8th International Conference on Patient- and Family-Centered Care
Promoting Health Equity and Reducing Disparities

PROMOTING HEALTH EQUITY

REDUCING DISPARITIES

JUNE 11–13, 2018
BALTIMORE MARRIOTT WATERFRONT
BALTIMORE, MD
Promoting Health Equity and Reducing Disparities

The 8th International Conference provides inspiring examples of innovation in patient- and family-centered care.

With an emphasis on increasing health equity, over 100 presentations and 80 posters share advancements in partnerships 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 institutes
- Schools of medicine, nursing, and other health and helping professions

Whether beginning your patient- and family-centered efforts or focused on advanced transformation, this conference provides the information, tools, and connections to energize and further your journey.

Join us and your peers at this important event!
CONFERENCE OVERVIEW

Who Should Attend

• Patient and Family Advisors/Leaders
• Administrative Leaders and Board Members
• Patient Experience and Patient Relations Personnel
• Physicians, Nurses, Social Workers, Therapists, Pharmacists, Child Life Specialists
• Chaplains, Security, and Other Staff
• Leaders for Safety, Quality, Diversity, and Health Equity
• Researchers and Evaluators
• Human Resources Personnel
• Community-Based Agency Leaders and Personnel
• Faculty and Students in Schools of Medicine, Nursing, Social Work, and Allied Health
• Policy Makers, Government Agency Leaders, and Funders

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 partnerships among health care professionals, educators, researchers, and patients and families, particularly those from diverse and underserved communities.

• **Explore** patient- and family-centered approaches to address current priorities in health care—specifically, addressing social determinants of health and achieving health equity, reducing readmissions, decreasing harm, improving pain management and decreasing opioid use, providing safe care transitions, improving cost efficiency, and enhancing workforce capacity.

• **Discuss** how to integrate patient- and family-centered concepts in the education of health care professionals, research, quality improvement, patient safety, risk management, evaluation, strategic planning, and development of health standards.

• **Define** the roles of senior executives in providing leadership for patient- and family-centered care.

• **Delineate** patient- and family-centered best practices and related benefits, value, and outcomes.

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: This Live activity, 8th International Conference on Patient- and Family-Centered Care: Improving Health Equity and Reducing Disparities, with a beginning date of 06/11/2018, has been reviewed and is acceptable for up to 18.25 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 NASW for 16.5 continuing education contact hours.

PATIENT EXPERIENCE: The program has approval from the Patient Experience Institute (PXI) to offer 16.5 Patient Experience Continuing Education credits (PXEs.)

Important: Visa Requirements for Your Trip to the U.S.

IPFCC welcomes attendees, presenters, and exhibitors from all over the world to Baltimore, MD for The 8th International Conference on Patient- and Family-Centered Care.

Participants without a US Passport, traveling on the Visa Waiver Program, are required to have a US Travel Authorization.

With leadership support from

JOHNS HOPKINS MEDICINE

And program support from

Patient-Centered Outcomes Research Institute (PCORI)
Conference Partners

The Johns Hopkins University School of Medicine, School of Nursing and hospital are the founding institutions of modern American medicine. The teaching hospital and biomedical research facility was founded in 1889 by a philanthropist and business man, Johns Hopkins. The Johns Hopkins Hospital counts many “firsts” among its achievements during its early years: the first major medical school in the United States to admit women; the first to use rubber gloves during surgery; the first to develop renal dialysis and CPR. We are honored to provide leadership support as a partner with the Institute for Patient- and Family-Centered Care for the 8th International Conference on Patient- and Family-Centered Care.

LEADERSHIP SUPPORT FROM JOHNS HOPKINS MEDICINE

The mission of The Johns Hopkins Hospital is to improve the health of our community and the world by setting the standard of excellence in patient care. Continuous improvement efforts in clinical care, quality, and patient- and family-centered care are at the forefront of our daily work. At The Johns Hopkins Hospital, we believe that patients, families, and caregivers are often the most knowledgeable members of the care team, and can offer unique perspectives and valuable feedback regarding the care they receive.

Patient-Centered Outcomes Research Institute

PROGRAM SUPPORT FOR DIVERSITY IN RESEARCH PARTNERSHIPS

This conference is partially funded through a Eugene Washington PCORI Engagement Award from the Patient-Centered Outcomes Research Institute (EAIN-4421). The content does not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors, or Methodology Committee.

The Johns Hopkins Hospital Tour

The Johns Hopkins Hospital will be offering a tour of their facility on Sunday, June 10th from 2 – 5 pm. The tour will offer a glimpse into what makes Hopkins Hopkins! The tours will be in small groups and will include a Patient Experience coach, Patient and Family Advisory Council members, and unit staff. One area to be toured will be the Sheikh Zayed Tower for Cardiovascular and Critical Care. The tour will also feature a poster presentation expo where all areas in JHH will showcase their patient- and family-centered initiatives. This tour will fill up quickly, so go online to register early. The cost of the tour is $10.

LEARN, SHARE, CONNECT

To register for the 8th International Conference, visit: www.ipfccc.org/events/conference.html
8TH INTERNATIONAL CONFERENCE PROGRAM ADVISORY COMMITTEE

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<th>Institution/Location</th>
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<td>Physician</td>
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<td>Ottawa, ON, Canada</td>
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<td>Barbara Burke, MA, LPC</td>
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<td>Ann &amp; Robert H. Lurie Children’s Hospital of Chicago</td>
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<td>Uyara Talmate Jesus Camara</td>
<td>Registered Nurse</td>
<td>University of São Paulo</td>
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<td>São Paulo, Brazil</td>
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<td>Bryant Campbell</td>
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<td>Joanna F. Celenza</td>
<td>March of Dimes/CHaD ICN Family Support Specialist</td>
<td>Intensive Care Nursery</td>
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<td>Children’s Hospital at Dartmouth</td>
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<td>Lebanon, NH</td>
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<td>Chapel Hill, NC</td>
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<td>Sheryl Chadwick</td>
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<td>Kansas City, MO</td>
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<td>Jill MacLaren Chorney, PhD, RPsych</td>
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<td>Halifax, NS, Canada</td>
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<td>Claremont Consulting Partners</td>
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<td>Arlington, MA</td>
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<td>Jim Conway, MS</td>
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<td>Woburn, MA</td>
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<td>Liz Crocker</td>
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<td>Marlet Felzien, MA</td>
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<td>Faculty, Northeastern Junior College</td>
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<td>Marlene Fondrick</td>
<td>Patient Partner</td>
<td>Perham Health and Perham Living</td>
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<td>Calgary, AB, Canada</td>
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<td>Vancouver, BC, Canada</td>
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<td>Sylvia Hernandez</td>
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<td>Libby Hoy</td>
<td>Founder/CEO</td>
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<td>Kori Jones, MEd, BBA</td>
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<td>Farmington Hills, MI</td>
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<td>Amir Karmali</td>
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<td>Client and Family Integrated Care</td>
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The positions listed are those that individuals held at the time reviews were completed.
## Program At-A-Glance

### SUNDAY, JUNE 10, 2018

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<td>4:00–7:00 pm</td>
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### MONDAY, JUNE 11, 2018

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<tr>
<td>7:00–8:00 am</td>
<td>Registration, Continental Breakfast</td>
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<td>Networking Breakfast for Patient and Family Advisors/Leaders</td>
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<tr>
<td>8:00–9:45 am</td>
<td>Welcome and Opening Plenary Session</td>
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<tr>
<td>9:45–10:45 am</td>
<td>Poster Presentations (<em>Staffed</em>) and Break</td>
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<tr>
<td>11:00 am–12:00 pm</td>
<td>Concurrent Breakout Sessions</td>
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<td>12:00–1:30 pm</td>
<td>Lunch Break (<em>On Your Own in Baltimore Harbor</em>)</td>
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<td>1:30–2:30 pm</td>
<td>Concurrent Breakout Sessions</td>
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<td>2:45–3:45 pm</td>
<td>Concurrent Breakout Sessions</td>
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<tr>
<td>4:15–5:00 pm</td>
<td>Concurrent Breakout Sessions</td>
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<tr>
<td>5:30–7:00 pm</td>
<td>Welcome Reception</td>
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### TUESDAY, JUNE 12, 2018

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<th>Time</th>
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<tbody>
<tr>
<td>7:00–8:00 am</td>
<td>Registration, Continental Breakfast</td>
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<td>Networking Breakfast</td>
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<td>8:00–9:00 am</td>
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<td>9:15–10:00 am</td>
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<td>10:00–11:00 am</td>
<td>Poster Presentations (<em>Staffed</em>) and Break</td>
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<tr>
<td>11:00 am–12:30 pm</td>
<td>Plenary Session</td>
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<tr>
<td>12:30–1:45 pm</td>
<td>Federal Roundtable Lunch (<em>Optional – Registration Required</em>)</td>
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<tr>
<td>12:30–2:00 pm</td>
<td>Lunch Break (<em>On Your Own in Baltimore Harbor</em>)</td>
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<tr>
<td>2:00–3:00 pm</td>
<td>Concurrent Breakout Sessions</td>
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<tr>
<td>3:30–4:30 pm</td>
<td>Concurrent Breakout Sessions</td>
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### WEDNESDAY, JUNE 13, 2018

<table>
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<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>7:00–8:00 am</td>
<td>Registration, Continental Breakfast</td>
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<tr>
<td></td>
<td>Networking Breakfast: Strengthening Diversity in Research Partnerships</td>
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<tr>
<td>8:00–9:00 am</td>
<td>Concurrent Breakout Sessions</td>
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<tr>
<td>9:15–10:15 am</td>
<td>Concurrent Breakout Sessions</td>
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<tr>
<td>10:45 am–12:15 pm</td>
<td>Spotlight on Exemplars</td>
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<tr>
<td>12:15–1:45 pm</td>
<td>Lunch and Chat with Authors (<em>Registration Required</em>)</td>
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<tr>
<td>1:45–2:45 pm</td>
<td>Concurrent Breakout Sessions</td>
</tr>
<tr>
<td>3:00–4:00 pm</td>
<td>Closing Plenary</td>
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**Poster Presentations**
Interactive poster sessions with the presenters will be featured on Monday and Tuesday during the morning breaks. Come meet the presenters and discuss their work. Posters can be viewed at any time in the Exhibit and Poster area from Monday morning through Wednesday morning.

**Exhibits**
Selected vendors will feature products, services, and resources that promote and support patient- and family-centered care. Participants are encouraged to take advantage of this opportunity to network with our exhibitors in an informal atmosphere.

**2018 IPFCC Partnership Award**
Presentation of the award, recognizing teams of health care professionals and patients/families who have done innovative and collaborative projects. Information about nominations is available on our website, [www.ipfcc.org](http://www.ipfcc.org).

**Participant Meals**
For your planning purposes, a continental breakfast is included as part of your registration Monday, Tuesday and Wednesday morning.

**Guest Badge**
Guest badges may be purchased for these special activities: Welcome Reception and Continental Breakfasts (Monday-Wednesday) Cost $200.

*Guest Badge does not include participation in or attending any educational sessions.*

**Federal Roundtable**
**Tuesday, June 12th**
Enjoy a box lunch and dialogue with key leaders in Federal agencies, discussing current and future initiatives to enhance partnerships with patients and families, enhance access to quality, safe, and patient- and family-centered care, and reduce health care disparities.

*(Cost $25 – Registration required)*

**StoryCorps**

**StoryCorps' Legacy**
A team from the nationally acclaimed StoryCorps will be onsite facilitating and recording stories during the conference. Come and learn more from the team about how the StoryCorps process can assist your efforts in capturing the lived experiences of patients, families, clinicians, staff, and researchers for inspiration, education, and transformation.

**Lunch and Chat with Authors: Writing and Healing**
**Wednesday, June 13th**
In his unforgettable 2017 memoir, *CROSSINGS: A Doctor-Soldier’s Story*, Jon Kerstetter details his exceptional life of transformations: from civilian to doctor to soldier, trained to heal yet trained to kill; from doctor and soldier to stroke victim; and, eventually, from stroke patient to writer. Liz Crocker, co-author of *Privileged Presence: Personal Stories of Connections in Health Care* and *Transforming Memories: Sharing Spontaneous Writing Using Loaded Words*, will guide a conversation with Jon about both challenges and insights gained moving from healer to one who needed to be healed, what mattered most in that transition and what it meant to write and share his story. A book signing with the authors will be held directly after the session.

*(Cost $25 – Registration Required)*
Hotel Information
The Baltimore Marriott Waterfront is located in the lively Harbor East district of the city, minutes away from the Inner Harbor and Fells Point; the National Aquarium is also a short distance away. The Baltimore Marriott Waterfront overlooks the Baltimore Inner Harbor, offering an encompassing view of one of the city’s greatest assets. The harbor boasts a promenade filled with shops, restaurants and museums as well as a historic marina.

Reservations
The Baltimore Marriott Waterfront is holding a limited number of rooms for conference participants at the group rate of $249 USD until May 20, 2018. We encourage you to make your reservations early, as rooms may sell out before the cut-off date. To make your reservations, contact the hotel at (877) 212-5752 and indicate that you are with the “IPFCC 2018 International Conference” to receive the special group rate. Hotel reservations may also be made online at https://aws.passkey.com/go/PatientandFamilyCenteredCare.

Hotel reservations must be guaranteed by a major credit card. If you must cancel a reservation, the hotel requires notification 24 hours prior to arrival. Check-in is at 4:00 pm and check-out is at 12:00 pm. The special group rate will be in effect three days before and after the conference for those arriving early or extending their stay to enjoy the city. Conference attendees staying at the Baltimore Marriott Waterfront will enjoy complimentary Internet in their rooms if they are Marriott Rewards Members. To become a Marriott Rewards Member, please sign-up at the Marriott website.

Transportation & Parking
The hotel offers front door valet parking as well as off-site parking in the garage one block away. For local participants or those driving to the hotel, onsite parking fees for conference attendees are $45 USD daily for valet parking or $26 USD daily for off-site parking. Please keep in mind that the parking garage’s height clearance is 6 feet 8 inches and does not accommodate oversized vehicles.

The airport closest to Baltimore is:
- Baltimore/Washington International Thurgood Marshall Airport (Airport Code: BWI) – 12 miles from the hotel

Visit the Transportation & Parking section under Hotel & Travel on the IPFCC Conference website for complete details: www.ipfcc.org/conference.html.

