9TH INTERNATIONAL CONFERENCE ON PATIENT- AND FAMILY-CENTERED CARE: Partnerships for Quality, Safety, and Equity

> INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

GOING VIRTUAL!

_____ , , , _____

BRINGING NASHVILLE TO YOU

AUGUST 18 TO SEPTEMBER 10, **2020**

WITH LEADERSHIP SUPPORT FROM

VANDERBILT VINIVERSITY MEDICAL CENTER

WITH PARTNERSHIP SUPPORT FROM

Beaumont

Conference Overview



WE'VE GONE VIRTUAL!

IPFCC is bringing Nashville to you...join us for the *9th International Conference on Patient- and Family-Centered Care: Partnerships for Quality, Safety, and Equity* from August 18 - September 10, 2020.

Partnerships for Quality, Safety, and Equity

The *9th International Conference* will showcase exemplary programs dedicated to collaboration among health care professionals, patients, and families to address the challenges in our complex health care system. The Conference provides opportunities to share innovations across all settings at the direct care level as well as the organizational, community, regional, and national levels.

With an emphasis on partnerships for improving quality, safety, and equity, presenters will share their knowledge, strategies, and resources and highlight lessons learned from:

- Hospitals
- Primary care and other ambulatory settings
- Community-based programs
- Public health and mental health agencies
- Patient- and family-led organizations
- Research centers
- Schools of medicine, nursing, and other health and helping professions

Whether you are beginning your patient- and familycentered efforts or are advancing transformation, this Conference provides the information, tools, and connections to inspire, energize, and further your journey.

Join us and your peers at this important event!

Who Should Attend

- Patient and Family Advisors and Partners
- Executive Leaders and Board Members
- Physicians, Nurses, Social Workers, Therapists, Pharmacists, and Child Life Specialists
- Safety and Quality Personnel
- Diversity and Equity Personnel
- Coordinators for Patient and Family Advisory Programs
- Patient Experience and Patient Relations Personnel
- Human Resources Personnel
- Researchers and Evaluators
- Community-Based Agency Personnel
- Faculty and Students in Schools of Medicine, Nursing, Social Work, and Allied Health
- Policy Makers, Government Agency Leaders, and Funders

LEARN • SHARE • CONNECT Register for the 9th International Conference

Conference Learning Objectives

- Gain understanding of patient- and familycentered care and how it can be applied to settings across the continuum of care to enhance quality, safety, and the experience of care for all.
- Identify strategies to support and sustain authentic partnerships among health care professionals, educators, researchers, and patients and families.
- **Discover** effective methods to create and sustain patient and family advisory councils and programs.
- **Explore** patient- and family-centered approaches to address current priorities in health care—specifically addressing social determinants of health and achieving health equity, improving approaches to behavioral health, improving pain management and decreasing opioid use, providing safe care transitions, and engaging communities in health promotion.
- Discuss how to meaningfully integrate individuals with lived experience into the education of health care professionals, research, quality improvement, patient safety, development of health standards, and strategic planning.
- **Define** the roles of senior executives in providing leadership for patient- and family-centered care.

Continuing Education

Nurses: This continuing nursing education activity was approved by the Maryland Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation (ANCC COA). This activity has been awarded up to 48 contact hours.

Physicians: This program has been reviewed and is acceptable for up to 23 prescribed credit(s) by the American Academy of Family Physicians. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Social Workers: This program is approved by the National Association of Social Workers for up to 29 continuing education contact hours.

Patient Experience: The conference is approved for up to 10 Patient Experience Continuing Education Credits (PXEs) from the patient Experience Institute. Participants interested in receiving PXEs must claim their credits within 30 days of attending the Conference.

REGISTER NOW

REGISTRATION FEES

Registration Type	Fee
Health Professionals/Individuals	\$500
Patient-Family Advisors/Leaders	\$400
Students	\$400

"Great content and very good speakers. Patientand family-centered care has come alive for me." – 2018 Conference Attendee



Thank You to Our Supporters

With great appreciation, IPFCC would like to thank our sponsors for their support and their commitment to patient- and family-centered care.

VANDERBILT VUNIVERSITY

MEDICAL CENTER

Beaumont









Keeping families close[®]



American Association of Colleges of Pharmacy







HONORING NURSES INTERNATIONALLY IN MEMORY OF J. PATRICK BARNES





LEADERSHIP SUPPORT FROM

VANDERBILT VUNIVERSITY

MEDICAL CENTER

Through the exceptional capabilities and caring spirit of its people, the mission of **Vanderbilt University Medical Center (VUMC)** is to lead in improving the healthcare of individuals and communities regionally, nationally, and internationally. We will combine our transformative learning programs and compelling discoveries to provide distinctive personalized care.

VUMC is one of the largest academic medical centers in the Southeast, and is the primary resource for specialty and primary care in hundreds of adult and pediatric specialties for patients throughout Tennessee and the Mid-South. The School of Medicine's biomedical research program is among the nation's top 10 in National Institutes of Health peer review funding. Vanderbilt University Adult Hospital and the Monroe Carell Jr. Children's Hospital at Vanderbilt are



consistently ranked among the nation's best in multiple specialties by *U.S. News & World Report.* Through the Vanderbilt Health Affiliated Network, VUMC is working with over 60 hospitals and 5,000 clinicians across Tennessee and five neighboring states to share best practices and bring value-driven and cost-effective health care.

VUMC is committed to patientand family-centered care and partnering with patients and families to improve health care. We are honored to provide leadership support and partner with IPFCC for the 9th International Conference on Patient- and Family-Centered Care.

PARTNERSHIP SUPPORT FROM Beaumont

Beaumont Health is Michigan's largest health care system and provides patients with compassionate, extraordinary care, no matter where they live. With eight hospitals, 145 outpatient locations, nearly 5,000 physicians and more than 38,000 employees, Beaumont's commitment to patient and family-centered care contributes to the health and wellbeing of residents throughout the community and beyond.



IPFCC 9th International Virtual Conference Schedule

Interactive Poster Gallery with over 60 posters, available for viewing <u>throughout the Confer</u>ence

*All times listed in EDT.

Tuesday, August 18, 2020

12:00 – 1:00 pm	Welcome and Opening Plenary
1:30 – 2:30 pm	Featured Breakout Sessions
3:00 – 4:00 pm	Featured Breakout Sessions
4:15– 5:00 pm	Virtual Happy Hour

Wednesday, August 19, 2020

12:00 – 1:00 pm	Plenary Session
1:30 – 2:30 pm	Featured Breakout Sessions
3:00 – 4:00 pm	Featured Breakout Sessions

Thursday, August 20, 2020

11:00 – 11:30 am	Networking Discussion Forum
12:00 – 1:00 pm	Featured Breakout Sessions
1:30 – 2:30 pm	Featured Breakout Sessions
3:00 – 4:00 pm	Plenary Session & IPFCC Partnership Award Announcement

Tuesday, August 25, 2020

12:00 – 1:00 pm	Concurrent Breakout Sessions
3:00 – 4:00 pm	Concurrent Breakout Sessions

Thursday, August 27, 2020

11:00 – 11:30 am	Ask an Expert
12:00 – 1:00 pm	Concurrent Breakout Sessions
3:00 – 4:00 pm	Concurrent Breakout Sessions

Tuesday, September 1, 2020

12:00 – 1:00 pm	Concurrent Breakout Sessions	
3:00 – 4:00 pm	Concurrent Breakout Sessions	

Thursday, September 3, 2020

11:00 – 11:30 am	Ask an Expert
12:00 – 1:00 pm	Concurrent Breakout Sessions
3:00 – 4:00 pm	Concurrent Breakout Sessions

Tuesday, September 8, 2020

12:00 – 1:00 pm	Concurrent Breakout Sessions
3:00 – 4:00 pm	Concurrent Breakout Sessions

Thursday, September 10, 2020

11:00 – 11:30 am	Ask an Expert
12:00 – 1:00 pm	Concurrent Breakout Sessions
3:00 – 4:00 pm	Concurrent Breakout Sessions
4:15 – 5:00 pm	Closing Celebration

Doctors take care of patients, we take care of families.

When a child is sick the entire family needs comfort and support; no family should have to deal with their child's medical crisis alone. We believe when families are together they cope better. We believe in supporting families throughout their healthcare journey.

Learn more at RMHC.org



Keeping families close

@2020 RMH0

Exceed patient expectations with simplicity.

Simple, effective text messages for patients and their families.



Status Updates
Wait Times
Education
Directions
Care Coordination
Covid Patient Flow

No portal to join No app to download No extra work for staff

MyCareText



visit www.mycaretext.com for more information

Featured Speakers

WELCOME



Paul Sternberg Jr., M.D.

Dr. Sternberg is the Chief Medical Officer (CMO) and Chief Patient Experience Officer (CXO) at Vanderbilt University Medical Center. As CMO, he serves as executive director for the 2500 physician Vanderbilt

Medical Group. In his CXO role, he oversees key programs related to service, including patient and family engagement and patient satisfaction surveying.

Dr. Sternberg is a graduate of Harvard College and University of Chicago Pritzker School of Medicine. After a residency in ophthalmology at Johns Hopkins, he completed a vitreoretinal fellowship at Duke. In 1985, he joined the faculty at Emory University in Atlanta. Dr. Sternberg came to Vanderbilt in 2003 as G. W. Hale Professor of Ophthalmology and to chair the Vanderbilt Eye Institute. He is a renowned retinal specialist and has been named one of the Best Doctors in America every year since 1994. In 2009, he was named Associate Dean for Clinical Affairs and CMO and was appointed CXO in 2014.

Dr. Sternberg has a long history of leadership, highlighted by serving as President of the American Academy of Ophthalmology and as the President of the Association of University Professors of Ophthalmology. Dr. Sternberg is the past Chairman of the Board of Trustees for the Cheekwood Botanical Garden and Museum of Art in Nashville and serves on the Board of Trustees for Leadership Nashville.

OPENING PLENARY

Patient- and Family-Centered Care: Vision for the Future



Beverley H. Johnson, BSN, FAAN Beverley H. Johnson is President and Chief Executive Officer of the Institute for Patient- and Family-Centered Care in Bethesda, MD. She

has provided technical assistance for advancing the practice of patient- and family-centered care and creating effective partnerships with patients and families to over 300 hospitals, health systems, federal, state, provincial agencies, and community organizations. She assists hospitals and ambulatory programs with leadership development, and the integration of patient- and family-centered concepts in policies, programs, and practices, as well as in the education of health care professionals, and research and evaluation.

Bev serves as a member of the Selection Committee for the American Hospital Association Quest for Quality Prize. She is currently a member of the Board of Directors for the Primary Care Collaborative (PCC) and the Association of American Medical Colleges (AAMC). In 2007, Bev received The Changemaker Award by the Board for the Center for Health Care Design. In 2017, she was recognized by the American College of Physicians with the Edward R. Loveland Memorial Award.

The relevance of patient- and family-centered care to modern medicine can not be overstated.

- 2018 Conference Attendee

Featured Speakers

WEDNESDAY PLENARY SESSION

Patient- and Family-Centered Care: Partnerships for Quality, Safety, and Equity



Victoria W. Bayless, MS, MHSA, FACHE

Victoria W. Bayless is the chief executive officer of Luminis Health, a multihospital system

headquartered in Annapolis, MD. Employing 6,400 staff, Luminis Health operates 635 licensed beds with \$1.1B in revenue and \$63M in community benefit. In partnership with its 1,300 volunteers and donors and 1,800 medical staff members, Luminis Health treats a region of more than 1.5M people across 8 counties. Bayless previously served as the president and chief executive officer of Anne Arundel Medical Center (AAMC) from 2011-2019, and held other executive positions at AAMC since 2005. Prior to joining AAMC, Bayless held various leadership positions with MedStar Health/Washington Hospital Center from 1993-2005. A fellow of the American College of Healthcare Executives, Bayless serves on several community boards including: The Joint Commission Board of Commissioners; the Maryland Hospital Association; and in 2015 she was appointed by Governor Larry Hogan to serve on the state's Health Services Cost Review Commission. Previously, Bayless served on the boards of: the United Way of Central Maryland; the Johns Hopkins Home Care Group; CareFirst/Blue Cross Blue Shield Board; and the American Hospital Association Region 3 Policy Board. Bayless received her bachelor of science from Tufts University and her master of health services administration from The University of Michigan School of Public Health.



Earl Shellner

After a devastating cancer diagnosis in his early thirties, Earl Shellner completed a year of aggressive treatment that included multiple surgeries, chemo, and radiation at Anne

Arundel Medical Center. Throughout his treatments, he asked insightful questions about processes and procedures, helping staff to see areas where they could improve patientand family-centered care. After his treatment was complete, Earl became a Patient and Family Advisor and an essential team member. Over seven years, he has participated in hundreds of projects, from PFCC training for physicians and nurses, to working with hospital leadership, to sharing his story with thousands of new employees during their orientation, to receiving international recognition for his innovation as a PFA. Earl's fellow Advisors nicknamed him "The Mayor" as a tribute to his tireless work, leadership, and charisma. His passion for PFCC is evident to all and AAMC is fortunate to have him as a partner.

THURSDAY PLENARY SESSION

Addressing Trauma, Fostering Equity, Building Community Resilience



Wendy Ellis, DrPH, MPH

Wendy Ellis is the Director of the Center for Community Resilience at the Milken Institute School of Public Health at George Washington University. The Building Community Resilience

(BCR) collaborative and networks are implementing the BCR process — a strategic approach for cross-sector partners (health care, social services, housing, public education, law enforcement and criminal justice and business development) to align resources, programs and initiatives with community based efforts to address adverse childhood experiences and adverse community environments — The Pair of ACEs. The strengths based approach is aimed at building the infrastructure to promote resilience in vulnerable communities by improving access to supports and buffers that help individuals 'bounce back' and communities thrive. In 2019, Dr. Ellis launched the Resilience Catalysts in Public Health using a novel framework that leverages local health departments. Dr. Ellis has spent the last decade developing and working to grow a 'resilience movement' to address systemic inequities that contribute to social and health disparities that are often transmitted in families and communities from generation to generation. In 2018 Dr. Ellis was selected as an Aspen Institute Ascend Fellow.

FEATURED SESSIONS

Primary Care: New Opportunities for Enhancing Safety and Access



Susan Edgman-Levitan, PA

Susan Edgman-Levitan is Executive Director of the John D. Stoeckle Center for Primary Care Innovation at Massachusetts General Hospital. She

is known for her advocacy of understanding the patient's perspective on healthcare. From 1995 to the present, Ms. Edgman-Levitan has been the co-principal investigator on the Harvard Consumer Assessment of Healthcare Providers and Systems (CAHPS). She is co-chair of the National Steering Committee for Patient Safety's Patient Engagement sub-committee. Ms. Edgman-Levitan also serves on several boards and national advisory committees, including the ABIM Foundation board, the AHRQ National Advisory Council, the Lucian Leape Institute, and the Patient-Centered Primary Care Collaborative. She is a senior fellow at IHI and an international expert on patient and familycentered care for ISQua.



