



# 8<sup>th</sup> 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

With leadership  
support from



**JOHNS HOPKINS**  
MEDICINE

And program  
support from

**Patient-Centered  
Outcomes Research  
Institute (PCORI)**

# Promoting Health Equity and Reducing Disparities



***The 8th International Conference on Patient- and Family-Centered Care: Promoting Health Equity and Reducing Disparities*** will be held June 11–13, 2018 at the Baltimore Marriott Waterfront. Those who work tirelessly to improve health care safety, quality, and equity will come together to share their expertise in fostering genuine partnerships among patients, families, health care professionals, researchers, and policy makers.

**Baltimore, Maryland** is a diverse city known for its breathtaking harbor, great restaurants, shopping, and distinctive neighborhoods and museums. It provides an exciting and historic setting for the conference.

Enjoy this wonderful opportunity to visit this vibrant city with a long history as an important seaport. Fort McHenry, birthplace of the U.S. national anthem, sits at the mouth of Baltimore’s Inner Harbor, home to shops, upscale crab shacks, as well as attractions like the Civil War–era warship the USS Constellation and the amazing National Aquarium.

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

## 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.

## 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.)

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## Conference Partners



### 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.

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*.

### 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.ipfcc.org/events/conference.html](http://www.ipfcc.org/events/conference.html)

## 8TH INTERNATIONAL CONFERENCE PROGRAM ADVISORY COMMITTEE

### **Marie Abraham, MA**

Vice President, Programming and Publications  
IPFCC  
Old Lyme, CT

### **Elizabeth Crocker, BA, MEd**

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

### **Nancy DiVenere**

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

### **Hala Durrah, MTA**

Patient/Family Engagement Consultant, Advocate, & Speaker  
Bowie, MD

### **Carol Fancott, PT, PhD**

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

### **Beverley H. Johnson**

President and Chief Executive Officer  
IPFCC  
Bethesda, MD

### **Maulik Joshi**

Executive Vice President of Integrated Care Delivery and Chief Operating Officer  
Anne Arundel Medical Center  
Annapolis, MD

### **B. Lee Green**

Vice President, Diversity, Public Relations and Strategic Communications and Senior Member, Health Outcomes and Behavior  
Moffitt Cancer Center  
Tampa, FL

### **Reverend Debra Hickman**

Patient/Family Advisor  
The Johns Hopkins Hospital  
Baltimore, MD

### **Michele Lloyd**

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

### **Julie Ginn Moretz, BS**

Assistant Vice President, Patient- and Family-Centered Care and Chief Experience Officer  
Augusta University Medical Center  
Augusta, GA

### **Lourdes Negron-McDaniel**

Director, Inclusion and Diversity  
The MetroHealth System  
Cleveland, OH

### **Wendy K. Nickel, MPH**

Director  
Center for Patient Partnership in Healthcare  
American College of Physicians  
Philadelphia, PA

### **Sherry B. Perkins, PhD, RN**

Executive Vice President/Chief Operating Officer  
Dimensions Healthcare System  
Cheverly, MD

### **Juliette G. Schlucter, BS**

Director of The Center for Child and Family Experience of the Sala Institute for Child and Family Centered Care  
NYU Langone Medical Center  
New York, NY

### **William E. Schwab, MD**

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

### **Terri Shelton, PhD**

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

### **Susan Sheridan, MBA, MIM, DHL**

Consultant  
Patient Engagement  
Washington, DC

### **Jacqueline Thomas-Hall**

System Director, Diversity and Inclusion  
Beaumont Health  
Troy, MI

### **Leslee J. Thompson, BSCN, MSCN, MBA**

President and CEO  
Accreditation Canada  
Ottawa, ON, Canada

### **Janice Tuft**

Principal and Patient Partner  
Hassanah Consulting  
Seattle, WA

## 8TH INTERNATIONAL CONFERENCE ABSTRACT REVIEWERS

### **Marie Abraham, MA**

Vice President, Programming and Publications  
IPFCC  
Old Lyme, CT

### **Jacqueline Alikhaani**

Executive Committee Member and Patient ADAPTOR  
pSCANNER CDRN UCLA  
Steering Committee Member, Health eHeart Alliance  
Ambassador and Citizen Scientist  
American Heart Association  
Los Angeles, CA