Please Note: The hotel does not provide shuttle service

Dress
We encourage relaxed and comfortable business dress throughout the conference. Bring a sweater or jacket to sessions as the temperature in meeting rooms often varies. The weather in Baltimore is typically moderately humid in mid-June with highs in the mid-80’s F and lows around mid-60’s F.

Special Needs
If you have mobility challenges or other special needs, IPFCC would like to know so we can be sure your needs are met. If IPFCC can assist in making your stay more comfortable by accommodating for special needs, please let us know.

"Excellent – extremely valuable overall!!!"
—2016 Conference Attendee
Partnerships for Promoting Health Equity and Reducing Disparities

LEANA WEN, MD

Dr. Leana Wen is the Commissioner of Health in Baltimore City, where she oversees the nation’s oldest health department and is reimagining the role of local public health. Facing an unprecedented number of people dying from overdose, Dr. Wen issued a blanket prescription for the opioid antidote, naloxone, to all 620,000 residents. In two years, this program has saved 1,500 lives. Other transformative projects include a collective impact strategy that has reduced infant mortality by nearly 40 percent in seven years; an initiative to get every child glasses who needs them; and a program to engage returning citizens and hospitals in treating violence as a contagious disease.

A board-certified emergency physician, Dr. Wen was a Rhodes Scholar, Clinical Fellow at Harvard, consultant with the World Health Organization, and professor at George Washington University. She has been published in over 100 articles including in The Lancet, JAMA, and Health Affairs. The author of When Doctors Don’t Listen, she is regularly featured on NPR, CNN, New York Times, Washington Post, and USA Today. In 2016, Dr. Wen was honored to be the recipient of the American Public Health Association’s highest award for local public health work, the Milton and Ruth Roemer Award.

The Power of Patient Voice, Tragedy to Transformation

JULIA LANHAM

Julia Lanham is an advocate for patient engagement and advocacy stemming from the death of her partner, Andrea, in 2013. She works professionally as a Learning and Organizational Development Consultant in the public sector.

Graduating from Christopher Newport University, Julia also completed coursework for her Masters of Science in Leadership from Pfeiffer University. She also participates within a large North Carolina healthcare network as a representative and advocate for patient and family engagement.

Julia’s goal is to advocate well enough for the Patient Voice that Sickle Cell Disease is better understood, leading to better healthcare treatment and outcomes for those who suffer.

All Voices Matter: One Hospital’s Journey to Foster Diverse Patient and Family Engagement

DEEJO MILLER

DeeJo Miller is the Patient and Family Engagement Program Manager at Children’s Mercy Kansas City Hospital. After the life-changing event of her daughter’s cancer diagnosis in 2004, DeeJo’s focus changed from running a preschool to helping families who enter the hospital system with their children. DeeJo was hired by Children’s Mercy Kansas City as a “parent on staff” in February 2008 to share her experiences and collaborate with staff by serving as a voice of the families. She serves as the facilitator of El Consejo de Familias Latinas/Hispanas, ensuring that Spanish speaking families have a role in hospital improvement. She is the wife of a policeman.
TUESDAY

PLENARY SESSION
11:00 am–12:30 pm

Science, Story, and Stigma: Understanding and Effectively Responding to the Crisis of Opioid Overdose and Addiction

SARAH WAKEMAN, MD

Dr. Sarah Wakeman is the Medical Director for the Mass General Hospital Substance Use Disorder Initiative, program director of the Mass General Addiction Medicine fellowship, and an Assistant Professor of Medicine at Harvard Medical School. She is also the Medical Director of the Mass General Hospital Addiction Consult Team, co-chair of the Mass General Opioid Task Force, clinical lead of the Partners Healthcare Substance Use Disorder Initiative, and Medical Director of RIZE Massachusetts. She received her AB from Brown University and her MD from Brown Medical School.

She completed residency training in internal medicine and served as Chief Medical Resident at Mass General Hospital. She is a diplomate and fellow of the American Board of Addiction Medicine. She is chair of the policy committee for the Massachusetts Society of Addiction Medicine. She previously served on Massachusetts’ Governor Baker’s Opioid Task Force.

Clinically she provides specialty addiction and general medical care in the inpatient and outpatient setting at Mass General Hospital and the Mass General Charlestown Health Center. Her research interests include evaluating models for integrated substance use disorder treatment in general medical settings, recovery coaching, physician attitudes and preparedness related to substance use disorder, and screening for substance use in primary care.

A Mother’s Story: Her Journey in Becoming a Community Advocate

TAMELA MILAN-ALEXANDER, MPPA, MCH

Tamila Milan is a part of the Maternal and Child Health Partnership and Outreach team at Access Community Health Network. She completed her Master’s Degree in Public Policy and Administration from National Louis University, building on her previously completed Bachelor’s and Associate degrees.

Ms. Milan came into the maternal and child health (MCH) field because of her high-risk child, and first worked with Healthy Start to achieve family goals. She then worked for many years as a Healthy Start parent advocate and transitioned to Westside Healthy Start Consortia Chair in 2003, a role she maintains today.

Tamela has more than 15 years’ experience in the MCH community working as a peer educator, developmental screener, and motivational speaker, as well as a Healthy Start case manager. She was one of the first consumers nominated for the National Healthy Start Association (NHSA) Board of Directors, where she served for several years. Ms. Milan has grown through many of her Healthy Start friends and has represented Healthy Start nationally and locally at organizations like Today’s Black Child, Bright Futures and the American Academy of Pediatrics.

A well-respected leader, Tamela also serves on the EverThrive Board of Directors and the Illinois CHW Advisory Board, and is Co-Chair of the Westside Healthy Start Community Action Network (CAN). Tamela is the mother of six and has four grandchildren.
FEATURED SPEAKERS

FEATURED SESSION
2:00–3:00 pm
Stigma: An Impediment to Good Health Outcomes
JOHN RUIZ, CHW

John Ruiz serves as Director for Consumer Engagement at the Commonwealth Care Alliance (CCA) in Boston, MA. He has over 35 years of professional experience in advocacy on behalf of marginalized populations and in human service and anti-poverty programs. He is trained in human service administration, community health work, and training facilitation. He is an experienced trainer for human service providers in the service of marginalized populations. He has experience in conducting one-on-one and group-level interventions on stigma and inspired many to manage internalized stigma and take control of their health and well being. He has personal experience living with HIV/AIDS for over 34 years and the resulting stigma.

WEDNESDAY

FEATURED SESSION
10:45 am–12:15 pm
Pursuit of Health Equity: Progress, Challenges, and Promise
A Panel Discussion
DORIANE MILLER, MD

A general internist, Doriane Miller, MD, has been providing care to under-served minority populations for more than 20 years. In addition to her role as a primary care physician, she has a special interest in behavioral health.

Under her leadership, physicians, educators and community members work to improve population health outcomes for residents on the South Side of Chicago through community-engaged research, demonstration and service models.

Dr. Miller’s research focuses on the intersection of health disparities and race. She has served as the project director for several studies designed to augment care by promoting collaboration among physicians, patients and families. Dr. Miller’s work in the area of improving asthma outcomes through school and community interventions was noted by the American Academy of Asthma, Allergy and Immunology with a 2006 Special Recognition Award. Dr. Miller also served on the PCORI Addressing Disparities Advisory Panel from 2013-2017 as co-chair.

JOE GALLAGHER

Joe Gallagher, Kwunuhmen, is Coast Salish of Tla’Amin First Nation ancestry and serves as the Chief Executive Officer for the First Nations Health Authority. Over the past decade, Mr. Gallagher was a lead in the formation of a new health governance partnership between BC First Nations, the province of BC, and the government of Canada which included the negotiation of the successful transfer of federal health services to BC First Nations control. This work, a first for Canada, led to the formation of the First Nations Health Authority, a wellness organization driven by the First Nations holistic and traditional perspective of health and wellness. A senior leader in health for the past 10 years, Joe brings over 25 years’ experience in community development, intergovernmental affairs and negotiations. Throughout his career, Joe has worked with all levels of government, First Nations communities and organizations in both rural and urban settings.

Prior to joining the University of Chicago in January 2009, Dr. Miller served as national program director of New Health Partnerships, a demonstration project funded by The Robert Wood Johnson Foundation and the California Health Care Foundation on collaborative self-management support.
CHERIE CRAFT, BS, MEd

Cherie Craft possesses a passionate commitment to bettering the lives of children and families “at-risk,” having grown up in a housing project in inner city Boston. With a BS in Sociology and a MEd in Counseling Psychology, Ms. Craft gained much of her early professional experience working in the Department of Pediatrics at Boston Medical Center, formerly Boston City Hospital. Initially recruited as a Family Advocate/Case Worker, before being recruited to lead the movement toward family-centered care. Ms. Craft created the program, Parents as Partners, where she recruited, trained, and supervised diverse parent advocates from the community. She and her advocates taught the principles and practices of family-centered care to medical students and residents.

Ms. Craft then went on to work closely with SAMSHA, US Administration for Children and Families and the Federation of Families for Children’s Mental Health, on a number of community-based outreach, education and evaluation initiatives. Currently employed as the CEO/Founding Executive Director of Smart from the Start, in Boston and Washington, DC, she leads programs, which recognize and build on the strengths of individuals and families despite their challenges, and creates opportunities for them to take their place at the table and for their voices to be heard.

Ms. Craft serves as IPFCC senior faculty, and sits on the Community Advisory Board of Boston Children’s Hospital. She served two terms on the National Expert Panel on Substance Abuse and Child Welfare, and is widely recognized as a leading authority on cultural competence, community engagement and empowerment, and family support.

B. LEE GREEN, PhD

B. Lee Green, PhD, is the vice president of Diversity, Public Relations and Strategic Communications for Moffitt Cancer Center. He is also a professor in the Health Outcomes and Behavior Program at Moffitt. As VP for Diversity, Dr. Green is responsible for ensuring that Moffitt is responsive and actively creating a culture of diversity and inclusion as it strives to contribute to the prevention and cure of cancer. This includes addressing issues such as awareness and education of cancer prevention and control, community outreach activities, cultural competency, equity and inclusion issues, development of strong partnerships with community organizations and support for other key initiatives. In 2014, Dr. Green added the role of vice president for Public Relations and Strategic Communications with responsibility for guiding the institutional strategy for both internal and external communications.

Dr. Green’s research interests focus on cancer health disparities, particularly minority participation in research studies. His work related to minority participation in research studies led to Dr. Green’s membership on the Tuskegee Syphilis Study Legacy Committee and an invitation to the White House for the formal governmental apology.

Prior to joining Moffitt in 2006, he was an associate professor in the College of Education and Human Development at Texas A&M University. He was also the director of the Texas A&M University Center for the Study of Health Disparities. He serves on various national and regional advisory boards.

LUNCH AND CHAT WITH AUTHORS
12:15–1:45 pm

JOHN KERSTETTER, MD, MFA

Unfulfilled by his business career, Jon Kerstetter enrolled in medical school at thirty-four to pursue his long-held dream of becoming a doctor. After graduating, he practiced emergency medicine, but was soon frustrated by the many mundane cases that passed through his ER. Despite the fact that, at forty-two, he was older than the maximum age for commissioning, Kerstetter was given an age waiver and accepted into the Iowa Army National Guard, eventually becoming a flight surgeon. His thirst for intensity led him to volunteer in war-torn Rwanda, Kosovo, and Bosnia. His military experienced culminated in three tours in Iraq at the height of the fighting.
At the peak of his military and medical career, Kerstetter had a stroke; within hours, his life as a soldier and physician was over. Left with serious cognitive and physical disabilities compounded by PTSD and excruciating pain, he began his painstaking, years-long recovery efforts, the intimate details of which he shares in his 2017 memoir, *CROSSINGS: A Doctor-Soldier’s Story.*

At a loss to come up with vocational rehab appropriate for Kerstetter’s background, his neuropsychologist suggested he try an experimental therapy: writing about his medical and war experiences as a way to help him order his thinking, reform vital brain connections, and, ultimately, heal.

**In Conversation: Writing and Healing**

**LIZ CROCKER, BA, MEd**

In addition, she has been a Clinical Teaching Associate with the Learning Resource Centre at Dalhousie University working as a Simulated Patient with medical students. She has created and directed a large Child Life Department, served as Treasurer and President of the Board of the Association for the Care of Children's Health, and was President of the Canadian Institute for Child Health. Liz has been a hospital trustee and now serves on the board of a hospital foundation. Liz is also a Board Member of the Saskatchewan Health Quality Council. In the past, she has been a broadcaster and journalist, worked in the political arena, and mentored young entrepreneurs. Along with Bev Johnson, she co-authored *Privileged Presence,* which is now in its second edition. She is the lead author of a new book, *Transforming Memories, Sharing Spontaneous Writing Using Loaded Words.* Liz is a fun-loving grandmother to three children.

**CLOSING PLENARY SESSION**

3:00–4:00 pm

Enhancing Partnerships with Patients and Families in New Models of Care

**TOYIN AJAYI, MD, MPHIL**

Dr. Toyin Ajayi is Chief Health Officer at Sidewalk Labs’ Care Lab, a New York–based health and social services company focused on providing integrated health and social care for low-income urban populations with complex health and social needs. Prior to this, Dr. Ajayi served as Chief Medical Officer at Commonwealth Care Alliance (CCA), a Massachusetts nonprofit health plan and integrated care delivery system created to provide high quality care to people with complex health needs. In this role, she directed clinical programs and oversaw clinical care delivery, care management, and clinical operations.

Dr. Ajayi is a board-certified family physician and maintains an active clinical practice. Prior to joining CCA in 2013, Dr. Ajayi was an attending physician at BMC’s Department of Family Medicine where she was awarded the Department’s Faculty Teaching Award in 2013, and a clinical instructor at Boston University’s School of Public Health.

Dr. Ajayi received her undergraduate degree from Stanford University; an MPhil from the University of Cambridge; and her medical degree, with Distinction in Clinical Practice, from King’s College London School of Medicine.

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**LEARN, SHARE, CONNECT**

To register for the 8th International Conference, visit: [www.ipfcc.org/events/conference.html](http://www.ipfcc.org/events/conference.html)
HEALTH EQUITY THROUGH PARTNERSHIPS
Initiatives grounded in collaboration with underserved and vulnerable communities to eliminate disparities in health and health care.

PATIENT AND FAMILY ADVISORS—ESSENTIAL ALLIES
Strategies and tools proven effective in establishing patient and family advisory programs and in expanding roles for experienced patient and family advisors/leaders.

ROLE OF LEADERSHIP
Leadership practices resulting in widespread adoption of PFCC, cultural competency, and measurable change.

