The 7th International
CONFERENCE ON PATIENT-
AND FAMILY-CENTERED CARE
PARTNERSHIPS IN CARE, INTERPROFESSIONAL EDUCATION, AND RESEARCH

July 25–27, 2016 • New York Marriott Marquis • New York, NY
Now fully updated, Privileged Presence is a collection of over 50 stories that reflect people’s health care experiences from the points of view of compassion, communication, collaboration, respect and dignity . . . or their absence.
Welcome to New York City!

The Institute for Patient- and Family-Centered Care (IPFCC) is honored to have you participate in The 7th International Conference on Patient- and Family-Centered Care: Partnerships in Care, Interprofessional Education, and Research. We are pleased to host this important conference in New York City, one of the world’s most spectacular cities and the perfect backdrop to celebrate, network, and learn from each other.

Making the necessary changes and improvements in health care requires that we focus on strategies that achieve results. Collaboration with all stakeholders—patients, families, health care professionals, researchers, educators, and policymakers is key. Together, we can best plan and put into action policies, programs, and practices that address the significant challenges we face.

This unique conference assembles more than 160 patient and family advisors and leaders as presenters and co-presenters with over 280 health care professionals, researchers, educators, and policy makers. These experts and innovators will help your organization in developing authentic, effective, and sustainable partnerships with patients and families at every level. Our acclaimed plenary and featured speakers bring inspiration and a clear message that collaboration is essential to redesigning health care and improving the quality, safety, and experience of care.

IPFCC is proud to partner with Hassenfeld Children’s Hospital of New York at NYU Langone in convening this conference. At Hassenfeld Children’s Hospital, a family-centered culture is nurtured, where children and their families are integral members of the healthcare team.

Teams from Hassenfeld Children’s Hospital will be presenting throughout the conference and sharing their innovative and collaborative approaches to leadership, safety efforts, technology, interprofessional education, and research.

Enjoy the conference and New York! Thank you for joining us.
The Institute for Patient- and Family-Centered Care is grateful to Hassenfeld Children’s Hospital of New York at NYU Langone for helping to bring this conference to New York City. We are proud to partner with this exemplary organization and to highlight their significant work in advancing the practice of patient- and family-centered care.
July 25, 2016

Dear Friends:

It is a great pleasure to welcome everyone to The Institute for Patient- and Family-Centered Care’s 7th International Conference and to New York City.

Only by ensuring the wellbeing of all people can New York truly become one city where everyone rises together, and my team and I are taking steps to provide all our residents with equal access to outstanding healthcare. Since 1992, IPFCC has been an important ally in these efforts, working to strengthen the relationships between patients, families, and medical professionals in order to provide the best quality care. By fostering partnerships between researchers and leading institutes, caregivers, patient and family advisors, and clinicians, IPFCC is helping to improve the safety and delivery of vital services that are helping people live happier, healthier lives. This conference is a wonderful occasion for attendees to come together and discuss the latest innovative methodologies and advancements that are improving the health of so many across our city and beyond, and I commend IPFCC for working to connect New Yorkers to the vital care they need and deserve.

On behalf of the City of New York, please accept my best wishes for an enjoyable and informative conference and a wonderful stay in our great city.

Sincerely,

Bill de Blasio
Mayor
IPFCC Resources
Visit IPFCC’s Resource Booth located near the Exhibit Hall and Registration area. IPFCC publishes a variety of resources to provide health care professionals and patient and family leaders with the necessary tools to enhance collaborative relationships and to implement patient- and family-centered practices.

Receive 10% off IPFCC resources when purchased at the conference and online until September 30, 2016. Visit ipfcc.org/resources to purchase materials through our simple and secure online marketplace. Use discount code ‘newyork’ to receive the discount.

Access Conference Materials on the IPFCC Live Learning Library
All conference materials and session Presentations (without audio) can be accessed at no charge to attendees on the IPFCC Learning Library – www.intelliquestmedia.com/library/IPFCC2016Handouts.

More than 120 sessions will also be professionally audio recorded by IntelliQuest, combined with the Presentation materials and made available for purchase 2–3 weeks after the Conference.

Recordings can be purchased and accessed Online or you can upgrade to a hard copy version on a thumb drive.

Take advantage of the "early bird" discount and place your order by phone (866-651-2586) or online at www.intelliquestmedia.com/store/search.php?a=E&c=201613.

Online Access (120+ sessions):
**Early-bird Price** (before July 24, 2016): $99
**Regular Conference Price** (after July 24, 2016): $159

Thumb Drive (also includes Online Access):
**Early-bird Price** (before July 24, 2016): $129
**Regular Conference Price** (after July 24, 2016): $179

**Individual Sessions:**
Downloads: $20 (available 2-3 weeks following Conference)
Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care.

Patient- and family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of patients of all ages. They acknowledge that emotional, social, developmental, and spiritual support are integral components of health care. They promote the health and well-being of individuals and families and restore dignity and control to them.

**CORE CONCEPTS OF PATIENT- AND FAMILY-CENTERED CARE**

**Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

**Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

**Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

**Collaboration.** Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation, and evaluation; in facility design; and in professional education, as well as in the delivery of care.

**Conference Learning Objectives**

- **Gain understanding** of patient- and family-centered care and how it can be applied to all settings across the continuum of care to enhance quality, safety, and the experience of care.

- **Identify strategies** to support and sustain patient and family engagement and meaningful partnerships among patients, families, health care professionals, educators, and researchers.

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

- **Discuss** how to integrate patient- and family-centered concepts in the education of health care professionals, research, quality improvement, risk management, patient safety, facility design, HIPAA and other privacy regulations, evaluation, and strategic planning.

- **Explore** patient- and family-centered approaches to address current priorities in health care—specifically, reducing readmissions, decreasing infections and preventable errors, improving medication management, providing safe care transitions, improving cost efficiency, and enhancing workforce capacity.

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

NYU Langone Medical Center is one of the nation’s premier academic medical centers. Our trifold mission to serve, teach, and discover is achieved daily through an integrated academic culture devoted to excellence in patient care, education, and research.

Located in Manhattan, with facilities throughout the New York City area, NYU Langone is listed number 12 in the nation on U.S. News & World Report’s “Best Hospitals 2015–16 Honor Roll,” with 12 nationally ranked specialties. In 2013, 2014, and 2015, NYU Langone was ranked number 1 for overall patient safety and quality among leading academic medical centers that were included in the University Health System Consortium Quality and Accountability study.

At NYU Langone’s Hassenfeld Children’s Hospital, infants, children, and adolescents receive highly comprehensive and advanced care. Our doctors are leaders in their fields and offer medical and surgical care for simple or complex childhood conditions, in outpatient and inpatient settings.

We understand that when we treat children, we treat families. The Sala Institute for Child and Family Centered Care was established to create a new model for the care of children and families at Hassenfeld Children’s Hospital. We nurture a family-centered culture, where children and their families are integral members of the healthcare team.

PROGRAM SUPPORT FOR PARTNERSHIPS IN RESEARCH

Patient-Centered Outcomes Research Institute (PCORI)

This conference was partially funded through a PCORI Engagement Award Initiative (EA-1467-IPFCC). The content does not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors, or Methodology Committee.

Conference Partners

HASSENFELD CHILDREN’S HOSPITAL OF NEW YORK AT NYU LANGONE

Continuing Education

NURSES: This continuing nursing education activity was approved by the Maryland Nurses Association, an accredited approver by the American Nurses Credentialing Center’s Commission on Accreditation (ANCC COA). This activity has been awarded 19 contact hours. Activity Approval Code: 115-95-0725-0612.

PHYSICIANS: This Live activity, The 7th International Conference on Patient- and Family-Centered Care – Partnerships in Care, Interprofessional Education, and Research, from 07/25/2016–07/27/2016, has been reviewed and is acceptable for up to 19.75 Prescribed and 1.0 Elective credits by the American Academy of Family Physicians. Since some sessions run concurrently, no more than 19.75 credits may be reported. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

SOCIAL WORKERS: This program is pending approval from the National Association of Social Workers. Please note: CEUs are unavailable for social workers licensed in the New York state. CEUs are pending approval for social workers licensed in all other states.

CHILD LIFE SPECIALISTS: 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 provided as documentation of your IPFCC conference participation.

PATIENT EXPERIENCE: This conference is pending approval for up to 18 Patient Experience Continuing Education Credits (PXEs) from the Patient Experience Institute. Participants interested in receiving PXEs must claim their credits within 30 days of attending the conference.
Creating Capacity for Sustainable Partnerships with Patients and Families in Research

In April 2015, IPFCC received a Patient-Centered Outcomes Research Institute (PCORI) award to explore how Patient and Family Advisory Councils (PFACs) can innovatively and effectively partner with researchers and health care professionals in all stages of research. IPFCC’s project, Creating Capacity for Sustainable Partnerships with Patients and Families in Research, is designed to:

1. Identify, prepare, and support researchers and advisors from seven diverse health care institutions, tracking and monitoring researcher and advisor partnership processes;
2. Create programming within IPFCC's 7th International Conference to showcase exemplary partnerships in research; and
3. Develop and disseminate a toolkit offering strategies, tools, and lessons learned to guide others in creating and sustaining research partnerships with PFACs.

Seven institutions with geographic, demographic, and clinical diversities were identified as project sites and received education and support for building or strengthening partnerships among their PFACs, researchers, and staff. Representatives from each of these organizations will be sharing their successes and challenges at the Conference in the presentations listed below.

In addition to these, the 7th International Conference offers many other presentations and posters that focus on research. Just look for sessions marked with the magnifying glass icon in the syllabus. If you want to learn more about research partnerships or connect with others, a Special Networking Breakfast: Partnering with Patients and Families in Research is scheduled for Wednesday, July 27, from 7:00–8:00 am.

ABOUT PCORI
PCORI is an independent, non-profit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and healthcare decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work. Learn more about projects they fund and how to apply at www.pcori.org.

<table>
<thead>
<tr>
<th>Organization</th>
<th>Title of Research</th>
<th>Presentation – Date and Time</th>
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<tbody>
<tr>
<td>Middlesex Hospital, CT</td>
<td>Our Journey: Patient Family Advisory Council and Research at a Community Based Hospital</td>
<td>Poster Session Monday July 25 Stuffed from 9:45–10:30 am and 11:45 am–1:15 pm</td>
</tr>
<tr>
<td>Sala Institute for Child and Family Centered Care, NYU Langone Medical Center, NY</td>
<td>A Quality Improvement Framework to Advance Patient and Family Engagement in Research</td>
<td>G10 Tuesday July 26 2–3 pm</td>
</tr>
<tr>
<td>Moffitt Cancer Center, FL</td>
<td>Effective Advisory Council Collaborations: Enhancing the Impact of the ORIEN Research Protocol</td>
<td>G10 Tuesday July 26 2–3 pm</td>
</tr>
<tr>
<td>Ohio State University Wexner Medical Center, OH</td>
<td>Improving the Patient Experience Through Patient and Researcher Partnerships</td>
<td>H8 Tuesday July 26 3:15–4:15 pm</td>
</tr>
<tr>
<td>Stanford Health Care, CA</td>
<td>Partnering with Patients and Families in Research Design: What’s Said versus Heard During ICU Bedside Rounds</td>
<td>H8 Tuesday July 26 3:15–4:15 pm</td>
</tr>
<tr>
<td>Essentia Health, MN</td>
<td>Leveraging Technology to Increase Speed and Quality of Dialogue with Geographically Dispersed Patient Advisors</td>
<td>M5 Wednesday July 27 1:45–2:45 pm</td>
</tr>
<tr>
<td>Vidant Medical Center, NC</td>
<td>Patient and Family Advisor Impact on Physician Communication</td>
<td>M5 Wednesday July 27 1:45–2:45 pm</td>
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### 7TH INTERNATIONAL CONFERENCE PROGRAM ADVISORY COMMITTEE

<table>
<thead>
<tr>
<th>Marie R. Abraham, MA</th>
<th>Vice President, Programming and Publications</th>
<th>IPFCC</th>
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<tr>
<td>Old Lyme, CT</td>
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<tr>
<td>Paul Boucher, MD</td>
<td>Medical Director, ICU, Clinical Associate Professor, University of Calgary, IPFCC</td>
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<tr>
<td>COMMITTEE Co-Chair, Dep. of Critical Care</td>
<td>Foothills Medical Center, Alberta Health Services</td>
<td>Calgary, AB, Canada</td>
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<tr>
<td>Elizabeth Crocker, BA, MEd</td>
<td>Author and Advocate</td>
<td>Vice President, Board of Directors IPFCC</td>
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<tr>
<td>Nancy DiVenere</td>
<td>Former President</td>
<td>Parent to Parent USA</td>
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<tr>
<td>Maureen Fagan, DNP, MHA, WHNP-DC, FNP</td>
<td>Associate Chief Nurse-OB/GYN</td>
<td>Executive Director, Center for Patients and Families</td>
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### 7TH INTERNATIONAL CONFERENCE ABSTRACT REVIEW COMMITTEE

<table>
<thead>
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<tr>
<td>Jacqueline Alikhaani, MBA</td>
<td>Ambassador</td>
<td>Patient-Centered Outcomes Research Institute</td>
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<tr>
<td>Pam Bell, MDiv, BA</td>
<td>Director of Patient Family Centered Care</td>
<td>The Valley Hospital</td>
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<tr>
<td>Janet Bell Taylor, MBA, CPHM</td>
<td>Director, Patient Family Services &amp; The Michael Fux Family Center</td>
<td>Nicklaus Children’s Hospital</td>
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<tr>
<td>Patty Black, BS</td>
<td>Program Coordinator for Patient and Family Centered Care</td>
<td>PeaceHealth Medical Group</td>
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<tr>
<td>Kimly Blanton, MIS, MLS</td>
<td>Patient Family Advisor</td>
<td>Vidant Health</td>
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<tr>
<td>Paul Boucher, MD, FRCP</td>
<td>Intensivist, Medical Director, ICU</td>
<td>Foothills Medical Center</td>
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### Additional Information

