Patient- and Family-Centered Care and Pediatric Partnerships during COVID-19:

Moving Forward with New Learnings and Strategies

10.29.20

Chat Log

From Bev Johnson: Welcome everyone. Please introduce yourselves and tell us where you are from.

From MOHD NASRI NORDIN To All Panelists: I am Nasri from RMHC Malaysia

From Joanmarie Button: Joanmarie Button - Director, Cleveland House Program - Ronald McDonald House Charities of Northeast Ohio

From Cristina Di Silvestre To All Panelists: I am Cristina Di Silvestre from Faculty of Medicina, Universidad del Desarrollo, Santiago de Chile

From Nicole DeGrace To All Panelists: Hello! Nicole DeGrace Manager and Facilitator of Psychiatry Family Advisory Board at Seattle Children’s Hospital

From Mary Minniti: Mary Minniti, IPFCC, Eugene, Oregon.

From Deborah Dokken: Welcome again, everyone! We will start right at noon so in the meantime, tell us who you are.

From Joanna Sobolewska: Joanna Sobolewska - CEO of the first foundation i Poland that educates about emotional suport for kids who are being medically treated.

From Adrienne Jacoby: Adrienne Jacoby, Anne Arundel Medical Center (Luminis Health) in Annapolis, MD

From DeeJo Miller: Hello from Children's Mercy Kansas City! I'm looking forward to today's webinar.

From MOHD NASRI NORDIN: Nasri Nordin, Organizational Leader, RMHC Malaysia

From Sheryl Chadwick: Hello from Sheryl Chadwick, Children's Mercy Kansas City!

From Issam Nimri To All Panelists: hello from RMHC Jordan

From April Slowenski: Hello from Bristol Myers Squibb Children's in New Jersey

From Joy Hales: Joy Hales, Family Support Network of Greater Forsyth in Winston-Salem, NC

From Toni Millar: Hello from Toni Millar, CCLS Project Sunshine

From Lisa Digman: Hello from Iowa as a member of the University of North Carolina Newborn Critical Care Family Advisory Board

From David Garrett: Greetings from North Mississippi Health Services in Tupelo, MS!

From Courtney Nataraj: Hello from Courtney Nataraj, NewYork-Presbyterian Komansky Children’s Hospital

Rosalind Graham: Hello from Rosalind Graham, UF Health CHaMP Program

From Sara Scott: Hello from Family Voices of Tennessee!

From Susan Colburn: Susan Colburn, Family leader working with Alabama's CYSHCN Program

From Meg Rider: Hello from Magee Rehabilitation Jefferson Health in Philadelphia, PA

From Jeffrey Cousins: Jeff Cousins, Family-Centered Care Consultant, AdventHealth for Children, Orlando

From Cyndi Fisher: Hello all from Cyndi Fisher, Care Connection Children's Hospital of The King's Daughters

From Lindsay Hartman: Greetings from Lindsay Hartman, Nemours Alfred I duPont Hospital for Children Family Advisory Chair in Wilmington, DE

From Bev Johnson: Here is the link for the handout that Deborah mentioned… it will also be posted on our website: <https://ipfcc.org/events/10-29-20_Webinar_Handout-Pediatric_PFACs_and_PFAs_in_COVID.pdf>

From MOHD NASRI NORDIN: ty Bev

From Adrienne Jacoby: Digital Engagment Committees are a really really good idea.

From Mary Minniti: Please chat in questions, ideas, and comments as you listen to the presentation.

From Adrienne Jacoby: How did Golisano push this out to the community?

From Deborah Dokken: Golisano shared information through hospital mechanisms but also partnered with a group of community organizations. Some of the resources were shared in “hard copy” as well as web for families who might not have access.

From Adrienne Jacoby: Interesting. Were those partnerships with the community organizations already in existence or were they formed during COVID?

From Deborah Dokken: I think it was a mix: some new for this initiative, some existing.

From Adrienne Jacoby: Our PFAC is still working on creating those community partnerships. So media was NOT involved in helping to spread the news about the community conversations?

From Deborah Dokken: Adrienne, if you reach out later, we can connect you to delve further into the Golisano work. We will be putting a profile on the COVID section of our website soon.

From Adrienne Jacoby: Deborah that would be great. My email is 4jacoby@gmail.com. I don't believe I have yours. Thank you so much.