### **Lisa Allen, MA, PhD**

Chief Patient Experience Officer  
Johns Hopkins Medicine  
Baltimore, MD

### **Pam Bell, MDIV**

Director, Patient Family Centered Care  
The Valley Hospital  
Ridgewood, NJ

### **Patty Black**

Coordinator of Patient Centered Care  
PeaceHealth Medical Group  
Eugene, OR

### **Terrie Black, DNP, MBA, CRRN, FAHA, FAAN**

Clinical Assistant Professor  
University of Massachusetts  
College of Nursing  
Amherst, MA

### **Paul Boucher, MD, FRCPC**

Medical Director, ICU  
Foothills Medical Center  
Clinical Associate Professor  
University of Calgary  
Calgary, AB, Canada

# 8TH INTERNATIONAL CONFERENCE ABSTRACT REVIEWERS

## **Robert Boxer, MD, PhD**

Physician  
Brigham and Women's Hospital  
Boston, MA

## **Mireille Brosseau**

Program Manager, Patient Partnerships  
Health Standards Organization (HSO)  
& Accreditation Canada  
Ottawa, ON, Canada

## **Barbara Burke, MA, LPC**

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

## **Uyara Talmatare Jesus Camara**

Registered Nurse  
University of São Paulo  
São Paulo, Brazil

## **Bryant Campbell**

Patient and Family Advisor  
Providence Medical Group  
Portland, OR

## **Joanna F. Celenza**

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

## **Crystal Cené, MD, MPH, FAHA**

Associate Professor, Division of General  
Internal Medicine  
UNC School of Medicine  
CHER Associate with the Center for  
Health Equity Research  
Chapel Hill, NC

## **Sheryl Chadwick**

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

## **Jill MacLaren Chorney, PhD, RPsych**

Pediatric Complex Pain Team  
IWK Health Centre  
Associate Professor  
Department of Anesthesia,  
Pain Management, and  
Perioperative Medicine  
Dalhousie University  
Halifax, NS, Canada

## **Amy Cohen, PhD, BCBA, PMP**

Patient- and Family-Centered Care  
Program Manager  
Jeffords Institute for Quality  
The University of Vermont  
Medical Center  
Burlington, VT

## **Sue Collier, MSN, RN, FABC**

Clinical Content Development  
Lead (outbased)  
American Hospital Association/Health  
Research & Educational Trust  
Chicago, IL

## **Maureen Connor**

Health Care Consultant  
Claremont Consulting Partners  
Arlington, MA

## **Jim Conway, MS**

Trustee, Lahey Health System &  
Winchester Hospital  
Woburn, MA

## **Liz Crocker**

Author and Advocate  
Vice President, IPFCC  
East Chester, NS, Canada

## **Pam Dardess, MPH**

Principal Researcher  
American Institutes for Research  
Chapel Hill, NC

## **Caroline DeLongchamps**

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

## **Nancy DiVenere, BA**

Board Member, IPFCC  
Co-Founder and Former Past President  
Parent to Parent USA  
Essex, VT

## **Deborah Dokken, MPA**

Coordinator for Patient and  
Family Partnerships  
IPFCC  
Bethesda, MD

## **Hala Durrah, MTA**

Patient/Family Engagement  
Independent Consultant & Advocate  
Washington, DC Metro Area

## **Maret Felzien, MA**

Community Advisory Council Member  
High Plains Research Network  
Faculty, Northeastern Junior College  
Sterling, CO