Jeffrey Brady, MD, MPH

Jeffrey Brady, MD, MPH, has served as the Director of AHRQ's Center for Quality Improvement and Patient Safety since 2014. He is as

a member of the AHRQ Senior Leadership Team and manages a part of the Agency that conducts several AHRQ programs, including: patient safety research, prevention of healthcare-associated infections, and others focused on improving health care quality for patients. Dr. Brady led the AHRQ Patient Safety Research Program from 2009 to 2014, and in a prior position, he led the team that produces the National Healthcare Quality and Disparities Report, an annual report to Congress on the status of health care quality in the United States. Dr. Brady served as a medical officer for the Food and Drug Administration's Office of Vaccines. Additionally, he has held positions as a medical epidemiologist and primary care physician while serving in the U.S. Navy.

Partnering with Patients to Improve Care and Learning of our Healthcare Workforce



Vineet Arora, MD, MAPP

Vineet Arora, MD, MAPP, is the Herbert T. Abelson Professor of Medicine Assistant Dean Scholarship & Discovery at the Pritzker School of Medicine and

the Associate Chief Medical Officer-Clinical Learning Environment for the University of Chicago Medicine. She is a hospitalist who specializes in improving the learning environment for medical trainees and the quality, safety and experience of care delivered to hospitalized adults. She is an internationally recognized expert on patient handoffs in health care and also has extensive expertise using technology such as social media to improve the workplace learning in teaching hospitals on a variety of topics. Her educational videos on handoffs, supervision, professionalism and costs of care have been used by numerous educators around the country and have been featured on *NPR* and in the *New York Times*.

Combatting Diagnostic Error: How Patients and Families are Leading the Charge Toward Safety



Paul L. Epner, MBA, MEd

Paul L. Epner, MBA, MEd is the Chief Executive Officer and Co-founder of the Society to Improve Diagnosis in Medicine (SIDM). He is Chair of the

Coalition to Improve Diagnosis, a collaborative of nearly 60 professional societies, health systems, patient organizations, and organizations focused on improving quality. He is a member of the National Steering Committee for Patient Safety, a joint initiative of AHRQ and the Institute for Healthcare Improvement (IHI). Paul is a Past President of the Clinical Laboratory Management Association. He was recently a member of the CDC's "Clinical Laboratory Integration into Healthcare Collaborative" and a consultant to their Laboratory Medicine Best Practices program (an evidence-based practice initiative). Paul is an Associate Editor for the peerreviewed journal, DIAGNOSIS. Previously, Paul volunteered for the Crohn's Colitis Foundation where he was a Board member, Midwest President. and founder of three chapters or satellites focused funding research and providing patient self-help.



Suz Schrandt, JD

Suz Schrandt is a patient and patient engagement advocate with a health and disability law background. Among other roles, she serves as the Senior Patient

Engagement Advisor to the Society to Improve Diagnosis in Medicine. Suz previously served as Director of Patient Engagement at the Arthritis Foundation, and as Deputy Director of Patient Engagement for PCORI. Her career spans work in health reform, bioethics, genetic discrimination, and chronic disease self-management, as well as a long history in patient-led health professions education. She is one of nine voting members on the FDA's inaugural Patient Engagement Advisory Committee, the Chairperson for the International Society of Pharmacoeconomics and Outcomes Research North American Patient Roundtable, and has been an invited speaker at numerous US and international conferences. Suz received her law degree from the University of Kansas and has co-authored multiple, peer-reviewed articles on health policy and the value of patient engagement.

A Patient Revolution for Careful and Kind Care for All



Victor Montori, MD

Victor M. Montori, MD is a Professor of Medicine at Mayo Clinic. An endocrinologist and health services researcher, Dr. Montori is the author

of more than 600 peer-reviewed publications and is among the top one percent of researchers with most cited papers in clinical medicine and in social science worldwide in the last decade. He is a recognized expert in evidence-based medicine and shared decision making, and developer of the concept of minimally disruptive medicine. He works in Rochester, Minnesota, at Mayo Clinic's Knowledge and Research (KER) Unit, to advance person-centered care for patients with diabetes and other chronic conditions. He is the author of the book *Why We Revolt – A Patient Revolution for Careful and Kind Care.*

Partnering with Purpose: Embedding Lived Experiences in Standards and Assessments



Heather Thiessen

Heather Thiessen has been a patient in the Canadian health care system for the past 30 years, as she has been dealing with two chronic neurological conditions. Now in her

10th year as a patient partner with the Saskatchewan Health Authority (SHA), Heather has sat on many advisory committees, and has been involved in peoplecentred care (PCC) education. Heather helped develop an orientation for all new patient and family advisors and helped with the orientation for all new employees in the SHA. Heather has partnered with Accreditation Canada (AC) and Health Standards Organization (HSO) as a patient partner, faculty member, patient surveyor, as well as patient engagement lead. Heather is a champion for PCC and works tirelessly to make sure the patient and family voice is not only heard but fully integrated in health care to improve the patient experience.



Hélène Campbell

Hélène Campbell is a patient Engagement Lead with Health Standards Organization who assists in enabling meaningful, purposeful, and effective partnerships with

patients. In partnership with patients and caregivers, she helps facilitate/lead the co-design of Accreditation Canada's products. Her passion for partnership helps her build relationships with people across Canada and around the world.



Sylvie Lachapelle, MSS, CHE

Sylvie Lachapelle is an experienced leader in health care planning, external resource management, and program management. In her current role as Director of the

Surveyor Secretariat with Accreditation Canada and Health Standards Organization (HSO), Sylvie is responsible for the leadership, strategic orientation, and ongoing business evolution of the Surveyor Secretariat program. In this capacity, she is accountable for the management of 700 senior health care professionals who act as external peer reviewers in the assessment of health care organizations using national standards of excellence. Prior to this, Sylvie worked as a health care planner with the French Language Health Services Network and with the Council on Aging of Ottawa, coordinating various community projects. Sylvie holds a Master of Social Services from University of Ottawa (Specialization in health), a Bachelor of Arts, and is a Certified Health Executive.

Learning from Lived Experience: Building Supportive Systems of Care



Chase Holleman, LCSW, LCAS

Chase Holleman is a social worker specializing in the needs of persons affected by substance use. Chase's areas of focus are recovery-oriented systems

of care and harm reduction. He brings both personal experience, as a person in long-term recovery from drug use, and professional experience as an advocate and as a provider of direct services. Chase is now the program director for the Guilford County Solution to The Opioid Problem, a program designed to serve some of our community's most vulnerable populations; people who have overdosed and others who are at high risk for opioid-related mortality. Chase also serves as an adjunct professor for The University of North Carolina at Greensboro, Department of Social Work.



Sonya Ballentine, BS

Sonya Ballentine graduated from Georgia State University with a BS in Finance and worked for several years in the business sector before being hospitalized and

diagnosed with bi-polar disorder in 2007. Ms. Ballentine leads a team of patients and providers in designing an interactive community-based participatory research (CBPR) training manual and implementing two CBPR projects in Chicago. Her CBPR experience began in 2012 with designing a peer navigator training manual to improve integrated care for homeless African-Americans with serious mental illness in Chicago. As her mental health has stabilized, she is proud to once again be a healthy and productive member of society.



Katie Donovan

After experiencing the addiction journey with her daughter Brittany, Katie Donovan left her corporate career in order to focus on family recovery. Katie is a sought-out

expert for consulting, speaking, training, and coaching. Katie sits on several boards, has been invited to congressional hearings, and has testified in front of the FDA. Katie has been awarded the PAARI Leadership award for her advocacy work, received the Cousino High School Distinguished Alumnus award, and a Global Humanitarian Award. Katie is a certified family recovery coach, interventionist, and an executive life coach. She has been interviewed on ABC, NBC, Fox Sports, and featured in Time and Money Magazine. Visit Katie's blog, www.amothersaddictionjourney.com.

Recognizing Extraordinary Nurses: Why Meaningful Recognition Matters to Patients and Their Families



Cindy Lefton, PhD, RN, CPXP

Dr. Cindy Lefton has combined her knowledge as an Organizational Psychologist with her extensive experience as a Registered Nurse to

develop strategies aimed at helping hospitals across the country positively impact their communication and collaboration. As a Consultant for Psychological Associates, Volunteer Researcher for The DAISY Foundation, and Nurse Rounder for Waiting Areas, Emergency Department at Barnes-Jewish Hospital, Dr. Lefton utilizes a variety of evidence and resources to guide health care professionals in creating and sustaining healthy work environments. Dr. Lefton has published articles on these topics and presented at national conferences.



Amy Kratchman, BA

Amy Kratchman has been working with clinicians and researchers since 2008 as a family representative. She is the mother of three children with special

healthcare needs. She is the Family Discipline Coordinator for NJLEND and the Director of Family-Professional Collaboration for the LEND program at the Children's Hospital of Philadelphia. Amy served as a family consultant for the Children's Hospital of Philadelphia where she served on the Family Advisory Council and worked with senior administration and physician leadership at the strategic planning level to enhance family-centered care. She recently transitioned to a newly created role at CHOP, Senior Research Family Consultant, where she works with primary investigators to recruit and train patients and families to participate on research teams and advisory groups. Amy leads Research Family Partners an innovative program developed and implemented at CHOP to maximize the meaningful engagement of families in all stages of the research process. She is the co-creator of a nationally recognized interactive training program called FYREworks, to help stakeholders meaningfully engage in research. She also serves in various capacities on national boards and advisory councils to advance family engagement in pediatric health outcomes research.

The Fine Line Between Health Information Access and Privacy: What Do Patients Need to Know?



Erin A. Mackay, MPH

Erin A. Mackay is the Associate Director of Health Policy and Programs at the National Partnership for Women & Families, where she manages a diverse portfolio of health

policy issues related to health system transformation and patient/family engagement. Erin is a respected consumer advocate with subject matter expertise in health information technology policy and consumer health data access. She represents the consumer voice in federal and private sector efforts, including participation in expert panels and working groups on health data and privacy, patient-centered care, and quality measurement. Prior to joining the National Partnership, Erin worked for the Healthcare Leadership Council (HLC) and monitored implementation of delivery system and payment reform initiatives. Erin has undergraduate degrees in English literature and women and gender studies from the University of Virginia. She received a master's degree in public health with a concentration in community health from George Mason University.



Deborah Wachenheim, MPP

As the assistant director of the OpenNotes dissemination team, Deborah Wachenheim helps to spread the implementation of OpenNotes across the country. Deborah has

a background in consumer engagement in health care. Prior to joining OpenNotes, she worked at Health Care For All Massachusetts, a consumer health advocacy organization, engaging consumers in speaking up about the need to improve the quality of health care. She oversaw the successful consumer campaign to mandate that all Massachusetts hospitals establish Patient and Family Advisory Councils (PFACs) and she developed a statewide network to provide technical assistance and resources to the PFACs. Deborah previously worked at Jewish Vocational Service of Greater Boston, where she developed and ran a food stamp outreach and education program. Before that, she coordinated a campus social justice program through the Jewish Community Relations Council of Greater Boston. Deb also worked at RESOLVE, the national infertility organization, as Director of Government Relations.



Stephen F. O'Neill, LICSW, BCD, JD

Steve O'Neill had been the Associate Director of Ethics programs at Beth Israel Deaconess Medical Center and Social Work Manager for Psychiatry,

Primary Care, Opioid Services, and Infectious Disease. He completed a Fellowship in Bioethics in the Division of Medical Ethics at Harvard Medical School. Steve remains active in teaching in clinical and organizational ethics in the Center for Bioethics at Harvard Medical School as well as an Adjunct Assistant Professor at Simmons University School of Social Work. Steve also continues to work in the OpenNotes Program, where in 2014, he led the efforts to open up, for the first time ever, psychotherapy notes/records directly to patients via secure portals. Steve has continued to work to open up behavioral health notes across the USA and Canada, as well as more globally, as part of an effort to improve patient engagement and partnerships. He is an active lecturer and the author of a number of articles, chapters and a book. Mason University.



Rosie Bartel, MA

Rosie Bartel, MA is a wife, mother, grandmother and an educator. In August of 2009 she underwent a total right knee replacement that developed

into a MRSA staph infection. This infection led to the amputation of her right leg, hip and part of her pelvic bone. She wants a world without serious infections. She believes that this cannot be accomplished without patients sharing personal experiences that can drive patient and family outcomes in the future.

Partnering Together to Meet the Challenges of Pain Management



Tom Bauer, MBA, RT(R)

Thomas K. Bauer is the Senior Director of Patient and Family Education at Johns Hopkins Medicine. Mr. Bauer is a leading authority, speaker and advocate

for patient engagement, health literacy, and patient education programs to improve cost, quality, and satisfaction, with his research being presented in over 30 publications or presentations. His work has been recognized by the National Academy of Science for the successful deployment of health literacy tactics addressing the 10 attributes of a health literate organization, and has been featured in two case studies being published by the Agency for Healthcare Research and Quality (AHRQ).



Paul Allen, MA

Paul Allen received his masters in Psychology and worked in private practice for over 20 years. He also taught psychology courses at a state

university and has published research articles. After a career in psychotherapy, he was trained and licensed in medical massage therapy and worked for 15 years in private practice. Paul's patient experience is linked to his recently discovered genetic disorder called Stickler Syndrome; a genetic variant that affects collagen and connective tissue. This syndrome caused him to experience progressive osteoarthritis in his teens as well as lose his vision as a child due to retinal detachment. He has experienced severe pain throughout his entire adult life and has been using pain medication, off and on, for over 45 years. In January 2019 he had a spinal fusion of five lumbar vertebrae, and has been pain free since his post-op recovery. He participated in Johns Hopkins Peri-Operative Pain program where he was weaned from opioids prior to his fusion surgery. He has not used narcotic pain medications since and was able to climb Machu Picchu in Peru one year later. He has been involved with the JHM Opioid Clinical Community to lend a patient perspective to the literature and approach.

Boots on the Ground: How Patient and Family Advisors Are Turning Stories of Harm into Positive Change



Susie Becken

Susie Becken is a Patient Member with Kaiser Permanente's Southern California Diagnostic Excellence Program and a Patient Partner for the Society to

Improve Diagnosis in Medicine. She serves on the Kaiser Permanente Southern California Regional Patient Advisory Council. Early on, Susie's Human Resources career in hospitality focused on her ability to meet and exceed customers' expectations. When Susie's son experienced a diagnostic error, she realized she could translate this ability to patient advocacy in the medical field. Improving the patient experience, by empowering the patient and family to openly communicate with medical providers, is Susie's passion. She believes it can lead to improved patient care, from diagnosis to recovery.



