

# INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

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# Patient and Family Panels: Inspiring and Energizing Staff

TCPi Webinar  
August 21, 2019



## BEFORE WE BEGIN

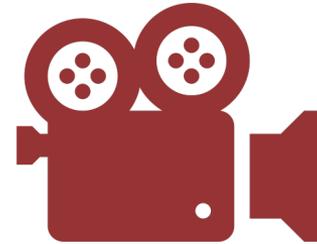
The screenshot shows the GoToWebinar interface. At the top, there are icons for Webcams, Zoom, and Screenshot. Below these is the Speaker Panel with two silhouettes. To the right is the GoToWebinar Control Panel, which includes an Audio section (MUTED), a Talking section with Handouts (Resources.pdf, Slides.pdf), and a Questions section. At the bottom, there is a Slide Show area with a presentation slide titled 'Exploring Peer Support in Ambulatory Care - Lessons from the Field'. The slide features the Patient-Centered Primary Care Collaborative (PCPC) logo and the text 'Test 2 Webinar ID# 757-797-627' and 'GoToWebinar'.

1. Click the Handouts pane to download slides and additional resource materials.
2. Submit your questions anytime by typing in the box. We'll do Q&A at the end of each session.
3. Raise you hand ( ) if you'd like to speak, ask questions, or participate in the conversations – You will be unmuted
4. Adjust the size of the speaker panel and the slide show

## AFTER THE WEBINAR



Please complete the post-webinar survey. Your feedback will be appreciated!



We will send you the recording and post the slides and additional materials for download at [www.pcpcc.org/webinars](http://www.pcpcc.org/webinars)



# ABOUT PCPCC



## Patient Centered Primary Care Collaborative (PCPCC)

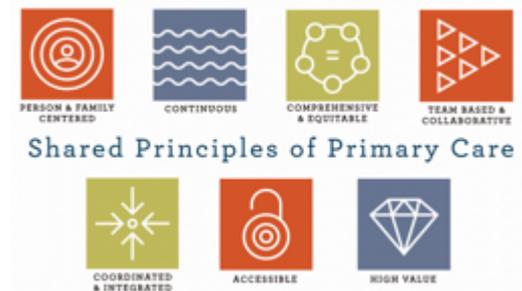
### Mission:

To promote collaborative approaches to primary care improvement

- ▶ Patient-Centered Care
- ▶ Person Family Engagement
- ▶ Patient Activation
- ▶ Improved Cost/Quality/Experience Outcomes

### PCPCC Support and Alignment Network (PCPCC SAN)

is a collaborative approach to improving person and family, clinician, and community strategies for engagement



PCPCC facilitates development of webinars/learning sessions, a resource library, and tools that are being spread to a wider audience through our members and supporters.

- Online Initiatives Map
- Size-Sized Learning Modules
- PFCC.Connect by IPFCC
- Choosing Wisely (CW)
- Patient Family Engagement (PFE) Resource Library
- Y USA Community-based Resource
- Parent to Parent (P2P) Raising Special Kids Program

Visit PCPCC website for our innovative resources at [www.pcpcc.org/tcpi](http://www.pcpcc.org/tcpi)

# Presenters

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**Bev Johnson, BSN, FAAN**  
*IPFCC President & CEO*



**Deborah Dokken, MPA**  
*IPFCC Coordinator for Patient  
and Family Partnerships*



# In our time together . . .

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- ◆ Review best practices for planning and facilitating patient and family panels.
- ◆ Describe how to identify panelists and prepare and support them for successful panel participation.
- ◆ Share ideas for preparing leaders, clinicians, and staff to learn from patient and family panels.
- ◆ Discuss other ways to share personal and professional stories as part of the process of changing organization culture and bringing about transformational changes within ambulatory practices.



# Patient- and Family-Centered Core Concepts

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- ◆ People are treated with **respect and dignity**.
- ◆ 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 and professional education, as well as in the delivery of care.





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Patient- and family-centered care is working with patients and families, rather than just doing to or for them.



# Transforming Healthcare: A Safety Imperative

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“We envisage patients as **essential and respected partners in their own care and in the design and execution of all aspects of healthcare.** In this new world of healthcare:

**Organizations publicly and consistently affirm the centrality of patient- and family-centered care.** They seek out patients, listen to them, hear their stories, are open and honest with them, and take action with them...”