## **Marlene Fondrick**

Patient Partner  
Perham Health and Perham Living  
Perham, MN

## **Joan Forte MBA, BSN, NE-BC**

Consultant  
Former Administrative Director of  
Patient and Community Engagement  
Stanford Health Care  
Sunnyvale, CA

## **Joanne Ganton, BComm, CPXP**

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

## **Milton Gardner**

Senior Principal  
Architect AIBC, Architect  
AAA, AIA, FRAIC  
Kasian Architecture Interior Design  
and Planning Ltd  
Vancouver, BC, Canada

## **Terry Griffin**

Neonatal Nurse Practitioner  
St. Alexius Medical Center  
Long Grove, IL

## **Leanne Heppell, RN, BScN, MScn, MAL**

Vice President, Acute Care & Chief  
Nursing Officer  
Providence Health Care  
Vancouver, BC, Canada

## **Sylvia Hernandez**

Director, Family Centered Care and the  
Kreamer Resource Center for Families  
Children's Mercy Kansas City  
Kansas City, MO

## **Libby Hoy**

Founder/CEO  
PFCCpartners  
Long Beach, CA

## **Nicole Iarrobino**

Senior Project Administrator, Patient  
& Family Advisory Councils  
The Johns Hopkins Hospital  
Baltimore, MD

## **Shawanna Jackson, MHA**

Operation Manager Cardiology &  
CVIR Research  
Adventist Healthcare, Shady Grove  
PCORI Ambassador  
Rockville, MD

## **Kori Jones, MEd, BBA**

Director, Patient and  
Family-Centered Care  
Beaumont Health  
Farmington Hills, MI

## **Amir Karmali**

Family-Centred Care Specialist  
Client and Family Integrated Care  
Holland Bloorview Kids  
Rehabilitation Hospital  
Toronto, ON, Canada

## **Malori Keller, BA, MPA**

Patient Engagement & Empowerment  
Platform Lead, SCPOR  
Saskatchewan Health Quality Council  
Saskatoon, SK, Canada

# 8TH INTERNATIONAL CONFERENCE ABSTRACT REVIEWERS

**Patricia Kritek, MD, EdM**

Professor  
Division of Pulmonary, Critical Care and  
Sleep Medicine  
University of Washington  
Seattle, WA

**Linda R. Larin, MBA, FACHE**

Associate Hospital Director  
for Cardiovascular and  
Neurosciences Programs  
Michigan Medicine  
Ann Arbor, MI

**Jennifer Lastic**

Program Coordinator  
Office of Patient Experience  
The MetroHealth System  
Cleveland, OH

**Danielle Lavallee, PharmD, PhD**

Research Associate Professor  
Surgical Outcomes Research Center  
Department of Surgery  
University of Washington  
Seattle, WA

**Kathy Lease, EdD**

Patient- and Family-  
Centered Care Advisor  
University of Arkansas for  
Medical Sciences  
Little Rock, AR

**Michele Lloyd**

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

**Roslyn Marshall, RN, BSN, MHA**

Nurse Manager Neuroscience  
Augusta University Medical Center  
Augusta, GA

**Maureen E. Maurer, MPH**

Principal Researcher  
American Institutes for Research  
Chapel Hill, NC

**DeeJo Miller, BA**

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

**Doriane Miller, MD**

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

**Mary Minniti, BS, CPHQ**

Senior Policy and Program Specialist  
IPFCC  
Eugene, OR

**Julie Ginn Moretz**

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

**Lisa Morrise, MArts**

Project Patient Care / Consumers  
Advancing Patient Safety  
LAM Professional Services, LLC  
Salt Lake City, UT

**Margaret Murphy**

Patient Advocate  
External Lead Advisor  
WHO Patient Safety  
Cork, Ireland

**Karen L Myers, PhD**

Director of Grants &  
Foundation Relations  
Lowell Community Health Center  
Lowell, MA

**Wendy K. Nickel, MPH**

Director, Centers for Quality and Patient  
Partnership in Healthcare  
American College of Physicians  
Philadelphia, PA