Desiree Collins-Bradley

Desiree Collins-Bradley is a Patient Network Lead for ATW Health Solutions. Her passion is patient and family engagement in healthcare and ensuring

that patients' voices are always represented at all levels of shared decision making. She is a mother of three wonderful children. Her daughter Deonc was born with a genetic disorder, Jarcho Levin Syndrome, which is extremely rare and often carries a very high mortality rate and grim prognosis. Deonc's medical journey has inspired Desiree to become an advocate not only for her daughter, but in the medical community as a whole. She serves as Co-Chair of the Newborn Center Family Advisory Committee at Texas Children's Hospital, as a Family Advisor for the Vermont Oxford Network, and as Project Coordinator for Project DOCC Houston. Desiree runs an active Facebook group, Patient Partner Innovation Community, encouraging patients to partner with their healthcare providers to drive innovative changes. She lives in Houston, TX.

Expressing Gratitude To Nurses For Over 20 Years



Conference Scholarships 🏶 Reduced ANCC Certification Fees & Tuition 🏶 DAISY Medical Mission Grants 🏶 DAISY Award for Patient Safety

Go to DAISYFoundation.org for more information

national awareness campaign Pharmacists for Healthier Lives

PHARMACISTS ARE:

Accessible Always there for their patients

Knowledgeable The medication experts on the healthcare team

Highly Educated

Critical Helping to ensure optimal outcomes

Learn more at PHARMACISTSFORHEALTHIERLIVES.ORG

Conference Topics

The following topics will be featured in Conference presentations in over 60 posters and 48 breakout sessions. To help you select sessions to attend and posters to view, each session and poster will be labeled with its relevant icon.



Essential Allies—Patient and Family Advisors and Partners

Effective strategies and tools to increase the capacity and diversity of patients and families to serve as advisor and partners in improving and transforming health care.



Better Together—Patients and Families as Partners in Inpatient Care

Strategies used in hospital and postacute settings to welcome and include patients and families as partners in care, care planning, and decision-making.



Partnerships in Primary and Other Ambulatory Care

Programs and initiatives in which patients and families are actively involved in changing the outcomes and experience of care.



Partnerships in Research and Evaluation

Projects focused on research and evaluation planned and conducted with patients and families.



Role of Leadership

Leadership practices resulting in widespread adoption of PFCC and measurable change and improvement.



Education for Interprofessional and Collaborative Practice

Educational programs planned and delivered in partnership with patients and families.



Health Equity Through Partnerships

Initiatives grounded in collaboration with underserved and underrepresented communities to eliminate disparities in health and health care.



Safety

Efforts that prepare and support patients and families to be key allies for enhancing safety and reducing harm.



Emerging Innovations

Programs and initiatives that address urgent issues in health care in partnership with patients and families.

"This is a powerful community and the conference showcases the wealth of knowledge and meeting your peers in this work can be a huge inspiration when times get tough."

– 2018 Conference Attendee



The Peterson Center on Healthcare is dedicated to transforming U.S. healthcare into a high-performance system by finding innovative solutions that improve quality and lower costs, and accelerating their adoption on a national scale.

To learn more, visit petersonhealthcare.org.



AUGUST 18, 2020

*All times listed in EDT.

DAY AT-A-GLANCE

12:00 – 1:00 pm	Welcome and Opening Plenary
1:30 – 2:30 pm	Featured Breakout Sessions
3:00 – 4:00 pm	Featured Breakout Sessions
4:15– 5:00 pm	Virtual Happy Hour

12:00 – 1:00 PM OPENING PLENARY SESSION

Welcome

Paul Sternberg Jr., MD Chief Medical Officer; Vanderbilt University Medical Center; GW Hale Professor and Chairman; Vanderbilt Eye Institute, Nashville, TN



Paul Sternberg

Patient- and Family-Centered Care: Vision for the Future

Beverley H. Johnson, BSN, FAAN, President and CEO; Institute for Patient- and Family-Centered Care, Bethesda, MD



Bev Johnson



1:30 – 2:30 PM FEATURED BREAKOUT SESSIONS



Susan Edgman-Levitan, PA-C, Executive Director, MGH Stoeckle Center for Primary Care, Co-Chair NSC Patient Engagement Committee; Massachusetts General Hospital, Boston, MA; P. Jeffrey Brady, MD, MPH, Director, Center for Quality Improvement and Patient Safety; Agency for Healthcare Research and Quality, Rockville, MD

This session will provide an overview of the National Steering Committee on Patient Safety's overarching recommendations with a specific emphasis on the recommendations and interventions for engaging patients and families in reducing harm (recommendations to be released in mid-September).



Susan Jeffrey Brady Edgman-Levitan

Partnering Across Borders: Metter Together in the U.S. and Canada

Deborah Dokken, MPA, Coordinator, Patient and Family Partnerships; Institute for Patient- and Family-Centered Care, Bethesda, MD; Agnes Barden, DNP, RN, CPXP, Vice President, Office of Patient & Customer Experience; Northwell Health, New Hyde Park, NY; Jessie Checkley, Senior Improvement Lead; Julie Drury, Strategic Lead, Patient Partnership; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario

Launched in 2014, Better Together: Partnering with Families, is a campaign to recognize and support the role of families as partners in care for hospitalized patients. Hear how the initiative spread across Canada through a partnership between the Canadian Foundation for Healthcare Improvement and IPFCC and how it was implemented in one large health system in New York State. Responses to COVID-19 will be discussed.

AUGUST 18, 2020 continued

3:00 - 4:00 PM FEATURED BREAKOUT SESSIONS

Partnering with Patients to Improve Care and Learning of Our Healthcare Workforce

Vineet Arora, MD, MAPP, Herbert T. Abelson Professor of Medicine, Assistant Dean Scholarship and Discovery; Pritzker School of Medicine; Associate Chief; Medical Officer Clinical Learning Environment, University of Chicago Medicine, Chicago IL

As Associate Chief Medical Officer-Clinical Learning Environment, Dr. Arora is a bridging leader who integrates frontline clinical staff into the quality, safety and value missions of UChicago Medicine. She will review several initiatives that integrate patients into clinical learning environments.



Vineet Arora

Combatting Diagnostic Error: How Patients and Families are Leading the Charge Toward Safety

Paul L. Epner, MBA, MEd, Chief Executive Officer and Co-Founder, Suz Schrandt, JD, Senior Patient Engagement Advisor; Society to Improve Diagnosis in Medicine, Evanston, IL

Diagnostic errors are the most common and costly of all medical errors and cause between 40,000 and 80,000 hospital deaths each year. This session will provide an overview of diagnostic quality and safety, including the main contributors to diagnostic error and the complexity and difficulty of trying to improve diagnosis.



Paul L. Epner





AUGUST 19, 2020

DAY AT-A-GLANCE

12:00 – 1:00 pm	Plenary Session
1:30 – 2:30 pm	Featured Breakout Sessions
3:00 – 4:00 pm	Featured Breakout Sessions

12:00 - 1:00 PM **PLENARY SESSION**

Patient- and Family-Centered Care: Partnerships for Quality, Safety, and Equity

Victoria Bayless, MS, MHSA, FACHE, Chief Executive Officer; Luminis Health, Inc.; Earl Shellner, Member, Patient and Family Advisory Council; Anne Arundel Medical Center, Inc., Annapolis, MD



Victoria Bayless Earl Shellner

1:30 - 2:30 PM FEATURED BREAKOUT SESSIONS

A Patient Revolution for Careful and Kind Care for All

Victor Montori. MD. Professor of Medicine: Mayo Clinic, Rochester, MN

In this conversation, Dr. Montori will discuss the state of the healthcare industry and make the case for change toward careful and kind care for all.



Victor Montori

AUGUST 19, 2020 continued

Partnering with Purpose: Embedding Lived Experiences in Standards and Assessments

Helene Campbell, Patient Engagement Lead; Health Standards Organization – Accreditation Canada, Ottawa, Ontario; Heather Thiessen, Patient Surveyor; Accreditation Canada; Patient Advisor; Saskatchewan Health Authority, Saskatoon, Saskatchewan; Sylvie Lachapelle, Director, Surveyor Secretariat; Health Standards Organization - Accreditation Canada, Ottawa, Ontario

People-Centred Care requires a culture change at the system, organization, and direct care levels in order to be truly effective. By developing global health and social service standards with patients and family members and including patients as surveyors on assessment teams, HSO and AC are partnering with purpose to inspire positive change to save and improve lives.



Helene Campbell Heather Thiessen Sylvie Lachapelle

"Participation in this 🕖 conference allowed for exposure to innovative techniques to further enhance PFCC and improve patient safety, experience, and outcomes within my own organization."

🧳 – 2018 Conference Attendee

3:00 – 4:00 PM FEATURED BREAKOUT SESSIONS

Learning from Lived Experience: **Building Supportive Systems of Care**

Chase Holleman, LCSW, LCAS, Program Director; Guilford County Solution to The Opioid Problem (GCSTOP), UNC Greensboro, Greensboro, NC; Sonya Ballentine, BS, Project Manager; Chicago Health Disparities Center, Illinois Institute of Technology, Chicago, IL; Katie Donovan, NCIP, NCFRC, Life and Relationship Coach; Macomb, MI; Moderated by Mary Minniti, BS, CPHQ, Senior Policy and Program Specialist; IPFCC, Eugene, OR

Individuals and families with lived experience are essential partners in developing respectful and collaborative strategies to address the Opioid epidemic. Each of these panelists bring this experience and expertise to their work. They will be discussing their work in building supportive systems of care and research.



Chase Holleman Sonya Ballentine Katie Donovan

Recognizing Extraordinary Nurses: Why Meaningful Recognition Matters to Patients and Their Families

Cindy Lefton, PhD, RN, CPXP, Vice President, Organizational Consulting; Psychological Associates, St. Louis, MO; Amy Kratchman, BA, Senior Research Family Consultant; Children's Hospital of Philadelphia, Philadelphia, PA

While the attributes associated with a positive patient experience are documented, literature about why recognizing nurses matters to patients/families is scant. This session presents findings from a study that explored patient/family member perceptions regarding the impact of their gratitude.



Cindy Lefton

Amy Kratchman

AUGUST 20, 2020

DAY AT-A-GLANCE

11:00 – 11:30 am	Networking Discussion Forum
12:00 – 1:00 pm	Featured Breakout Sessions
1:30 – 2:30 pm	Featured Breakout Sessions
3:00 – 4:00 pm	Plenary Session & IPFCC
	Partnership Award Announcement

11:00 - 11:30 AM **Networking Discussion Forum**

Grab a coffee or tea and join a networking discussion on our online chat forum. Chat and network with your peers:

- Patient and Family Advisors/Partners
- Canadians
- Researchers

12:00 - 1:00 PM FEATURED BREAKOUT SESSIONS

The Fine Line Between Health Information Access and Privacy: What Do Patients Need to Know?

Erin Mackay, MPH, Associate Director, Health Policy; National Partnership for Women & Families, Washington, DC; Deborah Wachenheim, MPP, Assistant Director, Dissemination; Stephen O'Neill, LICSW, BCD, JD, Social Work Manager for Behavioral Health; OpenNotes Program, Beth Israel Deaconess Medical Center, Boston, MA; Rosie Bartel, MA, Patient Advisor, Bellin Health, Green Bay, WI

New digital tools are promising easy access to medical records. But who controls the information shared? Is privacy at risk? In this session we'll help you understand what's at stake and strategize how PFACs can help navigate important tech decisions.





Deborah





Erin Mackay

Wachenheim

Stephen O'Neill

Insights from the Field: Reported Influences and Impacts of Partnership in Patient-Centered Outcomes Research

Maureen Maurer, MPH, Principal Researcher; Rikki Mangrum, MLS, Senior Researcher; American Institutes for Research, Chapel Hill, NC; "Dolly" Jane Stokes, CMT, CPT, Patient Stakeholder, UAB/ Lakeshore Collaborative; PCORI Grant TEAMS Study; Fairhope, AL; Tracy Flemming Tracy, OT, MSCS, Clinical Research Coordinator; Tanner Foundation, Birmingham, AL

This panel session will present findings from a qualitative study exploring the influence and impact of patient and stakeholder partnership in PCORI's funded research. A researcher and patient partner from a current project will share experiences and lessons learned.

1:30 - 2:30 PM FEATURED BREAKOUT SESSIONS

Partnering Together to Meet the Challenge of Pain Management

Thomas Bauer, MBA, RT(R), Senior Director of Patient Education and Engagement; Paul Allen, MA, Patient Partner; Johns Hopkins Health System, Baltimore, MD

This presentation will highlight how patients who have experienced acute and chronic pain helped create the Johns Hopkins Health System's patient education and engagement strategies for pain management in addressing the Opioid Crisis.



Thomas Bauer Paul Allen

AUGUST 20, 2020 continued

Equitable Patient and Family Engagement: Building a Framework with Diversity and Inclusion

Christine Kouri, BSCN, MHA, Manager, Patient Experience; Christine Dalgleish, Family Advisor; Children's Hospital of Eastern Ontario, Ottawa, Ontario

This session will highlight how to ensure an inclusive patient/family engagement framework that is customized to your own organization's diverse end users. Such an approach ensures your engagement values and strategies support inclusivity of the voices which are shaping your organization.

3:00 - 4:00 PM PLENARY SESSION

Addressing Trauma, Fostering Equity, Building Community Resilience

Wendy Ellis, DrPH, MPH, Director; Center for Community Resilience, Milken Institute School of Public Health at George Washington University, Washington, DC



Wendy Ellis

"Wonderful conference. I leave with a sense of enthusiasm and some lasting connections. Thank you!"

– 2018 Conference Attendee

AUGUST 25, 2020

DAY AT-A-GLANCE

12:00 – 1:00 pm	Concurrent Breakout Sessions
3:00 – 4:00 pm	Concurrent Breakout Sessions

12:00 – 1:00 PM

Boots on the Ground: How Patient and Family Advisors Are Turning Stories of Harm into Positive Change

Susie Becken, Patient Member, Kaiser Permanente Southern California Diagnostic Excellence Program – USA and Patient Partner; Society to Improve Diagnosis in Medicine, Los Angeles, CA; Desiree Collins-Bradley, Patient Network Lead; ATW Health Solutions, Chicago, IL; Moderated by Suz Schrandt, JD, Senior Patient Engagement Advisor; Society to Improve Diagnosis in Medicine, Evanston, IL

Presented by two Patient and Family Advisory Council leaders and mothers of children who experienced significant diagnostic error and harm, this session will provide guidance and tangible examples for those working to improve diagnostic safety in their home institutions and health systems.







Susie Becken Desiree

Desiree Suz Schrandt Collins-Bradley

Shifting Organizational Culture – Embracing a Joint Advisory Council to Improve Patient and Provider Communication and Respect

Marla Dorsey, MS, Quality Improvement Advisor; Children's Hospital of Orange County, Orange, CA; Aran Zouela, MPH, Research Consultant; The Lewin Group, Falls Church, VA; Leigh Ann Kingsbury, Gerontologist, MPA, Managing Consultant; The Lewin Group, New Bern, NC

Presenters will share how the bold aims of the Transforming Clinical Practice Initiative inspired the Children's Hospital of Orange County to create a combined Joint Advisory Council of patients, family members, and physicians to improve measurable health outcomes.

