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Strategies to Keep PFAs Connected and Informed



Created a closed Facebook group for PFAs as well as a newsletter



Weekly "Office Hours" developed with Children's Hospital leadership



Held PFA "Summits" on key issues, including telehealth



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Telehealth/Telemedicine



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SERVICES

For local, national and international partnering providers, we offer the following services:

- Live video visits
(urgent and non-urgent)
- Provider to Provider phone consults
(urgent and non-urgent)
- Chart review
- Mobile services
- Second opinion
- Store and forward
(dermatology, wounds)
- Virtual grand rounds
- Distance learning and education
(clinical/medical education, mentoring)



Children's National. Telehealth

COVID-19 has been an unexpected disruptive force to the hospital's traditional in-person care model.

The telemedicine team — clinicians, patients, & families — have quickly adapted to rapidly expand telemedicine options.



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Telehealth Statistics at Children's National week of April 13th	
Number of active clinicians	1,001
Telehealth meetings in the past week	2,279 meetings 318,445 minutes
Ambulatory telehealth visits in the past week	2,406

Telehealth Statistics at Children's National week of June 8th	
Number of active clinicians	1,316
Telehealth meetings in the past week	3,390 meetings 553,386 minutes
Ambulatory telehealth visits in the past week	2331



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Key COVID-19 Patient Navigator Initiative: Tele-Medicine

- ◆ Inclusion Criteria:
 - Children 0-21 years with complex medical needs
- ◆ Patient Navigator Role:
 - Enhance care and family engagement for Children with Medical Complexity
- ◆ Family Benefit:
 - Window into home setting & care environment
 - Child and family are often more relaxed in the home
 - Provider can see what life is like: care, feeding, sleeping, medications, therapies
 - Helpful in addressing and coordinating care with significant technology, mobility and/or transportation issues



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Key COVID-19 Patient Navigator Initiative: Tele-Navigation

- ◆ **Inclusion Criteria:**
 - Children 0-21 years with complex medical needs
- ◆ **The Patient Navigator Role:**
 - Assist families in linking with providers through HIPPA-compliant Tele-Medicine platform
 - Host PN Virtual Family Resource events (English, Spanish)
 - Participate in Virtual Town Hall workshops (English, Spanish, Amharic)
 - Connect families to virtual support groups
 - Provide virtual peer-to-peer support



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Partnering with PFACs and PFAs to Develop Telehealth

- ◆ Serving as members of Digital Engagement Committees
- ◆ Preparing patients and families for telehealth visits through peer support and/or website resources
- ◆ Serving as faculty to share communication best practices in telemedicine with clinicians (e.g., eliciting patient/family voice, building trust, making a connection, sharing test results and other clinical information)
- ◆ Reviewing and responding to information about telehealth from patient experience reports
- ◆ Partnering in evaluation and research about the impact of telehealth
- ◆ Advocating for appropriate funding and other support for telehealth



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Mental Health



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Worsening mental health for parents occurred alongside worsening behavioral health for children in nearly 1 in 10 families, among whom 48% reported loss of regular childcare, 16% reported change in insurance status, and 11% reported worsening food security.

(From Patrick et al, June 2020, Pediatrics)



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**Join our
Community Conversations**

UR Medicine Pediatric Behavioral Health & Wellness is hosting a series of online webinars to discuss topics related to child and teen mental health care. Our panelists are here to answer questions from participants.

Panelists include UR Medicine mental health professionals, representatives from community organizations, and parent representatives. Please join us by registering for these free events.

- **Partnering with Schools During the COVID-19 Public Health Emergency**
Sept. 24, 2020 • 5:30 pm
<https://rochester.zoom.us/j/9648163081?pwd=QjZlVjR0a1p0YzRlR0w=>
- **What to Expect when Looking for and Getting Behavioral Health Services for Children and Teens**
Oct. 22, 2020 • 5:30 pm
<https://rochester.zoom.us/j/9648163081?pwd=QjZlVjR0a1p0YzRlR0w=>
- **What you Need to Know about Deciding If and When to Use Medication for Behavioral Health Challenges in Youth**
Dec. 3, 2020 • 12:00 pm
<https://rochester.zoom.us/j/9648163081?pwd=QjZlVjR0a1p0YzRlR0w=>

This series is sponsored by the Greater Rochester Health Foundation.