- Robert Boxer, MD, PhD | Physician | Brigham and Women’s Hospital | Boston, MA |
- Mireille Brossseau, MA | Patient/Family Engagement Specialist | Children’s Hospital of Eastern Ontario | Ottawa, ON, Canada |
- Barbara Burke, MA | Senior Director, Patient-Family Experience | Center for Excellence | Ann & Robert H. Lurie Children’s Hospital of Chicago | Chicago, IL |
- Martha Carnie, BA | Senior Patient Advisor | Brigham and Women’s Hospital | Boston, MA |
- Celeste Castillo Lee, BS | Chair, Patient Family Partnership | Council and Board of Directors | Kidney Health Initiative | Chapel Hill, NC |
- Joanna Celentano, MA, MBA | March of Dimes/CHaD ICN Family Support Specialist | Intensive Care Nursing | Children’s Hospital at Dartmouth | Lebanon, NH |
- Sheryl Chadwick, BS | Family Centered Care Coordinator | Children’s Mercy Kansas City | Kansas City, MO |
- Julie Ginn Moretz, BS | Associate Vice Chancellor, Patient- and Family-Centered Care | University of Arkansas for Medical Sciences | Little Rock, AR |
- Debra L. Ness, MS | President | National Partnership for Women & Families | Washington, DC |
- 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 | Hassenfeld Children’s Hospital of New York at NYU Langone | New York, NY |
- Beth Lown, MD | Medical Director | The Schwartz Center for Compassionate Healthcare | Boston, MA |
- 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 Chair for Research and Professional Development | The Carol Jenkins Mattocks Distinguished Professor | The University of North Carolina at Greensboro | Board Member, IPFCC | Greensboro, NC |
- Susan Sheridan, MBA, MIM, DHL | Director, Patient Engagement | Patient-Centered Outcomes Research Institute (PCORI) | Washington, DC |
- Nancy DiVenere, BA | Former President | Parent to Parent USA | Board Member, IPFCC | Essex, VT |
- Liz Crocker, MEd | Patient Advocate | Vice President | IPFCC | East Chester, NS, Canada |
- Pam Dardess, MPH | Principal Researcher | American Institutes for Research | Chapel Hill, NC |
- Caroline Delongchamps, BS Manager, Patient- and Family Centered Care, Staff Liaison, Patient Family Advisory Council | MUSC Children’s Hospital | Charleston, SC |
- Michelle Esquivel, MPH | Director, Division of Children with Special Health Care Needs | American Academy of Pediatrics | Elk Grove, IL |
the positions listed are those that individuals held at the time reviews were completed.
# Program At-A-Glance

## Sunday, July 24, 2016

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>1:00 pm–6:00 pm</td>
<td>Registration</td>
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## Monday, July 25, 2016

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<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>7:00 am–8:00 am</td>
<td>Registration, Continental Breakfast, Exhibits, Poster Displays</td>
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<tr>
<td>8:00 am–9:45 am</td>
<td>Opening Keynote, sponsored by Peterson Center on Healthcare</td>
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<tr>
<td>9:45 am–10:30 am</td>
<td>Break Exhibits/Poster Presentations (Staffed) sponsored by American College of Radiology</td>
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<tr>
<td>10:45 am–11:45 am</td>
<td>Concurrent Sessions</td>
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<tr>
<td>11:45 am–1:15 pm</td>
<td>Lunch—Exhibits/Poster Presentations (Staffed), sponsored by American College of Radiology</td>
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<tr>
<td>1:15 pm–2:15 pm</td>
<td>Concurrent Sessions</td>
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<tr>
<td>2:30 pm–3:30 pm</td>
<td>Concurrent Sessions</td>
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<tr>
<td>3:30 pm–4:00 pm</td>
<td>Break—Exhibits/Poster Displays</td>
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<tr>
<td>4:00 pm–5:00 pm</td>
<td>Concurrent Sessions</td>
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<tr>
<td>5:30 pm–7:00 pm</td>
<td>Welcome Reception and Book Signing – Exhibits/Poster Displays, Welcome Reception sponsored by Ronald McDonald House Charities</td>
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## Tuesday, July 26, 2016

<table>
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<tr>
<th>Time</th>
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<tbody>
<tr>
<td>7:00 am–8:00 am</td>
<td>Registration, Continental Breakfast, Exhibits, Poster Displays</td>
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<tr>
<td>8:00 am–9:30 am</td>
<td>Plenary Session</td>
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<tr>
<td>9:30 am–10:00 am</td>
<td>Break—Exhibits/Poster Displays</td>
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<tr>
<td>10:00 am–11:00 am</td>
<td>Concurrent Sessions</td>
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<tr>
<td>11:15 am–12:15 pm</td>
<td>Concurrent Sessions</td>
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<tr>
<td>12:15 pm–1:45 pm</td>
<td>Lunch—Exhibits/Poster Displays</td>
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<tr>
<td>2:00 pm–3:00 pm</td>
<td>Concurrent Sessions</td>
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<tr>
<td>3:15 pm–4:15 pm</td>
<td>Concurrent Sessions</td>
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<tr>
<td>4:30 pm–5:30 pm</td>
<td>Concurrent Sessions</td>
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## Wednesday, July 27, 2016

<table>
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<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>7:00 am–8:00 am</td>
<td>Registration, Continental Breakfast</td>
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<tr>
<td>8:00 am–9:00 am</td>
<td>Concurrent Sessions</td>
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<tr>
<td>9:15 am–10:15 am</td>
<td>Concurrent Sessions</td>
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<tr>
<td>10:15 am–10:45 am</td>
<td>Break</td>
</tr>
<tr>
<td>10:45 am–12:15 pm</td>
<td>Spotlight on Exemplars</td>
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<tr>
<td>12:15 pm–1:45 pm</td>
<td>Lunch Break (On your own)</td>
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<tr>
<td>1:45 pm–2:45 pm</td>
<td>Concurrent Sessions</td>
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<tr>
<td>3:00 pm–4:00 pm</td>
<td>Closing Plenary</td>
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# Conference Topics

The symbols listed below represent the various topics that are featured in the Conference Sessions and Posters. A brief description of each topic is provided. To help you in your selection, each Session and Poster is identified with the appropriate topic symbols.

**Better Together**
- Strategies and resources developed with patients and families that use a comprehensive approach to change hospital policies from restrictive to those that welcome family presence and participation in care and decision-making.

**Design**
- Environment and design projects that have meaningfully involved patient and family advisors in the planning process.

**Health Equity**
- Initiatives that demonstrate how partnerships with patients, families, and communities help reduce disparities in health care and increase access for all.

**Interprofessional Education**
- Approaches, curricula, and programs for interprofessional education that have been guided by collaboration with patients and families.

**Leadership**
- Effective practices that leaders can use to advance patient- and family-centered care and achieve widespread adoption and measureable change.

**Patient Education and Support**
- Strategies, tools, and programs that provide patients and families with information, education, and support and have been developed in partnership with patients and families.

**Quality Improvement**
- Best practices for creating partnerships among patients, families, and health care professionals in improving health care.

**Research**
- Projects and innovative strategies that prepare and support researchers, health care professionals, patients, and families to partner in all phases of research.

**Safety**
- Initiatives that prepare and support patients and families to be key allies for enhancing safety and reducing harm.

**Tools and Strategies for Advisors**
- Methods and materials to strengthen the knowledge and skills of patient and family advisors and patient and family advisory councils.
## Exhibit Hall Activities and Special Events

### ACTIVITIES AT-A-GLANCE

**Sunday, July 24, 2016**
- 1:00 pm-6:00 pm  **Registration**

**Monday, July 25, 2016**
- 7:00 am–8:00 am  **Registration, Continental Breakfast—Exhibits/Poster Displays**
- 8:00 am—1:00 pm  **Networking Breakfast for Patient and Family Advisors/Leaders**
- 9:45 am–10:30 am  **Break—Exhibits/Poster Presentations (Staffed)**
- 11:45 am–1:15 pm  **Lunch—Exhibits/Poster Presentations (Staffed)**
- 3:30 pm–4:00 pm  **Break—Exhibits/Poster Displays**
- 5:30 pm–7:00 pm  **Welcome Reception**
- **Exhibits/Poster Displays and Book Signing**

**Tuesday, July 26, 2016**
- 7:00 am–8:00 am  **Registration, Continental Breakfast – Exhibits/Poster Displays**
- 9:30 am–10:00 am  **Break—Exhibits/Poster Displays**
- 12:15 pm–1:45 pm  **Lunch Break (On your own)**

**Wednesday, July 27, 2016**
- 7:00 am–8:00 am  **Registration, Continental Breakfast**
- 12:15 pm–1:45 pm  **Lunch Break (On your own)**

### Poster Presentations

*Monday’s poster presentations sponsored by ACR*

Poster presentations will showcase innovative programs and patient- and family-centered initiatives from hospitals, health care systems, universities, and community organizations. Come meet the presenters and discuss their work. Posters can be viewed near the Exhibit Hall on Monday and Tuesday. Interactive poster sessions with the authors will be featured on Monday during the morning break and lunch break.

### StoryCorps

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

### Book Signings

Find books written by conference speakers at our onsite bookstore, and meet some of your favorite authors at the book signing during Monday’s Welcome Reception.

### Exhibits

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

### Participant Meals

For your planning purposes, a continental breakfast is included as part of your registration Monday - Wednesday. Lunch tickets are also provided for all participants on Monday and Tuesday and can be redeemed in the Exhibit Hall.

### Guest Badge

Guest badges may be purchased for these special activities: (Guest badge does not include participation in or auditing of any educational sessions.)

- Welcome Reception and Continental Breakfasts (Monday-Wednesday): Cost: $150
MONDAY, JULY 25

7:00–8:00 am
Special Networking Breakfast for Patient and Family Advisors/Leaders
Want to connect with other patients and families who are partnering with health care professionals in change and improvement? Grab breakfast and come join us for informal networking and discussion.

9:45–10:30 am and 11:45 am–1:15 pm
Poster Session Sponsored by American College of Radiology
All poster presenters will be present for discussion of posters. Refreshments served.

5:30–7:00 pm
Welcome Reception Sponsored by Ronald McDonald House Charities
Join colleagues for this social gathering in the Exhibit Hall. Cash bar; light hors d’oeuvres. Guest badges are available. There will also be a book signing by presenters of the Monday afternoon session, Why Stories Matter: Writers Reflect on Experiences, Motivations, and Hopes by distinguished authors, Liz Crocker, Will Schwalbe and Tilda Shalof.

TUESDAY, JULY 26

7:00–8:00 am
Special Interest Breakfast
Hassenfeld Children’s Hospital of New York at NYU Langone
Measurement that Matters in Patient and Family-Centered Care: From Theory to Practice
Attend breakfast to explore hot topics in patient- and family-centered measurements. In facilitated table topic discussions, share challenges in measurement, explore innovative ideas and learn from each other.

Special Networking Breakfast: “Better Together – Changing the Concept of Families as Visitors”
Join us for breakfast to learn more about IPFCC’s Better Together: Partnering with Families campaign and how you can change visiting policies at your hospital.

Other networking breakfasts can be arranged based on interest and will be announced during the conference and posted at the registration desk.

12:15–1:45 pm
Special Lunch for Ronald McDonald House Charities
Delegation from RMHC will meet informally with representatives from children’s hospitals to talk about enhancing practice around family presence and participation. (By invitation)

Networking Lunch-Translating Theory into Action for NICUs: A Hands on Workshop for Tackling Your Family Centered Care Challenges
You’re invited to join March of Dimes NICU Initiatives staff for a special, interactive working lunch to discuss opportunities for improvement to support creating a more family centered environment in the NICU. This session will include stations to learn about family centered innovations in NICUs across the country, and an opportunity to learn more about other NICUs through online polling. All participants who complete the session will receive a gift card. This session is NICU focused and is limited to 50 participants.

7:00 pm
Informal Networking Dinner
For anyone interested in meeting and networking with other conference attendees, we will organize small groups to dine at local restaurants. Please refer to information at the registration desk.

WEDNESDAY, JULY 27

7:00–8:00 am
Special Networking Breakfast: Partnering with Patients and Families in Research
Are you interested in learning more about how to create meaningful and sustainable partnerships or want to meet others with experience in collaborating with patients and families in research? Join us for this networking event.

Other Networking Breakfasts
Breakfasts can be arranged based on interest and will be announced during the conference and posted at the registration desk.
Continuing Education

Eligibility
The 7th International Conference on Patient- and Family-Centered Care offers continuing education (CE) credits for approved sessions through multiple professional associations. Continuing education credits are available for eligible nurses, physicians, social workers, child life specialists, and patient experience professionals.

General Certificates of Attendance are available upon request and will be provided electronically to conference attendees after the conference.

Daily Sign-In/Online Evaluation
To accommodate the needs of many licensees who must verify their attendance daily, IPFCC provides an electronic system of badge scanning. To be eligible, a participant requesting continuing education certification must have their badge scanned daily at the CEU Desk (located near the IPFCC Conference Registration Desk) and complete the daily online evaluations no later than Friday, August 26, 2016 — the online evaluations will not be accessible after this date. Participants can either complete each day’s evaluation after the last session of each day, or complete the daily evaluations in their entirety after the conference.

To complete the online evaluations accessible immediately after the last session of each day, go to:
www.ipfcc.org/conf-eval-day1.html
www.ipfcc.org/conf-eval-day2.html
www.ipfcc.org/conf-eval-day3.html

Presenter’s Disclosure
The Maryland Nurses Association, Inc. follows the standards that continuing education programs will be free from commercial bias. In accordance with this standard and the criteria set forth by the ANCC COA, speakers have disclosed any relationship they have to companies producing pharmaceuticals, medical equipment, prosthetics, etc. that might be germane to the content of their lecture. To be in compliance with ANCC COA and other accreditation organizations, such disclosure is not intended to suggest or condone bias in a presentation, but is elicited to provide the attendee with information that might be of potential importance to them. Disclosure materials will be made available to attendees upon request.

Nurses: This continuing nursing education activity was approved by the Maryland Nurses Association, an accredited approver by the American Nurses Credentialing Center’s Commission on Accreditation (ANCC COA). This activity has been awarded 19 contact hours. Activity Approval Code: 115-95-0725-0612.

Physicians: This Live activity, The 7th International Conference on Patient- and Family-Centered Care - Partnerships in Care, Interprofessional Education, and Research, from 07/25/2016–07/27/2016, has been reviewed and is acceptable for up to 19.75 Prescribed and 1.0 Elective credits by the American Academy of Family Physicians. Since some sessions run concurrently, no more than 19.75 credits may be reported. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Social Workers: This program is pending approval from the National Association of Social Workers. Please note: CEUs are unavailable for social workers licensed in the New York state. CEUs are pending approval for social workers licensed in all other states.

Child Life Specialists: 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 provided as documentation of your IPFCC conference participation.

Patient Experience: This conference is approved for up to 18 Patient Experience Continuing Education Credits (PXEs) from the Patient Experience Institute. Participants interested in receiving PXEs must claim their credits within 30 days of attending the conference.
KEYNOTE AND PLENARY SPEAKERS

MONDAY

Partnerships in Care, Interprofessional Education, and Research

EILEEN WHALEN, MHA, RN

Eileen Whalen, MHA, RN, serves as the President of the University of Vermont (UVM) Medical Center. The UVM Medical Center, formerly Fletcher Allen Health Care, is part of the University of Vermont Health Network, a four hospital network serving a population of more than 1 million people in Vermont and northern New York. The UVM Medical Center provides a full range of tertiary-level inpatient and outpatient services and provides primary care services at ten Vermont locations. UVM Medical Center has earned the distinction of being designated a Level I Trauma Center and serves as the home to the University of Vermont Children’s Hospital.