Leape, L., Berwick, D., Clancy, C., & Conway, J., et al. (2009). Transforming healthcare: A safety imperative, *BMJ's Quality and Safety in Health Care*. Available at: <http://qshc.bmj.com/content/18/6/424.full>



Patient-Centered  
**Primary Care**  
 COLLABORATIVE

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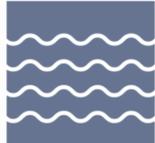

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## Shared Principles of Primary Care

Moving the United States toward a vibrant future of person-centered, team-based, and community aligned primary care



PERSON & FAMILY  
CENTERED



CONTINUOUS



COMPREHENSIVE  
& EQUITABLE



TEAM BASED &  
COLLABORATIVE

**Shared Principles of Primary Care**



COORDINATED  
& INTEGRATED



ACCESSIBLE



HIGH VALUE

Other Resources

- [Shared Principles FAQ](#)
- [PDF Download](#)
- [Organization Sign On](#)

Medical Home



**Primary care is grounded in mutually beneficial partnerships among clinicians, staff, individuals and their families, as equal members of the care team. Care delivery is customized based on individual and family strengths, preferences, values, goals and experiences . . .**

[www.pcpcc.org/about/shared-principles](http://www.pcpcc.org/about/shared-principles)



# Patient and Family Panel

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## Patient and Family Panel

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An opportunity to learn from patients and families about the experience of care within the ambulatory practice and across transitions of care





## Benefits of the Panel Format

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- ◆ Opportunity to hear from a group of experts (patients/families) who bring different perspectives than clinicians, staff, and administrative leaders.
- ◆ Facilitation of interaction among panelists vs. prepared statements from individuals.
- ◆ Encouragement of dialogue among patients, families, clinicians, staff, and administrative leaders.



# Learning from a Patient and Family Panel

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Karen . . .

“Care coordination customized for me as the patient...

Collaboration within and across care teams WITH me, the patient.”



# Learning from a Patient and Family Panel

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## **What was helpful . . .**

I have a big Latino family, my Grandmother started the phone tree and everyone came.

Support of family and friends... they never let me give up. Therapists saw that I was capable of doing more.

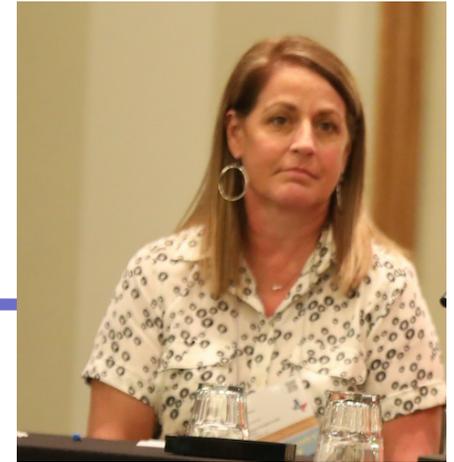
## **What would have been more helpful to you . . .**

Everyone was talking about me, but around me... No one was talking to me...no one was saying that I was going to be OK. I could hear and remember everything, but I could not speak.



# Learning from a Patient and Family Panel

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## What was helpful to you . . .

“We had a good team...they helped us learn about Lindsay’s health needs and TAUGHT us how to be an advocate for our daughter. We sat around a table and collaborated in developing a care plan...

There was no roadmap for her rare condition... we had to pave that road...”

“I created a health journal for my daughter, Lindsay . . . She is becoming her own health advocate.



# Learning from a Patient and Family Panel

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Barry . . .

“I want you to work with me.”

“My doctor also conveyed uncertainty honestly...and arranged appointments and diagnostic tests in a timely way.”





# Key Steps in Planning a Patient and Family Panel

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- ◆ Identification and selection of patient/family panelists.
- ◆ Moderator preparation.
- ◆ Preparation of panelists.
- ◆ Support during the panel itself.
- ◆ Follow-up.



# Identification of Patient and Family Panelists

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- ◆ Develop list of characteristics of “good candidates.”
- ◆ Encourage HCPs to rely on their own personal knowledge of patients and families.
- ◆ Work to achieve variety and balance in patients/families represented.
- ◆ Turn to other resources (e.g., community organizations, advocacy groups) to identify patients/families.
- ◆ Rely on patient/family “self-selection.” Individuals know when they’re ready to participate as educators!