From Toni Millar: Project Sunshine (www.projectsunshine.org) has created free, live, play programming called TelePlay for children facing medical challenges (physical and behavioral health) in and out of the hospital. Our goals is to bring the healing power of play and promote socialization during this time of isolation. Please share our TelePlay play calendar with children you know who are facing medical challenges bit.ly/TelePlaySessionSignUp. Here is a video of what TelePlay looks like TelePlay looks like https://www.youtube.com/watch?v=73DZWYZM3QE. Please email me at teleplay@projectsunshine.org

From Deborah Dokken: ddokken@ipfcc.org

From Mary Minniti: Thank you, Toni for sharing this virtual resource.

From Deborah Dokken: Thanks for sharing that resource, Toni!

From Deborah Dokken: A future article in the “Family Matters” section of Peds Nursing will look at an intervention specially for fathers.

From Lindsay Hartman: I am very proud to say that the FAC for Nemours AI duPont Hospital for Children met even more frequently than usual to discuss the ever changing hospital policies regarding covid-19. We felt it was imperative to have our council involved and aware of the constantly changing circumstances

From Deborah Dokken: Great, Lindsay. We’ve heard that from others.

From Nicole Abair: Are there privacy concerns around PFACs virtually connecting with patients and families?

From Mary Minniti: What additional questions do you have for Bev and/or Deborah? Please chat them in now.

From Katherine Harris: Ideas on how to best include families in medical rounds which are being done via a virtual platform?

From Adrienne Jacoby: How does a PFAC even begin to engage with a school system to make those connections during a time when the schools systems are still so overwhelmed and trying to figure out how to accommodate school/student needs? It's a great idea but it seems like a difficult time to make that connection if your PFAC has not before.

From Lindsay Hartman: I love this question. It's also very difficult when you have a patient population from multiple states and counties

From Laura Rohde: can you share the website with the COVID articles available for free again?

From Nicole DeGrace: Great Question, I am happy to speak more to this

From Deborah Dokken: For free COVID articles in Peds Nursing: [www.pediatricnursing.net](http://www.pediatricnursing.net/)

From Sheryl Chadwick: Children's Mercy has a peer support program (POPS) Parents Offering Parent Support. Our online application has a release of information that has been approved by our legal department. The application can be seen here: <https://cmhredcap.cmh.edu/surveys/?s=JCHXMR89AC>

From Heidi Shannon: Does anyone have suggestions for recruiting MH advisors. We struggle with the inability to make a commitment, attend meetings consistently. Hard to recruit.

From Adrienne Jacoby: Thank you Nicole!!!

From Deborah Dokken: Re resources related to COVID health: IPFCC’s website has a whole COVID section

From Nicole DeGrace: <https://mhttcnetwork.org/>

From Nicole DeGrace: This website has regions which you can look at the different info based on region. I will share a few links that I know of and we have referenced and used and also shared with others.

From Mary Minniti: Thanks, Sheryl for sharing your release of information form as an example to address privacy issues.

From Nicole DeGrace: School Mental Health Info: <https://mhttcnetwork.org/centers/mhttc-network-coordinating-office/school-mental-health>

From DeeJo Miller: Starting our Mental Health PFAC we set up virtual meetings individually with recommended parents and the PFAC parent chair and a parent on staff. This helped build relationships and trust.

From Mary Minniti: IPFCC Website related to COVID: <https://www.ipfcc.org/bestpractices/covid-19/index.html>

From Heidi Shannon: Thank you, so helpful!

From DeeJo Miller: Some current PFAC members may also be interested in joining a Mental Health PFAC

From Deborah Dokken: Survey link for today's webinar: <https://www.surveymonkey.com/r/Pediatric_New_Learning_and_Strategies_Oct20ning_>

From Mary Minniti: Great idea, DeeJo!

From Nicole DeGrace: My email Nicole.degrace@seattlechildrens.org I am more than happy to connect with anyone related to mental health PFAC questions and the school related connections

From Lisa Digman: This was so helpful, thank you very much!!

From Irma Dadic: Thank you all! This was very helpful and inspiring to push forward

From Nicole DeGrace: <https://mhttcnetwork.org/centers/global-mhttc/training-and-events-calendar> this link has a bunch of free trainings and events that are very helpful

From Adrienne Jacoby: Deborah I would love to connect via email a little later and perhaps also grab those links from Nicole. Thanks everyone!!! I feel like so many new ideas came up today and I've been on these calls since COVID started!

From Mary Minniti: Thank you everyone for joining us today! We so appreciate your interest and the good work you are doing out in your communities.

From Leslie Louie: Thank you for the session Bev!

From Suzanne Dunbar To All Panelists: thank you for this great info

From Nicole Abair: Thank you!

From Allison Sohanlal: Thank you!

From Susan Colburn: Thank you!