A COVID Year in Review: What We’ve Learned About Partnerships Across the Continuum

March 11, 2021
Your Hosts

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General Tips

• All participants will be muted upon entering
• Please use the chat box for all questions and comments
• A recording of this presentation and all handouts will be available on www.ipfcc.org
• If you come across any technical difficulties, please call or text Natasha Reed at 646-789-1613
Supporting PFCC Practices and Strategies in the Time of COVID-19

Goal: Provide a resource and “clearinghouse” for up-to-date, easily accessible, information about ways to stay grounded in PFCC core concepts during COVID-19

- IPFCC will identify, develop, and disseminate information related to COVID-19 across adult health care settings.
- Target audience: Adult healthcare settings across the continuum including hospitals, ambulatory and primary care settings as well as continuing care/retirement communities
- The series of free webinars and online conversations occurs monthly from July 2020 through April 2021.
- Funded by a grant from:
Objectives

• Explore ways that partnerships with PFAs were strengthened in the midst of a pandemic
• Learn how PFAs have influenced policy, programs, and services to help address the challenges of COVID to improve safety and quality
• Review three new tools for “revisiting” recent restrictions on family presence in health care settings and learn how to use them with a collaborative decision-making team, including patient and family advisors
• Reflect on partnership lessons learned
In a pandemic, 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.
Living in a Pandemic is Hard

• Healthcare workers surveyed are overwhelmed, worried about loved ones, not getting enough emotional support and stretched too thin 1,2

• In January 2021 Kaiser Survey 41% of adults are feeling anxious and depressed 3

• Overall, the research demonstrates that COVID-19 is affecting the mental health of children and adolescents and that depression and anxiety are prevalent including among young people of color and among lesbian, gay, bisexual, transgender, and queer and/or questioning (LGBTQ) youth. 4,5

YOU, ME, EMPATHY
Introducing a new IPFCC guidance resource...
Deborah Dokken, MPA, Family Leader and IPFCC Coordinator for Patient and Family Partnerships

Bev Johnson, FAAN, IPFCC President and CEO

Hazel J. Markwell, PhD, DTh, Chair in Bioethics, St. Paul University Ottawa and Theology, Ethics, and Policy Advisor, Catholic Health Alliance of Canada
“A hospital without loved ones is slowly becoming our new normal, a reality that threatens to upend the role of the family in the care of our hospitalized patients . . . Unless we focus on hospital visitor policies with real urgency, regularly and openly revisiting these rules as the coronavirus caseloads change in a given region, I can see our gains slipping away.”

Critical care physician, NYTimes, 8/17/20
“We believe that infection control, public health concerns and family-centered care can coexist and urge reconsideration of family member presence at the bedside of patients during COVID-19.”

2014 . . . United States & Canada

Better Together
Partnering with Families

Changing the Concept
From Families as “Visitors” to Families as Partners
Families are allies for quality and safety, holders of vital information about the patient, essential to transitions of care, and contributors to mental health and well-being for all.
Disruption of family connections has lifelong implications . . .

“The psychological impact of COVID-related separation on ICU families will reverberate for years and likely result in high numbers of people needing trauma-related services.”
Montauk & Kuhl, *Trauma Psychology*, 2020
“Increased anxiety and stress, decreased care and learning opportunities for families, and interrupted bonding may all have a lasting impact on long-term outcomes for babies, as well as on the mental health of family members.”

Parents from the Vermont Oxford Network

“The depression and sense of aloneness affecting my fellow residents, it’s terrible. Having our relatives come back in to see us, it’s an absolute necessity for our well-being.”

Nursing home resident in Georgia
“Much has been said about preventable deaths related to Covid-19. Little has been said about preventable suffering. We may today be better prepared to diagnose and treat the disease than we were in the spring, but we are not better prepared to address the collective trauma of Covid-19 patients being separated from their families.”