# Preparation of Patient and Family Panelists

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- ◆ Explain goals of the panel and overall educational event.
- ◆ Emphasize that patients/families bring unique experience.
- ◆ Share the key questions that will be asked and how the panel will be moderated.
- ◆ Describe the composition of the audience and what members might be most interested in.
- ◆ Outline nuts-and-bolts details and logistics, e.g., other participants, dress, travel arrangements and directions, expenses and reimbursement.





## PATIENT AND FAMILY PANEL WORKSHEET

Name:

Contact Information:

Hospital or Clinic Name and Location:

- I am a patient with a chronic health condition (e.g., diabetes, heart failure, asthma, depression, arthritis).
- I help a family member or friend in managing a chronic health condition.

What types of health care services have you used (clinic, hospital, emergency department, home care, other):

Briefly introduce yourself and your family and how you have used health care:

Share a positive experience. . . an experience where you and your family felt respected or supported, where you had the information you needed and wanted, or where you and your family could participate in your health care decisions in ways that you wanted.

What did doctors and staff do that gave you confidence, comfort, and was helpful to you?

Share another experience that was not so helpful.

Tell us how this experience could have been better...How it could have been changed or improved... tell us how doctors or staff could have handled the situation differently.

If you had a magic wand, and could change and improve health for you and your family, what changes would you want to make?



# Key Roles of the Moderator

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- ◆ Prepare panelists.
- ◆ Introduce the session...set the stage for learning.
- ◆ Guide “flow” of session.
- ◆ Respect “emotional moments” of panelists.
- ◆ Field and clarify questions from the audience.
- ◆ Manage time.



# Helpful Hints/Tips for the Moderator

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- ◆ In addition to a few key questions, it can be helpful to have a “prompt” for panelists to react to, e.g., a video clip, a short case.
- ◆ It’s often beneficial to have panelists meet one another with the moderator, a short time before the actual panel session.
- ◆ Set respectful limits about length of panel member responses, e.g., Announce, “Each panelist will give a very short intro about his/her experience.”
- ◆ Have key questions prepared but let panelists interact with one another – to truly have a “discussion.”
- ◆ Establish boundaries about audience Q & A, e.g. a panelist can opt to not respond to a question asked of him/her.



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*“We may be openly emotional when sharing our experiences but that’s O.K. We’ve decided that the benefit of being an educator outweighs the burden.”*

(A Family Member)

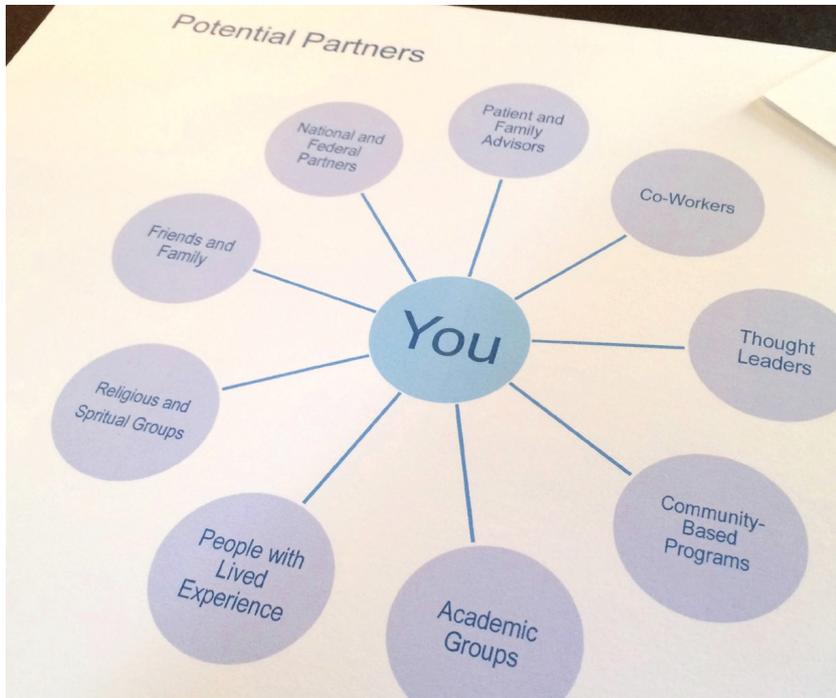


# Follow-Up After the Panel

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- ◆ Communicate with panelists after the panel, express appreciation for their participation, and invite additional comments.
- ◆ Share summarized of session evaluations, if available.
- ◆ Encourage follow-up from practice leaders to discuss possible roles for patients/families in future initiatives.