BETTER TOGETHER—PATIENTS AND FAMILIES AS PARTNERS IN HOSPITALS
Policies and practices implemented by hospitals to welcome and engage patients and families as partners in care and decision-making.

PARTNERSHIPS IN PRIMARY AND OTHER AMBULATORY CARE
Programs in which patients and families fundamentally drive transformation, outcomes, and experience.

PARTNERSHIPS IN RESEARCH AND EVALUATION
Studies and projects that reflect PFCC planned and conducted with patients and families, including those from typically under-represented communities.

EDUCATION FOR INTERPROFESSIONAL AND COLLABORATIVE PRACTICE
Educational programs planned and delivered in partnership with patient and family faculty.

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

DESIGN
Environment and design projects with meaningful involvement of patients and families in planning.
MONDAY CONFERENCE SESSIONS

JUNE 11, 2018

7:00-8:00 AM
SPECIAL NETWORKING BREAKFAST
Networking Breakfast for Patient and Family Advisors/Leaders

8:00–9:45 am
WELCOME
Bev Johnson, President and CEO, Institute for Patient- and Family-Centered Care, Bethesda, MD
Redonda Miller, MD, MBA, President of The Johns Hopkins Hospital, Baltimore, MD

OPENING PLENARY SESSION

Partnerships for Promoting Health Equity and Reducing Disparities
Leana Wen, MD, Commissioner of Health; Baltimore City Health Department, Baltimore, MD

The Power of Patient Voice, Tragedy to Transformation
Julia Lanham, Member, Patient and Family Advocate, Sickle Cell Community Advisory Board; Carolinas Health System, Charlotte, NC

All Voices Matter: One Hospital’s Journey to Foster Diverse Patient and Family Engagement
DeeJo Miller, Patient and Family Engagement Program Manager, Center for Clinical Effectiveness; Children’s Mercy Kansas City, Kansas City, MO

9:45–10:45 am
POSTER PRESENTATIONS/EXHIBITS
Visit with the Poster presenters, connect with exhibitors, and enjoy refreshments.

DAY AT-A-GLANCE

7:00–8:00 am
Registration, Continental Breakfast
Networking Breakfast for Patient and Family Advisors/Leaders

8:00–9:45 am
Welcome and Opening Plenary Session

9:45–10:45 am
Poster Presentations (Staffed) and Break

11:00 am–12:00 pm
Concurrent Breakout Sessions

12:00–1:30 pm
Lunch Break (On Your Own in Baltimore Harbor)

1:30–2:30 pm
Concurrent Breakout Sessions

2:45–3:45 pm
Concurrent Breakout Sessions

4:15–5:00 pm
Concurrent Breakout Sessions

5:30–7:00 pm
Welcome Reception

11:00 am–12:00 pm
CONCURRENT SESSIONS (A1-A10)

A1
Accepting the Challenge: One Team’s Journey to Authentic Engagement of Patient Family Advisors
Libby Hoy, BS, Founder, Chief Executive Officer; Stephen Hoy, BS, Chief Operating Officer; PFCCpartners, Long Beach, CA; Kayle Doyle, MBA, Program Manager; Brittany Wiley, BA, MEd, Senior Quality Improvement Facilitator; Telligen, Greenwood Village, CO

A2
Embracing the Voice of the Patient Through Active Participation on Hospital Committees
Sandra Kaus, BA, Member, Patient and Family Advisory Council for Quality and Safety; Nicole Duncan, BS, Assistant Vice President; Yasmin Yusuf, MHA, Administrator; Mary Herold, BSN, RN, System Clinical Safety Programs Operations Manager; MedStar Georgetown University Hospital, Washington, DC
A3

Engagement Capable Environments: Lessons Learned from Exemplar Organizations
G. Ross Baker, PhD, Professor, University of Toronto, Institute of Health Policy, Management, and Evaluation, Toronto, Ontario; Anya Humphrey, BA, Patient and Family Advisor; Christine Maika, MPH, BS, Senior Improvement Lead; Carol Fancott, PhD, BScPT, MSc, Director, Patient and Citizen Engagement; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario

A4

Implementing True Welcoming on Inpatient Psychiatry
Stacey Ward, RN, BSN, Nurse Manager, Inpatient Psychiatry; Amy Cohen, PhD, Director of Patient and Family Experience; Kate Purcell, Patient/Family Advisor, The University of Vermont Medical Center, Burlington, VT

A5

The Power of Personal Health Data: Exploring How Connected Health Benefits a Family-Centered Culture
Carrie Mamantov, BA, BS, Marketing Consultant; Alyx Vu, BA, PMP, Consultant; Orlando Chapa, NE-BC, RN, DNP, AVP Nursing; Cook Children’s, Fort Worth, TX

A6

Simulation-Based Education for Caregivers of Device-Dependent Children
Normaliz Rodriguez, MD, Pediatric Emergency Medicine Fellow; The Children’s Hospital of Minnesota, Visiting Fellow in Pediatrics; NewYork-Presbyterian Weill Cornell Medicine; Courtney Nataraj, Chair, Family Advisory Council; NewYork-Presbyterian Phyllis and David Komansky Children’s Hospital, New York, NY

A7

Centro SOL: A Community-Academic Partnership Promoting Health and Opportunities for Latinos in Baltimore
Flor Giusti, LCSW, Social Worker; Sarah Polk, MD, Assistant Professor Department of Pediatrics; Johns Hopkins University School of Medicine, Medical Director, Children’s Medical Practice; Johns Hopkins Bayview Medical Center; Kathleen Page, MD, Associate Professor, Division of Infectious Disease; Johns Hopkins University School of Medicine, Medical Director, HIV Clinic, Moore Clinic; Monica Guerrero Vazquez, BA, Program Coordinator; Johns Hopkins Centro Sol; Jennifer Mendez, BA, Student; University of Maryland, Baltimore County; Maribel Martinez, Advisory Board Member; Isabel Fernandez Abaunza, Community Outreach Specialist; Johns Hopkins Centro SOL, Baltimore, MD
A8
Developing a Research Agenda to Prevent and Control Cardiovascular Disease in Central Appalachia
Hadii Mamudu, MPA, PhD, Associate Professor; Timir Paul, MD, PhD, Assistant Professor; Liang Wang, MD, DrPH, Associate Professor; Mary Littleton, PhD, Associate Professor; East Tennessee State University; Lynn Frieron, BS, President; Mended Hearts; Johnson City, TN

A9
Engaging Racially and Ethnically Diverse Parents in Developing Measures of Family Centered Care in the NICU
Krista Sigurdson, BA, PhD, Postdoctoral Researcher; Stanford Neonatology, Stanford, CA; Lelis Vernon, Parent Advisor; NICU Baptist Children’s Hospital of Miami, Miami, FL; Jochen Profit, MD, MPH, Associate Professor; Stanford Neonatology and California Perinatal Quality Care Consortium, Stanford, CA; Linda Franck, RN, PhD, MSN, Professor; UCSF School of Nursing, San Francisco, CA

A10
I Wish You Knew...Patients, Parents, and Providers Share Perspective from the Bedside
Rebecca Trexler, BA, Patient and Family Centered Care Project Administrator; Tricia Willis, BSN, RN, Patient and Family Centered Care Coordinator; Suzanne Mead, MA, BA, Parent Advisor on Staff; Johns Hopkins Children’s Center, Baltimore, MD

1:30–2:30pm
CONCURRENT SESSIONS (B1-10)

B1
Eleven Years and Going Strong: Nourishing a Healthy and Thriving Family Advisory Council
Donna Provenzano, BS, Director, Family-Centered Care; Christian Pirl, BS, Member, Family Advisory Council; Pat O’Hanlon, Coordinator, Family-Centered Care, Family Advisor; Children’s Specialized Hospital, New Brunswick, NJ; Linda Waddell, BS, Family Faculty; Children’s Specialized Hospital, Mountainside, NJ

B2
Embedding a Culture of Patient and Family Centered Care: Patient Advisors Partnering with Leaders to Impact Strategic Organizational Priorities
Linda Fahey, RN, MSN, NP, Regional Director, Care Experience & Patient and Family Centered Care; Susie Becken, Patient Advisor; Barbara Lewis, MBA, Patient Advisor and Co-Chair, Regional Patient Advisory Committee; Kaiser Permanente Southern California, Pasadena, CA

B3
Patient and Family Involvement in Governance of Learning Healthcare Systems
Steven Joffe, MD, MPH, Chief, Division of Medical Ethics, Emanuel and Robert Hart Professor of Medical Ethics and Policy, Professor of Pediatrics; Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA; Rachel Grob, PhD, Senior Scientist, Director of National Initiatives, Associate Clinical Professor, Department of Family Medicine; University of Wisconsin, Madison, WI; Paul McLean, BA, Patient Advocate, Author; Brookline, MA

12:00–1:30 pm
LUNCH
Lunch on your own. Enjoy lunch at one of Baltimore Harbor’s renowned restaurants.
B4  Patients and Families as Leaders: Partnering with Patients and Families in the Design, Delivery, and Evaluation of the Better Together Campaign in Canada
Christine Maika, MPH, Senior Improvement Lead; Angela Morin, Patient Experience Advisor; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario

B5  Demystifying Patient Engagement: Principles and Strategies
Karen Estrin, Engagement Leader; British Columbia Patient Safety and Quality Council, Vancouver; Cathy Almost, MA, Engagement Leader; British Columbia Patient Safety and Quality Council, Terrace; Cherie Mercer, Patient Partner; Patient Voices Network, Gitlax'taamiks, British Columbia

B6  No Show, Oh No! Engaging Patients and Families in Improving Appointment Adherence
Lauren Tanzer, MBA, MS, PMP, Program Manager, Pediatrics; Darlene Barkman, MA, Family Consultant; Children’s Hospital of Philadelphia, Philadelphia, PA

B7  Every Voice Matters: StoryCorps Legacy in Partnership with Stanford Health Care
Eddie Gonzalez, MFA, Manager, Community Training; StoryCorps, Brooklyn, NY; Bryanna Gallaway, MPA-HSA, CPXP, Director, Service Excellence; Dan Roskowski, MPH, Project Manager, Service Excellence; Stanford Health Care, Stanford, CA

B8  Person and Family Centered Care in Mental Health and Substance Use Services: A Whole Continuum Approach to Improve Health Equity
Natalie McCarthy, MSW, Director, Mental Health and Substance Use, VCH-Richmond; Lisa Ramage, BA, Registered Psychiatric Nurse, Manager, Mental Health and Addictions; Lynn Ottoson, Nurse, Inpatient Mental Health; Sheila Dunn, MA, Partner Advisor, Mental Health and Substance Use, VCH-Richmond; Mike Tibbles, CEBS, CPHR, Partner Advisor, Mental Health and Substance Use, VCH-Richmond; Andrew Birch, Parent Advisor; Vancouver Coastal Health Authority, Richmond, British Columbia

B9  Reflections on the Research Process and Communication Strategies in a PCORI-Funded Project
Amanda Young, PhD, Associate Professor; Joy Goldsmith, PhD, Associate Professor; M. Paige Powell, PhD, Assistant Professor; University of Memphis; Marlene Strong, Member, Patient and Family Council and Patient Stakeholder Council; United for Better Health Outcomes, Memphis, TN; Judy Seals-Togbo, MSW, Manager, Faith-based Initiatives and Minority Health Programs; Mens Health Network, Washington, DC

B10  A Multi-Disciplinary Partnership to Create a Patient Story Workshop and Family Faculty Program
Kelly Loyal, BA, Family Faculty; Angela Egner, BA, MA, Chief Learning Officer; Caroline DeLongchamps, BS, Manager, Patient and Family Centered Care; The Medical University of South Carolina, Charleston, SC
2:45–3:45 pm
CONCURRENT SESSIONS (C1-C10)

C1
Pediatric Transition: Patient Advisor Roles for Positive Experiences Among Young Patients – The PAROLE-Pediatric Transition Program
Marie-Pascale Pomey, MD, PhD, Professor and Physician; University of Montréal and CRCHUM; Anne Fournier, MD, Physician; Centre Hospitalier Universitaire de Ste-Justine; Guillaume Dumais-Lesvesque, Medical Student; University of Montréal; Lino Durand, Patient Advisor; Centre Hospitalier Universitaire de Ste-Justine, Montréal, Quebec

C2
Partners Against Harm: Engaging the Family Voice in Infection Prevention
Darlene Barkman, MA, Family Consultant; Victoria Barkwell, MBA, BSN, RN, Safety Quality Specialist; Jeneane Sullivan, MSN, RN, CPON, Patient/Family Education Nurse Specialist; Children’s Hospital of Philadelphia, Philadelphia, PA

C3
Collaborative Community: Driving Best Practices Among Patient and Family Advisory Councils in a Large Health System
Takiya Reavis-Benjamin, BS, MBA, MPH, Manager, Patient Experience; Johns Hopkins Bayview Medical Center, Baltimore, MD; Vicki Stearn, BS, Patient and Family Advisor Co-Chair; Suburban Hospital, Bethesda, MD; Patricia Eanet, BA, JD, Patient and Family Advisor Co-Chair; Sibley Memorial Hospital, Washington, DC; Charlene Rothkopf, BA, MA, Clinical Community Co-Chair; The Johns Hopkins Hospital, Baltimore, MD

C4
The Spread of Interdisciplinary Bedside Rounding Across the Health System in One Canadian Province
Adrienne Danyliw, RD MSc, Policy and Project Consultant; Jenny Basran, MD, Geriatrician; Joy Stang, BA, Patient and Family Advisor/Advocate; Health Quality Council Saskatchewan, Saskatoon, Saskatchewan

C5
Opening up Mental/Behavioral Health Notes Directly to Our Patients: Lessons Learned From 3+ Years of Transparency
Stephen O’Neill, MSW, LICSW, BCD, JD, Social Work Manager for Psychiatry and Primary Care; Beth Israel Deaconess Medical Center, Harvard Medical School; Stacey Whiteman, Patient Advisor; Beth Israel Deaconess Medical Center, Boston, MA