Leiter & Gelfand, STAT, 1/9/21
Balancing Benefits and Harms
• Learnings about restrictions on family presence during SARS and H1N1;
• Evidence about the benefits of family presence and emerging evidence about infection spread and family presence and the harms caused by the restrictions;
• Core concepts of patient- and family-centered care, i.e., dignity and respect, information-sharing, participation, and collaboration; and
• Key ethical principles, i.e., autonomy (grounded in respect for persons), beneficence, non-maleficence and justice.
The four core concepts of patient- and family-centered care can serve as the framework to improve value, reliability, safety, quality, the experience of care, AND the work experience.
Connecting PFCC Core Concepts and Key Ethical Principles

- Dignity and Respect
- Information Sharing
- Participation
- Collaboration

- Respect for Persons
- Beneficence, i.e., do good
- Non-maleficence, i.e., avoid harm
- Justice
Tools for Guiding Decision-Making for Family Presence and Participation

- The initial tool is a graphic outlining a 10-step iterative, collaborative, decision-making process
- The second tool outlines key questions for each of the 10 steps
- The third tool, a matrix, supports the decision-making team in considering the relative balance of benefits and burdens/harms to key groups in both the short and the longer-term
10-Step Iterative Process
10-Step Iterative Process

Key Questions for Each of the 10 Steps
Interactive Matrix to Balance Relative Benefits and Harms

- For key groups
- In short-term and longer-term

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</tbody>
</table>

Note: Indicate relative significance/relative impact for each item listed using high (H), medium (M), or low (L) in H/M/L columns above. For high (H) put 3 in column, for medium (M) put 2 in column, for low (L) put 1 in column.
Additional Resources

• 42 references, over half from 2020 or 2021
• https://www.ipfcc.org/bestpractices/covid-19/IPFCC_Family_Presence.pdf
• https://www.ipfcc.org/bestpractices/covid-19/Partnerships_with_Patients_and_Families_During_COVID.pdf
• https://www.ipfcc.org/bestpractices/covid-19/index.html
Learning from the Frontlines...
COVID Changed Everything
PFA Work During Emergency Operations

- Family presence and visitation guidelines - ongoing
- Review of patient facing materials
- Safety Rounds
- Diversity and Inclusion video for the Patient Story Library
- Document and policy reviews
- **Weekly PFA office hours (in addition to PFAC meetings)**
- Pre-admission checklist
- Covid webinar consultation
- External signage review
- **Diversity and Inclusion Task Force**
  - To improve the diversity of our PFAC’s
- EOL visitation family presence for Covid + patients
- Human Resources: **PFA’s included in all interviews for new leaders (administrator and above)**
Lessons Learned

- The Power of One
- Never underestimate how nimble people are.
  - PFA’s accrued more hours than ever!
- PFAC Planning Meetings
- The pandemic taught us how to problem solve in new ways.
- Being virtual is not all bad!
- In the wake of tragedy, we can make positive changes together.
EXPERIENCES OF A PATIENT ADVISOR DURING COVID-19


- March 2020 to February 2021: Served as the only public-patient advisor on the Institute for Health Services Work Group with the University of Washington Health System, providing PFA prioritization insights on submitted COVID19 research proposals. 57 projects were funded for study.

- March 2020 to present: Provides input on interventions and evaluation for Healthcare for the Homeless -COVID19 care in King County, WA including isolation and quarantine strategies and implementation efforts for testing and vaccination hesitancy.

- October 2020 to present: Serves on national and international evidence projects identifying social determinants of health needs and emergent COVID issues for research prioritization.

Janice Tufte  www.janictufte.com
@Hassanah2017  @hassanah2017
LESSONS LEARNED

- When no COVID patients are available, say YES to participation so patient/family voice and lived experience can be present.

- Be thankful for what you bring; recognize you are part of a community all learning on the go; mutual respect is important should be extended to all.

- Built relationships during the crisis and humbled by the gravity of the danger healthcare workers were in yet they continued to persevere.

- Be curious, use critical thinking skills and be okay with steep learning curve

- Compensation for participation is needed if voices of those disproportionally impacted are to be involved meaningfully

Janice Tufte  www.janicetufte.com  @Hassanah2017
Covid-19 Patients Are Doing Their Own Research

To advance scientific knowledge of the disease, lay people are organizing to generate data about their experiences.