**Doug Niehus, MD**

Clinic Medical Director Scholls  
Medical Director of Patient Engagement  
Providence Medical Group  
Tigard, OR

**Elizabeth Nolan, MS, RN**

Retired, Director, Patient Education and  
Mardigian Wellness Resource Center  
Frankel Cardiovascular Center  
University of Michigan Health  
Ann Arbor, MI

**Jim Pantelas**

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

**Kelly Parent, BS**

Vice President, Patient and  
Family Experience  
Beaumont Health  
Ann Arbor, MI

**Marilyn Potgiesser, BS, RNC**

System Manager, Patient & Family  
Centered Care  
Bronson Healthcare Group  
Kalamazoo, MI

**Tanielle Randall**

Member, Family Advisory Council  
Nemours Children's Hospital  
Orlando, FL

**Debra Rosen, RN, MPH**

Director, Quality and Health Education  
Northeast Valley Health Corporation  
San Fernando, CA

**Judy Roudebush, RN, NE-BC**

Consultant, Programs for  
Women and Infants  
Woodinville, WA

**Jeffrey Schlaudecker**

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

**Terri L. Shelton, PhD**

Vice Chancellor for Research  
and Engagement  
Carol Jenkins Mattocks  
Distinguished Professor  
The University of North Carolina  
at Greensboro  
Greensboro, NC

**Mary Song, MPH**

Manager, Patient & Family Partner  
Program and Volunteer Resources  
Service Excellence  
Stanford Health Care  
Stanford, CA

**Perry Spencer, CPP, CPHA**

Director, Health System Security  
University of Michigan Division of Public  
Safety and Security  
Ann Arbor, MI

**Janice Tuft**

Ambassador, PCORI  
PCORNet CDRN PORTAL PEC Member  
UW CERTAIN Patient Advisory Network  
Patient Partner Thought  
Leader in Health Systems  
Improvement Research  
Seattle, WA

**Kathy Wade, MSW, PhD**

Director, Social Work  
University of Michigan Health System  
Ann Arbor, MI

**Susan Wozniak, MSHS, RN, OCN**

Patient Advocate  
Principal Consultant  
Strategic Health Solution, LLC  
Walled Lake, MI

*The positions listed are those that  
individuals held at the time reviews  
were completed.*

# CONFERENCE AGENDA

## Program At-A-Glance

SUNDAY, JUNE 10, 2018		
4:00–7:00 pm	Registration	
MONDAY, JUNE 11, 2018		
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 ( <i>Staffed</i> ) and Break	
11:00 am–12:00 pm	Concurrent Breakout Sessions	A1–A10
12:00–1:30 pm	Lunch Break ( <i>On Your Own in Baltimore Harbor</i> )	
1:30–2:30 pm	Concurrent Breakout Sessions	B1–B10
2:45–3:45 pm	Concurrent Breakout Sessions	C1–C10
4:15–5:00 pm	Concurrent Breakout Sessions	D1–D10
5:30–7:00 pm	Welcome Reception	
TUESDAY, JUNE 12, 2018		
7:00–8:00 am	Registration, Continental Breakfast	
	Networking Breakfasts	
8:00–9:00 am	Concurrent Breakout Sessions	E1–E10
9:15–10:00 am	Concurrent Breakout Sessions	F1–F10
10:00–11:00 am	Poster Presentations ( <i>Staffed</i> ) and Break	
11:00 am–12:30 pm	Plenary Session	
12:30–1:45 pm	Federal Roundtable Lunch ( <i>Optional – Registration Required</i> )	
12:30–2:00 pm	Lunch Break ( <i>On Your Own in Baltimore Harbor</i> )	
2:00–3:00 pm	Concurrent Breakout Sessions	G1–G10
3:30–4:30 pm	Concurrent Breakout Sessions	H1–H10
WEDNESDAY, JUNE 13, 2018		
7:00–8:00 am	Registration, Continental Breakfast	
	Networking Breakfast: Strengthening Diversity in Research Partnerships	
8:00–9:00 am	Concurrent Breakout Sessions	I1–I10
9:15–10:15 am	Concurrent Breakout Sessions	J1–J10
10:45 am–12:15 pm	Spotlight on Exemplars	K1–K6
12:15–1:45 pm	Lunch and Chat with Authors ( <i>Registration Required</i> )	
1:45–2:45 pm	Concurrent Breakout Sessions	L1–L6
3:00–4:00 pm	Closing Plenary	