C6
Patient and Family Engaged Care: Shifting Policies and Culture to Improve Health and Reduce Disparities
Cynthia Baur, PhD, Endowed Chair and Director; Herschel S. Horowitz Center for Health Literacy, College Park, MD; Janice Tufte, Patient Stakeholder and Co-Investigator; Hassanah Consulting, Seattle, WA; Melissa Simon, MD, MPH, Professor, Department of Obstetrics & Gynecology, Preventive Medicine; Northwestern University Feinberg School of Medicine, Chicago, IL; Kalpana Ramiah, DrPH, MSc, CPH, Director of Research; America’s Essential Hospitals; Michelle Johnston-Fleece, MPH, Senior Program Officer; National Academy of Medicine, Washington, DC; Kimberlydawn Wisdom, MD, MS, Senior Vice President of Community Health & Equity, Chief Wellness & Diversity Officer; Henry Ford Health System, Detroit, MI
C7
Integrating Equity and Quality: A Multidisciplinary Approach to Hypertension Equity Through Partnerships with Patients, Clinical Staff, and Community Allies
Sarah Cox, MSPH, BSBA, Population Health Project Manager and Analyst; LaKisha Garduño, BA, MD, Interim Medical Director, Potrero Hill Health Center; Menelik (Alonzo) Walker, Patient Advisor; Southeast Health Center; San Francisco Health Network—Primary Care, San Francisco, CA

C8
10-Step: Mapping and Resourcing Patient and Stakeholder Engagement
Hillary Edwards, MPH, Associate Director of Program Management & Evaluation, PATIENTS Program; University of Maryland School of Pharmacy; Barbara Jean Robinson-Shaneman, Founding Executive Director; St. Matthew’s Community Long-Term Outreach Center, Baltimore, MD

C9
Researcher-Patient Engagement: How Lived Experience Shaped Asthma Disparities Research To Be Patient-Centered
Lisa Stewart, MA, Engagement Officer; PCORI, Washington, DC; Elliot Israel, MD, Professor of Medicine; Brigham and Women’s Hospital, Pulmonary Division, Boston, MA; Stephen Teach, MPH, MD, Chair, Department of Pediatrics; Children’s National Health System, Washington, DC

C10
Teaching and Role Modeling Patient and Family-Centered Care from Day One: The Role of Patient Family Advisors in New Hire and Nursing Orientation
Derek Drake, RN, NE-BC, DNP, CNML, CNL, Chief Nursing Officer; Mary Knighten, RN, NE-BC, DNP, Patient/Family Advisor, Former CNO/VP Patient Care Services; Alice Gunderson, BS, BA, Lead Patient/Family Advisor; St. Francis Medical Center, Lynwood, CA

4:15–5:00 pm
CONCURRENT SESSIONS (D1-D10)

D1
The Success and Challenges of Creating a Patient Advisory Committee
George Keulan, MDiv, Patient Advocate, Founder, Patient Advisory Committee; Providence Health Care, Vancouver, British Columbia

D2
Patients as Partners: Neonatal Allies in Quality Improvement
Madeleine Ottosen, PhD, RN, Assistant Professor; University of Texas Health Science Center at Houston School of Nursing; Kim Hokanson, MSN, RN-BC, Nursing Manager, NICU; Meghann Andrew, BA, Parent Advisor; Children’s Memorial Hermann Hospital, Houston, TX; Klaus Nether, DHSc, MT(ASCP) SV, MMI, CSSMBB, Director, Solutions Development; Joint Commission Center for Transforming Healthcare, Oakbrook Terrace, IL
MONDAY CONFERENCE SESSIONS

D3
An Unconventional Use of Lean Principles to Improve the Patient Experience at NYC Health + Hospitals/Bellevue
Linda Lombardi, PhD, Chief Experience/Strategy Officer; Nathan Link, MD, Medical Director; NYC Health + Hospitals/Bellevue, New York, NY

D4
Improving Hospitalists’ Communication with Patients and Families
Toby Levin, JD, Patient/Family Advisor; Shanthi Nadar, MD, Senior Hospitalist; Suburban Hospital, Bethesda, MD

D5
Development of CenteringPregnancy Program for Latina Women in Baltimore
Rachel Chan-Seay, MD, Centering Program Facilitator; Catalina Humphrey, Program Coordinator; Jacqueline Burg, MHA, Program Administrator; Melissa Pelaez-Linares, Patient Advisor and Program Participant; Johns Hopkins Bayview Medical Center, Baltimore, MD

D6
Testing a Culturally Adapted Family Model of Diabetes Self-Management Education with Marshallese in Arkansas
Pearl McEllish, MBA, PhD, Associate Vice Chancellor; Jellesen Rubon-Chutaro, Community Research Coordinator; University of Arkansas for Medical Sciences, Fayetteville, AR

D7
Measuring Perceptions of Client-Centered Care by Clients, Families, and Staff in an Adult Day Home Setting
Dee-Ann Schwanke, MSc, Chair, Parent Advisory Group for ECHO (Evidence in Child Health to Enhance Outcomes); Capital Care, Edmonton, Alberta

D8
Partnering with Patients and Families to Advance Kidney Research in Canada
Helen Chiu, MHA, MS, Patient Engagement Liaison; Leah Getchell, MA, Coordinator, Communications & Patient Partnerships; Can-SOLVE CKD Network, Vancouver, British Columbia

D9
Partnerships in Research: Supporting Meaningful Engagement of Patients and Families on Research Teams
Agnes Black, BSN, MPH, Director, Health Services & Clinical Research and Knowledge Translation, Professional Practice; Christine Wallsworth, Volunteer; Providence Health Care, Vancouver, British Columbia

D10
Developing Leadership Skills for African American Patients with Serious Mental Illness
Sonya Ballentine, BS, Project Manager; Lindsay Sheehan, PhD, Senior Research Associate; Illinois Institute of Technology, Chicago, IL
TUESDAY CONFERENCE SESSIONS

JUNE 12, 2018

7:00–8:00 am
SPECIAL NETWORKING BREAKFASTS

8:00–9:00 am
CONCURRENT SESSIONS (E1–E10)

E1
The Journey of the Development and Growth of the Family Advisory Council at Maria Fareri Children’s Hospital from Its Inception to Its 5th Year Anniversary
Annmarie Shisler, RN, BSN, PCCN, Family Advisory Council Member; Mary Delaney, MSW, Director of Family Support and the Family Resource Center; Megan McDonnell Busenbark, Family Advisory Council Member; Maria Fareri Children’s Hospital at Westchester Medical Center, Valhalla, NY

E2
Patient and Family Surveyors: Quality Detectives Par Excellence!
Mireille Brosseau, MA, Program Manager, Patient Partnerships; Mario Di Carlo, BA, Patient Partner; Health Standards Organization, Ottawa, Ontario; Suann Laurent, RN, BSN, MHS, Chief Operating Officer; Saskatchewan Health Authority, Saskatchewan; Marie-Pascale Pomey, PhD, Professor/Researcher, University of Montréal, Montréal, Quebec

E3
Powerful Partnerships: Patients and Families Drive Enhancements in the Children’s Mercy’s Strategic Planning Process
Stacey Koenig, MS, Senior Director; Sylvia Hernandez, MSW, Program Manager, Volunteer and Guest Services; Krista Nelson, BS, Director, Innovation Development; Children’s Mercy Hospital, Kansas City, MO

E4
Leading Patient and Family Centered Care in a Matrix Organization – Opportunities, Challenges and Stories to Learn From
Georgiann Ziegler, AD, Patient Advisor; Linda R. Larin, MBA, FACHE, Associate Hospital Director for Cardiovascular and Neurosciences Programs; Molly Dwyer-White, MPH, Administrative Director, Office of Patient Experience; Michigan Medicine, Ann Arbor, MI

E5
Better Together: Partnering with Families — Education and Support for NYC Hospitals
Deborah Dokken, MPA, Coordinator for Patient and Family Partnerships; Institute for Patient- and Family-Centered Care, Bethesda, MD; Evelyn Borges, MSN, Senior Associate Director; New York City Health + Hospitals/Bellevue; Alfreda Weaver, RN, MSN, Director; New York City Health + Hospitals, New York, NY
E6
Engaging Patients in Preparation to Transition Safely Between Ambulatory Settings
Sue Collier, BSN, MSN, RN, Interim Vice President of Clinical Quality; Health Research & Educational Trust, Chicago, IL; Tiffany Christensen, BA, Vice President, Experience Innovation; The Beryl Institute, South Lake, TX; Kristina Davis, BS, MSN, MS, MPH, RN, Program Manager; Health Research & Educational Trust, Chicago, IL

E7
Engagement Practices Among High-Performing Community Organizations Pursuing the Triple Aim
Christine Maika, MPH, Senior Improvement Lead; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario; David Caten, PARC Relief Housing Worker and COTA Peer Specialist; PARC Parkdale Activity-Recreation Centre, Toronto, Ontario

E8
Infant Mortality Reduction Initiative: Bridging Medical and Behavioral Health Strategies to Address Racial and Health Inequities
Kelly McKay, MSW, Program Coordinator; Cheron Phillips, Advisor; Richelle Smith, Advisor; St. Louis Integrated Health Network, St. Louis, MO

E9
PFCC Tools and Dashboard: Integrating a System Approach
Dana Snyder, MBA, Program Manager, PFCC; Lisa Muma, RN, BSN, Pediatric Oncology Nurse Navigator; Beverly Crider, Patient/Family Advisor; Lauren Osantowski, Director, Nursing Analytics; Beaumont, Southfield, MI

E10
Developing a Multi-Level Model for Patient Engagement in a Practice-Based Research Network
Nate Warren, MPH, Research Associate; Deirdre Baker, Patient Investigator; Nikki Stover, Research Coordinator; OCHIN, Inc., Portland, OR

9:15–10:00 am
CONCURRENT SESSIONS (F1-F10)

F1
PFAC Statewide Collaboration to Improve Patient/Family-Centered Care
Donna Drouin, MS, PFAC Advisor and Co-Chair; Middlesex Hospital, Middletown, CT; Ellen Crowe, BSN, RN, Director, Clinical Excellence & Care Redesign; Connecticut Hospital Association, Wallingford, CT

F2
Partnering with Peer Mentors to Improve Outcomes for Patients with Diabetes
Ashwin Patel, BA, MD, PhD, Chief Medical Officer; Shaun Persaud, BA, MPH, Clinical Coordinator; InquisitHealth, River Edge, NJ; Celia Shmukler, MD, Medical Director; 1199SEIU National Benefit Fund, New York, NY

F3
Families at the Forefront: Making Patients’ Families Strategic Partners in Driving Hospital-Wide Experience Efforts
Marcie Brostoff, MS, RN, NE-BC, Associate Chief Nurse and Vice President, Nursing/Patient Care & Clinical Operations; Katie Litterer, BA, Family Partnerships Coordinator, Boston Children’s Hospital, Boston, MA
F4  
Patient and Family Centered Care and Infection Prevention Efforts for Pediatric Spinal Surgery: Differing Priorities Within Systems of Care  
Tina Steen, Parent Partner; University of Colorado Anschutz Medical Campus; Lisa McLeod, MD, Assistant Professor, Pediatric Hospital Medicine; University of Colorado Anschutz Medical Campus, Aurora, CO

F5  
The Centering Healthcare Model: A Model of Patient- and Family-Centered Care to Achieve Health Equity  
Alia Rawji, BS, Practice Services Manager; Sunshine Muse, BA, Consultant & Health Disparities Contractor; Centering Healthcare Institute, Boston, MA

F6  
Sharing Our Medicine – Taking Steps in a Journey to Indigenous Culturally Competent Care  
Neil Fowler, Project Assistant, Urban Health & Aboriginal Health; Kate McNamee, RN, MSN, Practice Consultant - Leader Care Experience; Providence Health Care, Vancouver, British Columbia

F7  
Peer Navigation in Transgender Care: A Case Study in CoDesigning Care  
Jonathan Bullock, BA, National Lead, Person and Family Centered Care; Janet Borrowman, CPXP, CHIE, Director, National Care Experience; Kaiser Permanente, Oakland, CA

F8  
ORIEN: A National Partnership to Promote Data Sharing and Collaborative Learning to Advance Cancer Research in Diverse Populations  
Barney Morris, ORIEN Patient Advisory Council Member; ORIEN, Tampa, FL

F9  
New Standards in Blood Collection: Lessons in Patient-Inspired Innovation  
Eric Stone, MBA, Chief Executive Officer & Co-Founder; Velano Vascular, San Francisco, CA; Patrick Charmel, President & Chief Executive Officer; Joan R., Patient Advisor, Griffin Health, Derby, CT

F10  
Patient Empowerment in the Age of Digital Health: What Do Patients Say?  
Tracie Risling, RN, PhD, Assistant Professor; Tyler Moss, Patient Co-Investigator; University of Saskatchewan, Saskatoon, Saskatchewan

10:00–11:00 am

POSTER PRESENTATIONS/EXHIBITS
Visit with the Poster presenters, connect with exhibitors, and enjoy refreshments.
TUESDAY CONFERENCE SESSIONS

11:00 am–12:30 pm

PLENARY SESSION

Science, Story, and Stigma: Understanding and Effectively Responding to the Crisis of Opioid Overdose and Addiction

Sarah E. Wakeman, MD, Medical Director, Substance Use Disorders Initiative, Program Director, Addiction Medicine Fellowship; Mass General Hospital, Boston, MA; Assistant Professor of Medicine; Harvard University, Cambridge, MA

A Mother’s Story: Her Journey in Becoming a Community Advocate

Tamela Milan-Alexander, MPPA, MCH, Partnership and Outreach Worker; Access Westside Healthy Start Community Action Network, Chicago, IL

12:30–1:45 pm

FEDERAL ROUNDTABLE

Enjoy a box lunch and dialogue with key leaders in Federal agencies, discussing current and future initiatives to enhance partnerships with patients and families, enhance access to quality, safe, and patient- and family-centered care, and reduce health care disparities.

(Cost $25 – Registration required)

12:30–2:00 pm

LUNCH

Lunch on your own. Enjoy lunch at one of Baltimore Harbor’s renowned restaurants.

2:00–3:00 pm

CONCURRENT SESSIONS (G1-G10)

G1

System Development of Patient Family Advisory Councils to Partner with Local and System Health Care Providers

Roberta Mori, MSN, RN, Director, Patient Family Engagement; Morgan Horwood, MA, Project Coordinator; Diane Goodman, Patient Family Advisor; Sutter Health, Sacramento, CA

G2

Light and Joy: Creating Opportunities for Collaborative, Intersectional Care for Transgender Youth and Their Families

Charlotte Safran, BS, Patient- and Family-Centered Care Coordinator; Denise ‘Toni’ Foote, Patient/Family Advisor; Ciaran Gilmore, Patient/Family Advisor; University of Vermont Medical Center, Burlington, VT

G3

Partnering with Patients and Families: Building a Region for Patient and Family Centred Care

Valrie Stewart, MA, RN, CPXP, Clinical Facilitator, Patient and Family Centred Care; Paul Wright, BSN, CNN(C), Manager, PFCC; Alberta Health Services, Calgary, Alberta

LEARN, SHARE, CONNECT

“It was inspiring to see how much of an impact the concept of PFCC is espoused in so many facilities around the globe.”