- The work of the Patient-Led Research for Covid-19 group—including a rapid survey and analysis of 640 patients and a detailed paper tracking symptoms in thousands of patients who have been sick for over 28 days—is helping to drive partnerships with researchers.
- “COVID has helped us see some of our blind spots in the clinical and research enterprise,” said Dr. Helen Burstin, CEO of the Council of Medical Specialty Societies, which focuses on improving care and health research. “We need to figure out how we actually work with patient-led research efforts when the patients are the ones in leadership.”

https://www.wsj.com/articles/covid-19-patients-are-doing-their-own-research-11611982860
Advice from a Nursing Home Leader

- Value families and residents partnerships - seek their input and work together to **determine what can be controlled** when so much is out of our control.
- Utilize **family members as caregivers** when staffing is in crisis. You will never find a more invested group of people to help in a pinch.
- PFCC doesn't fare well with authoritarian-style leadership. **Give up the "power" and collaborate whenever you can.** In the pandemic, some switching back and forth between leadership styles will be required.
- Community Partnerships are key to success. Build ongoing relationships with those across continuum and outside of healthcare. **Seek solutions together.**
Lessons Learned from Maryland Aged Home

• For minority populations, resources come late and provide little compared to what is needed. What works is to plan for self reliance and care.
• We saved lives by shutting down as soon as possible, purchasing needed supplies before shortages. Stockpiled more than needed and share with others in community later. Prevented unnecessary contact with outside world and instituted continuous sanitations and cleaning.
• Respond with empathy to residents, family, and staff. Check-in: how they are doing and feeling. Remember little things: Food, Fun, Virtual fellowship and counseling was important in keeping the team and family emotionally healthy.
Hopeful Next Steps:

• Vaccines have been administered to both staff and residents (86% & 92%)
• Vaccinated family members can visit in private rooms indoors
• All others can visit outside – residents on porch; family in yard.
• Virtual connections still supported.
• Reliance on the science was guide.
IPFCC Webinar COVID Year in Review
March 11th, 2021
Strengthening Partnerships in the midst of a Pandemic

March 2020
PFAC Chair involved in Incident Management Response Team (IMRT)

• Ministry and Public Health Restrictions
• How to keep Our Patients, Our Staff and Our Community safe

March-April 2020
PFAC provided Feedback on:
• Letters to our Patients and families
• COVID FAQ sheet
• Pandemic Line
• Signage

April-present day
• PFAC Zoom Meetings
• Gratitude Letter to all staff
• “Together We Stay Strong” T-Shirts to all staff & PFAC members
• Presenting at DCP Orientation
• Review of HDGH Patient info
• Benevolent Fund Requests x5

Missed only 2 meetings due to COVID (March & April)

PFAC Member Joins Foundation Board:
October 2020 AGM
Training: October

2nd PFAC member joined HDGH Board
Training: November

Finance Committee:
November 2020

PFAC co-presented “Embedding Partnerships Across Healthcare Systems”
June 2020

PFAC Chair & Co-Chair Poster Presentation “HDGH Consultation to Shared Leadership”

PFAC Virtual Visits for Patients at HDGH

August 2020
Coordinated Care Program
More than a Visitor…

- PFAC members assisted with designing the program, co-teach the orientation and participate in an ongoing advisory committee to guide the work forward
- DCPs attend a mandatory Orientation to ensure they understand their responsibilities, boundaries and infection prevention and control measures
- Designated Care Partners (DCP) are chosen and trusted by the patient
- DCPs know the patient very well and are familiar to subtle changes in the patient’s personality and frame of mind
- DCPs are allies and active partners in care, committed to assisting with communication when needed, supportive decision making, discharge planning and any other support that may benefit the patient
- DCPs will be an integral part of family presence beyond the pandemic
- Surveys completed by DCP’s to enlist their feedback for Quality Improvements to program

99%
Feel confident and prepared to act as DCP

545 DCP’s Completed training

123 current Active DCP’s

99%
Understand roles & responsibilities to act as DCP
Lessons learned...

- Always involve the Patient Family voice in decision making...especially during a Pandemic.
- Don’t lose momentum on work you are doing
- When faced with a challenge, stop and asking the question “How might we?”