Questions?
 Contact Zena Shuber at
 Zena.Shuber@URMC.Rochester.edu




Golisano Children’s Hospital, UR Medicine Rochester, New York

The Family Advisory Board and the Family Advisory Group, recruited specifically during the pandemic, participated in the planning of these community conversations and other useful resources for families.

www.urmc.rochester.edu/childrens-hospital/behavioral-health-wellness/resources-for-families.aspx




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Seattle Children’s
HOSPITAL • RESEARCH • FOUNDATION

Psychiatry Family Advisory Board

- ◆ Has grown significantly in the last three years — 16 members
- ◆ Supports all psychiatric services: Inpatient, Ambulatory Programs, and Psych Emergency Department
- ◆ Has met virtually on a monthly basis since March
- ◆ Open Forum supports “real time” parent input in each meeting
- ◆ Currently parents are embedded in key committees:
 - ◆ Psychiatry Leadership Committee
 - ◆ Equity Taskforce
 - ◆ Specific Improvement Work Committees
- ◆ Parents provide Mental Health First Aid training to school districts
- ◆ Planning to expand parent collaboration about COVID-19 issues with school districts



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Partnering with PFACs and PFAs in Mental Health

- ◆ Serving as members of a Mental/Behavioral Health PFAC
- ◆ Highlighting mental/behavioral health needs during the pandemic in discussions of all PFACs
- ◆ Helping develop communication to patients and families about mental/behavioral health needs during the pandemic
- ◆ Identifying, developing, and reviewing new resources for patients and families about mental/behavioral health needs and for information on the organization's website
- ◆ Collaborating with community organizations to disseminate information about mental health resources during the pandemic
- ◆ Partnering in research and evaluation of mental health resources and programming related to the pandemic



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Family Presence



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Impact of COVID Restrictions

“Clinicians and hospital staff said that keeping families away had been among the darkest experience of their professional lives.



The restrictions run counter to a hospital's desire to keep patients and families together, not only for the salutary effect of something as simple as a hand held, or a chair pulled close to a bed, but because having a relative present can ease the workload of the medical team. It can also provide crucial information that a confused patient may not be able to offer.”

New York Times, 3/29/20



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Organizational Advocacy to Re-Visit Restrictions on Family Presence

Person-Centered Guidelines for Preserving Family Presence in Challenging Times

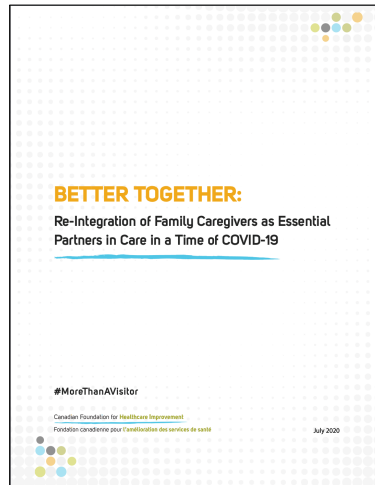
May 2020

Developed by a coalition of 60 organizations led by
Planetree International and the Pioneer Network



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Organizational Advocacy



Re-Integration of Family Caregivers As Essential Partners in Care: Case Report

July 2020

Developed by Rapid Response Expert Group led by

Canadian Foundation for Healthcare Improvement



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Organizational Advocacy: Shared Findings

- ◆ Distinction between family caregivers and “visitors”
- ◆ Risks result from restrictions on family presence
- ◆ Reliance on evidence, with re-assessment
- ◆ Need for compassionate exceptions and appeals process
- ◆ Involvement of PFAs and PFACs



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From a survey of families, PFAs, and clinicians about the impact of restrictions on NICUs conducted by Vermont Oxford Network

. . . the inability to be able to support your wife and newborn child amidst the chaos and uncertainty of a pandemic is something I would not wish upon anyone. (NICU father)

I have witnessed the challenge this pandemic has been (for) our Family Partners. They have been creative in supporting Families online . . . but it has been hard to connect emotionally. (Clinician)

(From "Family Presence in the NICU: Constraints and Opportunities In the COVID-19 Era," *Pediatric Nursing*, Sept./Oct. 2020, www.pediatricnursing.net)



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Partnering with PFACs and PFAs to Address Family Presence

- ◆ Reviewing changes to policies related to family presence and participation during the pandemic
- ◆ Participating in the development of messaging (website, signage, informational materials) to communities served about the changes in policies and practice
- ◆ Helping develop and conduct training for front-line staff and administrative leaders related to communication with patients and families about changes in policy and practice due to the pandemic
- ◆ Helping to design, implement, and evaluate systems to include families or designated care partners virtually in supporting patients



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Diversity and Inclusion



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Hale Family Center for Families Boston Children's Hospital