—2016 Conference Attendee
G4
One Hospital’s Journey Adapting a Traditional Intensivist-Led Intensive Care Unit Model to Include Patients and Families, Leading to Improved Satisfaction and Better Clinical Outcomes
Bev Crider, President and CEO, Patient & Family Partnerships, Inc., Founder and Co-Chair, Patient and Family Advisory Council; Brittney Harper, BA, Manager, Service Excellence and Guest Relations; Janie Berezny, BSN, BS, Clinical Manager, ICU/IMC; Ahmad Maarouf, MD, FACP, FCCM, FASN, Director of Critical Care; Beaumont Hospital, Trenton, Trenton, MI

G5
Building an Effective Health Care System Through the Voice of the Customer
Barbra Sappah, EdD, CPHQ, PHR, SHRM-CP, Senior Human Resources Manager; Elizabeth Rasmussen, Program Coordinator; Southcentral Foundation, Anchorage, AK

G6
Implementing Effective Strategies to Increase Access to and Utilization of Health Care Services: From “Visitor Code of Conduct” to “Partnering with Patients and Families”
Roberta Sonnentag, BSN, MSOLQ, CNML, Administrative Director, Women’s and Children’s Services; Emil Juni, Patient/Family Advisor; Tammy Kundinger, BA, RRT, Manager, Respiratory Therapy; Austine Duru, MA, MDiv, Regional Director, Mission, Ethics and Pastoral Care; SSM Health St. Mary’s Hospital, Madison, WI

G7
Diverse Representation to Promote Diversity, Equity, and Inclusion: Integrating Patient Experience in the Creation of Organizational Initiatives
Stefanie Peters, FACHE, MSW, MPA, Chief Administrative Officer, Frankel Cardiovascular Center; Denise Williams, PhD, MS, SHRM-SCP, SPHR, Performance Consultant, Inclusion and Engagement; Risa Kirschner, JD, Patient and Family Advisor, Frankel Cardiovascular Center; Michigan Medicine, Ann Arbor, MI

G8
Stigma: An Impediment to Good Health Outcomes
John Ruiz, CHW, Consumer Liaison-Director of Member Voices; Commonwealth Care Alliance, Boston, MA

G9
Engaging Affected and Under-Represented Communities in Research Priority Setting and Funding Decisions
Linda Franck, RN, PhD, MS, Professor; Monica McLemore, RN, MPH, PhD, Assistant Professor; UCSF School of Nursing; Schyneida Williams, Case Manager; Homeless Prenatal Program; Shanell Williams, Community Engagement Specialist; UCSF Preterm Birth Initiative, San Francisco, CA

G10
Carrying the Load: Improving Clinical Outcomes by Strengthening Patient/Family Caregiver Relationships
Barbara Kivowitz, MSW, MA, Clinician and Researcher; San Francisco, CA; Joan Forte, BSN, MBA, Consultant, Former Administrative Director of Patient and Community Engagement at Stanford Health Care; Sunnyvale, CA
3:30–4:30 pm

CONCURRENT SESSIONS (H1-H10)

H1
Engaging Immigrant Latino Families as Patient Advisors
Lisa DeCamp, MD, MPH, Assistant Professor, Department of Pediatrics; Tatiahna Rivera Rodriguez, MS, Research/Program Coordinator, Johns Hopkins University; Monica Guerrero Vazquez, MS, Centro SOL Coordinator; Johns Hopkins Centro SOL; Sarah Polk, MD, Assistant Professor Department of Pediatrics; Johns Hopkins University School of Medicine, Medical Director, Children’s Medical Practice; Johns Hopkins Bayview Medical Center; Maribel Martinez, Advisory Board Member; Isabel Fernandez Abaunza, Community Outreach Specialist; Johns Hopkins Centro SOL, Baltimore, MD

H2
Engaging Partners, Growing Leaders: Partnering with Patients for Improvement
Fiona McCaughan, BS, RN, MS, MBA, Senior Director, Primary Care Nursing; Ziva Mann, MA, Patient Partner Lead; Cambridge Health Alliance, Somerville, MA

H3
Patient Family Advisors in Merger and Acquisition Transitions: The Constant During Turbulent Times
Derek Drake, RN, DNP, CNML, CNL, NE-BC, Chief Nursing Officer; Alice Gunderson, BS, BA, Lead Patient Family Advisor; Mary Lynne Knighten, RN, DNP, NEA-BC, Patient Family Advisor; St. Francis Medical Center, Lynwood, CA

H4
Enhancing the Practice of Family Centered Rounds for Parents and Providers in Pediatric Hospital Settings
Deborah Waltermire-Burton, MHS, OTR/L, Parent Advisor; Pamela Donohue, ScD, Associate Professor; Johns Hopkins Children’s Center, Baltimore, MD

H5
Meaningful Partnerships: Utilizing Patient and Family Advisory Council Led Quality Improvement to Address the Unique Needs of Vulnerable Populations
Jeffrey Schlaudecker, MD, MEd, Program Director of Geriatric Medicine Fellowship; Keesha Goodnow, BA, PFAC Coordinator/Program Manager; Megan Rich, MD, Associate Program Director of The Christ Hospital/University of Cincinnati Family Residency Program; Anna Goroncy, MD, Assistant Professor in Family Medicine and Geriatric Medicine, University of Cincinnati, Cincinnati, OH
H6
Innovations in Patient and Family Engagement Across the Care Continuum
Kelly Smith, PhD, Director; MedStar Institute for Quality and Safety, Columbia, MD; Margie Shofer, BSN, MBA, Director, General Patient Safety Program; Agency for Healthcare Research and Quality, Rockville, MD; Pam Dardess, MPH, Vice President, Strategic Initiatives & Operations; Institute for Patient- and Family-Centered Care, Bethesda, MD; Helen Haskell, Founder; Mothers Against Medical Error, Columbia, SC; Sue Collier, BSN, MSN, Interim Vice President of Clinical Quality; Health Research and Educational Trust/ American Hospital Association, Chicago, IL; Ushma Patel, Researcher; American Institutes for Research, Chapel Hill, NC

H7
LGBTQ+PFAC: A Strong Voice for Equality, Diversity, and Inclusion in Healthcare
Linda Lombardi, PhD, Chief Strategy Officer, Chief Experience Officer; Mark Swann, LGBTQ+ PFAC Chairperson; Evelyn Borges, MSN, Senior Associate Director; New York City Health + Hospitals/Bellevue; Alfreda Weaver, RN, MSN, Director, New York City Health + Hospitals, New York, NY

H8
Research Family Partners: Creating a Program to Train, Maintain and Measure Caregiver and Patient Engagement
Amy Kratchman, BA, Family Consultant; Christopher Gantz, MBA, Clinical Research Program Manager; Anne Marie Richards, Program Coordinator; Children’s Hospital of Philadelphia, Philadelphia, PA

H9
From Community-Based Participatory Research to Community-Based Participatory Healing
C. Daniel Mullins, PhD, Professor and Chair, Pharmaceutical Health Services Research Department; University of Maryland Baltimore; Franklin Lance, DMin, Senior Pastor; Mt. Lebanon Baptist Church, Baltimore, MD

H10
Simply the Best at Every Encounter Adding Value to the Care Experience Through the Voice of the Customer – A Co-Design Activity with Patients
Haritha Rachamallu, MD, Chief of Professional Education and Co Lead of Patient Family Advisory Council; Kaiser Permanente San Jose; Ruma Kumar, MD, Assistant Physician-In-Chief; The Permanente Medical Group; Phil Fouts, MSW, Patient Advisor; Kaiser Permanente San Jose Medical Center; Michelle Morgan, Manager, Volunteer Services & MPAC Co-Lead; Kaiser Permanente San Jose, San Jose, CA

Calling all baseball fans!
The Baltimore Orioles will host the Boston Red Sox on June 12 at home in the beautiful Oriole Park at Camden Yards. Take the evening off and relax while watching these two rival teams go up against each other for one of the season’s most anticipated games!

www.mlb.com/orioles/tickets/single-game-tickets
WEDNESDAY CONFERENCE SESSIONS

JUNE 13, 2018

7:00-8:00 AM
SPECIAL NETWORKING BREAKFAST
Strengthening Diversity in Research Partnerships

8:00–9:00 am
CONCURRENT SESSIONS (I1-I10)

I1
E-visors: A Quantum Leap in Patient/Family Advisory Participation
Terrell Smith, MSN, RN, Senior Director, Patient and Family Engagement; Lynn Ferguson, BS, Past Chair, Vanderbilt Patient and Family Advisory Council; Vanderbilt University Medical Center, Nashville, TN

I2
The Power of Patient and Family Partnership to Effect Epic Organizational Change
Maria Flores, MPH, Chair, Patient Family Advisory Council; Annette Mercurio, MPH, Director of Programs, Supportive Care Medicine; Zelia de Sousa, AIA, Architect; City of Hope, Duarte, CA

I3
Lead, Listen, and Build: Creating a Center for Transgender Health in Academic Medicine
Paula Neira, RN, MSN, BSN, BS, JD, Clinical Program Director; Johns Hopkins Center for Transgender Health; Deborah Baker, BSN, MSN, DNP, Senior Vice President for Nursing; Johns Hopkins Health System, Baltimore, MD

DAY AT-A-GLANCE

7:00–8:00 am Registration, Continental Breakfast
Networking Breakfast: Strengthening Diversity in Research Partnerships

8:00–9:00 am Concurrent Breakout Sessions

9:15–10:15 am Concurrent Breakout Sessions

10:45 am–12:15 pm Spotlight on Exemplars

12:15–1:45 pm Lunch and Chat with Authors (Registration Required)
Lunch on Your Own

1:45–2:45 pm Concurrent Breakout Sessions

3:00–4:00 pm Closing Plenary

I4
A Collaborative Approach to Teach-Back: Integrating the Patient Voice to Build Staff Capacity
Rita Kang, MEd, BSW, Manager, Patient and Family Education; Toronto Western Hospital, University Health Network; Kathryn Zander, Patient Partner; University Health Network; Leah Sultan-Khan, EdD, MA, CHES, Patient & Family Education Coordinator; Toronto Western Hospital, University Health Network, Toronto, Ontario

I5
Partnering with Families to Design an Autism Friendly Patient Experience in an Ambulatory Care Setting
Amy Kratchman, BA, Family Consultant; Patricia Richards, BA, Senior Director of Specialty Care and Ambulatory Services, Main Campus; Lynne Tracy, AIA, Senior Facilities Project Manager; Children’s Hospital of Philadelphia, Philadelphia, PA
I6  Capturing the Voice of Patients and Families with Limited English Proficiency and Improving Their Hospital Experience Through Real Time Feedback Programs
Dan Roskowski, MPH, Project Manager, Service Excellence; Stanford Health Care, Palo Alto, CA; Carolina Tejada, Patient and Family Partner; Stanford Health Care, Stanford, CA

I7  How Can Patient and Family Caregivers, Providers, and Researchers Create New Information Together?
M. Paige Powell, MHA, PhD, Assistant Professor, School of Public Health; Amanda Young, PhD, Associate Professor, Department of Communication; Joy Goldsmith, PhD, Associate Professor, Department of Communication; University of Memphis; Foster Adams, Patient Partner, Memphis, TN

I8  Our Strategy for Safety: How We, the Patients, Shape Strategies and Action Plans to Improve Patient Safety in Canada
Maaike Asselbergs, Member; Patients for Patient Safety Canada; Ioana Popescu, MBA, Patient Safety Improvement Lead; Canadian Patient Safety Institute, Edmonton, Alberta

I9  Patient/Family Advisors’ Perceptions – Participating in Qualitative Research
Cortney Forward, MBA, Program Manager; Sharon Cross, MSW, CPXP, Program Director; Mary Anne Perez, Patient and Family Experience Advisor; Ohio State University Wexner Medical Center, Columbus, OH

I10 Integrating the Patient and Family Voice Into Medical Professional Educational Conferences
Wendy Nickel, MPH, Director, Centers for Quality and Patient Partnership in Healthcare; American College of Physicians, Philadelphia, PA; Janice Tuffe, Independent Consultant; Hassanah Consulting, Seattle, WA; Desiree Bradley, Project Coordinator; Project DOCC Houston, Houston, TX

9:15–10:15 am
CONCURRENT SESSIONS (J1-J10)

J1  CELESTE CASTILLO LEE
PEER MENTOR LEADERSHIP LECTURE
Successful National Telephonic Peer Mentor Program: Review of National Kidney Foundation’s Peer Program
Kelli Collins, MSW, Vice President of Patient Engagement; National Kidney Foundation, New York, NY; Risa Simon, Founder/CEO, Transplant First Academy, Path 2 Transplant; Scottsdale, AZ; Ashwin Patel, MD, PhD, Chief Medical Officer; InquisitHealth, River Edge, NJ

J2  Bringing Patient and Family Advisors to Comprehensive Unit-Based Safety Programs (CUSP) Teams
Stephen Bokat, BA, JD, Patient/Family Advisor and PFAC Co-Chair; Judy Holloway, BSMT, Quality & Patient Safety Coordinator; Kimberley Kelley, BSN, MBA, Nursing Director, Critical Care; Suburban Hospital, Johns Hopkins Medicine, Bethesda, MD
A Checklist for Creating an Enterprise-Wide Infrastructure to Promote Family-Centered Practices
Karen Wayman, PhD, Director of Family Centered Care; Michele Ashland, BS, FCC Coordinator; Kirsten McGowan, BS, FCC Parent Coordinator; Mariel Spengler, BA, FCC Parent Coordinator; Stanford Children’s Health, Palo Alto, CA

Promoting Family Engagement During Critical Illness: Strategies for Success
Bruce Hanson, Pastor, Patient and Family Advisor; Garnavillo, IA; Kathy Vermoch, Manager, Quality Implementation Programs; Society of Critical Care Medicine, Mount Prospect, IL

Partnering with Patients and Families to Enhance Quality in Primary Health Care, Nova Scotia: Strategies, Tools, and Innovations Driven by Citizen Engagement and Organizational Values
Elizabeth Michael, BScHE, MPH, Operations Consultant, Primary Health Care; Gail Blackmore, BScN, MHA, Senior Director, Quality Improvement, Safety and Patient Relations; Judy Porter, Patient and Family Advisor; Nova Scotia Health Authority, Halifax, Nova Scotia