What we hope to sustain...

- Patient and Family Leadership
- Designated Care Partner Program; strengthening family presence and the role of families as partners in care
- Increased Collaboration among patients, families and staff
Lessons Learned

• Staff need critical thinking and crucial conversation support. (Prepare them to ask questions to understand patient requests rather than just say “no”.)

• Virtual PFACs are not to be feared. Contributions:
  • Texting friends and family  • Cares Act  • Social determinant platform
  • communication liaison  • website update  • 24 hour post d/c phone calls
  • medication management  • transition planning  • strategic planning
  • recognition program  • whiteboard use for d/c planning
  • remembrance program  • hazardous medication communication
  • workplace violence  • visitation updates and management
  • patient portal education
PFAC Composition:
29 TOTAL Advisors
• 13 Patient Advisors
• 4 Staff Advisors
• 10 Resident Physician Advisors
• 2 Faculty Physician Advisors

Clinic Metrics:
Established 2016
• Urban, community teaching hospital.
• 9 faculty physicians
• 26 resident physicians
• 7000 patients
• 23,000 annual visits
• 60% Medicare/Medicaid

The PFAC is a great way to take the pulse of the group of patients and how they are approaching their own health during this time. It is a scary time and people need encouragement to go to the doctor and utilize all they have to offer. When sometimes it is hard to determine what to believe from the media and social media, I see the PFAC leading the way to increase communication and help ease fears during these uncertain times.

~Patient Advisor
PFAC HIGHLIGHTS:
1) Feedback on *Telehealth Visits* in era of COVID-19
2) Input on *clinic patient flow adjustments* to preserve social distancing
3) Prioritization of *relevant resources for patients* in Community Resource Guide specific to pandemic assistance.
4) Launch *handwritten notes from physicians and staff* for patients/families needing encouragement in the pandemic.
5) Develop *two-page information sheet with COVID-19 FAQ* to build vaccine confidence and reduce hesitancy.

PFAC LESSONS LEARNED:
1) *One-on-one virtual meetings* with advisors who need extra technology help *were valuable* to increase participation and promote confidence.
2) *Patient advisor attendance INCREASED* with remote meetings (possible in-person barriers: *transportation, travel time, childcare*). Resident advisor and staff advisor attendance also increased.
3) *Maintain emotional connectivity* while being apart. Build community and trust by encouraging small talk and catching up, 15 minutes prior to meeting start time. PFAC business begins promptly at scheduled time.
Cincinnati Children’s Hospital

Developed app for adolescents on coping:
Reflections on Bedside Partnerships with Parents

• Corporate messaging (shown) re: family presence was confusing at times (who are the “visitors”? Parents are NOT visitors in our context).

• Strong CHaD leadership advocated for continued commitment to family-centered strategies including (healthy) parents as partners at the bedside.

• Unwavering and uninterrupted commitment to welcoming BOTH (healthy) parents (or mother and support person) at all times as integral members of the care team.

• Supported additional family members as needed in end-of-life situations.

• Evidence/science-based policies, such as travel restrictions were applied equally to staff AND parents.

• Leveraged telehealth to keep families connected to decision-making and planning.

Intensive Care Nursery
Reflections on Family Advisor Partnerships

• The ICN Parent Council has met virtually for years and has a robust online platform which allows for real-time collaboration on policy, documents, and projects.
• **Family leader representation at weekly ICN Leadership meetings.**
• Council was available for policy discussions related to COVID
• Council was able to quickly **co-create key family communications** such as:
  - Family presence clarification
  - Revised rounding strategies
  - Breastmilk safety education
  - Screening question changes for families (i.e., travel)
  - Mask-wearing education/reinforcement
  - OB inpatient testing changes
  - Bonding with baby tips for parents
• Council helped alleviate burden of creating documents from staff by being a just-in-time resource to initiate and collaboratively edit communications for families.
• Council helped to facilitate messages of hope and thanks from community to staff and current families.