AUGUST 25, 2020 continued

Partnering with Patients and Families in the Big Data Era: Building Trust, Transparency and Education in Creating a Research Database

Amy Kratchman, BA, Senior Research Family Consultant; Heather Cathrall, BA, MBE, Assistant Director, Clinical Trial Support Office; Children's Hospital of Philadelphia, Philadelphia, PA

The Children's Hospital of Philadelphia (CHOP) Research Institute has partnered with families as they build a large database (Arcus) connecting clinical, research, and specimens records in order to improve research outcomes. Families guide transparency, educational programs, and privacy/ security expectations.



3:00 - 4:00 PM



Kara Adams, Director; Family Voices of Tennessee; Sara Hanai, MSPT, Senior Patient Experience Consultant; Vanderbilt University Medical Center, Nashville, TN

We will share a model of partnership and collaboration among a healthcare setting and community agency to implement and maintain a quality, thriving parent-toparent support model for children who have a special health care need, chronic illness, disability, or mental health concern.

A Co-Created Strategy to Improve Patient and Family Experience During a Hospital Discharge Delay in Ontario, Canada

Kerry Kuluski, MSW, PhD, Research Chair in Patient and Family Centered Care; Institute for Better Health, Trillium Health Partners, Mississauga, Ontario; Ida McLaughlin, HBA, Caregiver Partner; Etobicoke, Ontario; Gordon MacGregor, Caregiver Partner; Lisa Bennett, Caregiver Partner; Toronto, Ontario; Lucy Bilotta, Clinical Coding Specialist; Unity Health (St. Michael's Hospital), Toronto, Ontario

Our team of patients, caregivers and researchers have co-designed a strategy to improve experiences during a hospital discharge delay (HDD). HDD is a confusing and stressful time for patients, families and providers and costly for health care systems.

Growing Up with Chronic Illness: Patient and Family Priorities for Research and Health System Transformation

Emily von Scheven, MD, MAS, Professor of Pediatrics; Linda Franck, RN, PhD, Professor, Department of Family Health Care Nursing; Rosa Kelekian, Patient Partner; Bhupinder Nahal, Project Manager; Christina Frenzel, Patient Partner; Victoria Vanderpoel, Patient Partner; University of California, San Francisco, San Francisco, CA

We are conducting research to identify patient and family priorities for research to inform the design of health delivery systems that address the unique needs of children growing up with diverse chronic diseases.

AUGUST 27, 2020

DAY AT-A-GLANCE

11:00 – 11:30 amAsk an Expert12:00 – 1:00 pmConcurrent Breakout Sessions3:00 – 4:00 pmConcurrent Breakout Sessions

11:00 – 11:30 AM

Ask an Expert: Promising Partnership Practices During COVID-19

Caroline DeLongchamps, Manager, Patient-and Family–Centered Care Quality and Safety; MUSC Health, Charleston, SC

Caroline DeLongchamps coordinates the patient and family advisor program for MUSC Health. She has implemented a number of strategies to keep patient and family advisors connected and engaged in providing input during the pandemic. Bring your curiosity and questions for Caroline!



Caroline DeLongchamps

12:00 – 1:00 PM

PFACs at the System and Organization Level Lisa Morrise, Executive Director; Consumers Advancing Patient Safety, Salt Lake City, UT

PFACs have long informed in hospitals and, more recently, in ambulatory care settings. New models are now in use to drive system level improvement work and research. Non-profit and QIN-QIO (Quality Innovation Network-Quality Improvement Organizations) models will be highlighted in the presentation.



Better Together: Implementing a Patient-Oriented Transition from Hospital to Home

Agnes Black, RN, MPH, Director, Research and Knowledge Translation; Christine Wallsworth, Patient and Family Partner; Providence Health Care, Vancouver, British Columbia

Patients and families need support to successfully transition home from hospital. Surveys show that many patients don't feel comfortable with current discharge support. The patient-oriented discharge bundle, co-designed by patients and families, offers support and can reduce unnecessary hospital readmissions.

UAB Parent Engagement Consultation Service: Caregiver Leaders as Patient Engagement Peer Coaches in a Pediatric Hospital

Wayne H. Liang, MD, MS, Assistant Professor, Pediatrics and Informatics Institute; Sophia McFarland, Parent Consultant; Viette Smith, Parent Consultant; University of Alabama at Birmingham, Birmingham, AL

Patients and caregivers have rich expertise in illness self-management, but their expertise is not wellutilized in healthcare settings. The UAB Parent Engagement Consultation Service is an innovative program that integrates patient leaders as patient engagement consultants in a pediatric hospital.

3:00 - 4:00 PM

El Concilio (Spanish Patient and Family Advisory Council): Advancing Partnerships to Enhance the Patient Experience

Lucia Lemus Mejia, MSW, LCSW, Clinical Social Worker and Co-Chair of El Concilio; Mariela Gallo, MPH, CHES, Senior Health Education Specialist and Co-Chair of El Concilio; Blanca Gonzalez, Family Advisor, El Concilio Co-Chair; City of Hope, Duarte, CA

City of Hope's El Concilio has helped drive a greater understanding of the unique needs of Spanishspeaking patients and families. Our integrated model has advanced collaborative efforts across the institution to powerfully influence strategic planning for patient experience initiatives.

AUGUST 27, 2020 continued

Opening Up Mental Health Notes: Patient and Therapist Perspectives on What We Are Learning After 6+ Years

Stephen O'Neill, LICSW, BCD, JD, Social Work Manager for Behavioral Health; Stacey Whiteman, Patient Advisor; OpenNotes Program, Beth Israel Deaconess Medical Center, Boston, MA

In 2014, outpatient therapy notes were opened up directly to patients. This presentation by a participating patient and the social work manager for the project will review the experiences and will advocate for greater transparency for improved care.

COVID-19 Hospital Restrictions: Trends and Impacts on Patient- and Family-Centered Care

Linda Franck, RN, PhD, FAAN, Jack and Elaine Koehn Endowed Chair in Pediatric Nursing and Director, Postnatal Research; Rebecca Kriz, RN, MS, Postnatal Research Manager; California Preterm Birth Initiative; University of California, San Francisco; Beverley H. Johnson, BSN, FAAN, President and CEO; Institute for Patient- and Family-Centered Care, Bethesda, MD

We will present the results of a survey conducted during the first wave of the COVID-19 pandemic in North America and other countries. The survey tracks changes to hospital and clinical unit policies and practices regarding family presence and support and the engagement of patient and family advisors to plan and implement the changes.

SEPTEMBER 1, 2020

DAY AT-A-GLANCE

12:00 – 1:00 pm	Concurrent Breakout Sessions
3:00 – 4:00 pm	Concurrent Breakout Sessions

12:00 – 1:00 PM

The Role of the Patient and Family Advisory Council in Behavioral Healthcare

Rhonda Ashley-Dixon, MA, Vice President, Strategic Partnerships & Engagement; Vanderbilt Behavioral Health; Avni Cirpili, DNP, RN, NEA-BC, Chief Nursing Officer; Vanderbilt Psychiatric Hospital/Vanderbilt Behavioral Health; Kathy Woodard, BS, PFAC Past Chair/ Current Member, Patient and Family Advisory Council; Vanderbilt Behavioral Health, Nashville, TN

We will discuss the impact of establishing a Patient and Family Advisory Council to promote collaboration and excellent patient and family-centered care practices in a behavioral healthcare setting.

Organizational Partnerships Supporting Rural Hospital Patient Family Engagement

Libby Hoy, BS, Founder and CEO; PFCCpartners, Long Beach, CA; Katie Frazier, BS, PFE Regional Leader; Comagine Health, Portland, OR; Lindsey Galli, BS, Director of Education; PFCCpartners, Long Beach, CA

PFCCpartners and Comagine Health partnered to support rural hospitals in developing partnerships with patients and families. Hospitals participated in a 1.5-day Boot Camp, to create a strategy to engage their community through action planning, which was implemented at the hospital.

Senior Strength: Collaboration with Peer Support Specialist Can Improve More than Mental Health

Douglas Hulst, BA, Peer Specialist Workforce Development Program Manager; Depression and Bipolar Support Alliance, Chicago, IL

Integrating community-based peer support services with primary care can improve overall health of seniors. Preliminary results of two demonstration projects will be shared describing the collaborative integration among community-based organization, PCP, behavioral health, certified peer support specialist and senior patients.

SEPTEMBER 1, 2020 continued

3:00 - 4:00 PM

Addressing Food Insecurity Among Cancer Patients: What a Patient Family Advisory Council Was Called To Do

Ann W. Jackson, DPT, PT, MPH, Member, University of Chicago Comprehensive Cancer Center Patient Family Advisory Council; Bobby Lester, Operations Director for Cancer Services; UChicago Medicine, Chicago, IL

Cancer-treatment centers historically have addressed issues of appetite loss and malnutrition when addressing a cancer patient's nutritional needs. New light is being shown on the growing issue of food insecurity among cancer patients. Our PFAC addressed the problem ourselves.

Bridge-to-Home – Partnering with Patients and Caregivers to Improve Quality and Patient Experience Through Care Transitions: Results and Lessons Learned

Haley Warren, MHSc, Improvement Lead; Isabel Jordan, Patient Partner; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario

Bridge-to-Home focused on implementing a patient-oriented care transitions bundle with patient partners engaged at all levels of the collaborative. Improvements were noted in the patient and caregiver experience of care transitions, and team capacity to engage effectively with patients.

Partnering with Parents to Provide Trauma-Informed Care Conference Simulation Education for Interprofessional Teams

Jill Karnes, MS, MSW, LISW-S, Clinical Social Work Supervisor; Amanda Kennedy, LISW-S, MSW, MA, Clinical Social Work Program Coordinator; Christina O'Keeffe, Member, Family Advisory Council; Nationwide Children's Hospital, Columbus, OH

This presentation highlights a simulation approach that trains interprofessional teams to facilitate trauma-informed family care conferences. Family advisory council members collaborated in the creation and teaching of this tool as parent actors, providing opportunities to enhance communication and identify needs.

SEPTEMBER 3, 2020

DAY AT-A-GLANCE

11:00 - 11:30 amAsk an Expert12:00 - 1:00 pmConcurrent Breakout Sessions3:00 - 4:00 pmConcurrent Breakout Sessions

11:00 – 11:30 AM



Ask an Expert: Family Presence During COVID-19

Kathy Quinlan, Healthcare Manager of Quality and Clinical Projects; Hôtel-Dieu Grace Healthcare Windsor, ON Canada

Hôtel-Dieu Grace Healthcare has created an Incident Management Team to address COVID-19 issues. They have involved PFAs on the team and continue to rely on the PFAC to provide guidance on policies related to Family Presence. Join Kathy Quinlan to discuss HDGH's work and learn how family presence is being addressed. Bring your curiosity and questions!



Kathy Quinlan

12:00 – 1:00 PM

Family Faculty Programs: The Future of Engaging Medical Teams in Family-Centered Care

Brittany Guzinski, Chair, Family Advisory Council; Jill Gautier, Family Advisor, Family Faculty Leader, Family Advisory Council; Courtney Nataraj, Family Advisor, Past Chair, Family Advisory Council; Gerald Loughlin, MD, Pediatrician-in-Chief; Komansky Children's Hospital at NewYork Presbyterian-Weill Cornell, Jennifer DiPace, MD, Residency Program Director; Weill-Cornell Medicine, New York, NY

This presentation covers the components of a successful Family Faculty Program including: support from physician educators and hospital leadership; using family advisors to co-educate medical teams on the tenets of family-centered care; and future initiatives in this area.

SEPTEMBER 3, 2020 continued

Implementation of the Patient Safety Specialist & LEAP® Training at Beaumont Hospital Dearborn

George Jenkins III, BSN, RN, Assistant Nurse Manager; Thomas Moylan, Patient and Family Advisor; Beaumont Health, Dearborn, MI

A gap in fall prevention knowledge and communication with behavioral health patients was identified on the Neuro-Medical Unit. In collaboration with patient and family advisors, LEAP techniques were employed through a pilot position resulting in a 75% reduction in the fall rate.

Engagement Resources: Research Fundamentals & Building Effective Multi-Stakeholder Research Teams

Lee Thompson, MS, Senior Researcher; American Institutes for Research; Michelle Johnston-Fleece, MPH, Senior Program Officer; PCORI, Washington, DC; Rebekah Angove, PhD, Vice President for Patient Experience and Program Evaluation; Patient Advocate Foundation, Hampton, VA; Brendaly Rodríguez, MA, CPH, Senior Manager, Community and Stakeholder Engagement; University of Miami CTSI, Miami, FL; Jennifer O'Rourke-Lavoie, Patient Partner Co-Investigator; University of Vermont, Huntington, VT; Pam Dardess, MPH, Vice President, Strategic Initiatives and Operations; Institute for Patient- and Family-Centered Care, Bethesda, MD

The Patient-Centered Outcomes Research Institute (PCORI) has created two online trainings for multistakeholder research teams to provide foundational knowledge in PCOR to non-scientist participants, and to provide training and resources to research teams comprising researchers, patients, and public stakeholders to support teams working together.

Great conference! Very powerful and eye opening!

– 2018 Conference Attendee 🕌

3:00 – 4:00 PM

Right People + Right Place + Right Time = Right Solution

Joan Forte, BSN, MBA, Healthcare Consultant; JForte Consulting, Morgan Hill, CA; Jonathan Bullock, National Leader, Person and Family Centered Care; Alphonso Gomez, Patient Partner; Kaiser Permanente, Oakland, CA

Hear from a leading PFCC expert on innovative practices to grow your PFCC program. Recruit the Right People, emphasizing equity, diversity, and inclusion, embed them in the Right Place, moving beyond the PFAC, and identify the Right Time for co-design.

Let's Talk About Antibiotics: Partnering with English and Spanish Speaking Parents to Develop Tools to Reduce Misconceptions About Antibiotics

Andrea Bradley-Ewing, MPA, MA, Director of Community Engaged Research; Terrence Gallagher, MArch, Parent Advisor; Children's Mercy Kansas City, Kansas City, MO

This study examines the process of partnering with English and Spanish speaking parents to develop family-centered resources to reduce parental misconceptions and facilitate effective parentprovider discussions about antibiotics.

Multiple Methods for Engaging Patients as Partners in Contract Research

Nyna Williams, PhD, Senior Researcher; Mathematica, Washington, DC; Donald Young, Rochester, NY; Benjamin Fischer, MA, Principal Program Analyst; Mathematica, Chicago, IL; Amanda Lechner, MPP, Researcher; Mathematica, Oakland, CA; Crystal Blyler, PhD, Senior Researcher; Mathematica, Washington, DC

We will highlight four initiatives that engage patients as research partners—(1) a patient and family advisory board (PFAB), (2) human-centered design (HCD), (3) community-based participatory research (CBPR), and (4) a peer-staffed psychiatric crisis respite program.