- ◆ With the onset of the COVID-19 pandemic, the Center never closed, but scaled back services, creatively modified services, and made safety modifications to the physical environment of the Center.
- ◆ Miranda Day, a former patient at the hospital, serves as the Director of Family Services (Hale Family Center for Families, Patient Family Housing Program, and Volunteer Services).



www.facebook.com/BostonChildrensHospital/videos/we-are-boston-childrens-meet-miranda-day/282757475769369/



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Hale Family Center for Families Support for Spanish Speaking Families

- ◆ Prior to COVID-19, Spanish support group met monthly facilitated by Spanish speaking moms serving in paid positions.
- ◆ Changed to weekly virtual meetings; held 46 sessions since April 2020, with average attendance of 6-8.
- ◆ Many of these sessions were for general support, covering topics such as balancing family presence and participation with “visiting” restrictions, voting, Census 2020, remote learning, and telehealth visits.
- ◆ Some sessions were facilitated by staff focusing on more specific health issues like Autism, epilepsy, the OWL program (Optimal Weight for Life).



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Hale Family Center for Families Adaptations for Safety & Family Support

- ◆ From the beginning of the pandemic, offered families quick services: daily parking vouchers, family sleep space with enhanced cleaning protocol, laundry tokens.
- ◆ Communal housing program closed initially. Then partnered with hotels, and now opened some homes, scaled back significantly, for safety.
- ◆ Pawprints, the pet therapy program, and a variety of wellness programs (reiki and yoga) transitioned to virtual formats for patients, families, and staff. Some wellness programs in person now selectively.



A Pawprints
Virtual Visit



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Other Inspiring Examples from the Field



Through e-advisor community, surveyed Spanish and Arabic-speaking families about returning to services at the hospital



Developed a loaner program for Android tablets and helped families with Internet/data plan fees



Collaborated with Ibero-American Action League in New York to disseminate resource materials on behavioral health



Provided support to help Spanish-speaking parents with telehealth



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Partnering with PFACs and PFAs to Address Health Inequities and Structural Racism

- ◆ Partnering with Diversity, Equity, and Inclusion Officer(s) within the organization to connect them with advancing patient- and family-centered practice
- ◆ Designing and implementing special systems to provide additional support and services to vulnerable populations during the pandemic
- ◆ Collaborating with community organizations to connect with these populations during the pandemic
- ◆ Planning intentionally to involve a diversity of PFAs reflective of communities served in addressing pandemic priorities
- ◆ Collecting and using data to bring about change in both the composition of the PFAC and other PFAs, and in the work they are doing



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(Big Dipper)

In times like these, the core concepts of patient- and family-centered care (PFCC) can serve as a North Star, to help inform decision-making, practices, and public health strategies.

North Star

(Little Dipper)

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Questions and Comments

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INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE
Transforming health care through partnerships

Home About Us Our Services Educational Programs Resources Profiles of Change PFCC Best Practices

PFCC and COVID-19

IPFCC recognizes the enormous and tragic impact that COVID-19 is having on the health care system across the world. We remain firmly committed to advancing patient- and family-centered approaches that also adhere to the safest guidelines and pose the least burden on health care professionals.

In direct care, maintaining connections between patients and their families is vital to health and healing. Yet, to prevent the spread of the virus, health care facilities have understandably restricted the physical presence of families and others. The words used and the tone of communications related to COVID-19 are important to conveying the essential role of families and care partners. Many organizations are creatively establishing ways to connect patients, their families, and care partners and continue to support the concept that families are key partners for safety.

Spotlights
Helpful Resources

In this section of our website, we provide examples from the field and resources. If you want to share a best practice or resource, please email us at institute@ipfcc.org

<https://www.ipfcc.org/bestpractices/covid-19/index.html>

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A free online learning community dedicated to partnerships with patients and families to improve and transform care across all settings.

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE
PFCC.Connect

HOME COMMUNITIES - MY NETWORKS DIRECTORY EVENTS - PARTICIPATE - search

BROWSE - HELP/FAQS

Join the Discussion
 Ask or answer questions with your peers.
 Our dynamic discussion groups explore best practices in patient- and family-centered care.

ANNOUNCEMENTS Add

NEW FEATURES ON PFCC.CONNECT
 BY MARY MINNITI, 16 DAYS AGO
 Go to your profile and complete it! Then look under Network and see how many people that have similar roles or backgrounds as you! [More](#)

<http://pfcc.connect.ipfcc.org/home>

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Thank You for Joining Us!

Please fill out the survey on your experience today:

https://www.surveymonkey.com/r/Pediatric_New_Learning_and_Strategies_Oct20ning

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Patient- and Family-Centered Care and Pediatric Partnerships During COVID-19

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