Intensive Care Nursery
A COVID Year in Review: What We’ve Learned About Partnerships Across the Continuum

Children’s Mercy Kansas City
Highlights of Partnership

• Quickly transitioned all 18 PFACs to a virtual platform and published article https://pxjournal.org/journal/vol7/iss2/17
• Altered GME resident in-home immersion experiences with PFAs to a virtual platform
• Reviewed messaging for patients and families
  New visitor restrictions
  Screening and masking requirements
  Surgery and outpatient clinic cancellations
  COVID-19 website content in English and Spanish
  Family toolkit for social distancing
  Exemptions for visitor restrictions
  Communication for COVID-19 test results
  New electronic sign-in procedure in clinics
  Signage
  Sibling support during outpatient visits

• Provided feedback on telehealth platform and telehealth safety
• Conducted focus groups for recovery communication to assure families that it is safe to return to care
Highlights of Partnership (cont.)

• Created PFCC training video for non-employee screeners
• Sent thankful messages to staff and donations for staff respite room
• Offered COVID-19 vaccines to PFAs in accordance with state guidelines
• Co-presented “Patient- and Family-Centered Care and Pediatric Partnerships during COVID-19: Addressing the Mental Health Needs of Children” on IPFCC webinar in August
• Contributed to article “Mental Health Needs during COVID-19: Responses in Pediatric Health Care” in Pediatric Nursing Journal
  http://www.pediatricnursing.net/news/FamilyMatters_ND_20
• PFAs recorded videos for Behavioral Health education for nursing
Lessons Learned

• PFA engagement remained high despite move to virtual platform
• Consistent communication with PFAs regarding changes was important
• Hospital led Community Town Halls provided critical information and updates to patients, families and the public
• Residents found the virtual immersion experience with PFAs valuable
• The importance of taking the time to virtually meet each other and establish personal relationships with PFAs and new staff members
• Despite the pandemic and upheaval in everyone’s lives, PFAs wanted to remain engaged in their advisory roles
Our Partnership with Patients and Families Strengthened

Patient and Family Advisors are a key part of our team based approach to improve:

- Services
- Resources
- Programs
- Communication & Information
- Processes
- Policies
- Committee memberships – safety, executive, unit meetings, etc.
- Story Library – added COVID Patient Stories and Black Patient Experience
- Speakers bureau – continue to conduct patient panels across health system, medical school, and nursing college
- Peer mentors (30 groups – added “COVID Patient/Family Peer Mentor Program
- Focus groups – on topics ranging from visitor policy to health equity, telehealth and virtual care options, scripting, etc.
- Quality improvement projects – (Advisors initiated our “button project” – care teams wearing pins with their smiles showing)
- Observation and Interviews
- Patient and Family Advisory Councils – 37 in operation. Most were paused for March-April – but relaunched in May)
- Reviewing Patient Education Materials – and helped create a COVID Caregiver book

1,625 Patient and Family Advisors

MICHIGAN MEDICINE
OFFICE OF PATIENT EXPERIENCE
Lessons Learned

• Always reminded of the incredible value that patient and family perspectives provide – even when doing things that don’t appear patient and family centered (“visitor” restrictions, entrance screenings) Advisors helped us do this better!

• Advisors were eager and ready to contribute, even despite the complications – we paused our PFACs for 2-3 months. Though we needed a minute to adjust to remote “everything” – the value and regular structure of the PFACs was missed. I would have limited the time to relaunch.

• Some virtual platforms are more user friendly than others – we switched PFACs to Zoom after stumbling through some others.

• Remote gatherings have increased our Advisor attendance – we may keep this as a standard going forward, and gather in person less frequently.
UNIVERSITY OF ROCHESTER MEDICAL CENTER PFAC Structure