SEPTEMBER 8, 2020

DAY AT-A-GLANCE

12:00 – 1:00 pmConcurrent Breakout Sessions3:00 – 4:00 pmConcurrent Breakout Sessions

12:00 – 1:00 PM

What Have We Learned About The Relationship Between PFE and Organizational Performance?

Kellie Goodson, MS, CPXP, Director; Vizient, Irving, TX; Deborah Dokken, MPA, Coordinator, Patient and Family Partnerships; Pam Dardess, MPH, Vice President for Strategic Initiatives and Operations; IPFCC, Bethesda, MD

This session will review the findings of two new reports with quantitative and qualitative analyses of specific PFE activities that were found to influence organizational outcomes.

Patient and Family Advisors as Teaching Partners: The Impact on Emergency Department Staff Empathy

Andrew Eric Dundin, MSN, RN, CEN, Staff Nurse, Clinical Educator, PFAC Chair; Celene Wong, MHA, Program Manager; Dena Salzberg, RN, Patient/Family Advisor; Brigham and Women's Hospital, Boston, MA

Patient/family advisors partnered with emergency department clinical educators to develop a program focused on cultivating greater staff empathy and understanding of the patient experience. The program showed a positive influence on staff empathy when advisors served as teaching partners.

Peer Support Services for the Health and Wellness Needs of People with Mental Health Challenges

Charlotte Kauffman, MA, LCPC, Owner; Charlotte Kauffman Consulting, Springfield, IL

This project provides patients, peer support specialist and health care providers along with administrators information on research findings about peer support services to address health and wellness needs of people with mental health challenges.

3:00 – 4:00 PM

An Integrated Model of Family Advisory Councils: Creating Standard Work Across Councils to Increase Family Voice in Health Care Settings

Karen Wayman, PhD, Director, Family Centered Care; Mariel Spengler, BS, FAC Parent Lead/Parent Mentor; Lucile Packard Children's Hospital, Stanford, Palo Alto, CA

Both hospital-wide and service-line family-advisory councils (FACs) are critical to diffusing family-voice into the work of hospitals. This presentation identifies strategies to build an integrated FAC model: member orientation; leadership support; issues training. FAC evaluation methods will be shared.

Implementing Family Integrated Care in US NICUs

Linda Franck, RN, PhD, FAAN, Director, Postnatal Research; California Preterm Birth Initiative, San Francisco, CA; Quynh-An Phan, Parent; Priscilla Joe, MD, NICU Medical Director; UCSF Benioff Children's Hospital Oakland, Oakland, CA; Diana Cormier, DNP, APRN-CNS, MPH, RNC-NIC, CN III, Clinical Nurse Specialist-NICU; Community Regional Medical Center, Fresno, CA

Family Integrated Care (FICare) is an evidencebased model of NICU care not widely adopted in US NICUs. We created a partnership between healthcare professionals and parents of former preterm infants to implement FICare in California NICUs serving diverse communities.

Staying on the Rails: Journey Towards Innovative Engagement Ten Years From Now — We Ask Ourselves "What's Next"?

Helene Campbell, MSM, Patient Partnership Lead; Health Standards Organization - Accreditation Canada, Ottawa, Ontario; Heather Thiessen, Faculty/Presenter/ Author; Health Standards Organization, Saskatoon, Saskatchewan; Linda Hughes, RN, Co-Chair of Patients for Patient Safety Canada; Canadian Patient Safety Institute, Edmonton, Alberta

This panel presentation focuses on co-design of practices for meaningful engagement with patients and family members to prevent harm; from 'doing to', to 'doing with'. This is the essence of partnership with all.

SEPTEMBER 10, 2020

DAY AT-A-GLANCE

11:00 – 11:30 am	Ask an Expert
12:00 – 1:00 pm	Concurrent Breakout Sessions
3:00 – 4:00 pm	Concurrent Breakout Sessions
4:15 – 5:00 pm	Closing Celebration

11:00 – 11:30 AM

Ask an Expert: Health Equity

۵î۵ Consuelo Hopkins Wilkens, MD, MSCI, Vice President for Health Equity; Vanderbilt University Medical Center; Associate Dean for Health Equity, Vanderbilt School of Medicine, Nashville, TN

COVID-19 has illuminated the disparities in outcomes and care that have been present for some time. Health equity efforts are even more important than ever to reduce systemic barriers to health across populations. Consuelo Hopkins Wilkens leads the effort at Vanderbilt University Medical Center. She will be available to answer questions about their program and how it has influenced equity in their organization.



Consuelo Hopkins Wilkens

12:00 - 1:00 PM

Florida Family Leaders' Network (FFLN): a Grassroots, Family/Youth Leader Led State Supported Initiative to Develop A Network of Family/Youth Leaders

Angela Miney, BA, Family Partner; University of Florida Pediatric Pulmonary Training Center, Gainesville, FL

The Florida Family Leader Network (FFLN), led by family/youth leaders, fosters family-professional partnerships. It is a model, replicable across states, designed to break down silos by developing leaders steeped in the principles of patient and family centered care.

۵°۵ **Inclusion Created Through Engagement and Empowerment: Utilizing Integrative Health Strategies to Promote Healthy Communities**

Morris Carr, AA, Men's Health Coordinator; Tamela Milan-Alexander, MPPA, MCH, Westside Healthy Start CAN Coordinator; Access Community Health Network, Maywood, IL

Healthy Start utilizes a Community Action Network (CAN) model to serve as a collaborative advisory group that seeks to improve the social determinants of health of affected maternal and child health program participants.

3:00 - 4:00 PM

The Faces of a Family Advisory Council: It's Not Just Filling Buckets

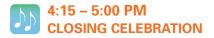
Sara Hanai, MSPT, Senior Patient Experience Consultant; Vanderbilt University Medical Center; Rhonda Scott Kinslow, JD, Family Advisor; Susan Waggoner, BA, Family Advisor; Monroe Carell Jr. Children's Hospital at Vanderbilt; Jama Mohamed, BA, Youth Program Coordinator; Family Voices of Tennessee, Nashville, TN

The purpose of this presentation is to differentiate between diversity for diversity's sake and being intentional about the value each advisor and their experiences bring. Identify strategies to bring underrepresented voices to the table.

5	Walk in My Shoes: Utilizing Patient Family Advisors as Educators in
M	Family Advisors as Educators in
Gradu	ate Medical Education

DeeJo Miller, BA, Program Manager, Patient and Family Engagement; Sheryl Chadwick, BS, Program Manager, Patient and Family Engagement; Terrence Gallagher, MArch, Patient Family Advisor; Children's Mercy Kansas City, Kansas City, MO

A Family as Faculty program enhances the teaching of patient-and family-centered care. With Patient Family Advisors serving as educators, residents experience a literal "walk in the shoes" of medically complex patients and families through storytelling and an in-home immersion experience.



"If I had to say what was most important about the conference, it was this: inspirational stories about the power of patient involvement, listening to scientists and doctors who are on the cutting edge of thinking about the connection between medicine and social justice, and warm interactions with individuals doing interesting work in various ways to bring more patients into the formerly closed circles of medical and hospital practice."

– 2018 Conference Attendee



At the Society to Improve

we believe the patient

perspective needs to be

incorporated into all we do.

Diagnosis in Medicine (SIDM)

INACCURATE AND DELAYED DIAGNOSES ARE THE MOST:

COMMON

CATASTROPHIC

COSTLY

OF SERIOUS MEDICAL ERRORS

Patient Engagement is Key to Improving Diagnosis

Among our projects:

- Patients Improving Research in Diagnosis (PAIRED) Program we've created an innovative curriculum and trained patient partners to participate in the design, execution and dissemination of research to improve diagnosis.
- DxIQ a new blog that helps patients navigate the healthcare system and take an active role in the diagnostic process.
- PFAC Engagement SIDM recently convened a 2-day conference with PFAC leaders to discuss strategies to increase PFAC and health system engagement in reducing harm to patients caused by diagnostic errors.
- Patient Summit Each year SIDM hosts a patient Summit, attended by advocates and leaders in the field to discuss important issues related to diagnostic guality.

Learn more about our efforts to improve diagnostic quality and safety at <u>www.improvediagnosis.org</u>



Become More Patient-and Family-Centered in Your Practice

The PFCC Toolkit is an online resource that offers hundreds of free practice-specific tools to help radiologists enhance patient-engagement skills and offer more patient-centered care.



Explore today at **PFCCtoolkit.acr.org**

Poster Sessions by Topic

POSTER SCHEDULE

August 18 - September 10, 2020

Poster presenters will be available to respond to questions and comments via chat during the conference period.

August 18 - December 31, 2020 Posters will be on display.



SESSENTIAL ALLIES—PATIENT AND FAMILY ADVISORS AND PARTNERS

A Family Retreat Room: An Alternative Space for Siblings, Parents, and Family to Encourage and Support Family Centered Care

Didi Wong, Patient Advisor, PFCCC Representative; Stephanie Bassler, Patient Advisor, PFCCC Representative; Jessica Rivera McGlothlin, Patient Advisor Co-Chair, PFCCC Representative; Andrew McGlothlin, Patient Advisor, PFCCC Representative; Julie Flores, BSN, RNC-MNN, CNIII; Mercedes Mendez, MSN, BSN, RNC-MNN, CN IV; Cedars-Sinai Medical Center, Los Angeles, CA

A collaborative design between families and care teams to produce a welcoming and calming family retreat room that allows siblings and families to adjust to the unfamiliar and overwhelming hospital environment.

A Structure to Bring National Patient and Family Voices Together

Libby Hoy, BS, Founder and CEO; Lindsey Galli, BS, Director of Education; PFCCpartners, Long Beach, CA

The Patient Family Advisor Network (PFAnetwork) provides a platform for PFAs to collectively partner on topics the network is passionate about. PFAnetwork Workgroups have addressed areas of healthcare improvement like patient access, PFA compensation, and the opioid epidemic.

Accreditation – Made Better Together with Patients and Families

Leslie Louie, BSW, RSW, Family Engagement Advisor; Sunny Hill Health Centre for Children; Kris Gustavson, RN, BSN, MSN, Corporate Director of Accreditation and Patient Experience; Provincial Health Services Authority, Vancouver, British Columbia

While there are some who love to hate accreditation, accreditation plays an important role in ensuring quality safety standards are met. When Accreditation Canada significantly increased the expectations regarding Patient-Centered Care, the Provincial Health Services Authority was ready.

Redefining Our Approach in the Way We Reach and Support Latino/Hispanic Families with Children with Disabilities Before and After COVID Tinisha Poitier, BA, Bilingual Parent Resources

Coordinator; University of Nebraska Medical Center, Omaha, NE

Research indicates that Latino/Hispanic families experience many health disparities and this is also true for Hispanic/Latino families that have children with disabilities. Our program has created strategies to assist Latino/Hispanic families of children with disabilities.

POSTER SESSIONS BY TOPIC continued

Co-Creating with Patient and Family Partners as a Strategic Priority

Julia Inglis, Volunteer Family Partner; IWK Health Centre,Halifax, Nova Scotia

With strong leadership support, the IWK evolved from simply understanding the role of patient/family advisors to actively involving patient/family partners in all elements of planning and improvement, through a commitment to co-creating with patients and families every day.

Collaborative Development of Infection Prevention and Control (IPC) Guidelines by Family Advisors, Healthcare Providers and IPC – Stollery Children's Hospital

Michelle Childs, Patient & Family Centred Care Coordinator; Stollery Children's Hospital, Edmonton, Alberta

Collaboration with patients, families and healthcare providers through an IPC and Patient Family Centred Care working group to understand gaps and develop IPC guidelines for patients on additional precautions to minimize risk of infections and address patient and family needs.

Designing a PFAC: The Role of Leadership

Vidya Ayyr, MPH, CHW, Director of Social Impact; Nina Rafiq, MBA, Social Impact Specialist; Parkland Health and Hospital System, Dallas, TX

The success of our Patient and Family Advisory Council (PFAC) was in the innovative design framework of its structure, involving leaders at all levels to contribute to the program development and implementation.

Developing Patients Encouraging and Engaging Peer Support (PEEPS) Program

Amanda Woelk, BS, CCLS, Child Life Manager; Maria Nordstrom, BS, Parent Support Program Coordinator; Children's Mercy Kansas City, Kansas City, MO

It is well known that AYA patients experience unique psychosocial struggles. This poster will address how we created a formalized peer match program to better meet these needs and offer ideas that could be adopted in other settings.

Feasibility of Patient and Caregiver-Led "Walkaround" Program: Gathering Current Patient Feedback in an Outpatient Setting

Renee Siegel, MSW, LCSW, Program Manager, Patient and Family Advisory Councils and Projects; Nicole Abair, BA, Co-Chair, Pedi PFAC; Dana-Farber Cancer Institute, Boston, MA

The Pediatric Patient and Family Advisory Council recently established a program to obtain direct feedback from patients and caregivers in the Jimmy Fund Clinic, the outpatient clinic for treatment of pediatric cancers and rare blood disorders at Dana-Farber Cancer Institute.

From the Bed to Embedded: Partnering with Patient and Family Advisors

Pam Cosper, DNP, RN, NEA-BC, Director, Patient Care Services; Emory University Hospital; Sylvia Bell, MEd, Patient and Family Advisor; Emory Healthcare, Atlanta, GA

To exemplify how engaging patient and family advisors (PFAs) from the bedside to the boardroom can improve organizational decisions, quality practices, and patient experience. Five examples of patient-centered care initiatives and positive impact on measurable results will be shared.

How Do You Share Your Story? Graphic Medicine – The Intersection of Art and Health Care

Rebecca Martinez, Chair, Family Advisory Council; Monroe Carell, Jr. Children's Hospital at Vanderbilt; Philip Walker, MLIS, MS, Director, Annette and Irwin Eskind Family Biomedical Library and Learning Center; Vanderbilt University; Lara Barnhouse, Past Chair, Family Advisory Council; Tamala S. Bradham, PhD, DHA, Immediate Past President, Family Advisory Council; Monroe Carell, Jr. Children's Hospital at Vanderbilt, Nashville, TN

The purpose of this poster is to share the use of graphic medicine—the intersection of comics and personal narrative—to explore health and illness from multiple perspectives—the patient, the caregiver, and the health professional.

POSTER SESSIONS BY TOPIC continued

Implementing A Patient and Family Advisory Council As Part of An Integrated Delivery Network: Health Plan, Medical Group, and Hospital

Susan Leet, Board Certified Chaplain with National Association of Catholic Chaplains, Chaplain Supervisor; SSMHealth St Mary's Hospital, Martha Hughes, MHA, Service Excellence Director; SSM Health Dean Medical Group, Madison, WI

To provide a more comprehensive continuum of care to enhance the patient and family experience within an Integrated Delivery Network (IDN).