Ms. Whalen has over 35 years of experience in health care. She joined UVM Medical Center from Harborview Medical Center in Seattle, WA where she served as chief executive. Harborview is the largest public hospital in the State of Washington and an academic medical center, part of the UW Medicine Network. Prior to taking the position at Harborview, she served as executive vice president at the University of Arizona Medical Center, Tucson, AZ. Ms. Whalen has also held numerous leadership positions in trauma, emergency and critical care services. She is a nationally recognized trauma systems expert and has served as the President and a founding member of the Society of Trauma Nurses, a published author and a Board member of prominent health care societies and associations. Ms. Whalen is a graduate of Niagara University, Niagara Falls, NY, where she received a Bachelor’s of Science in Nursing. She also holds a Master in Health and Hospital Administration degree from Chapman University, Sacramento, CA.

TUESDAY

Standards and Accreditation As a Catalyst for Achieving Transformative Change: The Canadian Health Care Experience

LESLEE THOMPSON, BSCN, MSCN, MBA

Leslee Thompson joined Accreditation Canada as President and CEO on February 1, 2016. Leslee is an experienced senior executive who has led multiple public and private sector organizations through major change, including Kingston General Hospital where she served as President and CEO for seven years. She has been appointed to many system leadership roles over the years and most recently these include: former Chair of Canadian Foundation for Healthcare Improvement, former chair of Council of Academic Hospitals of Ontario, and member of the Ontario Health Innovation Council. Leslee is internationally recognized for her pioneering work on co-creating the future of health and health care with patients and families.

ANGELA MORIN

Angela Morin has been partnering with healthcare professionals in quality improvement initiatives, policy and program development as a Patient and Family Experience Advisor at Kingston General Hospital since November 2011. She currently sits as Co-Chair of the KGH Patient and Family Advisory Council and as a member of the Southeast Regional Cancer Centre PFAC.

Angela has partnered with Accreditation Canada bringing the patient voice to the 2016 Accreditation Standards which support healthcare providers in the implementation of client and family centred care in their organizations. She is a Core Faculty Member and Collaborative Coach for the Canadian Foundation for Healthcare Improvement and was appointed as a Member of the Ontario Health Quality Council (HQO) in November 2014.

Angela believes partnering with patients and families at every level of the healthcare system is the right thing to do. Angela’s personal experiences as a patient and supporting loved ones through their healthcare journeys continues to motivate her to bring the patient and family voice to health care.
The Pursuit of Equity in Health and Healthcare: Creating the Climate for Change and Partnerships

B. LEE GREEN, PHD, MED, BS

B. Lee Green, PhD, MEd, BS, is the Vice President of Diversity, Public Relations and Strategic Communications and faculty member of the Health Outcomes and Behavior Department at the Moffitt Cancer Center. Lee is recognized for his work in the area of cancer health disparities, with particular interest in education, knowledge and awareness among minority populations. His interest also includes community based participatory research as well as minority participation in clinical trials and research studies. His role at the Moffitt Cancer Center is to lead and direct the efforts that address diversity and health disparities. In this role he is responsible for (1) the awareness and education of all Moffitt faculty and staff on diversity and health disparities; (2) directing efforts in the area of cultural and linguistic competency; (3) spearheading the community outreach efforts to minority and underserved communities; (4) management of equity and inclusion efforts; (5) development of strong partnerships within the cancer center and the community; and (6) providing support for departments within the cancer center in addressing supplier diversity, clinical trials participation of minorities, translation services, and human resources. Because of Dr. Green’s leadership on diversity issues, the Moffitt Cancer Center was recognized by DiversityInc as having one of the top 10 diversity programs in the country. Moffitt ranked #6 on the list. In Dr. Green’s role as the Vice President for Public Relations and Strategic Communications, he is responsible for the institutional strategy for both internal and external communications. This involves fostering a positive reputation and image of the Cancer Center among the community we serve.

FEATURED SPEAKERS

MONDAY

1:15–2:15 pm
OpenNotes and Psychotherapy: Is This Oil and Water for Patient Care? (B5)

STEPHEN F. O’NEILL, LICSW, BCD, JD

Stephen F. O’Neill, LICSW, BCD, JD, is the Associate Director of the Ethics Support Service at Beth Israel Deaconess Medical Center and is the Social Work Manager for Psychiatry, Primary Care, and Infectious Disease. He completed a Fellowship in Bioethics in the Division of Medical Ethics at Harvard Medical School, is a Clinical Instructor in the Department of Social Medicine and on Faculty in the Center for Bioethics at Harvard Medical School, and is an Adjunct Assistant Professor at Simmons College School of Social Work. Mr. O’Neill holds the positions of Director of Medical Education in Social Work at BIDMC and Social Work Consultant at the Massachusetts Medical Benevolent Society in Waltham. He chairs the National Association of Social Work’s Massachusetts Chapter’s Committee on Ethics and Professional Review, the adjudicatory arm of NASW, and is a member of the National Ethics Committee of NASW. He has extensive teaching experience, numerous committee assignments including the Professional Review Task Force of NASW, Harvard Medical School’s Clinical Ethics and Organizational Ethics Consortiums and Harvard Medical School’s Ethics Leadership Group. Through the OpenNotes Program, he started the first ever program in making behavioral health therapist notes transparent and available to patients. And he is a member of the Preventable Harm to Respect and Dignity initiative within health care at BIDMC. He is the author/co-author of a number of articles, chapters and a book entitled, Legal Issues in Social Work.

STACEY WHITEMAN

Stacey Whiteman serves on the Patient and Family Advisory Council at the Beth Israel Deaconess Medical Center (BIDMC) in Boston, MA. Additionally, she serves on the BIDMC Universal Access Advisory Council, the BIDMC Patient Site Steering Committee, and a new pilot program, Patient and Family Advisor Rounding, gathering information and observations from patients and families to help guide improvement efforts and staff training.

She is an advocate for Patient Site, BIDMC’s patient portal, and OpenNotes. She has shared her understanding of the importance of OpenNotes to patients by participating in panel discussions with the UK’s NHS Leadership Academy, as well as with several...
news organizations. She enjoys the opportunity to share her perspective “through the patient’s eyes” with the ultimate goal to help others.

Stacey began her volunteer work as an advisor after her 2012 diagnosis with progressive Multiple Sclerosis. Prior to the diagnosis, she had many years of experience supporting executive leaders in a number of companies. She lives in Dedham, MA with her family.

4:00–5:00 pm

Why Stories Matter: Writers Reflect on Experiences, Motivations, and Hopes (D9)

TILDA SHALOF, RN, BSCN, CNCC

Tilda Shalof has been an intensive care staff nurse for over 20 years in New York, Israel, and Canada. She currently works in the Medical-Surgical Intensive Care Unit at Toronto General Hospital of the University Health Network.

Tilda is the author of several books, starting in 2004 with the bestseller, A Nurse’s Story, followed in 2007 by The Making of a Nurse and Camp Nurse in 2010. Opening My Heart, published in 2011, chronicles Tilda’s experience of having heart surgery herself and being a patient in the intensive care environment where she worked. Tilda’s most recent book, Bringing It Home, examines health care beyond hospitals.

Tilda Shaloff is an outspoken patient advocate and passionate nurse leader. Her books have received wide critical acclaim in North America and internationally. A Nurse’s Story has been translated into French, Chinese, Japanese, and Vietnamese.

WILLIAM SCHWALBE

Will Schwalbe is the author of the New York Times bestseller, The End of Your Life Book Club (2012). This moving memoir about a mother-son book club earned an “A” from Entertainment Weekly, was an Indie Next pick, one of Amazon’s Top Ten books of 2012, and has been translated into thirteen languages. Will is also the co-author, with David Shipley, of the acclaimed book Send: Why People Email So Badly and How to Do It Better, a business shortlisted for the Quill Award for the Best Business Book of the Year.

In 2008, Will founded Cookstr.com, the world’s #1 collection of cookbook recipes available online. In 2013, he sold Cookstr to Macmillan publishers. He is now Executive Vice President, Editorial Development and Content Innovation for Macmillan.

Until 2008, he was Senior Vice President and Editor-in-Chief of Hyperion Books, a division of the Walt Disney Company. Previously he was a journalist, writing articles and reviews for such publications as The New York Times, the South China Morning Post, Insight for Asian Investors, Ms. Magazine, and Business Traveller Asia. He is on the board of governors of Yale University Press, the Asian American Writers’ Workshop, and the Kingsborough Community College Foundation. He has appeared several times on National Public Radio, and on Today, Good Morning America, CBS Sunday Morning, The Colbert Report, CNBC’s Power Lunch, and BBC’s The Money Programme, and has been quoted in publications around the world.

TUESDAY

10:00–11:00 am

A Conversation Exploring Current Progress and Additional Opportunities for CMS Quality and Innovation Programs to Enhance Partnerships with Patients and Families (E4)

DEBRA L. NESS, MS

Debra L. Ness, MS, is President of the National Partnership for Women & Families. Before assuming her current role as president in 2004, she served as executive vice president of the National Partnership for 13 years. Ness has played a leading role in positioning the organization as a powerful and effective advocate for today’s women and families.

Ness is a member of the Board of Directors and chairs the Consumer Advisory Council of the National Committee for Quality Assurance (NCQA). She was recently elected to serve as the first public member on the American College of Cardiology (ACC) Board of Trustees and sits on the management board of the National Cardiovascular Data Registry (NCDR). She is also one of the first public members of the American Board of Internal Medicine Board of Directors. Ness co-chairs the Consumer-Purchaser Alliance, a group of leading consumer, employer, and labor organizations working to promote high value care through the use of quality measurement, smarter payment, and effective Health Information Technology (HIT). She serves on the Executive Committee of the Health Care Transformation Task Force (HCTTF), and recently completed service on the Board of Directors of the National Quality Forum (NQF).
In addition, Ness serves on the Executive Committee of the Leadership Conference on Civil and Human Rights and co-chairs its Health Care Task Force. She also serves on the Board of Directors of the Economic Policy Institute (EPI).

Ness graduated summa cum laude from Drew University with a bachelor’s degree in psychology and sociology. After completing graduate work in social welfare and public health policy, she received her Masters of Science from Columbia University School of Social Work.

DENNIS WAGNER, MPA

Dennis Wagner, MPA is the Director of the Quality Improvement and Innovation Group in the Center for Clinical Standards and Quality. He also serves as the Co-Director of both the Partnership for Patients and the Transforming Clinical Practice Initiative. In these roles, Dennis leads a team of committed individuals in developing and delivering innovative and collaborative initiatives to improve healthcare.

Prior to his current roles at CMS, Dennis served as the Associate Deputy Director and then Acting Director of CMS’ Office of Clinical Standards and Quality. Dennis worked for 12 years at the Health Resources and Services Administration (HRSA), including a final stint as Acting Director of HRSA’s Office of Health Information Technology and Quality. While at HRSA, Dennis led major national initiatives to increase the donation and transplantation of organs. After years of relatively flat national organ donation levels, this work generated unprecedented and lasting national increases in organ donation over a four-year period.

Dennis is a national and international leader in the fields of healthcare quality improvement, the environment and social marketing. He is a frequent keynote speaker at national conferences and symposia, and has received numerous honors and awards for his work in public service. Dennis is recognized by his peers as an enthusiastic, thoughtful and strategic person who believes in committing to and delivering on bold aims in work and life.

Recently, Dennis, along with CMS colleagues Jean Moody-Williams and Dr. Paul McGann, were named 2016 Citizens Service Finalists for the prestigious Samuel J. Heyman Service to America Medals (SAMMIES). They were recognized for their efforts to create and lead a unique public-private sector initiative at CMS to increase patient safety and reduce readmissions to U.S. hospitals. Dennis received his undergraduate and graduate degrees from Montana State University. He recently co-authored a chapter entitled “The Key Elements of Effective Collaborative Design” in the book, All In: Using Healthcare Collaboratives to Save Lives and Improve Care.

2:00–3:00 pm

Partnering with Patients and Families: The Changing Roles of Risk Management (G4)

FRANCHESCA J. CHARNEY, RN, BS, MSHA, CPHRM, CPHQ, CPSO, CPPS, DFASHRM

Fran Charney is the Director of Risk Management for the American Society for Healthcare Risk Management (ASHRM) in Chicago. Fran has written numerous professional journal articles and has participated in several speaking engagements for national organizations. Fran has testified before the Commonwealth of Pennsylvania Legislative Committee for the 100K lives program. Fran’s participation in the Pennsylvania Color of Safety Initiative along with several other Pennsylvania hospitals won a HAP Innovation Award and Patient Safety Achievement Award. Fran also serves as faculty for the patient safety curriculum and TeamSTEPPS for ASHRM and has completed the HERT Patient Safety Leadership Fellowship. She served as a member of the Board of Directors for ASHRM prior to joining the American Hospital Association.

Fran began her career in 1980 as a registered nurse working in the ICU, OR and PACU units of hospitals in New Jersey and Pennsylvania. Most recently she has served as Director of Educational Programs for the Pennsylvania Patient Safety Authority.

Fran served as President of the Central PA Association of Health Care Risk Management, sat on the PA Medical Society Executive Council on Patient Advocacy, Patient Safety Advisory Group and Committee for Quality and Care Management for HAP. Fran has been accepted as a Population Health Associate for the Health Policy Forum for Jefferson School of Population Health. She is a certified trainer in Just Culture and a master trainer in TeamSTEPPS. Fran has also furthered her knowledge in Healthcare Risk Management by achieving certificates in Health Care Law and ASHRM Barton and Patient Safety Curriculums. Charney also has a certificate in Lean Six Sigma and Black Belt.

MICHAEL MIDSLEY, RN, JD, MPH, CPHRM, FASHRM

Mike Midgley has over 25 years of experience in the healthcare industry. He is an experienced healthcare risk manager, nurse, insurance professional and attorney. Mr. Midgley began his clinical experience as a nurse in intensive care and emergency medicine. Mike started his healthcare risk management career with a captive insurance company in New York City, having dedicated risk and claims management consulting responsibilities to a major tertiary care medical center. He then served as a risk manager at academic medical centers in New York City. Mr. Midgley later worked in the field as a
risk management consultant with medical malpractice insurance carriers. He is currently the Vice President of Healthcare Risk Engineering for Swiss Re Corporate Solutions in New York City where he provides expertise in risk management and patient safety.

Mr. Midgley earned his Juris Doctor (JD) from Fordham University School of Law. He has a Master of Public Health degree from the University of Medicine and Dentistry of NJ and a Bachelor of Science degree in nursing from Rutgers University School of Nursing. He is a Fellow of the American Society for Healthcare Risk Management (FASHRM) for outstanding achievement and has earned Certified Professional in Healthcare Risk Management (CPHRM) designation.

Mike is a Past President of the Association for Healthcare Risk Management of New York (AHRMNY) where he continues to serve on the Board of Directors. Mike is an active member of the American Health Lawyers Association, American Association of Nurse Attorneys, American Bar Association, NY County Lawyers’ Association, American Association of Notaries, American College of Healthcare Executives, Healthcare Leaders of NY and the NJ and FL ASHRM Chapters.

Mr. Midgley is a Clinical Assistant Professor at Stony Brook University School of Health Technology and Management teaching Advanced Practice for Risk and Safety Officers in the Master of Science in Patient Safety Program. Mike has authored risk management articles, including education modules for the Nursing Spectrum Journal. He routinely provides risk management lectures both locally and for national audiences.