## EXHIBITS AND SPECIAL EVENTS

### 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 AND TRAVEL INFORMATION

## 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](http://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.

## LEARN, SHARE, CONNECT

"Excellent – extremely valuable overall!!!"

—2016 Conference Attendee

## FEATURED SPEAKERS

# MONDAY

### PLENARY SESSION

8:00–9:45 am

#### 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 Addiction Working Group.

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.

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.

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.

## FEATURED SPEAKERS

### 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



NICOLE KERSTETTER

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 experience culminated in three tours in Iraq at the height of the fighting.

## FEATURED SPEAKERS

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



**Liz Crocker**, IPFCC Board Member, is an experienced businessperson, is the founder and owner of Canada's oldest children's bookstore, and the owner of a network of stores specializing in environmentally sound products.

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.

## LEARN, SHARE, CONNECT

To register for the *8th International Conference*, visit: [www.ipfcc.org/events/conference.html](http://www.ipfcc.org/events/conference.html)



## CONFERENCE TOPICS

The following topics are featured in Conference Presentations. To help you select sessions to attend and posters to view, each session and poster is designated with the relevant icons.



### HEALTH EQUITY THROUGH PARTNERSHIPS

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



### PARTNERSHIPS IN PRIMARY AND OTHER AMBULATORY CARE

Programs in which patients and families fundamentally drive transformation, outcomes, and experience.



### 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.



### 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.



### ROLE OF LEADERSHIP

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



### EDUCATION FOR INTERPROFESSIONAL AND COLLABORATIVE PRACTICE

Educational programs planned and delivered in partnership with patient and family faculty.



### 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.



### 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 ( <i>On Your Own in Baltimore Harbor</i> )
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; Kaylie 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*



**2017 IPFCC PARTNERSHIP AWARD RECIPIENT**

**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*



# MONDAY CONFERENCE SESSIONS

## 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 Frierson, 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



12:00–1:30 pm

## LUNCH

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

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



**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, Gitlaxt'aamiks, 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 Loyd, 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*



# MONDAY CONFERENCE SESSIONS

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*



# MONDAY CONFERENCE SESSIONS

## 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 Department of Public Health, 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; Barbarajean 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**

*Madelene 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*



**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 Centering Pregnancy 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 McElfish, 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**

*Annamarie 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*



### **DAY AT-A-GLANCE**

7:00–8:00 am	Registration, Continental Breakfast Special Networking Breakfasts
8:00–9:00 am	Concurrent Breakout Sessions
9:15–10:00 am	Concurrent Breakout Sessions
10:00–11:00 am	Poster Session (Staffed) and Break
11:00 am–12:30 pm	Plenary Session
12:30–1:45 pm	Federal Roundtable (Registration Required)
12:30–2:00 pm	Lunch Break (On Your Own in Baltimore Harbor)
2:00–3:00 pm	Concurrent Breakout Sessions
3:30–4:30 pm	Concurrent Breakout Sessions

**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*





## TUESDAY CONFERENCE SESSIONS

**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 Dispartites 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.