Care Plans: Co-Producing Care in a Safety Net Healthcare Organization
Ziva Mann, MA, Patient Partner Lead; Fiona McCaughan, BS, RN, MS, MBA, Senior Director, Primary Care Nursing; Cambridge Health Alliance, Somerville, MA

Roadmap to Health Equity: How Person and Family Engagement Can Help Hospitals Achieve Equity in Health Care Quality and Safety
Tandrea Hilliard, PhD, MPH, Health Care Policy Researcher; American Institutes for Research, Chapel Hill, NC; D’Anna Holmes, MSPH, CPXP, Patient Engagement Program Manager; Northwestern Memorial Hospital, Chicago, IL

Patients as Full Partners in Health Standards Development
Adrienne Zarem, BKin, DC, Family Leader; Accreditation Canada; Qendresa Hasanaj, MSc, Program Manager, Assessment Programs; Claudia Houle, BA, BS, Patient Expert; Neeta Gurnani MSc, Program Manager, Standards; Health Standards Organization, Ottawa, Ontario

Parents and Healthcare Professionals Co-Designing Mobile Technology and Care-Delivery Models to Improve Family Integrated Care in Neonatal Intensive Care Units
Linda Franck, RN, MS, PhD, Professor, UCSF School of Nursing; Robin Bisgaard, RN, MS, Clinical Nurse IV; UCSF Benioff Children’s Hospital, San Francisco, CA; Brittany Lothe, BS, MS, Co-Founder; Will’s Way Foundation, San Mateo, CA
Integration of Patient/Family Advisors into Interprofessional Education Teaching and Practice to Address Patient and Family Needs

Kathryn Neill, PharmD, Director of Interprofessional Administrative and Curricular Affairs; Stephanie Gardner, EdD, PharmD, Senior Vice Chancellor for Academic Affairs and Provost; Larry Taylor, Adjunct (Family) Faculty, UAMS College of Health Professions, Department of Respiratory and Surgical Technologies; University of Arkansas for Medical Sciences, Little Rock, AR

10:45 am–12:15 pm

SPOTLIGHT ON EXEMPLARS (K1-K6)

K1
Strengthening Patient- and Family-Centered Care: Building Parent Partnerships in Quality, Safety, and Patient Experience

Sheryl Chadwick, BS, Patient and Family Engagement Program Manager; Katie Taff, BA, MBA, MHA, CPXP, Program Manager, Patient and Family Engagement; DeeJo Miller, BA, Patient and Family Engagement Program Manager; Children’s Mercy Kansas City, Kansas City, MO

K2
Engaging Patients and Families in Co-Writing the Future of the Patient Experience

Lisa Allen, PhD, Chief Patient Experience Officer; Eloiza Domingo-Snyder, MS, Senior Director and Deputy Chief Diversity Officer; James E. Page, Jr., MBA, Vice President, Diversity and Inclusion and Chief Diversity Officer; Johns Hopkins Medicine, Baltimore, MD; Kathleen Plunkett, Member, Patient and Family Advisory Council; Lois Gutman, Member, Patient and Family Advisory Council; Howard County General Hospital, Columbia, MD

K3
The Evolution of Patient and Family Engagement: Insights from Four National Collaboratives

Carol Fancott, PhD, PT, Director, Patient and Citizen; Anya Humphrey, BA, Patient and Family Advisor; Angela Morin, BA, Patient Advisor; Christine Maika, MPH, BS, Senior Improvement Lead; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario

K4
When Clinician and Patient Cultures Clash: Lessons from OpenNotes Implementations

Deborah Wachenheim, MPP, Manager, Stakeholder Engagement; John Santa, MD, MPH, Director of Dissemination; OpenNotes, Boston, MA; Podge Reed, Member, Patient and Family Advisory Council; Johns Hopkins Medicine, Baltimore, MD; James Wallace, MD, Chair, Radiation Oncology, PFCC Executive Leader; Amy Cohen, PhD, Patient- and Family-Centered Care Program Manager; The University of Vermont Medical Center, Burlington, VT
## K5
**Pursuit of Health Equity: Progress, Challenges, and Promise**

Panel discussion moderated by Doriane Miller, MD, Associate Professor of Medicine; Director, Center for Community Health and Vitality; University of Chicago Medicine, Chicago, IL; Joe Gallagher, Chief Executive Officer; First National Health Authority, Vancouver, BC; Cherie A. Craft, BS, MEd, CEO & Founding Executive Director; Smart from the Start, Boston, MA; B. Lee Green, PhD, MEd, BS, Vice President, Diversity, Public Relations and Strategic Communications and Senior Member, Health Outcomes and Behavior; Moffitt Cancer Center, Tampa, FL

## K6
**Practicing Effective Communication and Building Trust Between Patients and Researchers**
Peggy Wagner, PhD, Director, Patient Engagement Studio; Greenville Health System, Clinical Professor, Department of Biomedical Sciences; Ann Blair Kennedy, DrPH, Associate Director, Patient Engagement Studio Greenville Health System and Assistant Professor, University of South Carolina School of Medicine Greenville; Cole Brown, MHA, Patient Expert; Pam Evans, BA, Patient Expert; Johnny Payne, BA, Patient Expert; Jessica Sterling, BS, Patient Expert; Greenville Health System, Greenville, SC

## Patients as Research Partners in the Development of a Tool to Enhance Shared Decision Making for Rheumatoid Arthritis
Melanie Cozad, PhD, Assistant Professor; Kaitlyn Crosby, MHA, Graduate Student, University of South Carolina; University of South Carolina Center for Effectiveness Research in Orthopaedics; Carmela Epright, PhD, Professor and Patient Co-Investigator; Pam Evans, Patient Co-Investigator; Peggy Wagner, PhD, Director, Patient Engagement Studio; Greenville Health System, Clinical Professor, Department of Biomedical Sciences; University of South Carolina School of Medicine Greenville, Greenville, SC

## 12:15-1:45 pm
**LUNCH AND CHAT WITH AUTHORS**

**In Conversation: Writing and Healing**
Moderated by Liz Crocker, BA, MEd, Author and Patient Advocate, Vice President, Board of Directors; IPFCC, Halifax, Nova Scotia; Jon Kerstetter, MD, MFA, Author; Iowa City, IA

## 1:45–2:45pm
**CONCURRENT SESSIONS (L1-L7)**

### L1
**From Passive to Active: Tips for Engaging Advisors Virtually**
Libby Hoy, BS, Founder/Chief Executive Officer; Stephen Hoy, BS, COO; PFCCpartners, Long Beach, CA; Brittany Wiley, BA, MEd, Senior Quality Improvement Facilitator; Kaylie Doyle, MBA, Program Manager; Telligen, Greenwood Village, CO

### L2
**Parents Taking the Lead: Integration of Parent Navigators into the Primary Care Medical Home Setting**
TjaMeika Purnell Davenport, BMus, Parent Navigator; Michelle Jiggetts, MD, MS, MBA, Program Administrator; Yanuario Orellana, BS, BA, Parent Navigator; Cara Biddle, MD, MPH, Associate Division Chief, Department of General Pediatrics & Community Health; Children’s National Health System, Washington, DC
**WEDNESDAY CONFERENCE SESSIONS**

**L3**  
Combining Patient Centered Care and Lean Principles: A Successful Framework for Cultural Transformation  
Catherine Bachner, EdD, BS, Patient Partner; Anne Campbell, BScN, MSN, VP Partnerships & Patient Experience, Chief Nursing Executive; Huron Perth Healthcare Alliance, Stratford, Ontario

**L4**  
Keeping Caregivers in Focus in the Emergency Room  
Vanessa Deen Johnson, MPH, Chair, E.D. Patient and Family Advisory Council; Viveta Lobo, MD, Emergency Medicine Physician, Advisor, E.D. Patient Family Advisory Council; Cathy Castillo, Member, E.D. Patient and Family Advisory Council; Stanford Health Care, Palo Alto, CA

**L5**  
“Centering”: Building a Village to Promote Health Equity for Our Community  
Kendra Ellison, RNC, MS, NEA-BC, C-EFM, NCEA-BC, Nurse Manager Womens Services; Pablo Argeles, MD, MPH, FACOG, Chair of OB/GYN Univ of MD BWMC and Univ MD School of Medicine; Paula Greer, MS, RNC, CNM, Director of Midwifery Services, UM-CMG Women’s Health Associate; Esther Liu, MD, FAAP, Chair of Pediatrics Univ of MD BWMC; University of Maryland - Baltimore Washington Medical Center, Glen Burnie, MD

**L6**  
Reduce Healthcare Disparities with Inclusive and Caring Communication  
Wendy Leebov, BA, EdM, EdD, Founding Partner; Language of Caring, LLC, Boynton Beach, FL

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**LEARN, SHARE, CONNECT**

“A 10 plus! The patient partner I brought with me was amazed at the things she learned.”

—2016 Conference Attendee

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3:00–4:00 pm  
**CLOSING PLENARY**  
Enhancing Partnerships with Patients and Families in New Models of Care  
Toyin Ajayi, MD, MPhil, Chief Health Officer; Sidewalk Labs’ Care Lab, New York, NY
POSTER SESSIONS BY TOPIC

HEALTH EQUITY THROUGH PARTNERSHIPS

A Unique Approach to Meeting Patient Preferences: A Look at the LGBTQ Rounding Program at University of Miami Hospital
Lauren Foster, Director of Concierge, LGBTQ Service Line; University of Miami Hospital, Miami, FL

Angela Johnson, Senior Outreach Specialist, Program for Multicultural Health, Community Health Services; Michigan Medicine, Ann Arbor, MI

Addressing Social Determinants of Health in Hospitals: How Are Hospitals and Health Systems Investing in Social Needs of Patients and Communities?
David Rabinowitz, MBA, Senior Manager; Deloitte Center for Health Solutions, Washington, DC

Building Bridges for Awasisak (Children in Cree) Indigenous Health
Sherri Di Lallo, BScN, RN, MN, Indigenous Child Health Nurse Coordinator; Chrystal Plante, Indigenous Relations, Indigenous Child and Family Engagement Coordinator; Stollery Children’s Hospital, Alberta Health Services, Edmonton, Alberta

CONFERENCE POSTER SCHEDULE

Monday, June 11, 2018
7:00–8:00 am Poster Displays
9:45–10:45 am Poster presenters available for questions and discussion
5:30–7:00 pm Posters on display during Welcome Reception

Tuesday, June 12, 2018
7:00–8:00 am Poster Displays
10:00–11:00 am Poster presenters available for questions and discussions

Dana-Farber’s PFAC Diversity Recruitment and Retention Project
Renee Siegel, MSW, LCSW, Program Manager, Patient and Family Advisory Councils, Division of Patient and Family Programs and Services; Gabriella Spear, Co-Chair, Adult PFAC; Dana-Farber Cancer Institute, Boston, MA

Discovering Diagnosis: The Patient and Family Perspective
Kirsten Morrise, Social Work Student; Utah State University, Logan, UT; Lisa Morrise, MA, Patient Advocate; Consumers Advancing Patient Safety (CAPS), Salt Lake City, UT

Expanding Our Reach Through Partnership and Education: Partnering with International Families and Hospital Staff to Provide Excellence in Cultural Competency
Darlene Barkman, MS, Family Consultant; Children’s Hospital of Philadelphia, Philadelphia, PA
From NICU to Home: A Communication Tool, Question Prompt List, for Latino Parents with Limited English Proficiency

Lisa DeCamp, MD, MSPH, Assistant Professor, Johns Hopkins Department of Pediatrics, Johns Hopkins Center for Salud/Health and Opportunity for Latinos Centro SOL; Pamela Donohue, ScD, Associate Professor, Pediatrics, Clinical Research Director, Neonatology, Johns Hopkins School of Medicine; Sara Munoz-Blanco, MD, Post-Doctoral Fellow; Neonatology, Johns Hopkins Medicine, Baltimore, MD

Newcomer Navigator Toolkit: Strengthening Families for a Vibrant Future

Sahar Zohni, MD, MBA, Program Manager; The Children’s Hospital of Eastern Ontario (CHEO), Ottawa, Ontario

Partnering with Community and Patients to Improve HIV Outcomes for Immigrant Latinxs

Kathleen Page, MD, Associate Professor; Alejandra Flores Miller, Outreach Worker; Johns Hopkins University, Baltimore, MD

Patient Partnerships and the Advancement of Health Equity

Kaitlynn Robinson-Ector, MPH, Program Associate, Healthcare Delivery and Disparities Research; Marisa Torres, MPH, Program Associate, Healthcare Delivery and Disparities Research; Patient-Centered Outcomes Research Institute (PCORI), Washington, DC

Salud al Día: A Spanish-Language mHealth Healthcare Navigation Support Program Developed in Partnership with the Community

Doris Valenzuela-Araujo, BS, Medical Student; Oregon Health & Science University, Portland, OR; Lisa DeCamp, MD, MPH, Assistant Professor, Department of Pediatrics; Johns Hopkins University, Baltimore, MD

Structural and Socio-Cultural Barriers to Prenatal Care in a US Marshallese Community

Jellesen Rubon-Chutaro, Project Coordinator; Pearl McElfish, PhD, Director, Office of Community Health and Research and Co-Director, Center for Pacific Islander Health; University of Arkansas for Medical Science-Northwest, Fayetteville, AR

The Preterm Birth Initiative: Addressing the Epidemic of Preterm Birth and Achieving Health Equity for Mothers and Babies Through Community Partnerships

Linda Franck, RN, PhD, MS, Professor; Monica McLemore, PhD, MPH, RN, Assistant Professor; UCSF School of Nursing; Schyneida Williams, Case Manager; Homeless Prenatal Program; Shanell Williams, Community Engagement Specialist; UCSF Preterm Birth Initiative, San Francisco, CA

To Accommodate or Not to Accommodate? Developing a Patient Preference Accommodations Policy

Eloiza Domingo-Snyder, MS, Senior Diversity Director/Deputy CDO; James Page, MBA, Vice President/Chief Diversity Officer; Johns Hopkins Medicine, Baltimore, MD
Transforming LGBTQIA Cultural Competency Practice in New Jersey Hospitals
Jackie Baras, MBA, MSN, RN, Quality Nurse Manager, Perioperative Services; Robert Wood Johnson Somerset, Somerset, NJ; Jennifer Sryfi, MHA, Director, Community Programs; Health Research and Educational Trust of NJ, Princeton, NJ