## Partnering with Patients and Families to Strengthen Approaches to the Opioid Epidemic

Pam Dardess • Deborah L. Dokken  
Marie R. Abraham • Beverley H. Johnson  
Libby Hoy • Stephen Hoy



INSTITUTE FOR PATIENT- AND  
FAMILY-CENTERED CARE®

It is important to hear the perspectives of individuals and families about pain management and the lived experience with substance use disorder.

[www.ipfcc.org/bestpractices/opioid-epidemic/index.html](http://www.ipfcc.org/bestpractices/opioid-epidemic/index.html)





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## A Strong Case for Sharing

The evidence is building steadily. Sharing notes can help you improve communication with your patients, build stronger, more trusting relationships, and enhance patient safety, without adding to your workload.

If your practice is implementing OpenNotes, a panel of patients and family members can help build understanding and commitment.

[www.opennotes.org](http://www.opennotes.org)



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*“We need to know that our participation had a purpose and will make a difference!”*

(A Family Member)



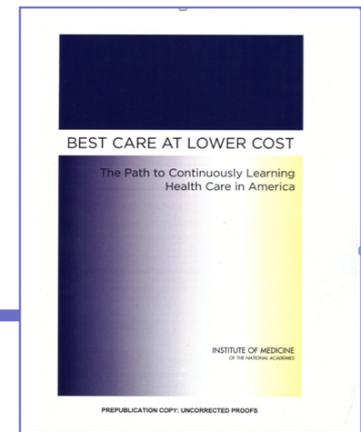
# Preparing Leaders, Clinicians, and Staff

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- ◆ Provide education about the key principles of PFCC.
- ◆ Talk about the benefits and value of learning from patients and families – and their lived experience.
- ◆ Ask staff to share any concerns so that they can be actively addressed.
- ◆ Identify a champion who can help obtain buy-in from other staff.
- ◆ Share the literature and provide examples of how other practices have collaborated with patients and families in clinician and staff training.



# Best Care at Lower Cost: The Path to Continuously Learning Health Care in America



The IOM report has 10 key recommendations; the 4<sup>th</sup> recommendation states:

*“Involve patients and families in decisions regarding health and health care, tailored to fit their preferences. Patients and families should be given the opportunity to be fully engaged participants at all levels, including **individual care decisions, health system learning and improvement activities, and community-based interventions to promote health.**” S-23.*

“In a learning health care system, patient needs and perspectives are factored into the design of **health care processes, the creation and use of technologies, and the training of clinicians.**” 5-5.



# A Key Lever for Leaders . . .

## Putting Patients and Families on the Improvement Team

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*In a growing number of instances where truly stunning levels of improvement have been achieved...*

*Leaders of these organizations often cite—putting patients and families in a position of real power and influence, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history.*

Reinertsen, J. L., Bisagnano, M., & Pugh, M. D. *Seven Leadership Leverage Points for Organization-Level Improvement in Health Care*, 2<sup>nd</sup> Edition, IHI Innovation Series, 2008. Available at [www.ihl.org](http://www.ihl.org).



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*"As health care professionals and patients delve into the challenges and rewards of serious storytelling in illness, we see with new clarity deep aspects of the illness, the sick person, the situation of care, and the person who cares for the sick."*

Rita Charon



# Other Ways to Use Stories of Patients and Providers

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- ◆ Standard opening for leadership and staff meetings.
- ◆ As “guided” case discussions for in-service education sessions.
- ◆ As illustrative examples of areas requiring improvement.
- ◆ Orientation for staff and clinicians.
- ◆ New meaning for the impact of communication coaching, and celebrating the hard work of health promotion and disease prevention.



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*“We have learned to use stories strategically . . . Thousands of our team hear stories at new employee, volunteer, and physician orientations . . .”*

Kathy Dutton, Vidant Medical Center  
in *Privileged Presence*, 2014



# Tools and Resources

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## Partnerships in Interprofessional Education



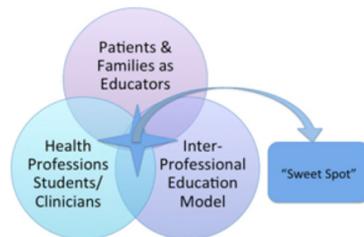
Family Faculty, Hassenfeld Children's Hospital of New York at NYU Langone

*The multidisciplinary focus and inclusion of families made this the best program I have participated in. Stepping outside of my "silo" broadened my sense of possibility and what we have left to achieve.*

— Physician, IPPC Educational Retreat

There is growing recognition of the need to include the "voice" of patients and their families in **every** aspect of health care to improve quality, safety, and patient experience.