- Board Quality of Care Committee
  - Advisors for Direct Patient Care Teams
  - URMC/SMH Patient and Family Advisory Council
    - Behavioral Health Consumer Advisory Council
    - Wilmot Cancer Center Advisory Council
    - Deaf Patient and Family Advisory Council
    - Transgender and Gender Diverse PFAC
  - Advisors for Support Teams
    - Children’s Hospital Advisory Council
    - NICU Advisory Council
### Some Partnership Highlights During COVID

| Listening | • To outpatients who helped us to **develop and refine conducting group therapy over Zoom**. Their input allowed us to proceed confidently and to tweak the process as we went. |
| Understanding | • That tele-mental health services work and would **decrease our “no show” rate** as a result of eliminating the barriers of transportation, parking, and child care. |
| Collaborating | • With our hospital leadership when they asked for feedback from all of our PFACs regarding the **COVID symptom survey tool** they would be rolling out to the entire community. Many PFAC members jumped at this opportunity with very helpful input! |
| Influencing | • Our ability to meet the needs of the varied populations we serve (e.g., Deaf and Hard of Hearing COVID communications required more visuals to adequately provide needed info as well as “see through” face masks so facial expressions and lips could be seen). |
Best Way to Communicate with a Deaf Person While Wearing Your Mask

**DO**

- Immediately call for an interpreter *(275-2222)*
- Keep your mask on correctly at all times!
- Use a mask with plastic over the lips, if available.
- Ask the individual how they prefer to communicate:
  - Write, type, or use gestures and visual aids
What you say through your mask is NOT accessible for Deaf people.

**DON’T!**

- Do not pull down your mask to speak!
- Do not think repeating yourself will make them comprehend.
- Do not leave without confirming mutual understanding.
COVID-19 Symptom Screening Tool

COVID-19 SYMPTOM CHECKER

I have symptoms?

- Cough, shortness of breath, difficulty breathing
  - YES
  - NO

- Fever or Chills
  - YES
  - NO

- Vomiting or diarrhea
  - YES
  - NO

- New loss of taste or smell
  - YES
  - NO

- Muscle or body aches
  - YES
  - NO

Have you been exposed to anyone who has COVID or have you been diagnosed?

- YES
- NO

Have you traveled outside NYS in the past two weeks?

- YES
- NO

We will take your temperature
Connecting with Patients During COVID-19

Kellie Goodson, MS, CPXP
kellie.goodson@vizientinc.com
Conducted Focus Groups
Conducted Short Pulse Surveys

Connected with patients and families from May 2020 to January 2021 about safely accessing health care services during the COVID-19 pandemic.

Key learnings:

- Processes and settings that limit the risk of exposure to COVID-19 are extremely important
- Personal risk analysis drives patient decision-making
- Technology that meets patient needs should continue to be used and improved upon
- Doctor/patient communication and relationships matter

Table 1. Pulse survey respondent demographics

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<td>7%</td>
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* When asked “Is your state currently experiencing, or has it recently experienced, a resurgence of COVID-19?” 95% said “yes” in response to the December survey compared to 60% for the September survey.

May N=47, July N=68, September N = 121, December N = 603

Thank You to Our Partners

Keesha Goodnow
Department of Family & Community Medicine University of Cincinnati

Kellie Goodson
Vizient

DeeJo Miller  Sheryl Chadwick
Children’s Mercy Kansas City

Molly White
Michigan Medicine

Janice Tufte
Patient Advisor

Caroline Nestro
University of Rochester Medical Center

Kelly Parent
Beaumont

Rev. Dr. Derrick
C. Dewitt, Sr.
The Maryland Aged Home

Tracy Hendrickx
Perham Living

Caroline deLongchamps
MUSC Health

Joanna F. Celenza
Children’s Hospital at Dartmouth-Hitchcock

Barb Masotti
Hôtel – Hôtel Dieu Grace Healthcare

Kathy Quinlan
Lisa Raffoul
IPFCC Website and PFCC.Connect

www.ipfcc.org and https://pfcc.connect.ipfcc.org
INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

Transforming health care through partnerships

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
Supporting PFCC Practices and Strategies in the Time of COVID-19

Upcoming Informal Conversation:

Where Do We Go From Here?

Tuesday, April 6\textsuperscript{th}, noon ET

https://us02web.zoom.us/meeting/register/tZUrdeyhrT4tH9NwmLDISXbDy05ovb5Ru6wAZ
“When it rains, look for rainbows; when it's dark, look for stars.”

Wilde
Thank You for Joining Us!

Please fill out the evaluation on the webinar:

https://www.surveymonkey.com/r/COVID_YR_Partnerships_Mar21

If you have any questions, please reach out to
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