WEDNESDAY

9:15–10:15 am

Partnering with Patient and Family Faculty in Interprofessional Education: The Perspectives of Leaders (K3)

STEVEN E. WEINBERGER, MD, MACP, FRCP

Steven Weinberger became Executive Vice President and CEO of the American College of Physicians (ACP) in 2010, after having served for 6 years as ACP’s Senior Vice President for Medical Education and Publishing. An internist and pulmonologist, Dr. Weinberger is also Adjunct Professor of Medicine at the University of Pennsylvania and Senior Lecturer on Medicine at Harvard Medical School. Prior to joining ACP, Dr. Weinberger served on the full-time faculty of Harvard and Beth Israel Hospital/Beth Israel Deaconess Medical Center for more than 25 years. He was Executive Vice Chair of the Department of Medicine at Beth Israel Deaconess Medical Center, Executive Director of the Carl J. Shapiro Institute for Education and Research, and Professor of Medicine and Faculty Associate Dean for Medical Education at Harvard. Dr. Weinberger has authored over 140 articles and book chapters as well as a popular textbook, Principles of Pulmonary Medicine, now in its sixth edition and available in several languages. He has served on the Editorial Board of The New England Journal of Medicine and was the Founding Editor-in-Chief of the Pulmonary and Critical Care Medicine component of UpToDate.

Dr. Weinberger received his M.D. from Harvard Medical School and residency training in internal medicine at the University of California-San Francisco Medical Center, followed by fellowship training in pulmonary medicine at the National Heart, Lung and Blood Institute. He is the recipient of numerous Harvard Medical School teaching awards. He has also received multiple national awards, including the Robert J. Glaser Distinguished Teacher Award from Alpha Omega Alpha and the Association of American Medical Colleges, the Clinical Educator Award from the Alliance for Academic Internal Medicine, and Mastership from the American College of Physicians.

SUSAN GRANT, MS, RN, NEA-BC, FAAN

Susan Grant, MS, RN, NEA-BC, FAAN, is Executive Vice President and Chief Nursing Officer at Beaumont Health. Beaumont is a not-for-profit organization formed by Beaumont Health System, Botsford Health Care and Oakwood Healthcare to provide patients with the benefit of greater access to the highest quality, compassionate care, no matter where they live in southeast Michigan. The organization consists of eight hospitals with 3,337 beds, 168 outpatient sites, nearly 5,000 physicians, 35,000 employees and about 3,500 volunteers. In 2015, the organization had 4.1 billion in net revenue with 177,934 inpatient admissions, 17,151 births and 530,860 emergency visits.

Susan joined Beaumont in 2015 to oversee the nursing practice for the 10,000 nurses across Beaumont. She came from Emory Healthcare in Atlanta where she served as Chief Nurse Executive and Chief Patient Services Officer since 2006. Under her leadership, Emory University Hospital achieved its first Magnet designation and Emory Saint Joseph Hospital achieved its fifth designation. Susan also served on the system executive team managing the successful admissions and communications related to the first two patients with Ebola virus disease treated in the United States. In addition, she served as Interim Dean of the Nell Hodgson Woodruff School of Nursing at Emory University and Associate Dean for Clinical Leadership.
Prior to joining Emory, Susan was Chief Nursing Officer and Senior Associate Administrator for Patient Care Services at the University of Washington Medical Center in Seattle, and Chief of Nursing and Patient Care Services at the Dana-Farber Cancer Institute in Boston. She began her career as a staff nurse at Emory University Hospital and the Medical College of Georgia.

Susan earned a Bachelor of Science in Nursing at the Medical College of Georgia and a master’s degree in psychiatric and community mental health nursing at the University of South Carolina. She was a Robert Wood Johnson Executive Nurse Fellow and a Wharton Nursing Executive Fellow. She is currently completing her doctorate of nursing practice at Vanderbilt University.

GEORGE E. THIBAULT, MD

George E. Thibault, MD became the seventh president of the Josiah Macy Jr. Foundation in January 2008. Immediately prior to that, he served as Vice President of Clinical Affairs at Partners Healthcare System in Boston and Director of the Academy at Harvard Medical School (HMS). He was the first Daniel D. Federman Professor of Medicine and Medical Education at HMS and is now the Federman Professor, Emeritus.

Dr. Thibault previously served as Chief Medical Officer at Brigham and Women’s Hospital and as Chief of Medicine at the Harvard affiliated Brockton/ West Roxbury VA Hospital. He was Associate Chief of Medicine and Director of the Internal Medical Residency Program at Massachusetts General Hospital (MGH). He is Chairman of the Board of the MGH Institute of Health Professions, and he serves on the Board of the New York Academy of Sciences, the Institute on Medicine as a Profession, and the Lebanese American University. He serves on the President’s White House Fellows Commission and for twelve years he chaired the Special Medical Advisory Group for the Department of Veteran’s Affairs.

Dr. Thibault graduated summa cum laude from Georgetown University in 1965 and magna cum laude from Harvard Medical School in 1969. He completed his internship and residency in Medicine and fellowship in Cardiology at Massachusetts General Hospital (MGH). He also trained in Cardiology at the National Heart and Lung Institute in Bethesda and at Guys Hospital in London, and served as Chief Resident in Medicine at MGH.

AMIR KARMALI

Amir Karmali joined Holland Bloorview as a parent advisor after his son went there for rehab after a sporting accident. He now oversees the Family Leadership Program at Holland Bloorview and is the staff lead for the Family Advisory Committee and staff advisor for the Bloorview Research Institute Family Engagement Committee. He is also an Enrollment Lead and sits on the project team for the newly launched client and family health portal. Amir is also a certified Healthcare Simulationist and teaches client and family centred care principles to all new clinical staff, existing staff and students through the use of simulations.

DEBORAH DOKKEN, MPA

Deborah L. Dokken, MPA, is currently a consultant to the Institute for Patient- and Family-Centered Care. Deborah’s career in family advocacy grew out of her own personal experiences, including the loss of two infants due to prematurity and her husband’s long battle with a rare abdominal cancer. As a result, Deborah became involved in programs that improve family support and enhance family participation in health care.

Deborah was the Associate Director of the Initiative for Pediatric Palliative Care (IPPC). She co-founded the nonprofit, community-based organization Partners in Intensive Care, and was a founding member of the Parent Partners Group at The George Washington University Hospital. Deborah has been a member of committees of the Institute of Medicine, the Food and Drug Administration, and the National Institutes of Health. At Sibley Memorial Hospital in Washington, DC, she is a member of the Patient and Family Advisory Committee. She is also co-editor of the Family Matters section of Pediatric Nursing journal, the co-author of several articles related to family-centered and pediatric health care, and has presented at many conferences.

JULIE MORETZ

Inspired by her son’s battle with heart disease—his multiple heart surgeries and heart transplant—Julie has spent the better part of her career as a family leader to improve health care for patients and families. Julie is the Associate Vice Chancellor for Patient- and Family-Centered Care at the University of Arkansas for Medical Sciences in Little Rock where she has overall institution leadership responsibility for the development of clinical and academic programs related to patient- and family-centered care.

Julie was the Director of Special Projects with the Institute for Patient- and Family-Centered Care (IPFCC) for nearly seven years. Julie oversaw IPFCC’s nationally acclaimed intensive training seminars, international conferences, and other educational programs. She has presented throughout North America and led a faculty team to Saudi Arabia to share the concepts of patient- and family-centered care.

Initially, Julie was Chair of the Family Advisory Council at the Medical College of Georgia in Augusta, and then...
hired as a family leader in the role of Director of Family Services Development to oversee programs supporting adult and pediatric services. This included managing advisory councils, developing the Family Faculty program to incorporate patient- and family-centered care concepts in medical education, and serving as a faculty tutor for first-year medical students.

Julie serves on the Patient-Centered Outcomes Research Institute’s (PCORI) Advisory Panel on Patient Engagement. Julie is the co-founder of the Children’s Heart Program, which supports special programs for children with heart disease and their families. She is a recipient of the Woman of Excellence in Health Care Award and the American Heart Association’s Lifetime Achievement Award. Julie and her family were featured in the PBS remaking American Medicine series, Hand-in-Hand, where she was named “Champion of Change.” Julie and her husband, David, have three children – Lee, Morgan, and Daniel, forever 14.

9:15–10:15 am

Building Partnerships in the Research Community: Promising Practices and Future Directions (K8)

SUSAN E. SHERIDAN, MIM, MBA, DHL

Susan E. Sheridan is currently the Director of Patient Engagement of the Patient-Centered Outcomes Research Institute (PCORI). She is responsible for creating networks and engaging patients across the nation to provide broad-based input on the development and execution of PCORI’s research. Sheridan is Co-Founder and Past President of Parents of Infants and Children with Kernicterus, which works in partnership with private and public health agencies to eradicate kernicterus. In 2003, Sheridan co-founded Consumers Advancing Patient Safety, a nonprofit organization that seeks a safe, compassionate and just healthcare system through proactive partnership between consumers, providers of care and policy makers. Sheridan served at President of CAPS from 2003-2010.

Sheridan served as Program Lead from 2004-2011 for the World Health Organization’s Patients for Patient Safety initiative, a program under the WHO Patient Safety Program that embraces the collective wisdom of the patient, patient empowerment and patient centered care.

10:45 am–12:15 pm

Patient and Family Faculty in High Impact Interprofessional Education—From Classroom to Simulation Center (L1)

JULIETTE SCHLUCHTER

Juliette Schlucter has over two decades of experience leading health care professionals in patient-and family-centered care assessment, programming and implementation. She is currently the Director of The Center for Child and Family Experience at the Sala Institute for Child and Family-Centered Care at Hassenfeld Children’s Hospital of New York at NYU Langone.

From 1995 through 2010, Juliette provided leadership for hospital-wide implementation of patient- and family-centered care at The Children’s Hospital of Philadelphia (CHOP). While at CHOP, Juliette created and served as lead author of The Promise of Partnership, a toolkit used to teach health care professionals best practice behaviors for patient- and family-centered care. Juliette also co-created the Family Faculty, an award-winning program in which parents teach health care professionals about the experience of illness.

Juliette has served as a contributing author for numerous publications, including Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System.

Since 1996, Juliette has served as Faculty to IPFCC. She has also served on advisory councils for the Accreditation for Graduate Medical Schools and the Association of American Medical Colleges. Juliette came to her work, over 22 years ago, following her son and daughter’s diagnosis with Cystic Fibrosis.

JEREMY DONOVAN

Jeremy Donovan is a teacher, coach, and administrator at The Stony Brook School, a college preparatory boarding school in Stony Brook, NY. Jeremy grew up in Maryland and North Carolina, where he earned a BS in Mathematics from Campbell University. Jeremy and his wife, Jennie, have two children: Caroline, 4, and William, 3. William was born with hypoplastic left heart syndrome, and the outstanding care that he received from the Congenital Cardiovascular Care Unit at NYU Langone Medical Center has inspired Jeremy’s involvement with the Family Advisory Council. Through the NYU Langone Family Faculty program, Jeremy teaches physicians, medical students and other healthcare professionals about the practices and approaches that are most effective to support strong partnerships between families, patients and health care teams.
DENNIS SKLENAR

Dennis Sklenar, LCSW is the Assistant Director of Social Work and Child Protection Coordinator at New York University Langone Medical Center. In this role he has administrative responsibility for facilitating the daily operations of a large department of clinical social work staff. He has helped establish the medical center’s robust Child Protection Consultation Team. He has over 30 years of clinical experience working with children and families who have a wide range of medical diagnoses and chronic conditions. He is the supervisor for the social work clinical staff for the pediatric and obstetric units. He sits on a number of inter-hospital committees and two steering committees at the Sala Institute for Child and Family-Centered Care. His work to promote child and family-centered care involves work with the Sala’s Center for Family Resilience, Center for Child and Family Experience and Center for Quality and Safety. Dennis graduated with a Masters in Social Work from the New York University’s Silver School of Social Work, and is an Adjunct Professor at NYU Silver School of Social Work and at the Columbia School of Social Work.

JENNIFER DALY

Jennifer Daly is the mother of 3 year old Nathaniel, who has received care at NYU Langone for a congenital heart defect. A member of the Family Advisory Council since 2014, Jennifer became a Senior Family Advisor in 2016. As such, she shares her knowledge about being a parent of a child who receives medical care in order to advance child and family-centered care at NYU Langone Medical Center. As a member of the Family Faculty, she uses her story to teach clinicians about family partnership at the bedside, partners with clinical teams on safety committees to improve safe, quality care, and hosts Family to Family Hours by providing support and understanding to patients and families on pediatric inpatient units.

MICHAEL GOONAN, MD, FAAP

Michael is a Pediatric Hospitalist at NYU Langone Medical Center and part of the Center for Child and Family Experience at the Sala Institute for Child and Family-Centered Care. His work has focused on resident education, with a specific concentration on teaching professionalism, communication, cultural competency, and team dynamics. Through the Sala Institute, he is expanding his role to include multidisciplinary education for full care teams, aiming to further improve the patient experience throughout Children’s Services at NYU Langone.

Michael received his bachelor’s degree from Harvard University, and his medical degree from New York University School of Medicine. He completed residency training in Pediatrics at New York University and Bellevue Hospital Center in New York, where he also served as Chief Resident.

LEA DEVINS

Lea Devins is the Nurse Manager of the Pediatric Intensive Care Unit at NYU Langone Medical Center. In her role, Ms. Devins provides and integrates clinical leadership and management of patient care activities and support to sustain an environment dedicated to providing patient and family-centered care. Ms. Devins is the co-leader of several quality improvement projects and committees. She began her nursing career as a staff nurse working on the Pediatrics unit for 3 years before moving into a leadership role as the Assistant Nurse Manager of the same unit. Prior to her career in Nursing, Ms. Devins worked as a Public Relations Executive in New York. During her time working in public relations, she worked with a variety of clients in the entertainment and travel and tourism industries.
Sponsors

The Institute for Patient- and Family-Centered Care is pleased to recognize the sponsors and exhibitors for The 7th International Conference on Patient- and Family-Centered Care. Their commitment to the advancement of patient- and family-centered care is much appreciated. We are also grateful to the following organizations for providing conference program support:

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Michele Lloyd
Vice President, Children’s Services
530 1st Avenue, Suite 3F
New York, NY 10016
646.501.4315
Michele.Lloyd@nyumc.org
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Carol Steinberg
Executive Vice President, Business Development
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In addition, we are leading two NIH-funded randomized clinical trials to demonstrate the efficacy of peer mentoring.

Ashwin Patel, MD, PhD  
Chief Medical Officer  
41 Grand Avenue, Suite 102  
River Edge, NJ 07661  
201.232.9311  
ashwin@inquisithealth.com  
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March of Dimes NICU Family Support provides resources to hospitals to enhance the quality of family centered care in the NICU. We offer products that standardize parent education and promote consistent application of best practices in neonatal family centered care to all families, regardless of diagnosis or length of stay.