Implementing a Robust PFCC Awareness Month Leads to Advocacy Year-Round

Kathryn Berry Carter, CVA, CAVS, Director, Family, Guest and Volunteer Services; Hannah Crain, BS, Coordinator, Patient Family-Centered Care; Jennifer Chavez, BS, Parent Adviser, Patient Family-Centered Care; Jason Winkle, BS, Parent Adviser, Patient Family-Centered Care; Brittany Barnett, MS, BS, CAVS, Manager, Patient Family-Centered Care; St. Jude Children's Research Hospital, Memphis, TN

Gain ideas for how you can raise awareness during PFCC Awareness month and garner more support for PFCC, not just in the month of October, but year-round.

Mighty and Mature: Growing a Powerhouse PFAC

Annette Mercurio, MPH, CHES, Director of Patient and Family Services, Department of Supportive Care Medicine; Maria Flores, Patient Advisor; Zelia De Sousa, BArch, RA, Patient and Family Advisor; City of Hope, Duarte, CA

How can PFACs thrive over the long term and become powerful forces for transforming care? We will highlight strategies and tools for amplifying the impact of PFACs and fostering a culture in which patients and families are essential allies.

Partnering with Parents to Create Collective Change: The Development of a Hospital-Wide Bereavement Committee

Katie Tharpe, BA, Parent Advisor; Annie Duplechain, MEd, Graduate Student Researcher; Mary Ann Gill, MEd, Graduate Student Researcher; Jessika Boles, PhD, CCLS, Child Life Team Lead; Monroe Carell Jr. Children's Hospital at Vanderbilt, Nashville, TN

Families deserve well-coordinated, high-quality care at end of life, yet few evidence-based interventions are available. Therefore, this poster will detail the staff and parent partnerships leading to the creation and maintenance of a multidisciplinary, hospital-wide committee for improving bereavement care.

Power Up Your PFAC: Rebooting Your Partnerships with Patients and Families

Monica Mewshaw, MSN, MPH, BS, RN-C, Patient and Family Centered Care Coordinator; Patricia Holle, Patient and Family Advisor, PFAC Co-Lead; Amy Grigg, Patient and Family Advisor, PFAC Co-Lead; Anne Arundel Medical Center, Annapolis, MD

A perfect PFAC? That's not us. But by openly sharing the challenges of our PFCC program and how we responded to them, we'll help others assess the health of their PFACs and share strategies for moving forward.

Recruiting, Retaining, and Sustaining Diverse Advisors in Colorado's Medicaid Program: Listening at all Levels

Sarah Eaton, DMA, CAPM, Deputy Client Officer; Robert Conkey, Member Experience Advisory Council Member; Cathryn Griffith, Member Experience Advisory Council Member; Brent Pike, Member Experience Advisory Council Member; Jasmine White; Member Experience Advisory Council; Colorado Department of Health Care Policy and Financing, Denver, CO

Colorado is designing a more equitable and accessible Medicaid program through its Member Experience Advisory Council by recruiting a diverse demographic, removing barriers to participation, and creating trusted partnerships. Continuity and commitment are realized because members see their feedback implemented.

POSTER SESSIONS BY TOPIC continued

Shake, Rattle, and Roll: Involving Families in Quality Improvement in Health Care

Lara Barnhouse, Past Chair, Family Advisory Council; Vicki Jones, RN, MSN, NE-BC, Administrative Director, Inpatient Nursing Services; Janet Cross, MEd, CCLS, CPXP, Administrative Director of Patient- and Family-Centered Care; Autumne Harding, APRN, MSN, PCNS-BC, CPPS, Administrative Director, Quality and Safety; Monroe Carell, Jr. Children's Hospital at Vanderbilt, Nashville, TN

This poster provides an overview of how to create a successful partnership between families and hospital staff by creating a collaborative to improve the patient experiences and reduce hospital-acquired conditions.

Strategically Partnering with Patient and Family Advisors to Improve Quality, Safety, and the Patient Experience

Kathleen Denton, PhD, Director, Patient Experience; MD Anderson Cancer Center, Houston, TX

MD Anderson Cancer Center is strategically partnering with Patient and Family Advisors (PFA) on institutional committees, projects, and improvement efforts to improve quality, safety, and the patient experience. The culture of inclusion of PFA members and engagement are success drivers.

The Creation of the CPC+ Initiative and the Lucky 13 Patient/Family Advisory Councils (PFACs) in Primary Care

Cortney Forward, PhD, MBA, Patient Experience Manager; Sharon Cross, MSW, CPXP, Program Director; Kurt Morris, Patient/Family Advisor; OSU Wexner Medical Center, Columbus, OH

Our organization began extensive growth and recruited over 100 patients to participate on 13 new Patient/Family Advisory Councils (PFACs) for Primary Care. This brought several challenges due to the large-scale initiative; while highlighting the need for a streamlined approach.

The Turquoise Cart Program: Rolling Out Self-Care to Parents and Caregivers

Kimberly Muench, BA, Parents as Partners Program Coordinator; Cynthia Spezia, Parent Advisor; Krystal Jordan, Parent Advisor; Cook Children's Medical Center, Fort Worth, TX

Parents/caregivers should prioritize self-care to effectively advocate for their children. This 4-principled program utilizes parent volunteers with experience and training to provide support, resources, and encourage self-care for inpatient families. We will describe program creation and facilitation.

To Background Check or Not To Background Check? Different Councils and Their Needs

Sharon Cross, MSW, CPXP, Program Director; Cortney Forward, PhD, MBA, Manager, Patient Experience; Kurt Morris, Patient/Family Advisor; Ohio State University Wexner Medical Center, Columbus, OH

Patient/Family Advisory Councils are very different in the Ambulatory setting versus the inpatient hospital setting. This poster includes challenges of designing and maintaining PFACs with varied focuses and unique needs, including whether or not to credential members as a volunteer.

Utilizing a Virtual Adviser Community

Kathryn Berry Carter, CAVS, CVA, Director, Family, Guest and Volunteer Services; Hannah Crain, BS, Coordinator, Patient Family-Centered Care; Tasha Ives, BS, Parent Adviser, Patient Family-Centered Care; Erin Miller, BS, Parent Adviser, Patient Family-Centered Care; St. Jude Children's Research Hospital, Memphis, TN

Technology makes getting in touch with your patient population more accessible than ever. Learn how utilizing virtual platforms for surveys, content sharing, and patient engagement can vastly expand the reach of your patient family-centered care practices.

BETTER TOGETHER—PATIENTS AND FAMILIES AS PARTNERS IN INPATIENT CARE

Family-Centered Care for Children with Tracheostomies: Collaborating with Parents to Design Training Tools That Increase Caregiver Confidence

Kevin Mary Callans, RN, BSN, Case Manager; Katie Potter Catapano, BS, Volunteer Director of Parent Programs; Mass Eye and Ear Infirmary, Boston, MA

We will describe the five-year collaborative development of a suite of educational and training tools for parents of children receiving tracheostomies. Impacts on caregiver confidence are measured using a validated instrument.

Next Level PFAC: Engaging Your PFAC and Staff with Their "Eyes and Ears"

Sarah Owen, CPXP, Director of Service Excellence; SCL Saint Joseph Hospital, Denver, CO

Our purpose is to help improve patient experience by maximizing PFAC feedback through Gembas and Communication Simulations. They provide the feedback our staff needs from patients and loops that information back to the frontline.

Partnering with Patients and Families Through Daily Plan of Care Visits with the Healthcare Team

Lynne Fuller, BSHA, MBA, Healthcare Partner; Erin Brady Curtis, MBA, Volunteer Manager; Teri Lash-Ritter, MD, MBA, Chief Medical Officer; Cleveland Clinic Akron General, Akron, OH

Daily visits where the patient/family, bedside nurse and physician collaborate to develop the plan of care are driving high quality, patient and family centered care. Healthcare Partners were integral in the development, implementation, and evaluation of these visits.

Promoting Family-Centered Care Within Intensive Care Units: The Society of Critical Care Medicine Family Engagement Collaborative

David Y. Hwang, MD, FAAN, FCCM, FNCS, Associate Professor; Yale School of Medicine, New Haven, CT; Kimberly LaRose, MEd, IMH-E, Family Advisor; New York Presbyterian-Weill Cornell Medical Center, New York, NY

Family engagement during critical care hospitalization has proven beneficial for patients, families, and ICU teams. This poster discusses promoting family engagement in critical care via an international collaborative involving 37 ICU teams focused on implementing local family engagement initiatives.

Providing Care Transparency to Patients Through Implementation of MyChart Bedside

Crystal Clemons, BS, MPH, PMP, Clinical Redesign Consultant; Irma Dadic, MBA, CPXP, Coordinator of Patient and Family Engagement; Kevin O'Brien, BS, Patient and Family Advisory Council Member; Yale New Haven Hospital, New Haven, CT

The poster will provide an overview of how MyChart Bedside was implemented in response to the winning team's pitch at a Clinical Redesign Hackathon focused on improving patient experience and common hospital problems impacting throughput.

Research as a Gateway to Ongoing Parent Partnership in Care Delivery in the NICU

Linda Franck, RN, PhD, FAAN, Jack and Elaine Koehn Endowed Chair in Pediatric Nursing and Director, Postnatal Research; Rebecca Kriz, RN, MS, Postnatal Research Manager; Quynh- An Phan, Family Advisor and Parent Mentor; Jennifer Hutchison, Member, Parent-Clinician Advisory Board; California Preterm Birth Initiative, University of California, San Francisco, San Francisco, CA

The research trial evaluating Family Integrated Care (FICare) in U.S. NICUs has involved parents with lived experience in the development, implementation, and sustainability of FICare in the NICU, and in the analysis and dissemination of the mFICare study.

She's Not a Visitor She's My Wife: Changing the Practice from Visitation to Family Presence – Now Is the Time!

Valrie Stewart, RN, MA, CPXP, Consultant; Alberta Health Services, Calgary, Alberta

Inspired by our patient and family advisors and with a goal of improving the patient experience the Calgary Zone embarked on a journey to define family presence and eliminate visiting hours in Calgary Zone hospitals. We will share our journey.

The Voices, Lived Experience and Impact of Siblings in Paediatric Disability

Melissa Ngo, BA (Hons), Family Support Specialist; Bloorview Research Institute; Toronto, Ontario

With the amount of limited supports for young siblings as caregivers, it's important to foster spaces for, about, and by siblings. This panel discusses the concerns, experiences and needs of sibling caregivers to inform and advocate for meaningful sibling supports.

What Do Parents Want to Know About Caring for Their Preterm Infant?

Linda Franck, RN, PhD, FAAN, Jack and Elaine Koehn Endowed Chair in Pediatric Nursing and Director, Postnatal Research; California Preterm Birth Initiative, University of California, San Francisco, San Francisco, CA

Using a mobile app co-designed by parents and healthcare professionals, we gained new insights about the questions parents have about their preterm infant's care, particularly related to feeding, the infant's medical course, and their role as care providers.



PARTNERSHIPS IN PRIMARY AND OTHER AMBULATORY CARE

Building Collaborative Partnerships to Develop a Shared Decision Making Tool to Encourage Informed Colorectal Cancer Screening

Alicia Oostdyk, MPH, CHES, Student; University of South Carolina, Greenville, SC

Discussions between patients and physicians about colorectal cancer screening can be enhanced by integrating patient-centered shared decision making tools within clinical practice. Effective tool development requires transdisciplinary collaboration among patients, providers, health administrators, and improvement specialists.

Increasing Engagement of Providers, Staff, and Patients Within Ambulatory Care PFACs

Cortney Forward, PhD, MBA, Patient Experience Manager; Sharon Cross, MSW, CPXP, Program Director; OSU Wexner Medical Center, Columbus, OH

Since 2017, our organization has created lasting partnerships in ambulatory care between providers, staff, and patients with the creation of 14 PFACs including the departments of sports medicine, general internal medicine, and family medicine.

Inviting Patient and Family Partnerships to Improve Experience of Care Due to Cancelled Day Surgeries

Kate McNamee, RN, MSN, CHPCN(C), Leader, Person & Family Centred Care; Providence Health Care, Vancouver, British Columbia

A small team consisting of operations manager, quality improvement specialist, professional practice personnel, and patient partners set out on a journey to improve the experience of same day surgery cancellations.

Mission MRI

Kathleen Grobbel, MA, CTRS, CCLS, Supervisor, Child Life; Beaumont Health, Royal Oak, MI

The Reach the Moon Grant program was developed as a strategic component to create PFCC culture by giving staff, patients, and families the opportunity to improve care and experiences through innovative ideas. Mission MRI will be highlighted.

Providing Information and Resources to Families in Advance of Their Health Care: The Impact of Co-Creation

Melissa Ngo, BA (Hons), Family Support Specialist; Cheryl Peters, BMus, Family Leader; Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario

The value of a co-designed Outpatient Orientation by and for families has proven to be an impactful program at first point of contact. Family leadership produced these key outcomes: the improvement of mental health, connections, and support for new families.

The Radiology Patient Experience: Version 2.0

David Facchini, MBA(HCM), BSRT(R), Radiology Quality and Safety Manager; Yale New Haven Hospital, New Haven, CT

Our goal was to completely revamp our patient's Radiology experience (pre and post visit) by using innovative tools and enhanced, patient friendly communication.

PARTNERSHIPS IN RESEARCH AND EVALUATION

Engaging Patients in Research Design – How Do We Do It?

Sharon Cross, MSW, CPXP, Program Director; Cortney Forward, PhD, MBA, Manager, Family Medicine; Ohio State University Wexner Medical Center, Columbus, OH

As funders began to require patients in research design, our organization started a program to coordinate patient engagement and provide training. This poster includes required steps to ensure a successful program that is satisfying to both researchers and patients.

Former NICU Families Describe Gaps in Family-Centered Care

Linda Franck, RN, PhD, Jack and Elaine Koehn Endowed Chair in Pediatric Nursing; University of California, San Francisco, San Francisco, CA

The aim of this qualitative study was to understand the experience of NICU families in relation to principles of family centered care. We explored unmet needs for partnership in care/support, particularly experienced by parents of color and/or of low socio-economic status.

Implementing a Patient-Family Advisor Engagement Structure in a Complex Clinical Trial: Lessons from the Meta-LARC Advance Care Planning (ACP) Study

Chrystal Barnes, AS, OHSU Research Intern; Oregon Rural Practice-based Research Network (ORPRN), Portland, OR; Deb Constien, BS, PFA, Volunteer; Wisconsin Research and Education Network (WREN), Sun Prairie, WI; Kathy Kastner, Patient Partner; University of Toronto Practice Based Research Network (UTOPIAN), Toronto, Ontario

Creating meaningful engagement with Patient and Family Advisors (PFAs) in complex research requires strategic planning. This poster will include the template used to implement PFA research engagement, with a focus on participation structure, continuous quality improvement, and adaptations made.

Institutionalizing Youth and Family Partnerships: The CYSHCNet Model

Charlene Shelton, RN, MA, MPA, PhD, Research Instructor and Program Manager; University of Colorado, Anschutz Medical Campus, Aurora, CO

Families who partner on studies should be compensated. This guide provides a standard with concrete examples and recommendations for paying youth, patient, and family partners who work on studies as research partners.