UNITE for Better Health Outcomes in Memphis, TN: Identifying Pathways To Improve Trust and Communication in Cancer Care
Joy Goldsmith, PhD, Associate Professor; M. Paige Powell, PhD, Assistant Professor; Amanda Young, PhD, Associate Professor; University of Memphis, Memphis, TN

Actualizing Patient/Family Advisor Feedback: A Volunteer-Based Intervention to Improve ICU Care Transitions
Shannon Lawson, BA, Program Coordinator, Volunteer Services; Caroline Moore, MPH, Program Leader, Patient and Family Advisor; Kathryn Zieja, Senior Project Manager, Critical Care Quality; Beth Israel Deaconess Medical Center, Boston, MA

An Innovative, Integrated Approach to Patient and Family Centred Care in the Neonatal and Adult Intensive Care Unit
Carolyn Tyson, BA, Patient Family Advisor; Kristy Macdonell, MSW, Manager, Patient and Family Centred Care; Jan Haskings-Winner, MA, Patient Family Advisor; Scarborough and Rouge Hospital, Toronto, Ontario

CHOP Compass Care: Improving the Patient and Family Experience Through Comprehensive Care Coordination
Monica Jones, Family Consultant; Children’s Hospital of Philadelphia, Philadelphia, PA

Creating a Patient- and Family-Centred Culture Around Quality Improvement Through Patient Pathways
Alyson Kwok, BScPT, Healthcare Improvement Specialist; Glenrose Rehabilitation Hospital, Edmonton, Alberta

Digital Health at CHOP: Partnering with Patients and Families to Create the Interactive Patient Experience
Gayle Stidsen-Smith, MS, Senior Director, Digital Health and Data Integration; Esha Bhatia, MA, Principal IT Strategic Consultant; Anne Marie Richards, Family Consultant; Darlene Barkman, MA, Family Consultant; Children’s Hospital of Philadelphia, Philadelphia, PA

Empowering Families Through PFCC-Based Design in a Children’s Hospital: It Works!
Vivi Buijs, RN, Nurse Manager; Patricia Kalkman, MD, Pediatrician; Inge van’t Wout-Bilderbeek, RN, MBA, Nurse Manager; Barbara Sibbles, MD, Pediatrician; Erasmus MC Sophia Children’s Hospital, Rotterdam, Netherlands

Engaging Patient/Family Advisors as Multiple Mini Interview (MMI) Interviewers in the Medical School Admissions Process
Amy Cohen, PhD, Patient- and Family-Centered Care Program Manager; The University of Vermont Medical Center, Burlington, VT
Engaging Patients and Providers in Co-Production of a Hydroxyurea Digital Toolkit Using Design Thinking by a Regional Sickle Cell Network  
Lisa Shook, MA, Assistant Professor of Pediatrics; Cincinnati Children’s Hospital Medical Center, Cincinnati, OH

Establishing a Place for All NICU Families  
Elizabeth Moll, CPNP, RN, MSN, Developmental Care Specialist; Rachel Houck, LCSW, NICU Social Worker; Heather Murphy, MSN, NP-C, NICU Pain and Palliative Care Coordinator; Marnie Dyer, BA, Parent Support Coordinator; Maureen Heald, Parent Support Coordinator; Children’s Hospital of the King’s Daughters, Norfolk, VA

Integration of Patient/Family Advisors Into Nursing Professional Governance: A Model of Partnership to Drive Practice Innovation  
Amy Cohen, PhD, BCBA, PMP, Patient- and Family-Centered Care Program Manager; Kate FitzPatrick, RN, Chief Nursing Officer; Kelly Walters, MBA, Patient/Family Advisor; The University of Vermont Medical Center, Burlington, VT

Oh The Places You Will Go and All the In-Betweens: Novel Partnerships with PFAs from New Employee Orientation to Joint Commission Sessions  
Maureen Bennett, Specialist, Service Excellence; Beaumont Grosse Pointe, Grosse Pointe, MI; Rhonda Jordan, Manager, Service Excellence; Gary Cipolloni, MBA, BS, Patient and Family Advisor; Beaumont Dearborn, Dearborn, MI

Operating a High-Quality and Effective Mentor Program: Lessons Learned from the Past Five Years  
Brittany Barnett, MS, NCC, CAVS, Manager, Family Centered Care; Kathryn Berry Carter, BS, CVA, CAVS, Director of Volunteer, Guest and Family Services; St. Jude Children’s Research Hospital, Memphis, TN

Partnering with Patients and Families To Cultivate Patient Centeredness in a Level I Trauma Center  
Sharon Wilson, MA, GME Director of Operations; Bernadette White, RN-BC, NEA-BC, DNP, Director, Emergency Services; Tracy Nieto, Emergency Center Service Excellence Project Specialist; Beaumont Health, Royal Oak, MI

Partnering with Patients: Supporting Public Advisors in Cancer System Improvement Initiatives  
Leslie Hill, BSc, MLT, GradDip MHSM, Coordinator, Engagement, Diversity and Vulnerable Populations; Nova Scotia Cancer Care Program, Nova Scotia Health Authority, Halifax, Nova Scotia

Patient and Family Advisory Council Helps Create “The Methodist Experience”  
Barbara Gordin, BA, Patient Advisor; Kimberly Goode, MA, BS, Director, Service Quality & Guest Relations; Susan Teer, BSN, MSN, NEA-BC, Director of Nursing; Houston Methodist Hospital, Houston, TX
Patient and Family Advisory Councils: Recruiting and Supporting Members from Diverse and Under-Represented Communities

James Harrison, MPH, PhD, Assistant Professor; University of California San Francisco, San Francisco, CA; Catherine Hanson, Patient Stakeholder; University of Michigan, Ann Arbor, MI; Martha Carnie, Senior Patient Advisor, Brigham & Women’s Hospital, Boston, MA

Patient and Family Centered Care in Pathology – The Power of Stories

Dale Parry, BS, Patient and Family Advisor; Jeff Myers, MD, Vice Chair of Clinical Affairs and Quality, Director, Pulmonary Pathology Fellowship; Molly Dwyer-White, MPH, Administrative Director, Office of Patient Experience, Manager, PFCC Adult Services; Michigan Medicine, Ann Arbor, MI

Patient Family Advisors and Hospital Governance

Kenneth Hamilton, BS, MS, MBA, PhD, Co-Chair, Patient Family Advisory Council; Kristen Palaschak, BSN, MSN, Co-Chair, Patient Family Advisory Council; Richard Repeta, MPH, MD, Director, Hospital Operations and Strategic Planning; Fort Belvoir Community Hospital, Fort Belvoir, VA

Patient- and Family-Centered Care in the ICU Setting: Patient and Family Advisors Utilizing Experience-Based Co-Design in Shaping the Outcomes of a New Intensive Care Unit

Patricia Kenney, BScN, RN, MSN, DNP, Executive Director, Patient-Centered Care; Nancy Anne Teems, RN, BSN, MSN, Nurse Manager; Alexandra Copeland, Patient/Family Advisor; Barbara Alford, NEA-BC, BSN, MSN, VP/Chief Clinical and Nursing Officer; Tallahassee Memorial HealthCare, Tallahassee, FL

Patient/Family Advisor and Employee Perceptions of Partnership: Implications for Advancing Patient- and Family-Centered Care

Amy Cohen, PhD, BCBA, PMP, Patient- and Family-Centered Care Program Manager; The University of Vermont Medical Center, Burlington, VT

Recruiting and Retaining Patient and Family Advisors

Michelle Joyner, BA, MBA, Director, Quality, Patient Flow; Bernice King, Co-Chair, Patient and Family Advisory Council; St. Joseph’s Healthcare Hamilton, Hamilton, Ontario

The Cancer Center Designed by Patients for Patients – Reflections on an Evolving Patient and Family Advisory Council (PFAC)

Shiva Modarresi, BA, Program Manager, Cancer Networks; Sara Malm, RN, BSN, Clinic Operations Manager, PFAC Staff Advisor; Nancy Dickenson, BA, MLIS, Patient Experience Manager/ Librarian, PFAC Staff Advisor; Rose Simmons, BA, Chair, Patient and Family Advisory Council; Stanford Health Care, San Jose, CA

The Patient and Family Cafe: An Effort to Include a Diverse Patient Perspective

Danielle McQuigg, BSN, MSN, Director, Medical/Surgical Nursing; Howard County General Hospital, Columbia, MD; Debra Hill, BA, Patient and Family Advisor; Nicole Iarrobino, BA, Senior Project Administrator, Patient and Family Advisory Councils; The Johns Hopkins Hospital, Baltimore, MD
The Power of Partnering: Patient and Family Advisors Partnering to Continuously Improve the Patient and Family Experience in Healthcare

Therese Razzante, Program Manager, Our Voice, Healthcare Partners Program, March of Dimes NICU Family Support Specialist; Melissa Vandergriff, MA, Director of Continuous Improvement; Louie Hendon, Continuous Improvement Specialist; Cleveland Clinic Hillcrest Hospital, Mayfield Heights, OH

When Patients and Families Take Charge of Change

Joy Gehner, MA, Senior Family Advisor; Seattle Children’s, Seattle, WA

Why Training Patient and Family Advisors Can Benefit Your Organization – Lessons Learned 10 Years in the Making

Sharon Cross, MSW, CPXP, Program Director, Patient/Family Centered Care; Mary Anne Perez, Patient and Family Experience Advisor; Ohio State University Wexner Medical Center, Columbus, OH

Engaging Patients and Families in Healthcare Transformation Through Centers for Medicare and Medicaid Services National Initiatives

Kellie Goodson, BS, Director, HIIN & TCPI Delivery; Vizient Inc, Irving, TX

How You Want To Be Treated: A Providence Approach to Patient-Centred Design

Michele Trask, RN, BSN, Senior Clinical Planner, St. Paul’s Redevelopment Project; Providence Health Care, Vancouver, British Columbia

Role of Leadership in Adoption of Patient and Family Engagement Councils – Enterprise to Ambulatory Model

Haroon Hyder, MD, Medical Director PCMH, Medical Director PFEC; Bon Secours Virginia Medical Group, Richmond, VA

Better Together—Patients and Families as Partners in Hospitals

Accelerating Spread and Scale of Family Presence Across North America

Christine Maika, Senior Improvement Lead; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario


Vicki Kelley, MS, CCLS, Family-Centered Care Program Manager; Erikah Daley, BS, MA, Parent Advisor; Cook Children’s Medical Center, Fort Worth, TX
Creating a PICU Toolbox: Engaging Families to Support PICU Patients at the Bedside
Kimberly LaRose, MEd, Family Advisor; Alixandra FitzGerald, MS, CCLS, Certified Child Life Specialist; NewYork-Presbyterian Komansky Children’s Hospital/Weill Cornell Medical Center, New York, NY

Engaging Families – A Renewed Commitment
Miriam McCann, MSW, Advanced Practice Clinical Leader; Bryn MacPherson, Co-Chair, Family Advisory Committee, Centre for Addiction and Mental Health, Toronto, Ontario

Family Centered Rounds in a Dutch Academic Children’s Hospital Received with Mixed Feelings
Jolanda van der Velden, MSc - Nurse Practitioner; Vivi Buijs, Coordinator PFCC Sophia’s Children’s Hospital; Patricia Kalkman, MD, Pediatrician; Carine van Capelle, MD, PhD, Pediatrician; Liesbeth Hage, Nurse; Henny van Dam, Nurse; Monique van Dijk, PhD, Profesor of Nursing Science; Erasmus Medical Centre, Rotterdam, Netherlands

Improving Patient and Family Engagement in the Care of Patients Undergoing Mechanical Ventilation
Lavinia Edmunds, MA, Patient Advocate; Johns Hopkins Medicine; Hina Chaudhry, MPH, Research Coordinator; The Armstrong Institute for Patient Safety and Quality, Baltimore, MD; Joseph Neiman, MPH, MD, Medical Student; University of Nevada, Reno School of Medicine, Reno, NV

Improving the Care of Patients with Autism Spectrum Disorder in the Perioperative Complex
Amy Kratchman, BA, Family Consultant; Children’s Hospital of Philadelphia, Philadelphia, PA

Partnership for Safety – The Journey to Reduce Harm
Sally Umbro, RN, MSN, BSN, NEA-BC, Director, Quality and Safety; Megan Busenbark, Member, Family Advisory Council and Partnership for Safety Task Force; Linda Hurwitz, NEA-BC, RN, MS, Vice President, Patient Care Services; Maria Fareri Children’s Hospital at Westchester Medical Center Health Network, Valhalla, NY

Powerful Partnerships: Liaisons in the ICU
Carol Kummet, LICSW, MTS, Palliative Care Social Worker; Jean Madsen, BS, PFA and ICU Liaison; University of Washington Medical Center, Seattle, WA

The Effect of a Collaborative Care Model on Length of Stay and the Patient Experience
Sean Moore, RN, BSN, BS, PCCN, Staff Nurse 2; Erika Bowen, PhD, Researcher; UT Health San Antonio, San Antonio, TX
Better Together: Co-Design, Implementation, and Program Evaluation with Children and Families
Dianne Fierheller, MSW, Social Worker, Doctoral Student; Ian Zenlea, MD, MPH, Paediatric Endocrinology, Project Lead KidFit Health and Wellness Clinic; Trillium Health Partners, Mississauga, Ontario

Harnessing the Power of the Community to Promote Partnerships for Sustaining Daily Care
Katherine Raymond, MSW, Senior Program Associate; Mary Leigh Phillips, MA, Member, Champion Advisory Committee; Cystic Fibrosis Foundation, Bethesda, MD

Improvement of Access and Intake Operations in a Pediatric Ambulatory Care Setting
Patricia Richards, Senior Director, Ambulatory Services; Amy Kratchman, BA, Family Consultant; Children’s Hospital of Philadelphia, Philadelphia, PA

Involving Patients in Care Redesign
Jamie Lovell, MBA, Project Manager; Peterson Center on Healthcare, New York, NY

Partnerships in Ambulatory Care – Improving Access to Care by an Ambulatory Team Providing Hemodialysis in a Rehabilitation/Chronic Care Setting
April Mullen, BScN, RN, MBA Health Management, Manager; London Health Sciences Centre; Julie Gilvesy, RN, BScN, MA, Project Leader; St. Joseph’s Health Care London - Parkwood Institute; Elizabeth Clinton, Member, Patient and Family Advisory Council; Lori Harwood, RN, Nurse Practitioner; London Health Sciences Centre, London, Ontario