Jessamyn Ressler-Maerlender  
Manager, NICU Family Support  
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Nicole Rubin  
Consultant  
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StoryCorps

StoryCorps Legacy

StoryCorps is a national nonprofit whose mission is to preserve and share humanity’s stories in order to build connections between people and create a more just and compassionate world. StoryCorps Legacy provides people of all ages affected by serious illness, including families and caregivers, the opportunity to record, preserve, and share their stories. Since 2010, we have partnered with both curative and palliative care organizations around the country, training healthcare teams to incorporate the StoryCorps experience into their services and to record interviews using equipment we provide. Legacy recordings take place in a variety of settings, including people’s homes.

Eddie Gonzalez
Associate Manager, StoryCorps Legacy
80 Hanson Place, Floor 2
Brooklyn, NY 11217
646-723-7020 Ext. 68
gonzalez@storycorps.org
www.storycorps.org

BOOTH #12

The Beryl Institute

The Beryl Institute is the global community of practice dedicated to improving the patient experience through collaboration and shared knowledge. We define the patient experience as the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care.

Stacy Palmer
Vice President, Strategy & Member Experience
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The Peterson Center on Healthcare is a non-profit organization dedicated to making higher quality, more affordable healthcare a reality for all Americans. The organization is working to transform U.S. healthcare into a high-performance system by finding innovative solutions that improve quality and lower costs, and accelerating their adoption on a national scale. Established by the Peter G. Peterson Foundation, the Center collaborates with stakeholders across the healthcare system and engages in grant-making, partnerships, and research.

**Jorge Alday**
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712 Fifth Avenue, 17th Floor
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**The Josiah Macy Jr. Foundation**

The Josiah Macy Jr. Foundation is dedicated to improving the health of the public by advancing the education and training of health professionals.

**Yasmine Legendre, MPA**
Program Associate
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The Canadian Foundation for Healthcare Improvement (CFHI)

The Canadian Foundation for Healthcare Improvement identifies proven innovations and accelerates their spread across Canada by supporting healthcare organizations to adapt, implement and measure improvements in patient care, population health and value for money. CFHI is a not-for-profit organization funded by the Government of Canada, and is dedicated to accelerating healthcare improvement and transformation for Canadians.

Maria Judd
Senior Director / Directrice principale
Canadian Foundation for Healthcare Improvement
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The American College of Radiology

The American College of Radiology is a leading professional medical society dedicated to serving patients and society by empowering radiology professionals to advance the practice, science, and professions of radiological care. ACR Accreditation and Appropriateness Criteria are the standards for safe imaging and patient care. ACR’s 37,000 members include radiologists, radiation oncologists, nuclear medicine physicians and medical physicists.

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MONDAY, JULY 25, 2016

7:00-8:00 am  Broadway Ballroom, 6th Floor
SPECIAL NETWORKING BREAKFAST
Networking Breakfast for Patient and Family Advisors/Leaders
Want to connect with other patients and families who are partnering with health care professionals in change and improvement? Grab breakfast and come join us for informal networking and discussion.

8:00–9:45 am  Broadway Ballroom, 6th Floor
WELCOME
KEYNOTE
Partnerships in Care, Interprofessional Education, and Research
Eileen Whalen, MHA, RN, President and Chief Operating Officer; The University of Vermont Medical Center, Burlington, VT
Executive leadership is key to transformational change in the culture of health care organizations and the creation of meaningful partnerships with patients and families in care, education, and research. The voice of the patient and family has guided Eileen Whalen's professional practice as a nurse and as a leader of major academic medical centers. Story telling defines and binds all of us in a shared human experience. Ms. Whalen's personal story informs her perspectives and actions as a leader and underscores why she is a passionate patient and family advocate.

Keynote sponsored by

9:45–10:30 am  6th Floor
EXHIBIT HALL AND POSTER SESSION
Visit the exhibitors, meet with the Poster Presenters to discuss innovations in patient- and family-centered care.
Poster session sponsored by

10:45–11:45 am
CONCURRENT SESSIONS (A1-A10)

A1  Wilder, 4th Floor
Point of Care Interviews by Patient Partners (Advisors): Do We Make a Difference in the Patient/Family Hospital Experience?
Marlene Fondrick, BSN, MSN, Patient Partner; Perham Health and Perham Living; Jill Carlson, MSN, RN, Director, Family Centered Care; Perham Health, Perham, MN
A patient partner on the Quality Council led the hospital quality improvement project in developing a patient partner (advisor) interview program. Patient partners interview inpatients to get same day feedback about their hospital experience or concerns about their hospital stay.
**A2** Astor Ballroom, 7th Floor

**Initiating and Sustaining Improvements in Patient- and Family-Centered Practice Through the Partnership and Collaboration with Patient and Family Advisors**

DeeJo Miller, BA, Coordinator, Family-Centered Care; Sheryl Chadwick, BS, Coordinator, Family-Centered Care; Katie Taft, MBA, Patient Experience Specialist; Children’s Mercy Kansas City, Kansas City, MO

Patient and Family Advisors are integral partners in quality improvement processes at Children’s Mercy Kansas City. Custom tactical improvements are achieved by PFAs gathering real-time feedback from patients and families and their immersion on quality and safety teams and advisory councils.

**A3** Odets, 4th Floor

**Provincial Coordination = Advancing PFCC for One Million People**

Malori Keller, BA, MPA, Kaizen Specialist - Patient Engagement; Darlene A. Dyck, Family Advisor; Saskatchewan Health Quality Council, Saskatoon; Bernie Doepker, Director, Community Engagement; Five Hills Health Region, Moose Jaw, Saskatchewan

Thirteen health regions and five health agencies are working together to advance PFCC best practices. Aiming to ensure that patients and families experience a patient- and family-centered approach to care regardless of where they live in the province.

**A4** Liberty, 8th Floor

**Shifting the Paradigm: An Innovative Leadership Model Integrating Patient Experience, Safety, Quality, and Resilience Anchored in Partnership with Patients and Families**

Fiona Levy, MD, Executive Director; Lucy Pereira-Argenziano, MD, Director, Patient Safety and Quality; Juliette Schlucker, BS, Director, The Center for Child and Family Experience; K. Ron-Li Liaw, MD, Director, Center for Child and Family Resilience; Hasenfeld Children’s Hospital of New York at NYU Langone, New York, NY

In a reproducible model to advance high value care, tested in a children’s hospital, leaders established patient and family engagement as the foundation to integrate traditionally siloed domains of patient experience, safety, quality, and resilience.

**A5** O’Neill, 4th Floor

**Enacting Family Centered Care in Situations of Required Social Separation**

Rachel Biblow, LCSW, MSW, Senior Director, Patient and Family Services; Julia Sammons, MD, MSCE, Medical Director, Infection Prevention and Control; Amy Kratchman, BA, Family Consultant; The Children’s Hospital of Philadelphia, Philadelphia, PA

Children’s Hospital of Philadelphia shares their unique model for successfully maintaining Family Centered Care during unprecedented public health events. In partnership with Family Leaders CHOP designed specialized supports for use with patients and families receiving care for highly infectious diseases.

**A6** Ziegfeld, 4th Floor

**Building Health Literacy – Focus on Standardization of Patient Education at Vidant Health**

Kimly Blanton, MIS, MLS, Patient Family Advisor; Rose Ann Simmons, MPH, Administrator, Patient Family Engagement; Vidant Health, Greenville, NC

In 2012, the Vidant Health Patient Engagement Charter Team recommended a focus on building health literacy. One key strategy was to standardize patient education resources and processes. Patient Family Advisors provided input and leadership throughout the journey.

**A7** Brecht, 4th Floor

**Effectively Integrating Patient and Family Advisors as Co-Investigators in PCORI Initiatives**

Janet Cross, MEd, CCLS, Administrative Director, PFCC; Monroe Carell Jr. Children’s Hospital at Vanderbilt; Susan Morley, MBA, MS, PharmD, Chair Elect, Family Advisory Council; Monroe Carell Jr. Children’s Hospital at Vanderbilt; Assistant Professor of Pharmacy Practice; Lipscomb University College of Pharmacy, Nashville, TN

Family Advisory Councils are reservoirs for talent when conducting Patient-Centered Outcomes Research (PCOR). We will discuss the impact of utilizing patient and family advisors as co-investigators in a PCORI two-year grant evaluating non-routine events (NREs) in patient/families versus their clinicians.

**A8** Herald/Soho 7th Floor

**Partnering with Patient and Family Advisors to Validate a Patient-Centered Primary Care Tool**

Celene Wong, MHA, Project Manager; Maureen Fagan, MHA, DNP, WHNP-BC, FNP, Associate Chief Nurse-OB/GYN, Executive Director for the Center for Patients and Families; Martha Carne, BA, Senior Patient Advisor; Brigham and Women’s Hospital, Boston, MA

Patient/family advisors helped validate a Patient-Centered Primary Care Tool for use in performance improvement. This observational tool was designed to
evaluate the extent to which physicians and staff meet patients’ expectations of patient-centered care in the primary care setting.

**A9**

Hudson/Empire, 7th Floor

**Seeking and Embedding the Voice of the Patient: Partnering with Patients and Families to Deliver Sunnybrook’s Interprofessional “Education Bundles”**

Isabella Cheng, BSc, BHSc(OT), MSc, Professional and Education Leader, Occupational Therapy, Corporate Lead, Person-Centred Care; A.J. Lopez, BScN, MN/MHSc, Professional Leader, Nursing and Manager of Clinical Informatics; Guna Budrevics, CPHQ, CCHSA (A), Performance Improvement Specialist; Mathieu Wong, BPHIL, Patient and Family Partner; Paul Kocher, CPA, CA, BMath, Patient and Family Partner; Sunnybrook Health Sciences Centre, Toronto, Ontario

In partnership with patients and family members, Sunnybrook Health Sciences Centre delivers “education bundle” options of its “Seeking and Embedding the Voice of the Patient” education plan. These “education bundles” strive for consistent use of person-centred behaviours by interprofessional staff.

**A10**

Gotham/Chelsea, 7th Floor

**Partnering with Patients and Families to Develop, Implement, and Evaluate Five Novel PFCC Communication Simulation Programs Across the Medical Education Continuum**

Kori Jones, MEd, Parent Advisor; Colleen Schomaker, BA, Parent Advisor; University of Michigan Health and University of Michigan Medical School, Ann Arbor, MI

In a review of the development and evaluation of five novel patient and family centered care communication simulation programs included in three medical school courses and two fellowship training boot camps we will discuss lessons learned and overcoming barriers.

**11:45 am–1:15 pm**

**LUNCH/EXHIBITS/POSTER PRESENTATIONS**

Pick up a boxed lunch, visit the exhibitors and meet with the Poster Presenters to discuss innovations in patient- and family-centered care.

Poster session sponsored by

[ACR](https://www.acr.org/), Quality is Our Image

**1:15-2:15 pm**

**CONCURRENT SESSIONS (B1-B8)**

**B1**

Wilder, 4th Floor

**An Integrated Approach to Patient Engagement in Quality Improvement**

Karine Vigneault, PhD, Patient Partnership Coordinator; Alain Biron, PhD, RN, Assistant to the Director, Quality, Patient Safety, and Performance; Emmanuelle Simony, Patient Advisor; McGill University Health Centre, Montréal, Quebec

Since 2014, the McGill University Health Centre has developed an integrated and effective approach to patient engagement in the design, implementation and evaluation of quality improvement projects. We will discuss its key components, barriers and facilitators to its implementation.

**B2**

Astor Ballroom, 7th Floor

**Preparing Patient and Family Advisors by Developing the Core Competencies for Effective Partnership**

Julie Barnes, MSN, RN, Manager, Patient and Family Centered Care; Wake Forest Baptist Medical Center; Jodi Pardue, Patient Family Advisor; Brenner Children’s Hospital affiliated with Wake Forest Baptist Medical Center, Winston Salem, NC; Libby Høy, BS, Founder/CEO; Patient Family Centered Care Partners, Long Beach, CA; Tara Bristol Rouse, MA, Director, Patient & Family Partnerships; Perinatal Quality Collaborative of North Carolina, Chapel Hill, NC

Using the core competencies identified by patients and family members serving as advisors, participants will learn best practices for preparing advisors to be effective partners in improving the quality, safety, and experience of healthcare.

**B3**

Odets, 4th Floor

**Start a Movement: Influencing, Cultivating and Spreading a Culture of Patient- and Family-Centered Care**

Linda Fahey, RN, NP, MSN, Regional Director, Quality and Patient Safety, Lead and Co-Chair, Regional Patient Advisory Council; Amiee Andujo, Co-Chair, Regional Member Advisory Council; Kerry Litman, MD, Assistant Area Medical Director for Performance Excellence and Complete Care Physician Coordinator, Regional Member Advisory Council & eAutopsy Mortality Study; Kaiser Permanente Southern California, Pasadena, CA

We are in the midst of a movement embedding the “Patient’s Voice” into our organization’s DNA. Partnering with patients and families, we have put the four core concepts of Patient- and Family-Centered Care into action, impacting our organizational culture.
**MONDAY AGENDA**

- **B4** Manhattan Ballroom, 8th Floor

**Better Together – Spreading Family Presence Policy and Practice in Canada**

Margaret Melanson, BA, MS, MBA, Vice President, Quality & Patient Centred Care; Elizabeth Cormier, BA, Regional Director Volunteers, Auxiliary and Alumnae; Horizon Health Network, Saint John, New Brunswick; DeAnn Adams, BA, MA, Director, Patient and Family Centred Care; Fraser Health, Surrey, British Columbia; Angela Morin, BA, CFHI Coach and Faculty, Patient Experience Advisor; Christine Maika, BSc, Improvement Lead; Maria Judd, MSc, Senior Director, Patient Engagement and Improvement; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario

The session will feature two leading Canadian health authorities in their pursuit of family presence policies, and will share learnings from the Better Together campaign in Canada to build capacity and to spread best practices in family presence and participation.

- **B5** Brecht, 4th Floor

**OpenNotes and Psychotherapy: Is This Oil and Water for Patient Care?**

Stephen F. O’Neill, LICSW, BCD, JD, Social Work Manager for Psychiatry and Primary Care; Beth Israel Deaconess Medical Center; Associate Director, Ethics Support Service Faculty; Center for Bioethics, Harvard Medical School; Stacey Whiteman, Patient Advisor; Beth Israel Deaconess Medical Center, Boston, MA

Ever wonder what a psychotherapist might write in their patient’s record? OpenNotes is a program which allows patients to see their complete ‘medical record’ at any time from their personal computer. OpenNotes started with a focus on medical care and two years ago expanded to include behavioral/mental health notes. This has been quite controversial! Should patients openly see these notes without being in the presence of their therapist? Could these notes contribute to patients ‘decompensating’? What exactly are the risks and benefits? A patient consumer and a therapist will share with you what we have been learning!