Medical Shame: Implications for Patient-Centered Care and Research

Peggy Wagner, PhD, Senior Consultant, Patient Engagement Studio; Prisma Health/University of South Carolina School of Medicine, Greenville, SC

Little is known about the impact of shame in healthcare. Using existing conceptual frameworks and patient stories, this poster will assist attendees to formulate a patient-centered research and clinical agenda in medical shame.

Mindset Matters: Patient Experts' Tips and Tools for Scientists to Enhance Meaningful Engagement of Patients as Co-Investigators

Melanie Cozad, PhD, Assistant Professor, Health Services Policy and Management Center for Effectiveness Research in Orthopedics; Arnold School of Public Health, University of South Carolina, Greenville, SC

Frameworks for meaningful engagement of patients as research partners fail to describe the researcher mindset needed to enhance engagement quality. This poster discusses researcher attitudes, communication approaches, and behaviors that improve meaningful engagement.

Modified Delphi for Cardiovascular Disease Research Agenda Priorities in Central Appalachia

Dumisa Nyarambi, MPH, BS, Teaching Associate and Research Assistant; East Tennessee State University, Johnson City, TN

We present the findings from a modified Delphi Method study that engaged patients, family/nonlicensed caregivers, and professional stakeholders in consensus building for the purpose of identifying priorities for developing a cardiovascular diseases research agenda in Central Appalachia.

Patients as Research Partners: A Collaborative Approach to Achieve Diagnostic Excellence

Mimi Hugh, MA, MPH, Director, SCPMG Performance Assessment; Susan Becken, Patient Advisor; Southern California Permanente Medical Group, Pasadena, CA

Although diagnostic errors are often due to unintended and avoidable communication failures, diagnostic error reduction frequently focuses on the practitioner perspective. Engaging patients in developing interventions to address diagnostic errors allows greater applicability and development of patient-centered programs.

The Moffitt Cancer Center Patient-Researcher Forum: Engaging Patients and Researchers to Promote Bi-Directional Awareness, Compassion, and Patient-Centered Research

Anne Bidelman, BS, Manager, Patient Advisory and Executive Patient Program; Patti Halula, PFAC Co-Chair, Patient Advisor; H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL

During monthly Patient-Researcher Forums, patients and caregivers tour laboratories studying their cancer and meet and share their stories with biomedical researchers. They get insider views of the research realm and see how their stories can stimulate, motivate, and impact research.

The Power of Partnering with Patients to Design and Test a Mobile Application for Rheumatoid Arthritis

Melanie Cozad, PhD, Assistant Professor, Health Services Policy and Management Center for Effectiveness Research in Orthopedics; Arnold School of Public Health, University of South Carolina, Greenville, SC

Patients, researchers, and a rheumatologist worked collaboratively to design and test a mobile application that empowers patients to engage in the self-management of their RA and to share diseaserelevant information with their provider during the clinical encounter.

Turning Patient Questions into Research Projects: Creating Evidence that Matters to Patients

Peggy Wagner, PhD, Senior Consultant Patient Engagement Studios; Prisma Health, University of South Carolina School of Medicine Greenville, Greenville, SC

This poster presents activities that 1) demonstrate a conceptual framework to stimulate question development, 2) convert patient "wonderings" into comparative effectiveness research (CER), and 3) teach participants methods to encourage patientgenerated research productivity.

Valuing Patient and Caregiver Perspectives and Priorities in an 18-Hospital Comparative Effectiveness Trial

Debbie Hill, BS, FAHA, Caregiver, C3FIT Stakeholder Engagement Coordinator; Lombardi Hill Consulting Group, Gainesville, FL; Barry Jackson, BA, Stroke Survivor, Patient Co-Principal Investigator; C3FIT Study Vanderbilt University, Rockville, MD; Kenneth Gaines, MD, MBA, Vascular Neurologist, Professor, Neurology; Vanderbilt University School of Medicine, Nashville, TN

Physician investigators often do not rely on patients as partners in their research. The C3FIT trial seeks to change this by engaging patients and caregivers in all aspects including study design, implementation, outcome data interpretation, and results dissemination.

Creating a Culture of Safety Together: Families and Staff as True Partners in High Reliability

Pat O'Hanlon, Manager, Family Faculty; Children's Specialized Hospital, New Brunwsick, NJ; Linda Waddell, BS, Family Faculty; Children's Specialized Hospital, Mountainside, NJ; Donna Provenzano, BS; CTRS, Director, Family Centered Care; Children's Specialized Hospital, New Brunswick, NJ; Deidre Torrone, AS, Family Faculty; Children's Specialized Hospital, Toms River, NJ

We focus on how families and staff worked side by side to fully integrate our culture of HRO. We will share our unified strategy on how families are key drivers in promoting safety, high quality, and PFCC culture.

Increased HCAHPS Scores Through Standardizing Bedside Shift Report to Improve Patient Engagement During Handoff

Teri Ellis, MSN, RN, NE-BC, Director of Nurse Clinical Excellence; Baylor Scott & White, Baylor University Medical Center, Dallas, TX

After reviewing the evidence, nursing unit leaders adapted nursing bedside shift report to include a standardized template, on-going audits, real-time feedback for nurses, and patient/family participation with shift handoff. Standardized bedside shift report handoff resulted in higher HCAHPS scores.

The Role of the Embedded Patient Partner: Developing the Infrastructure to Become an Engagement Capable Environment

Isabel Jordan, Patient Partner; Haley Warren, MHSc, Improvement Lead; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario

The role of an embedded patient partner within a healthcare improvement organization has facilitated internal capacity development to enable consistent and purposeful engagement practices with patient partners, alongside leaders and staff to design, deliver, and evaluate improvement programs across Canada.

Transforming the Role of Patients and Families in Healthcare: From Consultation to Shared Leadership *Kathy Quinlan, Registered Nurse, Manager of Quality and Clinical Projects; Barbara Masotti, BA, BEd, Chair, Patient and Family Advisory Council; Hôtel-Dieu Grace Healthcare, Windsor, Ontario*

Involving patients and families is the right thing to do, but is there a right way to do it? Come see how HDGH used an evidenced based framework to successfully create a culture of shared leadership with patients and families.



EDUCATION FOR INTERPROFESSIONAL AND COLLABORATIVE PRACTICE

Companioning Families Through Loss Workshop: Family Advisors Leading the Way

Trina McCartney, Family Advisor to PFCC Council; Sarah Topilko, BEd, Coordinator, Patient & Family Centered Care; Stollery Children's Hospital, Edmonton, Alberta

This poster will demonstrate how the Stollery Children's Hospital Patient and Family Advisors (PFAs) worked collaboratively with the PFCC Coordinator and other NICU staff to plan, develop, and facilitate a staff education workshop about bereavement and loss in the NICU.

Learning with Families: An Interprofessional Program to Grow Understanding in Client and Family Centered Care

Leslie Louie, BSW, RSW, Family Engagement Advisor; Sunny Hill Health Centre for Children, Vancouver, British Columbia

Learning with Families (LWF) is an innovative client/family-centered care program to foster interprofessional education and collaborative practice by partnering staff/healthcare professionals with family leaders who share their lived experiences of caring for a child with complex health needs.

Parents Partnering with Medical and Nursing Schools: An Important Perspective

Laura Marcinauskis, Family Advisor; Christina Keating, Family Advisor; Karen Zrenda, BS, Family Resource Program Coordinator; Yale New Haven Children's Hospital, New Haven, CT

Parent Advisors for YNHCH have engaged with the Yale School of Nursing and Yale School of Medicine Student Orientation to be given the opportunity to meet with the students as they begin their internship on the pediatric inpatient units.



HEALTH EQUITY THROUGH PARTNERSHIPS

Addressing Health Disparities: Leveraging Healthcare Partners with Health Literacy Expertise

Erin Brady Curtis, MBA, Manager of Volunteer, Employee and Spiritual Care Services; Chandra Rudolph, BA, Healthcare Partner; Lynne Fuller, BS, Healthcare Administration, Healthcare Partner; Cleveland Clinic Akron General, Akron, OH

Cleveland Clinic Akron General launched a program with its patient and family advisors to improve patient understanding of healthcare literature. One of our Healthcare Partners is available to review and edit materials to a more appropriate literacy level.

Asking What Matters – How Lived Experience Will Transform Care in a Mental Health and Substance Use Program

Elizabeth Stanger, MA, Corporate Director, Care Delivery Integration; Renée Lukacs, Patient Partner; Kate McNamee, MSN, RN, HPCN(C), Practice Consultant – PFCC Leader, Foundational Value; Providence Health Care, Vancouver, British Columbia

Using a variety of engagement strategies, we asked "What Matters to You" of people with lived experience of mental health and substance use treatments and care. Over 70 respondents shared experiences and recommendations for improvement.

Educational Videos as a Tool to Improve the Latinx Patient Experience at an Urban Pediatric Hospital Setting

Adolfo Caldas, MSW, LICSW, Clinical Social Worker/ Children's Hospital Primary Care Center and Spanish Social Work Team; Maria Carvalho, MSW, LICSW, Clinical Social Worker; Cecilia Matos, BA, MA, Center for Families Program Coordinator; Boston Children's Hospital, Boston, MA

Multidisciplinary hospital staff and patients/families participated in creating staff and patient centered educational videos to improve the Latinx patient experience. The patient videos are available online for public viewing.

Enhancing Equity Learning for Radiology Professionals Through Patient-Centered Design Thinking

Lucy Spalluto, MD, MPH, Radiologist; Vanderbilt University Medical Center, Nashville, TN

Our purpose is to develop learning tailored to enhance radiology professionals' understanding of health equity through a patient-centered, design thinking experience.

Integrating Social Needs as a Primary Focus for a Patient Advisory Council

Lia Sebring, BS, Social Determinants of Health Coordinator; Oregon Health and Science University Family Medicine at Richmond, Portland, OR

This poster will describe how a Patient Advisory Council has integrated social needs by exhibiting examples of co-designing a social needs screener, adding a standing agenda item related to the social determinants of health and reviewing other best practices.

Mejorando La Salud: An Online Spanish Language Health Literacy Video Series

Adolfo Caldas, MSW, LICSW, Clinical Social Worker/ Children's Hospital Primary Care Center and Spanish Social Work Team; Maria Carvalho, MSW, LICSW, Clinical Social Worker; Cecilia Matos, BA, MA, Center for Families Program Coordinator; Olga Perez, MSW, LICSW, Clinical Social Worker/Spanish Social Work Team and Allergy/Immunology; Boston Children's Hospital, Boston, MA

A Spanish video series was created to educate others on how to access primary care; how to access mental health care; positive parenting; resources for individuals with special needs; nutrition; and transitioning into adulthood.

Partnering with Diverse Populations in Los Angeles County

Lindsey Galli, BS, Director of Education; Libby Hoy, BS, Founder and CEO; PFCCpartners, Long Beach, CA

Los Angeles County Department of Health Services (DHS) has a mission to create a Patient Family Engaged Care culture. DHS teams jointly participated in the Gateways Learning Collaborative to create and align patient engagement programs across the system.

Spanish Social Work Team: Tu Familia en el Hospital (Your Family in the Hospital)

Adolfo Caldas, MSW, LICSW, Clinical Social Worker/ Children's Hospital Primary Care Center and Spanish Social Work Team; Maria Carvalho, MSW, LICSW, Clinical Social Worker; Cecilia Matos, BA, MA, Center for Families Program Coordinator; Olga Perez, MSW, LICSW, Clinical Social Worker/Spanish Social Work Team and Allergy/Immunology; Boston Children's Hospital, Boston, MA

An urban pediatric hospital has a dedicated team of bi-cultural and native Spanish speaking clinical SWs who exclusively work with primarily Spanish speakers. This team may be a model to other settings with large number of limited English speakers.



EMERGING INNOVATIONS

A Patient- and Family-Centered Approach to Age-Friendly Healthcare: Piloting the 4Ms on a Geriatric Inpatient Unit at an Academic Hospital Mariu Duggan, MD, MPH, Clinical Director of Geriatric Operations; Vanderbilt University Medical Center, Nashville, TN

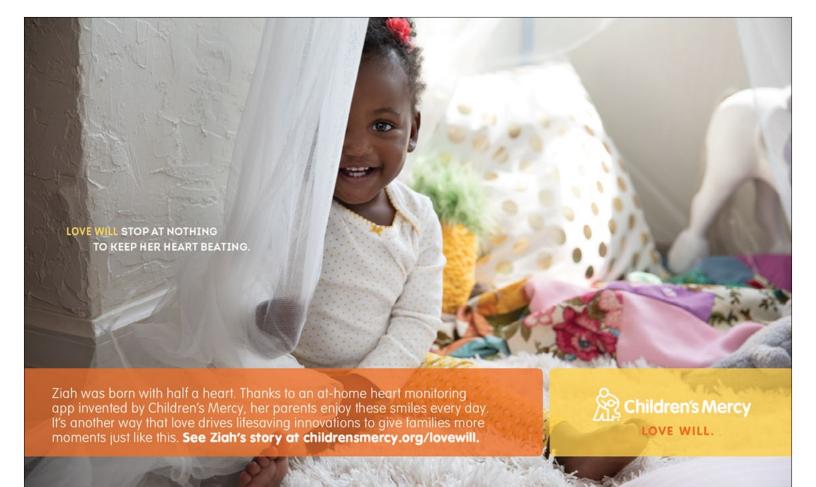
As part of the national Age-Friendly Health Systems initiative, we set out to develop an age-friendly geriatric inpatient unit using a patient- and familycentered approach. The poster presents our early outcomes and lessons learned.

THERE'S NO QUIT IN US. BECAUSE THERE'S NO QUIT IN YOU.

At Beaumont, we know the support of family and friends during a hospital stay is essential. While the COVID-19 pandemic has presented challenges around welcoming family and friends at our hospitals, through partnership and technology, Beaumont has created opportunities for patients and families to stay connected. This is what not quitting looks like.