Patient Advisors in Primary Care: How Patients Help Professionals with Their Reflective Practices
Marie-Pascale Pomey, MD, PhD, Professor and Physician, University of Montréal and University of Montréal Hospital Research Centre (CRCHUM); Lise Houle, Expert Patient Advisor; University of Montréal, Montréal, Quebec

Serving with the Underserved: Incorporating the Patient Voice in a Primary Care Safety Net Setting
Rachel Depperschmidt, BS, Quality and Research Coordinator; Jeneba Winfrey-Porter, MHA, Medical Operations Director; Church Health, Memphis, TN

Building a Strategy to Support Parent and Youth Partnerships in Patient-Oriented Research in the Canadian Maritimes
Lauren MacEachern, BS, MA, Research Assistant; Rebecca Mackay, BA, Parent Researcher; Janet Curran, RN, PhD, Affiliate Scientist; IWK Health Centre, Halifax, Nova Scotia

Collaborative Efforts Among Eight Patient-Centered Studies to Reduce Disparities in Asthma
Dionna Attinson, BS, Program Assistant; Julia Anderson, MPH, MEM, Program Associate; Ayodola Anise, MHS, Program Officer; Patient-Centered Outcomes Research Institute, Washington, DC

Comparison of Individual Interviews and Concept Mapping as Methods to Identify Patient-Important Outcomes
Kristin L. Rising, MD, MS, Director of Acute Care Transitions; Thomas Jefferson University, Philadelphia, PA
Engaging Patient Advisors to Make Clinical Research Studies More Patient-Centered: Lessons from Five Years with a Patient Advisory Committee
Mahima Mangla, MPH, Project Manager; Debbie Kanady, MA, Patient Advisor; Massachusetts General Hospital, Boston, MA

Evaluating Symptom Relief and Quality of Life for Adult Acute Leukemia Inpatients Receiving Integrative Medicine Therapies
Lauren Emmons, MSN, Nurse Clinician III; Colleen Apostol, MSN, OCN, Nurse Manager, Staff Liaison; Diane Carton, RN, Integrative Medicine Nurse; Larry Cohen, Patient Advisor; Patricia Davis, Caregiver Advisor; Katie Tracy, RN Candidate Student; Johns Hopkins Hospital, Baltimore, MD

Finding the Right Fit: Making Representation in Research Meaningful
Anna Barker, MS, Program Manager; Veterans Health Administration, Bedford, MA

I Am a Patient AND Partner of My Health System!
Marie-Pascale Pomey, MD, PhD, Professor and Physician; University of Montréal and University of Montréal Hospital Research Centre (CRCHUM); Valérie Lahaie, BScN, MPH, Health Promotion Senior Advisor; Centre Hospitalier de l’Université de Montréal; Cathy Bazinet, BA, MC, Senior Patient Advisor; University of Montréal, Montréal, Quebec

Partnering with Parents to Design Discharge Communication Interventions for Pediatric Emergency Care
Janet Curran, RN, PhD, Affiliate Scientist; Rebecca Mackay, BA, Parent Researcher, IWK Health Centre, Halifax, Nova Scotia

Patient and Family Advisory Councils: Identifying Challenges and Solutions to Support Engagement in Research
James Harrison, PhD, MPH, Assistant Professor; University of California San Francisco, San Francisco, CA; Catherine Hanson, Patient Stakeholder; University of Michigan, Ann Arbor, MI; Martha Carne, Senior Patient Advisor; Brigham & Women’s Hospital, Boston, MA

Research Explained by the National Pediatric Cardiology Quality Improvement Collaborative
Richard James, MSLIS, Liaison Librarian; National Pediatric Cardiology Quality Improvement Collaborative, Cincinnati, OH

Voicing Outcomes Important to Care for Patients with Diabetes
Kristin L. Rising, MD, MS, Director of Acute Care Transitions; Thomas Jefferson University, Philadelphia, PA

Multi-Stakeholder Engagement Advisory Committees in Patient-Centered Outcomes Research
Olayinka Ladeji, MPH, PATIENTS Program Specialist; University of Maryland, Baltimore School of Pharmacy, Baltimore, MD

Creating BALANCE: Building Alliances for Autism Needs in Clinical Encounters
Nancy Walker, Parent and Patient Advocate; Sharon Amey, MDE, Researcher, Centre for Pediatric Pain Research; IWK Health Centre, Halifax, Nova Scotia
Designing, Implementing, and Evaluating a Team-Based Transgender Cultural Education Program for an Ambulatory Women’s Health Practice
Luis Rosario-McCabe, RN, DNP, WHNP-BC, CNL, Senior Nurse Practitioner; UR Medicine Women’s Health Practice, Rochester, NY

Learning with Families Program
Karen Derry, MSc, Collaborative Practice Lead; Leslie Louie, BSW, Family Engagement Advisor; Sunny Hill Health Centre for Children, Vancouver, British Columbia

Patient and Family Centered Care Curriculum in Paediatric Residency Education
Clara Madrenas, MSW, Patient & Family Centred Care Specialist; Children’s Hospital, London Health Sciences Centre, London, Ontario

Physician Created Patient and Family-Centered Education Module: A Measure in Time
Michael Burry, DO, Physician; Beverly Crider, Patient/Family Advisor; Dana Snyder, MBA, Program Manager, PFCC; Beaumont Health, Southfield, MI

Through Our Patients’ Eyes – What They Need from Us as Caregivers
Chris Vittum, BA, MS, RN, Senior Director, Quality and Safety; Nikki Brezny, BA, Associate Director, Integrated Health Services; SCL Saint Joseph Hospital, Denver, CO

Training Chaplains to Support Family Presence During Codes
Linda Frommer, MPH, Veteran & Family Centered Care Program Manager; VA Palo Alto Health Care System, Palo Alto, CA

What Patients and Families Want You To Know About Becoming Their Doctor: Patients and Families Create Medical School Curriculum
Vanessa Johnson, MPH, Founder, Mindfulness Rx, Patient and Family Partner Program, Chair, Emergency Department; Barbara Kivowitz, MSW, MA, Consultant; Joan Forte-Scott, BSN, MBA, Consultant, Former Administrative Director of Patient and Community Engagement; Stanford University Hospital and Medical School, Stanford, CA
Please complete this form in its entirety. Use one form per registrant—copy form for additional registrants. Registrations can only be processed when this entire form is completed.

Registration is confirmed when you receive official email notification with confirmation number.

You may also register for this conference via the IPFCC website at www.ipfcc.org/events/conference.html.

Registration
The conference registration fee includes educational sessions, conference syllabus, refreshment breaks, breakfasts, and Welcome Reception.

Please note: Registration for this conference cannot be completed without full contact details. Pinwheel Sponsor discount ($50) is only available for the Healthcare Professionals registration fee.

### Full Conference Admission

<table>
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<th>Early-bird on or before April 16, 2018</th>
<th>After April 16, 2018</th>
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<td>Health Care Professionals</td>
<td>$1,065</td>
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<tr>
<td>Patient and Family Advisors/Leaders</td>
<td>$525</td>
<td>$575</td>
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<tr>
<td>Student</td>
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<td>$595</td>
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<tr>
<td>Teams of 4 or more (per person)</td>
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### Two-Day Admission

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<td>Mon–Tues</td>
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<td>Tues–Wed</td>
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### One-Day Admission

<table>
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<tbody>
<tr>
<td>Mon, Tues or Wed</td>
<td>$525</td>
</tr>
</tbody>
</table>

### Contact Details

Is your organization a Pinwheel Sponsor? (view the enclosed pinwheel sponsors list)  
☐ Yes  ☐ No

First Name ____________________________

Last Name ____________________________

Preferred Name (Nickname) ____________________________

Degrees/Credentials ____________________________

Position/Title ____________________________

Organization ____________________________

Organization Location (city, state) ____________________________

Mailing Address:  
☐ Work  ☐ Home

(For a hospital address, please include department, unit location, mail code, etc.)

Address 1 ____________________________

Address 2 ____________________________

City ____________________________

State/Province ____________________________ Zip/Mail Code ____________________________

Daytime Phone ____________________________

Cell Phone (in case of emergency) ____________________________

Email Address ____________________________

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**CEU Requirements**

To receive continuing education units (nurses, physicians, social workers, child life specialists, and patient experience professionals), participants must verify their attendance daily at the conference. IPFCC will have an electronic system of badge scanning to track conference attendance, and attendees must complete the daily online evaluations no later than Friday, July 13, 2018. The link to access the evaluations will be included in your conference materials. All conference attendees will receive a general attendance certificate.

For child life specialists seeking professional development hours, the content of the IPFCC conference is related to the Child Life Council’s exam content outline: Domain 1 – Professional Responsibility. A certificate of attendance will be required as documentation of your IPFCC conference participation.

**Continuing Education Credit**

Please indicate the profession for which you will be pursuing continuing education credits:

☐ Nurses ☐ Physicians ☐ Social Workers

☐ Child Life Specialists ☐ Patient Experience Professionals

Please indicate that you have reviewed the requirements for CEU/CME credits.

☐ I understand the requirements to receive CEU/CME credits for nurses, physicians, social workers, and child life specialists.

☐ N/A, as I am not applying for CEU/CME credits.

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Please continue to the next page
Information Request

- Yes, my organization is interested in becoming a Pinwheel Sponsor. Please contact me.

Special Mobility Requirements

Please indicate special mobility requirements:

________________________________________________________
________________________________________________________

How did you hear about our conference?
(Please select all that apply)

- Conference Brochure
- IPFCC Website
- IPFCC Email
- Pinwheel Pages e-Newsletter
- Colleague or Friend
- IPFCC Social Media: Facebook
- Twitter
- LinkedIn
- Sponsor Organization
- Other __________________________

Major Area of Interest (select interest)

- Administration
- Health Professional
- Pediatric Inpatient Education
- Adult Critical Care
- Maternity
- Pediatric Primary Care
- Adult Inpatient
- Maternity
- PICU
- Adult Primary Care
- Mental Health
- Public Health
- Emergency Care
- NICU
- Research
- Geriatrics
- Oncology
- Other __________________________

Meals

We do our very best to accommodate dietary restrictions, and we will work with the hotel to accommodate those needs. If you have a specific food allergy or dietary restriction, please indicate here:

________________________________________________________
________________________________________________________

Emergency Contact Person

Your Emergency Contact is the person you would like called first should you have an emergency.

Emergency Contact’s Full Name __________________________

Relationship __________________________

Contact’s Day Phone Number __________________________

Contact’s Evening Phone Number __________________________

Registration/Payment Inquiries Contact Person

Contact’s Full Name __________________________

Contact’s Day Email Address __________________________

Contact’s Work Phone Number __________________________

Terms and Conditions

Permission Statement:
I understand that my registration gives permission to the Institute for Patient- and Family-Centered Care to use my name and contact information in the conference syllabus, and that photos taken at the conference, in which I appear, may be used for IPFCC projects.

Refund/Cancellation Policy:

Cancellation Fee
Before or On May 4, 2018. $200 cancellation fee
After May 4, 2018. no refunds

Substitution Fee
$32 substitution fee

All special activities are non-refundable.

Please note that registration is not complete unless entire form is completed and you receive a confirmation number.

I agree to these Terms and Conditions.

Total Amount of Payment

U.S. Funds $ __________________________

Choose a payment type:

- Credit Card (Contact IPFCC to make a credit card payment. Credit card payment can be made with VISA or MasterCard)
- Check (Make check payable to: Institute for Patient- and Family-Centered Care)

For further information, contact:
Institute for Patient- and Family-Centered Care
6917 Arlington Road, Suite 309 • Bethesda, MD 20814
Ph: 301-652-0281 • www.ipfcc.org
The Institute for Patient- and Family-Centered Care 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 philosophy of care, and thus serve as role models to us all.

PLATINUM PINWHEEL PARTNER
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Nationwide Children’s Hospital Columbus, OH
NRC Health Lincoln, NE
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University of Arkansas for Medical Sciences Little Rock, AR
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Barnes-Jewish Hospital St. Louis, MO
Beaumont Health Southfield, MI
Boston Children’s Hospital Boston, MA
Brigham and Women’s Hospital Boston, MA
Bronson Healthcare Kalamazoo, MI
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Chatham Kent Health Alliance Chatham, ON, Canada
Children’s HealthSM Children’s Medical Center Dallas, TX
Children’s Hospital London Health Sciences Centre London, ON, Canada
Children’s Minnesota Minneapolis, MN
Children’s Mercy Hospitals and Clinics Kansas City, MO
Children’s National Medical Center Washington, DC
Children’s Specialized Hospital New Brunswick, NJ
Cleveland Clinic Hillcrest Hospital Mayfield Heights, OH
Dana-Farber Cancer Institute Boston, MA
Emory Healthcare Atlanta, GA
Hasbro Children’s Hospital/Rhode Island Hospital Providence, RI
Hassenfeld Children’s Hospital of New York at NYU Langone New York, NY
Henry Ford Health System Detroit, MI
Holland Bloorview Kids Rehabilitation Hospital Toronto, ON, Canada
IWK Health Centre Halifax, NS, Canada
Joe DiMaggio Children’s Hospital at Memorial Hollywood, FL
Johns Hopkins Medicine Baltimore, MD
Kaiser Permanente—San Diego San Diego, CA
Massachusetts General Hospital Boston, MA
Memorial Healthcare System Hollywood, FL
Michigan Medicine University of Michigan Ann Arbor, MI
Onslow Memorial Hospital Jacksonville, NC
Penn State Health Hershey Medical Center Hershey, PA
Quality Insights Charlestown, WV
Seattle Children’s Seattle, WA
SSM Health St. Mary’s Hospital Madison, WI
St. Louis Children’s Hospital St. Louis, MO
St. Luke’s Children’s Hospital Boise, ID
Stanford Health Stanford, CA
Stollery Children’s Hospital Edmonton, AB, Canada
The Children’s Hospital of Philadelphia Philadelphia, PA
The Children’s Hospital of San Antonio San Antonio, TX
Thunder Bay Regional Health Sciences Centre Thunder Bay, ON, Canada
UAB Hospital Birmingham, AL
University of New Mexico Children’s Hospital Albuquerque, NM
University of Vermont Medical Center Burlington, VT
Vanderbilt University Medical Center Family & Patient Engagement Nashville, TN
Vidant Health Greenville, NC

Commitments as of April 2018

Become a Pinwheel Sponsor! Call 301-652-0281 for information. www.ipfcc.org