- **B6** Liberty, 8th Floor

**Novel Interventions, Meaningful Outcomes: A Multi-Tiered Approach to Building Patient and Family Partnerships in Delivery System Research**

K. Ron-Li Liaw, MD, Director, Center for Child and Family Resilience; Beth Silber, MPA, Family Consultant; Sala Institute for Child and Family Centered Care, Hasenfeld Children’s Hospital of New York at NYU Langone; Mary Ann Harris, LCSW, Senior Pediatric Social Work Worker, Co-Leader, Patient and Family Advisory Council; Hasenfeld Children’s Hospital of New York at NYU Langone, Fink Children’s Ambulatory Care Center; Lauren Knickerbocker, PhD, Assistant Professor, Child and Adolescent Psychiatry, Child Study Center; Hasenfeld Children’s Hospital of New York at NYU Langone, New York, NY

Addressing increased risk for depression/anxiety in adolescent patients with chronic illness, this randomized control trial incorporates patients and families as partners in design, testing, and evaluation of a brief psychotherapy for patients with inflammatory bowel disease and co-morbid depression/anxiety.

- **B7** Duffy, 7th Floor

**FamiY Partnerships in a National Professional Medical Society**

Betsy Anderson, Co-Chairperson; Julie Beckett, Co-Chairperson; AAP FamiY Partnerships Network; Milan Tamela Alexander, BA, MPPA, Executive Committee Member; Carole Allen, MD, FAAP, Member, Board of Directors; American Academy of Pediatrics, Elk Grove Village, IL

The American Academy of Pediatrics (AAP) is a national professional medical society consisting of 63,000 pediatricians and pediatric subspecialty physicians. The AAP has made concerted efforts to increase family engagement through the establishment of a FamiY Partnerships Network.

- **B8** O’Neill, 4th Floor

**Leading Meaningful Patient- and Family-Centered Care Design Projects: How Partnering with Patients and Families Impacts and Improves Building Design and Operational Workflow**

Kelly Loyd, BA, Chair, Patient/Family Advisory Council; Caroline DeLongchamps, BS, Manager, Staff Liaison, Patient/Family Advisory Council; J. Melinda Biller, BA, CCRN, MSN, MSW, NE-BC, RN, Clinical Project Manager; Medical University of South Carolina, Charleston, SC; Laura Poltronieri, AIA, Principal; Poltronieri Tang & Associates, Swarthmore, PA

Leading meaningful patient- and family-centered care design requires partnering with patients and families during all phases of the design process. Patient/family input optimizes project outcomes and improves building design.
2:30–3:30 pm
CONCURRENT SESSIONS (C1-C10)

C1  Wilder, 4th Floor
Enhancing Timely Patient Access to Care: Collaboration in Action
Margot Wilson, MSN, Director, Chronic Disease Management; Robert Levy, MD, FRCP, Specialist Lead Shared Care; Delia Cooper, BA, Patient Representative, Patient Voices Network; Providence Health Care, Vancouver, British Columbia

Co-creation sessions are one method out of human-centred design used to collaborate with patients and families to make change. Experience co-creation activities used by Providence Health Care and learn how to run your own co-creation sessions.

C2  Odets, 4th Floor
Involving Patients and Families in Every Serious Safety Event Review
Sheryl Kalbach, MSW, LICSW, Family-Centered Care Specialist; Jen Faultner, Senior Family Advisor; Seattle Children’s Hospital, Seattle, WA

At Seattle Children’s Hospital, it is standard practice to involve a parent or family representative in every Root Cause Analysis. This presentation will discuss involving patients and families in safety work after an adverse event (unanticipated patient outcome) has occurred.

C3  O’Neill, 4th Floor
May Your Voice Be Louder: Enhancing the PFA Story by Aligning with Organizational Goals
Tiffany Christensen, BA, TeamSTEPPS Master Trainer, Respecting Choices Instructor, PFE Performance Improvement Specialist; North Carolina Quality Center, Cary, NC

The first step to culture change and embracing Patient and Family Centered Care is through the patient story. Embedding areas of PFCC focus specific to an organization within that story takes the PFA story to a new level.

C4  Liberty, 8th Floor
Harnessing Technology: Impact on Culture, Practice and Outcomes When Inpatients Have an Electronic Health Record Portal in Their Hands: A Leadership and Patient/Family View
Michele Lloyd, BSN, Vice President, Children’s Services; Jacquelyn Fuller, BSN, Nurse Manager; Nancy Beale, BSN, MSN, RN-BC, Vice President, Clinical Systems and Integration; Kimberly Klcoyne, BA, MS, Family Advisor and Family Faculty; Hassenfeld Children’s Hospital of New York at NYU Langone, New York, NY

As early adopters of technology, leaders needed to anticipate the challenges MyChart Bedside could bring. With patients and families as partners, technological, legal and clinical solutions were developed to realize the patient-centered benefits of improved communication and coordination of care.

C5  Ziegfeld, 4th Floor
Power of Partnering: Improving Healthcare by Including Families and Patients as Partners
Elizabeth Dapp, Parent Lead, IBD Parent Group; Darla Cohen, MS, Coordinator, Patient- and Family-Centered Care; Riley Hospital for Children at Indiana University Health, Indianapolis, IN

Gastroenterology departments at Riley Hospital for Children and C.S. Mott Children’s Hospital have created unique partnerships with families and patients. These partnerships resulted in innovative improvements to the healthcare experience. This presentation will describe how partnerships were created and fostered in healthcare.

C6  Duffy, 7th Floor
Peer Support in Primary Care– Improving Health Outcomes
Amy Gibson, MS, RN, Chief Operating Officer; Patient-Centered Primary Care Collaborative (PCPCC), Washington, DC; Brad Thompson, MA, LPC-S, Director; The Hali Project, Amarillo, TX; Edwin Fisher, PhD, Professor; University of North Carolina-Chapel Hill, Chapel Hill, NC

Peer support links family caregivers or people with a common illness that are able to share knowledge and experiences. It complements and enhances the primary care team by creating emotional, social and practical assistance necessary for managing chronic conditions.

C7  Manhattan Ballroom, 8th Floor
Developing a Meaningful Research Agenda Through Integrated Patient and Family Engagement
Lori Beesley, Family-Centered Care Specialist; Amir Karmali, Family-Centered Care Specialist; Gideon Sheps, Family Advisor; Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario

Holland Bloorview Kids Rehabilitation Hospital has successfully implemented a robust family engagement in research framework. In this interactive workshop they’ll share their experience in launching this program, and provide an opportunity for participants to explore engagement strategies at their organizations.

C8  Herald/Soho, 7th Floor
Building Meaningful Patient Engagement Within a Clinical Data Research Network
Nathaniel Warren, MPH, Patient Engagement Coordinator; John Lind, AA, Patient/Family Advisor; OCHIN, Portland, OR

The ADVANCE Patient Engagement Panel (PEP) includes 18 patient representatives serving in an advisory capacity in the design, implementation, and interpretation of comparative effectiveness research (CER). We present this successful model with lessons learned from our clinical data research network.
MONDAY AGENDA

C9  Hudson/Empire, 7th Floor
One Patient, One Student, Two Processes: Integrating Health and Education Transition
Angela Miney, BA, Family Partner; Susan Horky, LCSW, MSW, Co-Director, UF PPC Training Program and Social Work Faculty; University of Florida, Gainesville, FL

Presentation describes University of Florida (UF) Interdisciplinary Collaborative on Health and Education Transition (ICHET) – a workgroup focused on creating best practices to integrate health and education transition for youth and young adults with disabilities and ICIs (Invisible Chronic Illnesses).

C10  Gotham/Chelsea, 7th Floor
Partnering with Patient/Family Advisors in the Development of Patient/Family/Staff/Physician Educational Resources
Joan Forte Scott, BSN, MBA, CNE-BC, Administrative Director, Patient and Community Engagement; Laura Steuer, MA, Patient Leader, Patient and Family Faculty Program; Stanford Health Care, Palo Alto, CA

Starting with creating better patient education resources and telling their stories, the program has evolved into a Patient/Family Faculty program. Basic work like educational packets are still completed, but Patient/Family partners now design educational forums and determine content.

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

D1  Liberty, 8th Floor
PFCC: Setting the Patient Experience with New Admission Orientation and Point of Care Rounds
Erica Steed, BS, MBA, BBA, BAppSC, Manager; Christine Abbott, Administrative Specialist, Patient/Family Advisor; Augusta University Health, Augusta, GA

This improvement project is designed to set the patient's expectations and to hold the faculty and staff accountable. The information and education is disseminated to all new admissions. Patient advisors are involved in all aspects of the improving the Rounds Project.

D2  Wilder, 4th Floor
A Partnership for Safety: Staff and Family Collaboration in Reducing Never Events
Linda Hurwitz, BS, MS, RN, NEA-BC, Vice President, Patient Care Services; Mazen Maria, BS, MD, FAAP, Associate Director, Pediatric Hospital Medicine; Megan Busenbark, BA, MS, Patient/Family Advisor; Polly Vander Woude, BA, MHA, Patient/Family Advisor; Annmarie Shisler, BSN, RN, Patient/Family Advisor; Maria Fareri Children’s Hospital at Westchester Medical Center, Valhalla, NY

A team, including Family Advisory Council members, worked together to reduce harm by setting clear expectations for staff and families as partners in care. Tools to communicate risk and steps to prevent harm were developed and implemented. Outcomes will be shared.

D3  Odets, 4th Floor
Goal Setting: Developing an Annual Operating Model with Your Patient/Family Advisory Council
Tony Serge, BA, BS, Co-Chair, Adult Patient Family Advisory Council; Patricia Stahl, MEd, Manager, Volunteer Services and Programs, Staff Liaison, PFAC; Dana-Farber Cancer Institute, Boston, MA

Combining annual hospital goals with patient and family driven initiatives can be challenging. This presentation will outline a process that incorporates both objectives into a concise annual operating model that reflects a patient and family centered culture.

D4  O’Neill, 4th Floor
Dynamic Duo: Parent Partner and Care Coordinator
Liz Wall, BA, URLEND, Parent Partner; Dustina House, MA, URLEND Trainee, Care Coordinator; Summit Pediatrics; Kathy Ostler, MD, Pediatrician; Wasatch Pediatrics; Park City, UT

The Parent-Partner/Care-Coordinator team exemplifies patient and family centered care by identifying gaps between the medical recommendations, goals of the family, and barriers to care. The Parent-Partner/ Care-Coordinator team gathers unexpected information from families that can be barriers to care.

D5  Manhattan, 8th Floor
Bedside Shift Report: Bedside Scanning Ensures an Innovative, Simple, Reproducible Solution to a Complex Problem
Lillian Banchero, MSN, RN, Clinical Director, Patient Access, Observation Unit, ACE, Flex Nursing Unit, Central Staffing Office; Anne Arundel Medical Center, Annapolis, MD; Sherry Perkins, PhD, RN, Executive Vice President and Chief Operating Officer; Dimensions Healthcare System, Cheverly, MD; Charlene VanMeter, Patient/Family Advisor; Kristina Andersen, BSN, RN, Clinical Informatics Specialist; Christine Frost, MBA, MSN, Senior Director, Acute Care Services & Critical Care; Jeanne Morris, BSN, RN, Coordinator, Patient and Family Centered Care; Jill Smitley, BSN, RN, Clinical Director, Labor & Delivery; Anne Arundel Medical Center, Annapolis, MD

Simple bedside scanning technology, used with medications in most US hospitals, was implemented for bedside shift report. This forcing function necessitates nurse-to-nurse handoff at the bedside with the patient. Bedside shift report favorably impacts harm and patient satisfaction.
MONDAY AGENDA

D6 Ziegeld, 4th Floor
Empowering Families in Transition from Pediatric to Adult Care Through Family-Centered Education
Kristin Erekson, MA, CHES, Health Education Project Manager and Editor; Susan Shanske, LICSW, Clinical Social Worker; Amy Rucki, Former Co-Chair, Teen Advisory Committee; Boston Children’s Hospital, Boston, MA

As a free-standing pediatric teaching hospital, Boston Children’s Hospital recognizes the need to support its patients/families with the transition from pediatric to adult care. This presentation highlights several initiatives led by or created in collaboration with teen and parent advisors.

D7 Herald/Soho, 7th Floor
Developing UMHS Peer Mentoring Standards and Guidelines for System Wide Program and Developing Online Peer Management Toolkit
Stacy Brand, MBA, Outreach Manager, Transplant Center; Cedric Clark, Patient Advisor/Peer Mentor; Melissa Cunningham, BA, Family Advisor for Cardiovascular Center, Volunteer Coordinator; University of Michigan Health System, Ann Arbor, MI

In 2014, the University of Michigan Patient and Family Centered Care Program partnered with social work, the transplant center, and patient peers to create a standardized hospital-wide process for developing, training, and managing peer mentors. An online staff toolkit was also developed.

D8 Hudson/Empire, 7th Floor
Development of Patient- and Family-Centered Research Training for Multiple Stakeholders
Katherine Bevans, PhD, Assistant Professor, Pediatrics; Anna de la Motte, MSed, Senior Clinical Research Assistant; Amy Kratchman, BA, Family Consultant; The Children’s Hospital of Philadelphia, Philadelphia, PA

Training and educational opportunities are needed to prepare patients/caregivers and researchers to conduct partnership-based research. We will demonstrate interactive, web-based training modules that prepare patients/caregivers and researchers to establish research partnerships and support the implementation of best-practice patient/family-centered research strategies.

D9 Gotham/Chelsea, 7th Floor
Why Stories Matter: Writers Reflect on Experiences, Motivations, and Hopes
Liz Crocker, Co-Author of Privileged Presence: Personal Stories of Connections in Health Care; East Chester, Nova Scotia; Will Schwalbe, Author of The End of Your Life Book Club; New York, NY; Tilda Shalof, Author of Opening My Heart: A Journey from Nurse to Patient and Back Again; Toronto, Ontario

Liz Crocker will interview fellow authors, Will Schwalbe and Tilda Shalof, and will explore the authors’ motivations to share their stories and what has happened, personally and otherwise, as a result. As well, the authors will reflect on why stories matter and on Rachel Naomi Remen’s statement that “Facts bring us to knowledge: stories bring us to wisdom.” This session will be of particular interest to those who use (or want to use) stories in their work to promote and facilitate collaborative partnerships and those who are considering becoming authors themselves.

D10 Olmstead/Gramercy, 7th Floor
Partnerships in Training: Patients as Faculty and Collaborators in Simulation for Enhancing Patient- and Family-Centered Care
Mary Toye, MS, RN, CCRP, ACRN, Nursing Practice Research Director, PFAC Co-Facilitator/Founder; Diane Thomas, BSN, RN, Director, Patient Relations, PFAC Co-Facilitator/Founder; Anna Symington, MS, PFAC Chair-Elect, BMC Adult PFAC; Linda McShane, MEd, Chair, BMC Adult PFAC; Baystate Medical Center, Springfield, MA

We have demonstrated the power of Patient and Family Advisory Councils as Faculty in training healthcare workers to enhance our culture of patient and family centered care (PFCC). Simulation is a prominent modality in its ability to replicate clinical experiences.