Involving patients and their families in education is a newer area of focus but their insights and perspectives about the health care system can enhance learning for clinicians at all levels (students and experienced practitioners) and of all disciplines.



**The materials in this section of the website focus on that "niche" or "sweet spot" – the education of health professionals with the involvement of patients and families as educators.** The examples of successful programs and other tools are designed to help a variety of institutions (e.g., schools of medicine, nursing, allied health as well as hospitals and other organizations) begin or expand their efforts to involve patients and families in this important way.

▶ **IPE and Benefits of Partnership**

▶ **Exemplar IPE Programs**

▶ **Patients and Families as Educators**

▶ **Tools and Resources**



# Partnerships in Interprofessional Education

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## **Other IPFCC Resources**

<https://www.ipfcc.org/bestpractices/interprofessional-education.html>

## **Selected Bibliography**

<https://www.ipfcc.org/bestpractices/ipe/bibliography.html>





## ▶ Partnerships in Ambulatory Care Settings



*Our patients and their families are an abundant source of wisdom as we navigate the stormy seas of healthcare delivery. To go it alone without their partnership is foolish and unwise.*

— Joseph Bianco, MD, FAAP  
Director of Primary Care, Essentia Health

### Defining Ambulatory Care

### Key Initiatives Supporting Ambulatory Care and Primary Care

### Featured Programs

### Patients and Families as Partners

### Tools and Resources

Many ambulatory care settings are working to improve the patient experience, clinical outcomes, and provide a better work experience for clinicians and staff. Working in partnership with patients and family members has proven to accelerate positive changes in these settings and has generated renewed energy and inspiration for those working as health care professionals.

Examples of successful programs and other tools are provided to help clinicians in ambulatory care settings be more effective partners with patients and families – both in patient care itself and at the practice or organizational level.



# Partnerships in Ambulatory Care Settings

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## **Other IPFCC Resources**

<https://www.ipfcc.org/bestpractices/ambulatory-care/tools-and-resources.html>

## **Selected Bibliography**

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

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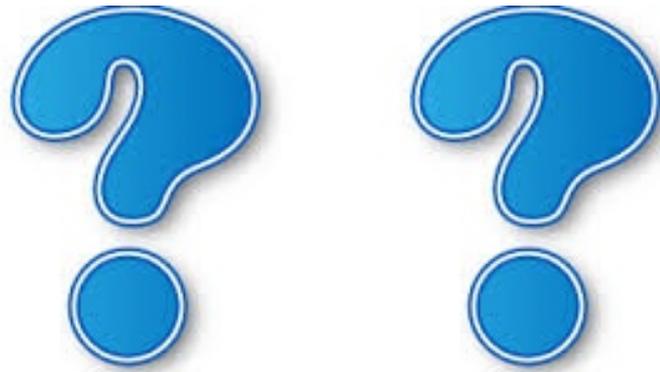


The screenshot shows the PFCC.Connect website. At the top left is a logo consisting of four triangles (two blue, two purple) arranged in a pinwheel pattern. To the right of the logo is the text "INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE" in a sans-serif font, and below that, "PFCC.Connect" in a larger, purple, italicized serif font. Below the header is a dark blue navigation bar with white text for "HOME", "COMMUNITIES", "MY NETWORKS", "DIRECTORY", "EVENTS", and "PARTICIPATE". There is also a search bar with the word "search" and a magnifying glass icon. Below the navigation bar, the main content area is divided into two columns. The left column features a large heading "Join the Discussion" in blue, followed by the text "Ask or answer questions with your peers." and "Our dynamic discussion groups explore best practices in patient- and family-centered care." The right column has a dark blue box with the text "ANNOUNCEMENTS" and a white "ADD" button. Below this is a section titled "NEW FEATURES ON PFCC.CONNECT" with a sub-heading "BY: MARY MINNITI, 16 DAYS AGO" and a paragraph of text: "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](#)".

Join PFCC.Connect to share and learn from others and participate in our monthly informal conversations.

<https://pfcc.connect.ipfcc.org>





## Questions and Comments

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# THANK YOU

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