Learn more at beaumont.org/staying-connected





9TH INTERNATIONAL CONFERENCE PROGRAM ADVISORY COMMITTEE

Marie Abraham, MA

Vice President, Programming and Publications IPFCC Old Lyme, CT

Brittany Bogan, FACHE, CPPS

Senior Vice President, Safety & Quality Michigan Health & Hospital Association MHA Keystone Center Lansing, MI

Sue Collier, MSN, RN, FABC

Vice President Innovation & Clinical Excellence North Carolina Healthcare Foundation North Carolina Healthcare Association Cary, NC

Cherie Craft, MEd

CEO and Founding Executive Director Smart from the Start Boston, MA

Elizabeth Crocker, BA, MEd

Author and Advocate Vice President, IPFCC Board of Directors Halifax, NS, Canada

Pam Dardess, MPH

Vice President, Strategic Initiatives and Operations IPFCC Durham, NC

Deborah Dokken, MPA

Coordinator for Patient and Family Partnerships IPFCC Bethesda, MD

Maureen Fagan, DNP, FNP-BC, FAAN

Chief Nursing Executive University of Miami Health System Miami, FL

Carol Fancott, PT, PhD

Director, Patient and Citizen Engagement for Improvement Canadian Foundation for Healthcare Improvement Ottawa, ON, Canada

Linda S. Franck, RN, PhD, FRCPCH, FAAN

Jack and Elaine Koehn Endowed Chair in Pediatric Nursing Professor, Department of Family Health Care Nursing Director of Postnatal Research, UCSF California Preterm Birth Initiative University of California San Francisco San Francisco, CA

Beverley H. Johnson, BSN, FAAN

President and Chief Executive Officer IPFCC Bethesda, MD

Susan M. Grant, DNP, RN, FAAN

Executive Vice President and Chief Nursing Officer Beaumont Health Southfield, MI

B. Lee Green

Vice President, Diversity and Community Relations Moffitt Cancer Center Tampa, FL

Michele Lloyd

Vice President Hassenfeld Children's Hospital at NYU Langone Health New York, NY

Natalie McCarthy, MSW

Operations Director, Richmond Regional Director, Strategic Initiatives Vancouver Coastal Health Authority Vancouver, BC

Doriane Miller, MD

Associate Professor of Medicine Director, Center for Community Health and Vitality University of Chicago Medicine Chicago, IL

Mary Minniti, BS, CPHQ

Senior Policy and Program Specialist IPFCC Eugene, OR

Julie Ginn Moretz, BS

Chief Experience Officer AVP, Patient- and Family-Centered Care Augusta University Medical Center Augusta, GA

William E. Schwab, MD

Professor and Vice Chair, Department of Family Medicine University of Wisconsin School of Medicine and Public Health Member, IPFCC Board of Directors Madison, WI

Terri Shelton, PhD

Vice Chancellor for Research and Economic Development and the Carol Jenkins Mattocks Distinguished Professor The University of North Carolina at Greensboro Member, IPFCC Board of Directors Greensboro, NC

Sue Sheridan MIM, MBA, DHL

Director, Patient Engagement Society to Improve Diagnosis in Medicine Boise, ID

Terrell Smith, RN, MSN

Senior Director, Patient and Family Engagement Vanderbilt University Medical Center Nashville, TN

Paul Sternberg, Jr., MD

G. W. Hale Professor and Chair, Vanderbilt Eye Institute Chief Medical Officer, Vanderbilt Medical Group Chief Patient Experience Officer Associate Dean for Clinical Affairs Vanderbilt University Nashville, TN

The positions listed are those that individuals held at the time they participated as Program Advisory Committee members.



9TH INTERNATIONAL CONFERENCE ABSTRACT REVIEWERS

Marie Abraham, MA

Vice President, Programming and Publications IPFCC Old Lyme, CT

Jacqueline Hawkins Alikhaani, BA

PCORI-American Heart Association Ambassador International Heart Health Citizen Diplomat Los Angeles, CA

Lisa Allen, PhD

Chief Patient Experience Officer Johns Hopkins Medicine Armstrong Institute for Patient Safety and Quality Baltimore, MD

Agnes M. Barden, DNP, MSN, RN, CPXP

Vice President Office of Patient and Customer Experience Northwell Health New Hyde Park, NY

Karen Beattie, PhD

Associate Professor, Medicine McMaster University Parent Partner McMaster Children's Hospital Hamilton, ON, Canada

Kathy Bernstein

Development Vice President Depression and Bipolar Support Alliance Chicago, IL

Paul Boucher, MD, FRCPC

Clinical Associate Professor University of Calgary Calgary, AB, Canada

Barbara Burke, MA, LPC

Senior Director, Patient-Family Experience Ann & Robert H. Lurie Children's Hospital of Chicago Chicago, IL

Bryant Campbell

Patient and Family Advisor Providence Medical Group Portland, OR

Martie Carnie

Senior Patient Advisor Brigham and Women's Hospital Boston, MA

Joanna F. Celenza, MA, MBA

March of Dimes/CHaD ICN Family Support Specialist Intensive Care Nursery Children's Hospital at Dartmouth Lebanon, NH

Sheryl Chadwick

Patient and Family Engagement Program Manager Improvement Institute Children's Mercy Kansas City Kansas City, MO

Amy Cohen, PhD, CPXP, PMP

Director, Patient and Family Experience The University of Vermont Medical Center Williston, VT

Valerie Colangelo, BS

Patient Family Centered Care Consultant Patient & Family Advisor The Valley Hospital Ridgewood, NJ

Cara Coleman, JD, MPH

Patient and Family Partnerships Specialist IPFCC Springfield, VA

Sue Collier, MSN, RN, FABC

Vice President Innovation & Clinical Excellence North Carolina Healthcare Foundation North Carolina Healthcare Association Cary, NC

Maureen Connor, RN, MPH

Consultant Claremont Healthcare Consulting Arlington, MA

Dr. Catherine Crock, AM

Physician, The Royal Children's Hospital Professor, Faculty of Health, Deakin University Chair, Hush Foundation Melbourne, Australia

Elizabeth Crocker, BA, MEd

Author and Advocate Vice President, IPFCC Board of Directors Halifax, NS, Canada

Pam Dardess, MPH

Vice President, Strategic Initiatives and Operations IPFCC Durham, NC

Caroline DeLongchamps

Manager, Patient- and Family-Centered Care Quality and Safety MUSC Health Charleston, SC

Nancy DiVenere

Former President Parent to Parent USA Member, IPFCC Board of Directors Essex, VT

Deborah Dokken, MPA

Coordinator for Patient and Family Partnerships IPFCC Bethesda, MD

Julie Drury

Strategic Lead, Patient Partnerships Canadian Foundation for Healthcare Improvement Ottawa, ON, Canada

Hala Durrah, MTA

Patient Family Engagement Consultant Washington, DC

Carol Fancott, PT, PhD

Director, Patient and Citizen Engagement for Improvement Canadian Foundation for Healthcare Improvement Ottawa, ON, Canada

Joan Forte, MBA, BSN

Nurse Administrator Consultant JForte Consulting Morgan Hill, CA

Phyllis Foxworth

Advocacy Vice President Depression and Bipolar Support Alliance Chicago, IL

Linda S. Franck, RN, PhD, FRCPCH, FAAN

Jack and Elaine Koehn Endowed Chair in Pediatric Nursing Professor, Department of Family Health Care Nursing Director of Postnatal Research, UCSF California Preterm Birth Initiative University of California San Francisco San Francisco, CA

Lindsey Galli

Director of Education PFCCpartners Long Beach, CA

Joanne Ganton, BComm, CPXP

Patient & Family Centred Care Specialist Alberta Health Services – Primary Health Care Calgary, AB, Canada

Nicole Giammarinaro, MSN, RN, CPXP

Director, Education & Research Office of Patient & Customer Experience Northwell Health New Hyde Park, NY

Terry Griffin, MS, APN-BC

Neonatal Nurse Practitioner St. Alexius Medical Long Grove, IL

James Harrison, MPH, PhD

Assistant Professor Division of Hospital Medicine University of California San Francisco San Francisco, CA

Leanne Heppell, RN, BScN, MScN, MAL

Chief Operating Officer Acute Care Chief of Professional Practice & Nursing Providence Health Care Vancouver, BC, Canada

9TH INTERNATIONAL CONFERENCE ABSTRACT REVIEWERS continued

Nicole Iarrobino, MS

Senior Project Administrator Patient Relations and Patient & Family Advisory Councils Johns Hopkins Health System Baltimore, MD

Kori L. Jones, MEd, BBA

Director, Patient and Family-Centered Care Beaumont Health Southfield, MI

Amy Kratchman

Senior Research Family Consultant Children's Hospital of Philadelphia Philadelphia, PA

Patricia Kritek, MD, EdM

Associate Dean – Faculty Development Professor – Division of Pulmonary, Critical Care and Sleep Medicine University of Washington School of Medicine Seattle, WA

Linda R. Larin, FACHE, MBA

Associate Hospital Director for Cardiovascular and Neurosciences Programs Office of the Executive Director – University Hospital/Cardiovascular Center Michigan Medicine Ann Arbor, MI

Jennifer Lastic, CPXP

Manager, Patient-Centered Care The MetroHealth System Cleveland, OH

Michele Lloyd

Vice President Hassenfeld Children's Hospital at NYU Langone Health New York, NY

Maureen E. Maurer, MPH

Principal Researcher American Institutes for Research Chapel Hill, NC

Brenda Miller, BFA

Manager Ronald McDonald House of Ann Arbor Ann Arbor, MI

DeeJo Miller

Patient and Family Engagement Program Manager Improvement Institute Children's Mercy Kansas City Kansas City, MO

Doriane Miller, MD

Associate Professor of Medicine Director, Center for Community Health and Vitality University of Chicago Medicine Chicago, IL

Mary Minniti, BS, CPHQ

Senior Policy and Program Specialist IPFCC Eugene, OR

Julie Ginn Moretz, BS

Chief Experience Officer AVP, Patient- and Family-Centered Care Augusta University Medical Center Augusta, GA

Lisa Ann Morrise, MArts

Executive Director Consumers Advancing Patient Safety Salt Lake City, UT

Wendy Nickel, MPH

Vice President of Prevention Colorectal Cancer Alliance Washington, DC

Elizabeth M. Nolan, MS, RN

Nurse Consultant Former Director, Patient Education Program & Mardigian Wellness Resource Center Frankel Cardiovascular Center Michigan Medicine Ann Arbor, MI

Jim Pantelas

Ambassador and Advisory Panel Member, PCORI Reviewer, PCORI, DOD-CDMRP, MICH-R Lung Cancer Patient & Research Advocate, Free To Breathe and Lung Cancer Alliance IRB Member, University of Michigan, VA and National Cancer Institute Howell, MI

Kelly Parent

Vice President, Patient and Family Experience Beaumont Health Southfield, MI

Ushma Patel, MSPH, PMP

Director for Special Projects & Educational Programs IPFCC Apex, NC

Marilyn Potgiesser, RNC, BS

System Manager, PFCC & Volunteer Services Bronson Methodist Hospital Kalamazoo, MI

Tanielle Randall, MBA

PFAC Co Chair Nemours Children's Hospital Orlando, FL

Judy Roudebush, RN, NE-BC, Retired

Consultant Programs for Women and Infants Woodinville, WA

Latoshia Rouse

Patient and Family Partner National Network of Perinatal Quality Collaboratives Knightdale, NC

Jeff Schlaudecker

Associate Professor, Kautz Endowed Chair for Geriatric Education Interim Director, Geriatric Medicine Division Program Director, Geriatric Medicine's Fellowship Program College of Medicine, Department of Family and Community Medicine University of Cincinnati Cincinnati, OH

Susan Shaw, MD, FRCPC

Chief Medical Officer Saskatchewan Health Authority Saskatoon, SK, Canada

Alyssa M. Stephany, MD, SFHM

Chief, Hospital Medicine Programs Children's Hospital of Wisconsin & Ascension – All Saints Associate Professor, Departments of Pediatrics & Medicine Medical College of Wisconsin Milwaukee, WI

Uyara Talmatare Jesus Camara

Registered Nurse University Medical Center Goettingen, Germany

Janice Tufte

Patient Partner Health Systems Research and Improvement Hassanah Seattle, WA

Deborah Wachenheim, MPP

Assistant Director of Dissemination OpenNotes Boston, MA

Peggy J. Wagner, PhD

Senior Consultant, Patient Engagement Studio Health Sciences Center, Prisma Health Distinguished Clinical Professor Emerita Behavioral, Social, and Population Health Sciences Department of Biomedical Sciences University of South Carolina School of Medicine Greenville Greenville, SC

The positions listed are those that individuals held at the time they participated as Abstract Reviewers.

Nothing about me without me.

Partnering with Purpose. Let's talk about people-centred care.

peoplepowered.info



ACCREDITATION CANADA



OpenNotes is the international movement supporting and studying the effects of transparent communication. We help patients, families, doctors, nurses, therapists and others to prepare and share meaningful notes describing a telehealth or office visit. We call these open notes.

For information specific to your care, right now, ASK!



Access your notes. Today, more than 50 million patients can read their notes on patient portals. If your health system already shares notes, you will be able to see them by registering for the portal. If not, ask your doctor to share them with you.

Share with those who care. Once you have access, you may choose to share your notes with people who help you manage your health. Studies show that care partners report important benefits from having access to notes.

Know the full story of your health and your care plan. Patients who read their notes feel more in control of their care and often catch crucial errors that help prevent medical issues later. Moreover, research shows that reading notes promotes trust between patients and doctors.

Pinwheel Sponsors

IPFCC appreciates the support of our Pinwheel Sponsors for their commitment to advancing the understanding and practice of patient- and family-centered care. These recognized leaders continue to make a significant difference in promoting this approach and serve as role models to us all.

PINWHEEL CHAMPION

Akron Children's Hospital Akron, OH

American Association of Colleges of Pharmacy Washington, DC

American College of Radiology Reston, VA

Ann & Robert H. Lurie Children's Hospital of Chicago Chicago, IL

Anne Arundel Medical Center Annapolis, MD

Augusta University Health Augusta, GA

Barnes-Jewish Hospital St. Louis, MO

Beaumont Health Southfield, MI

Bronson Healthcare Kalamazoo, MI

Cedars Sinai Los Angeles, CA

Centre for Addiction and Mental Health Toronto, ON, Canada

Chatham-Kent Health Alliance Chatham, ON, Canada **Children's Minnesota** Minneapolis, MN

Children's Mercy Kansas City Kansas City, MO

Children's Specialized Hospital New Brunswick, NJ

Dana-Farber Cancer Institute Boston, MA

Hasbro Children's Hospital/ Rhode Island Hospital Providence, RI

Holland Bloorview Kids Rehabilitation Hospital Toronto, ON, Canada

IWK Health Centre Halifax, NS, Canada

Joe DiMaggio Children's Hospital at Memorial Hollywood, FL

Massachusetts General Hospital Boston, MA

Memorial Healthcare System Hollywood, FL

MHA Keystone Center Okemos, MI

Moffitt Cancer Center Tampa, FL Nationwide Children's Hospital Columbus, OH

Nemours Children's Hospital Orlando, FL

Penn State Health Hershey Medical Center Hershey, PA

Providence Health Care Vancouver, BC, Canada

Seattle Children's Seattle, WA

Society to Improve Diagnosis in Medicine Evanston, IL

SSM Health-St. Mary's Hospital Madison, WI

Stanford Health Care Stanford, CA

Thunder Bay Regional Health Science Centre Thunder Bay, ON, Canada

University of Iowa Stead Family Children's Hospital Iowa City, IA

University of Miami Health System Miami, FL

Vanderbilt University Medical Center; Family & Patient Engagement Nashville, TN

Commitments as of May 2020