5:30–7:00 pm 6th Floor
WELCOME RECEPTION
Reception sponsored by

Please join us at the Conference’s Welcome Reception. Meet with colleagues, network with other attendees, visit with the exhibitors, get your favorite book signed by the authors, while enjoying light hors d’oeuvres and refreshments. Cash bar available.
TUESDAY, JULY 26, 2016

7:00–8:00 am  Liberty Room, 8th Floor

SPECIAL INTEREST BREAKFAST
Hassenfeld Children’s Hospital of New York
at NYU Langone

Measurement that Matters in Patient and Family-Centered Care: From Theory to Practice
Grab your coffee and breakfast and join Hassenfeld Children’s Hospital of New York at NYU Langone and patient and family-centered care leaders from across the country at networking tables to explore hot topics in patient and family-centered measurement including:

- HCAHPS and The Patient Experience
- Measuring Compassion and Empathy
- Measuring the Impact of Patient and Family Partnerships in Safety and Quality
- Measuring Clinician and Staff Engagement in PFCC
- Measuring the Impact of Patient and Family Engagement in Research

In facilitated table topic discussions, share challenges in measurement, explore innovative ideas and learn from each other.

7:00–8:00 am  Manhattan Ballroom, 8th Floor

SPECIAL NETWORKING BREAKFAST
Better Together—Changing the Concept of Families as Visitors

Join us for breakfast to learn more about IPFCC’s Better Together: Partnering with Families campaign.

DAY AT-A-GLANCE

Tuesday, July 26, 2016

7:00 am–8:00 am  Registration, Continental Breakfast, Exhibits, Poster Displays
Special Interest Breakfast—Measurement that Matters in Patient and Family-Centered Care: From Theory to Practice
Networking Breakfast—Better Together—Changing the Concept of Families as Visitors

8:00 am–9:30 am  Plenary Session

9:30 am–10:00 am  Break-Exhibits/Poster Displays
10:00 am–11:00 am  Concurrent Sessions (E1-E8)
11:15 am–12:15 pm  Concurrent Sessions (F1-F10)
12:15 pm–1:45 pm  Lunch-Exhibits/Poster Displays
Special Lunch for Ronald McDonald House Charities (By invitation)
Networking Lunch-Translating Theory into Action for NICUs

2:00 pm–3:00 pm  Concurrent Sessions (G1–G10)
3:15 pm–4:15 pm  Concurrent Sessions (H1–H10)
4:30 pm–5:30 pm  Concurrent Sessions (I1–I9)

8:00–9:30 am  Broadway Ballroom, 6th Floor

PLENARY SESSION
Standards and Accreditation As a Catalyst for Achieving Transformative Change: The Canadian Health Care Experience

Leslee Thompson, BScN, MScN, MBA, President and CEO; Angela Morin, Member, Client and Family-Centred Care Advisory Group; Accreditation Canada, Ottawa, Ontario

Join us for a conversation of courage, creativity and bold ambition between a CEO and a patient experience expert. They will ignite your passion for change and activate your will to make partnering with patients and families a reality.

9:30–10:00 am  6th Floor

BREAK
Visit the exhibitors and poster displays
10:00-11:00 am

CONCURRENT SESSIONS (E1-E8)

E1  Brecht, 4th floor
Improving Care in the Emergency Department Through Successful Parent Advisory Council Partnerships
Kerry Gold, BSN, CCRN, CEN, Administrative Nurse/Pediatric Liaison Nurse Emergency Department; Ronald Reagan UCLA Medical Center; Alison Beier, Member, Parent Advisory Council; Mattel Children’s Hospital UCLA, Los Angeles, CA

In 2012, the Mattel Children’s Hospital UCLA Parent Advisory Council identified areas for improvement in the care of pediatric patients within the UCLA Emergency Department. A successful long-term partnership was formed, resulting in new protocols that directly improve patient care.

E2  Duffy, 7th Floor
Going Home with Patient and Family-Centered Care: One Program’s Experience in Imbedding a Concept into a Home Care Culture
Tammie Ryan, MSN, RN, Clinical Director; Julie Kembel, EdD, MS, Patient/Family Advisor; Richard Elliott, MEd, Patient/Family Advisor; South Shore Visiting Nurse Association, Rockland, MA

A single patient story began a genuine cultural shift from patient-focused to patient-centered care. Involvement of PFCC advisors in all phases of operations contributed to an integration of PFCC principles into the most sensitive of care situations—the patient’s home.

E3  Wilder, 4th Floor
When the Rubber Hits the Road in Patient Engagement and Quality Improvement
Mireille Brosseau, MA, Patient/Family Engagement Specialist; Linda M. Jones, MPA, Patient/Family Partner; Angela Jones, MSW, Patient/Family Partner; Christine Kouri, MHA, Manager, Patient Experience & Acting Chief Privacy Officer; Morgan Cunningham-Fetch, Lean Black Belt, Six Sigma Black Belt, Lean Specialist & Quality Team Lead; Children’s Hospital of Eastern Ontario, Ottawa, Ontario

An example of how the integration of patient engagement and quality improvement efforts leads to deeper understanding of patient/family and staff experiences required to create optimal services, as well as better probabilities that care will be influenced by patient/family input.

E4  Astor Ballroom, 7th Floor
A Conversation Exploring Current Progress and Additional Opportunities for CMS Quality and Innovation Programs to Enhance Partnerships with Patients and Families
Debra Ness, MS, President; National Partnership for Women & Families, Washington, DC; Dennis Wagner, MPA, Director, Quality Improvement and Innovation Group, Center for Clinical Standards and Quality; Centers for Medicare and Medicaid Services (CMS), Baltimore, MD

Debra Ness will engage Dennis Wagner in a conversation, exploring the Centers for Medicare and Medicaid Services’ (CMS) vision for health care and the innovation programs that the agency is supporting in both ambulatory and hospital settings. They will discuss ideas for how we can build a health system that achieves the promise and potential of the Affordable Care Act in which patients, families, and health care professionals across all disciplines truly partner to drive innovation and improve outcomes, quality, safety, and the experience of care.

E5  Odets, 4th Floor
Developing a Family Caregiver Center: Supporting Families During Hospitalization at an Academic Medical Center
Karen Anderson, MSN, RN, PMHCNS-BC, Clinical Nurse Specialist, Patient and Family Centered Care; Anita McGinn-Natali, BFA, Co-Chair, PFAC; The Hospital of the University of Pennsylvania, Philadelphia, PA

Presenting the development of a Family Caregiver Center (FCgC) from inception, as a space for respite, to a volunteer-based program providing emotional support to family caregivers. Partnering with Patient/Family Advisors (PFAC) the FCgC has become an oasis for replenishment.

E6  O’Neill, 4th Floor
Developing a Tool to Measure Patient Partnership at the Clinical and Organizational Level
Marie-Pascale Pomey, MD, PhD, Professor; University of Montréal; Edith Morin, Patient Advisor; CIUSSS Mauricie, Trois Rivières, Quebec

As partnership of care is a relatively new concept, currently there are no tools to evaluate it at the clinical and organizational level. Our presentation describes how such a tool was developed and how patients were involved in designing it.
E7  Ziegfeld, 4th Floor

A Cold Splash of Reality: Nobody Owns a Single Task in Health Care—A Unique IPE Course to Bring Us All Together

Julie Moretz, BS, Family Leader/Associate Vice Chancellor for Patient- and Family-Centered Care; Kathy Lease, EdD, Patient/ Family Advisor, Adjunct Faculty for College of Health Professions; Erna Boone, DrPH, RRT, Associate Professor and Chair, Department of Respiratory and Surgical Technologies, College of Health Professions; University of Arkansas for Medical Sciences (UAMS), Little Rock, AR

Patient/Family Advisors—appointed as Adjunct Faculty in the College of Health Professions—partnered with PFCC and IPE staff, Simulation Center staff, and Allied Health faculty to develop and teach a three-part course: PFCC/IPE exposure session, on-line case studies, and clinical simulations.

E8  Herald/Soho, 7th Floor

Without Me You Have Nothing: Partnering with Families to Teach Patient-Family Centered Rounds

Alyssa Stephany, FAAP, MD, Physician Champion for Patient-Family Centered Care; Laura Fisher, BS, PE, Patient/Family Advisor; Jonathan Fisher, Patient/Family Advisor; Layna Langley, BS, Patient/Family Advisor; Duke Children’s Hospital, Durham, NC

Few providers are trained to incorporate patient-family perspectives into medical decision-making, or how to conduct rounds in a patient-family centered manner. By partnering with families, we developed an educational presentation which utilizes patient/family stories to teach Patient-Family Centered Rounding concepts.

11:15 am–12:15 pm

CONCURRENT SESSIONS (F1-F10)

F1  Wilder, 4th Floor

Beyond Advisory Councils: The Role of Patients and Families as Coaches in Accelerating Sustainable, Patient- and Family-Centered Improvement

Heather Thiessen, CFHI Coach, Patient Advisor; Carolyn Canfield, BA, CFHI Coach, Volunteer, Citizen-Patient and UBC Honorary Lecturer; Angela Morin, BA, CFHI Coach and Faculty, Patient Experience Advisor; Christine Maika, BSc, Program Officer, Patient Engagement and Improvement; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario

This session will explore how the Canadian Foundation for Healthcare Improvement devised a unique coaching model to engage experienced patient and family advisors in leadership roles to accelerate sustainability and patient and family centered quality improvement initiatives across Canada.

F2  Astor Ballroom, 7th Floor

After Medical Error, Disclosure, Transparency and Collaboration Can Meet the Needs of Everyone

Abdul Hamamsy, JD, MPH, MBBCh, ARM, Assistant Vice President, Claims & Litigation; Leilani Schweitzer, BA, Assistant Vice President, Communication & Resolution; The Risk Authority at Stanford Health Care, Palo Alto, CA

Nine years ago, Stanford Healthcare formally launched a communication and resolution program, PEARL, to respond to the needs generated by medical error. Since then, a patient representative has been fully integrated into the team that responds to these critical events.

F3  Odets, 4th Floor

Building Partnerships Between Family Consultants and Leaders for Culture Change

Rachel Biblow, LCSW, MSW, Senior Director, Patient and Family Services; Kathryn Conaboy, BA, Patient & Family Experience Manager; Amy Kratchman, BA, Family Consultant; The Children’s Hospital of Philadelphia, Philadelphia, PA; Jill Golde, BA, MS, Partner; Language of Caring, LLC, Saint Louis, MO

Children’s Hospital of Philadelphia (CHOP) shares their unique and replicable model for successfully engaging Family Consultants with the organization’s clinical and non-clinical leaders to accelerate culture change.

F4  O’Neill, 4th Floor

Restructuring Leadership, Embracing Partnership

Elizabeth Kruvand, BSc, Coordinator, Family Care Initiatives; St. Louis Children’s Hospital, Saint Louis, MO

The Patient and Family Centered Care program at St. Louis Children’s Hospital has evolved over the last 17 years, resulting in a new PFCC leadership model and structure that is proving invaluable in opening doors to partnership throughout the hospital.

F5  Ziegfeld, 4th Floor

Families Are More Than “Visitors” – Bringing the Voice of Patient/Family Advisors and Family Members into Quality Improvement Discussions

Denise Williams, MS, PhD, SPHR, SHRM-SCP, Staff/Patient Equity and Inclusion Consultant; University of Michigan Health System; Perry Spencer, MS, CPP, CHPA, Interim Manager; University of Michigan Health System and Hospitals Security, Ann Arbor, MI

Security data can inform quality improvement efforts by identifying opportunities to proactively address employee and family stressors that may result in conflict and sub-optimal cultural sensitivity. Patient/family advisors can play a crucial role in creating quality improvement strategies.
TUESDAY AGENDA

F6  Herald/Soho, 7th Floor
Getting Back into Life Through Peer to Peer Mentoring: One Hospital’s Journey
Mary Beth Tubiolo, MSN, RN-BC, Risk Management Coordinator; Kamila Frederick, PT, MPT, NCS, Director, Inpatient Rehabilitation and Respiratory Care Services; Judy Crane, Founding Mentor of the Power of 2 and Patient Advisor; Karla Balch-Reno, JD, Patient and Family Advisor; Anne Arundel Medical Center, Annapolis, MD
The purpose of this presentation is to discuss the value of peer to peer mentoring and to highlight one hospital’s journey, from developing a stroke mentoring program to creating a standardized process to expand these programs to other patient populations.

F7  Duffy, 7th Floor
Collaborating in Asthma Research: Patient and Family Partners in PCORI’s Asthma Evidence to Action Research Network
Judith Schaefer, MPH, Senior Research Associate, MacColl Center for Health Care Innovation; Group Health Research Institute, Seattle, WA; Lisa Stewart, MA, Engagement Officer; Patient Centered Outcomes Research Institute, Washington, DC
In this session we will examine the activities of patient partners in research for 14 studies comparing the effectiveness of treatments for asthma, and their role in designing and implementing research that patients and families care about.

F8  Hudson/Empire, 7th Floor
Parent and Teen Engagement in Pediatric Health Services Research Training
Brenda Allair, MEd, Volunteer, Member, Family Advisory Council; William O’Donnell, BS, Parent Co-Chair, Family Advisory Council; Erinn Rhodes, MD, MPH, Associate Director, Harvard-wide Pediatric Health Services Research Fellowship Program and Director of Endocrinology Healthcare Research and Quality; Boston Children’s Hospital, Boston, MA
At Boston Children’s Hospital, there has been an increasing appreciation for the contribution of patients and families in designing, conducting, analyzing, and interpreting research as collaborators. This presentation discusses how the Harvard-wide Pediatric Health Services Research Fellowship Program engages Boston Children’s patients and families.

F9  Gotham/Chelsea, 7th Floor
Bridging the Disconnected: Empowering Advisors for Change Through Social Media
Jessica Lamb, BSc, MScOT, Senior Patient Engagement Advisor, Strategic Clinical Networks; Alberta Health Services; Deb Runnalls, RSW, Patient Advisor, Co-Chair, Patient First Steering Committee; Vice-Chair, Provincial Patient & Family Advisory Group; Alberta Health Services; Senior Manager of Wellness and Support Services; The Kerby Centre; Calgary, Alberta
This presentation will describe how social media connects family and patient advisors to form a community of change agents across the province, whose goal is to bring about the best health care for all Albertans.

F10  Brecht, 4th Floor
Patient and Family Centered Care Management – What Does It Look Like?
Betty St. Hilaire, CCP, Care Navigator; Judy Ward, CCP, Care Navigator; Community Health Options, Lewiston, ME
This presentation will demonstrate how Community Health Options offers wrap around Care Management support that partners with providers and community resources while focusing on what matters most to our members and their families.

12:15–1:45 pm  6th Floor
LUNCH/EXHIBITS/POSTER DISPLAYS
Pick up a boxed lunch, visit the exhibitors and Poster Displays.

