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

GOING VIRTUAL!
BRINGING NASHVILLE TO YOU
AUGUST 18 TO SEPTEMBER 10, 2020

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

WITH LEADERSHIP SUPPORT FROM
VANDERBILT UNIVERSITY MEDICAL CENTER

WITH PARTNERSHIP SUPPORT FROM
Beaumont
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 family-centered 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

Conference Overview

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

- **Gain understanding** of patient- and family-centered 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:** Approval is pending for this activity by the Maryland Nurses Association which is accredited as an approver of continuing education by the American Nurses Credentialing Center’s Commission on Accreditation.

**Physicians:** An application for CME credits has been filed with the American Academy of Family Physicians. Determination of credit hours is pending.

**Social Workers:** This program is pending approval by the National Association of Social Workers.

**Patient Experience:** The program is pending approval from the Patient Experience Institute (PXI) to offer Patient Experience Continuing Education credits (PXEs.)

REGISTRATION FEES

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<th>Registration Type</th>
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<tr>
<td>Health Professionals/Individuals</td>
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<tr>
<td>Patient-Family Advisors/Leaders</td>
<td>$400</td>
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<tr>
<td>Students</td>
<td>$400</td>
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STAY CONNECTED  Follow #IPFCCVirtual2020 and @IPFCC on
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 patient- and 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.

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 well-being of residents throughout the community and beyond.
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<thead>
<tr>
<th>Day</th>
<th>Time</th>
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<tr>
<td><strong>Tuesday, August 18, 2020</strong></td>
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<tr>
<td>12:00 – 1:00 pm</td>
<td>Welcome and Opening Plenary</td>
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<td>1:30 – 2:30 pm</td>
<td>2 Concurrent Breakout Sessions</td>
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<tr>
<td>4:15– 5:00 pm</td>
<td>Virtual Happy Hour</td>
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<td><strong>Wednesday, August 19, 2020</strong></td>
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<tr>
<td>12:00 – 1:00 pm</td>
<td>Plenary Session</td>
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<td><strong>Thursday, August 20, 2020</strong></td>
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<td>11:00 – 11:30 am</td>
<td>Networking Discussion Forum (Topics to be determined)</td>
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<td>12:00 – 1:00 pm</td>
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<td>3:00 – 4:00 pm</td>
<td>Plenary Session &amp; IPFCC Partnership Award Presentation</td>
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<td>11:00 – 11:30 am</td>
<td>Ask an Expert (Topics to be determined)</td>
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<td>12:00 – 1:00 pm</td>
<td>3 Concurrent Breakout Sessions</td>
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<td><strong>Tuesday, September 1, 2020</strong></td>
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<td>11:00 – 11:30 am</td>
<td>Ask an Expert (Topics to be determined)</td>
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<td><strong>Thursday, September 10, 2020</strong></td>
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<td>11:00 – 11:30 am</td>
<td>Ask an Expert (Topics to be determined)</td>
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<td>3 Concurrent Breakout Sessions</td>
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<td>3:00 – 4:00 pm</td>
<td>3 Concurrent Breakout Sessions</td>
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<td>4:15 – 5:00 pm</td>
<td>Closing Celebration</td>
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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: A Vision for the Future**

**Beverley H. Johnson, BSN, FAAN** 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.
FEATUURED SPEAKERS

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.

Variant 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 patient- and 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.
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 family-centered care for ISQua.

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.

Combating 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 peer-reviewed 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.

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.
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 people-centred 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 cover stories. Katie’s blog, www.amothersaddictionjourney.com, reached over a million views in 146 countries within 30 days of its inception and has been syndicated in more than 30 publications, including USA Today and Babble by Disney.

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.

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.

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.
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.

Stay tuned for more program details...
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 designated with the relevant icons.

**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 post-acute 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.”

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“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.”

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