2:00–3:00pm

### **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 Berezney, 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; Tatianna 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 Rachamalla, 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](http://www.mlb.com/orioles/tickets/single-game-tickets)

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*



16

**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*



17

**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*



18

 **Our Strategy for Safety: How We, the Patients, Shape Strategies and Action Plans to Improve Patient Safety in Canada**

*Maaïke Asselbergs, Member; Patients for Patient Safety Canada; Ioana Popescu, MBA, Patient Safety Improvement Lead; Canadian Patient Safety Institute, Edmonton, Alberta*



19

**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*



110

**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 Tufte, 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*





**J3**

**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*



**J4**

**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*



**J5**



**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*



**J6**

**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*



**J7**

**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*



**J8**



**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*



**J9**

**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*



**J10**

**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–12:15pm

**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



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*



### LEARN, SHARE, CONNECT

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

—2016 Conference Attendee



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



### Addressing Racial Disparities in Breastfeeding Through Healthcare and Community Support: Lessons Learned from a Focus Group Study of African American Women and Healthcare Providers

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



## PATIENT AND FAMILY ADVISORS— ESSENTIAL ALLIES

## 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



## ROLE OF LEADERSHIP

## A Dynamic and Strategic Leadership and Education Model to Support Rapid Patient- and Family-Centered Care Commitment and Influence Organizational Culture Change

Amy Cohen, PhD, Patient- and Family-Centered Care Program Manager; Laurie Gunn, Vice President, Human Resources; James Wallace, MD, Chair, Radiation Oncology, PFCC Executive Leader; Kelly Walters, MBA, Patient/Family Advisor; The University of Vermont Medical Center, Burlington, VT



## 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



## Breaking News: “Patient/Parent Super Powers to Revitalize Bedside Shift Report!”

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, Professor of Nursing Science; Erasmus Medical Centre, Rotterdam, Netherlands



## Improving Care Partnerships Together

Roy Butler, PhD, VP, Patient Care and Risk Management; Karen Perkin, MSN, BScN, VP, Patient Care and CNE; Jacobi Elliott, PhD, Project Lead, Changing CARE Project; Carol Riddell-Elson, BA, EdD, Family Caregiver Partner; St. Joseph's Health Care London, London, Ontario



## 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





## PARTNERSHIPS IN PRIMARY AND OTHER AMBULATORY CARE



### 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*



## PARTNERSHIPS IN RESEARCH AND EVALUATION



### 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 Atkinson, 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



## 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



## 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 Carnie, 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

## EDUCATION FOR INTERPROFESSIONAL AND COLLABORATIVE PRACTICE

## 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



## Patients as Partners in Clinician Training: Clinician-Patient Communication to Enhance Health Outcomes

Sharona Cheung, Primary Care, Performance Improvement Coordinator; Amy Petersen, MPH, Primary Care, Care Experience Manager; Robin George, MPH, Primary Care, Workforce Experience Lead; San Francisco Health Network, San Francisco, CA



## 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



**BALTIMORE, MD**  
**JUNE 11–13, 2018**

# REGISTRATION FORM

## THE 8TH INTERNATIONAL CONFERENCE ON PATIENT- AND FAMILY-CENTERED CARE

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](http://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	Early-bird	After
	on or before April 16, 2018	April 16, 2018
Health Care Professionals	\$1,065	\$1,095
Patient and Family Advisors/Leaders	\$525	\$575
Student	\$495	\$595
Teams of 4 or more (per person)	\$975	\$1,045
Two-Day Admission		
Mon–Tues	\$950	\$1,050
Tues–Wed	\$950	\$1,050
One-Day Admission		
Mon, Tues or Wed	\$525	\$575

### 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 \_\_\_\_\_

### 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.

*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:      
 Sponsor Organization     Other \_\_\_\_\_

### Major Area of Interest (select interest)

- Administration     Health Professional Education     Pediatric Inpatient  
 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 \_\_\_\_\_

### 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.

### 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 \_\_\_\_\_



Expenses for education, registration, travel, lodging, and meals to maintain or improve professional skills may be tax deductible. Please consult your tax advisor.

### 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



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Atlanta, GA

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Island Hospital  
Providence, RI

Hassenfeld Children's Hospital of  
New York at NYU Langone  
New York, NY

Henry Ford Health System  
Detroit, MI

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