12:15–1:45 pm  Manhattan Ballroom, 8th Floor
NETWORKING LUNCH
Translating Theory into Action for NICUs: A Hands on Workshop for Tackling Your Family Centered Care Challenges
You’re invited to join March of Dimes NICU Initiatives staff for a special, interactive working lunch to discuss opportunities for improvement to support creating a more family centered environment in the NICU. This session will include stations to learn about family centered innovations in NICUs across the country, and an opportunity to learn more about other NICUs through online polling. All participants who complete the session will receive a gift card. This session is NICU focused and is limited to 50 participants.
12:15–1:45 pm  
**Columbia, 7th Floor**

**SPECIAL LUNCH FOR RONALD MCDONALD HOUSE CHARITIES**

Delegation from RMHC will meet informally with representatives from children’s hospitals to talk about enhancing practice around family presence and participation. *(By invitation)*

2:00–3:00 pm  
**CONCURRENT SESSIONS (G1-G10)**

**G1**  
**Wilder, 4th Floor**

**From Harm to Healing: Partnering in Quality Improvement**

Valerie Stewart, MA, RN, Manager, Patient- and Family-Centred Care; Alberta Health Services, Calgary, Alberta; Deborah Prowse, MSW, LLB, Alberta Health Advocate; Alberta Health Services, Edmonton, Alberta

Join us on this incredible journey of a family member and provider from harm to healing as we share the importance of partnership in fostering a patient safety culture and engaging the patient and family voice in quality improvement.

**G2**  
**Odets, 4th Floor**

**Applying Process Improvement to Patient and Family Engagement**

Mary Song, MPH, Manager, Patient/Family Partner Program; Paula Holwell, Patient Chair, Neuroscience Patient Family Advisory Council; Stanford Health Care, Palo Alto, CA

Stanford Health Care’s Patient Family Partner Program used Lean process improvement to improve the onboarding experience of new patient family partners, along with improving these volunteers’ experience in the program.

**G3**  
**O’Neill, 4th Floor**

**Thunder Bay Regional Health Sciences Centre: A Patient Family Centred Care Success Story**

Rhonda Crocker Ellacott, BScN, MSN, EdD, Chief Executive Officer; Nipigon District Memorial Hospital; Nipigon; Executive VP, Patient Services and Chief Nurse Executive; Thunder Bay Regional Health Sciences Centre; Keith Taylor, Co-Chair, Patient Family Advisory Council; Bonnie Nicholas, BSN, CNCC(C), CPTC, RN, Lead, Patient Family Centred Care, Patient Advocate; Thunder Bay Regional Health Sciences Centre, Thunder Bay, Ontario

While leadership endorsement is important in creating a culture of PFCC, TBRHSC has found that embedding multiple leadership practices (e.g., patients involved in strategic planning, Family Care Grants, PFCC Leadership Council) is essential to realize an organizational culture shift.

**G4**  
**Ziegfeld, 4th Floor**

**Partnering with Patients and Families: The Changing Roles of Risk Management**

Francesca Charney, RN, MS, CPHRM, CPHQ, CPPS, CPSO, FASHRM, Director, Risk Management; ASHRM; Michael Midgley, RN, JD, MPH, CPHRM, FASHRM, Vice President; Healthcare Risk Engineering at Swiss Re Corporate Solutions; President-Elect; American Society for Healthcare Risk Management; Chicago, IL; Deborah Dokken, Family Leader, Consultant, Institute for Patient- and Family-Centered Care, Bethesda, MD

Risk Management can play a key role within hospitals in developing partnerships with patients and families. This interactive session will discuss some of the potential barriers encountered in the development of those partnerships and talk about risk reduction through the lens of yesterday’s (traditional) risk manager and today’s. The American Society for Healthcare Risk Management is an organizational partner for IPFCC’s Better Together: Partnering with Families campaign.

**G5**  
**Herald/Soho, 7th Floor**

**A Shared Experience: Integrating Peer-to-Peer Support Models into Care Delivery Across Diverse Health Conditions**


Learning how to grow peer support programs from patient co-designed pilots to high functioning programs across diverse health conditions takes tenacity, patient involvement and flexibility. This presentation will guide participants through a replicable process of adoption and spread.
Patient Engagement in Outcomes Research: Perspectives on Patient Roles in a Large Research Project on Shared Decision Making for Asthma Care

Hazel Tapp, BS, PhD, Research Director; Diane Derkowski, RN; Melissa Calvert, MA, Patient Research Team Member; Carolinas HealthCare System, Charlotte, NC

Partnership formation is considered key to successfully pursuing patient-centered research. We have studied outcomes related to the implementation of shared decision making for patients with asthma over five years. Here we present partnership perspectives from two patients and a researcher.


Maria Judd, MS, BS, Senior Director, Patient Engagement and Improvement; Patricia O’Connor, RN, MSc, CHE, FCCHL, Senior Advisor, Patient Engagement, McGill University Health Centre & Clinical Improvement Advisor; Anya Humphrey, Patient/ Family Advisor; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario

Hear how an innovative, multi-method evaluation plan captured the impact of 22 teams partnering with patients and families for quality improvement in a pan-Canadian collaborative. Participants will obtain tools and methods to tailor to their engagement evaluation needs.

Enhancing Interprofessional Clinical Practice and Compassionate Communication with Patient/Family Advisor Faculty

Dorothea Handron, EdD, RN, APRN, Patient Advisor; Kathy Dutton, MSN, NEA-BC, RN, FABC, Senior Administrator, Office of Patient and Family Experience; Vidant Medical Center; Niti Armistead, MD, FACP, Medical Director, Quality Clinical Associate Professor of Medicine; East Carolina University, Greenville, NC

Essential skills of compassion and empathy are not routinely taught or prioritized in graduate medical education. Through education to faculty and residents and rounding with the interprofessional team, patient advisor faculty demonstrate the importance and application of these skills.

Family as Faculty: Students Experience Childhood Disability Through Innovative Home Visiting Program

Amir Karmali, Family-Centred Care Specialist/Parent Advisor; Lori Beesley, Family Centered Care Specialist; Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario

Holland Bloorview Kids Rehabilitation Hospital and University of Toronto launched a home visiting program for their students to learn about childhood disability. This program provides exposure to children with disabilities while introducing the concept of PFCC in an experiential way.

Creating Capacity for Partnerships in Research

Beth Silber, MPA, Family Consultant, Chair of Family Advisory Council; Randie Kozar, Family Advisor; The Center for Child and Family Experience, Sala Institute for Child and Family Centered Care, NYU Langone Medical Center, New York, NY

The Sala Institute of Child and Family-Centered Care at NYU Langone deployed a quality improvement framework to test, refine and measure engagement of patients and families as advisors in research. Initiatives, including preparation of research teams and training of advisors, influence a key driver aimed at increasing advisor participation.

Effective Advisory Council Collaborations: Enhancing the Impact of the ORIEN Research Protocol

B. Lee Green, PhD, MEd, BS, Vice President of Diversity and Community Relations; Faculty Member, Health Outcomes and Behavior Department; Barney Morris, Patient Advisor; Moffitt Cancer Center, Tampa, FL

Moffitt Cancer Center will present the power of sharing the collective patient voice by developing a process of including a patient advisor who serves on ORIEN’s Advisory Council as well as Moffitt’s Patient and Family Advisory Council.

3:15–4:15 pm

Concurrent Sessions (H1-H10)

Minnesota’s Transformative Partnerships

Bonnie LaPlante, MHA, RN, Director, Health Care Homes; Melissa Winger, Patient/Family Advisor; Rosemarie Rodriguez-Hager, BA, Community Integration Practice Transformation Supervisor; Minnesota Department of Health, St. Paul, MN

Partnering with patients and families is a strategic component and at the core of Minnesota’s Health Care Home (HCH) and State Innovation (SIM) models. Incorporating patient and family partnerships into health reform, positively impacts system improvements and primary care transformation.
**H2**

**Gotham/Chelsea, 7th Floor**

**Partnerships in Safe Care: Increasing Accountability from Principles to Practice**

Lucy Pereira-Argenziano, MD, Director, Patient Safety and Quality; Liza Cooper, LMSW, Coordinator, Child and Family Education; Jorge Navarro, MHA, Project Coordinator, Quality, Safety, and Strategic Initiatives; Beth Silber, BS, MPA, Family Consultant; Sala Institute for Child and Family Centered Care, Hassenfeld Children’s Hospital of New York at NYU Langone, New York, NY

A tiered approach to support safety partnerships, developed in collaboration with patients and families, created an institutional expectation that patients and families are essential in all aspects of a quality and safety program. Tools and techniques reinforce culture of accountability.

**H5**

**Duffy, 7th Floor**

**Let Them In: Collaborative Approaches to the Engaged, Humanized Intensive Care Unit**

Chris Benda, Patient/Family Advisory Council, Shock Trauma ICU; Lorie Mitchell, RN, MSN, Nurse Manager, Shock Trauma ICU; Ramona Hopkins, PhD, BSN, Clinical Research Investigator; Samuel Brown, MD, MS, Director, Center for Humanizing Critical Care; Assistant Director, Critical Care Echocardiography Service; Intermountain Medical Center, Murray, UT; Sarah Beesley, MD, Pulmonary and Critical Care Fellow; University of Utah, Salt Lake City, UT

In conjunction with our Patient-Family Advisory Council we are working to create an engaged, humanized ICU that personalizes care, involves family and patients at the bedside and in decision making, and reduces adverse psychological outcomes in patients and family members.

**H3**

**O’Neill, 4th Floor**

**Creating an Environment of Mutual Respect: Training PFAC Members to Effectively Communicate**

Tiffany Christensen, BA, PFE Performance Improvement Specialist; North Carolina Quality Center, Cary, NC; Allison Chrestensen, MPH, OTR/L, CHWC, Program Specialist, Duke University Health System, Durham, NC

Communicating in a PFAC environment requires a balance between emotions connected to personal experiences and operational considerations required to run a healthcare organization. This training focuses on meaningful and respectful communication enabling the PFAC to be a powerful resource.

**H6**

**Columbia, 7th Floor**

**Salud Para Todos: A Community-Based Approach to Enhancing Family-Centered Care for Hispanic Children and Their Families**

Luz Adriana Matiz, MD, FAAP, Associate Professor of Pediatrics; Columbia University, New York, NY; Alexandra Kuznetsov, BS, RD, Program Manager; National Center for Medical Home Implementation, American Academy of Pediatrics, Elk Grove Village, IL; Crismilda Faxas, Family and Peer Navigator; Rhode Island Parent Information Network, Providence, RI

Hispanic children are less likely to receive care within a family-centered medical home as compared to their non-Hispanic counterparts. This community-based project engaged Hispanic families in pediatric care to increase access to family-centered medical homes by Hispanic children and families.

**H4**

**Ziegfeld, 4th Floor**

**Yes! The Doctor Is In! Physician Partnerships to Improve the Experience of Care**

Julie Moretz, BS, Family Leader/Associate Vice Chancellor for Patient- and Family-Centered Care; Richard Turnage, MD, Chair, Department of Surgery, Executive Associate Dean for Clinical Sciences, Chief Service Line Officer for UAMS Medical Center, Former Interim Dean, College of Medicine, Past Chair, Hospital Medical Board; University of Arkansas for Medical Sciences (UAMS), Little Rock, AR

At UAMS, our physician leaders are totally ‘in’! We will discuss our Awareness/Engagement/Implementation strategy and how physicians have taken bold leadership steps to increase capacity in strengthening the patient experience: Access to Care, Communication Improvements, and Transparency Online 5-Star Ratings.

**H7**

**Herald/Soho, 7th Floor**

**Family Partnership in the Discharge Process: Improving the Transition from Hospital to Home**

Sandra Gage, FAAP, MD, PhD, SFHM, Associate Professor of Pediatrics, Division of Hospital Medicine; Medical College of Wisconsin, Milwaukee, WI; Snezana Osorio, FAAP, MD, MS, Associate Professor of Pediatrics; Jennifer Small, BA, Honorary Chair, Komansky Center Family Advisory Council; Snezana Osorio, MD, MS, Associate Professor of Pediatrics Komansky Center for Children’s Health; New York-Presbyterian Hospital/Weill Cornell Medical College, New York, NY

Transition from hospital to home presents safety risks to pediatric patients. Family partnership in building a discharge plan and effective communication during the hospital stay promote the family’s ability to assume home care responsibilities at the time of discharge.
CERTAIN CAPACITY FOR PARTNERSHIPS
IN RESEARCH

Improving the Patient Experience Through Patient and Researcher Partnerships

Cindy Sieck, PhD, MPH, Assistant Professor, Department of Family Medicine; Gene Parkison, Patient/Family Experience Advisor; Carol Parkison, Patient/Family Experience Advisor; Sharon Cross, LISW-S, CPXP; PFCC Program Director; Ohio State University Wexner Medical Center, Columbus, OH

This presentation will provide the opportunity to hear the perspectives of patients, researchers and organizational stakeholders participating in research together. The collaborative process of designing an intervention related to the use of patient portals in health care will be described.

Partnering with Patients and Families in Research Design: What’s Said Versus Heard During ICU Bedside Rounds

Mary E. Lough, PhD, RN, CCNS, FCCM, Clinical Assistant Professor; Laura Jammal, Patient and Family Partner; Joanne Koltnow, BA, MPA, Patient and Family Partner; Stanford Health Care, Palo Alto, CA

Stanford’s ICU Patient and Family Advisory Council present their experience as full partners in designing and implementing a research project. Significant learnings will be discussed along with recommendations and tools to facilitate the partnership in any setting.

ADVANCING COMPASSIONATE, COLLABORATIVE CARE (THE “TRIPLE C”) WITH PATIENTS, FAMILIES, INTERPROFESSIONAL EDUCATORS, AND CLINICIANS

Beth Lown, MD, Medical Director; The Schwartz Center for Compassionate Healthcare, Boston, MA; Shanie McIntosh, MHA, Senior VP and Chief Program Officer; The Arnold P. Gold Foundation, Englewood Cliffs, NJ; Juliette Schlueter, BS, Director, The Center for Child and Family Experience, Sala Institute for Child and Family Centered Care, Hassenfeld Children’s Hospital of New York at NYU Langone, New York, NY

Skills related to compassion and empathy are missing from existing educational and collaborative care quality frameworks. We present a new paradigm, the Triple C (Compassionate, Collaborative Care), and ‘best practices’ for integrating compassion into health professional education and healthcare.

ASK ONE QUESTION TO LEARN AND ACT ON WHAT MATTERS TO PATIENTS

Carolyn Canfield, BA, CPSI, Honorary Lecturer, Department of Family Practice, Faculty of Medicine; University of British Columbia, Vancouver, British Columbia; Andrew Carson-Stevens, PhD, Lead, Patient Safety Research; Wales School of Medicine, Cardiff University, Cardiff, Wales, UK; Nick Cork, BA, BSc, Medical Student; University of Cambridge School of Clinical Medicine, Cambridge, UK

When students felt high-pressured training missed opportunities to explore patient priorities, they initiated Ask One Question. Practice and take home an adaptable method to refresh student curiosity in their patients, fine-tune their listening skills and create real-time patient-centered improvement.
I3  Ziegfeld, 4th Floor

**Power Tools for High Impact Patient and Family Advisory Councils**

Zelia de Sousa, BArch, Chair, Patient and Family Advisory Council; Annette Mercurio, MPH, MCHES, Director of Programs, Department of Supportive Care Medicine and PFAC Co-Chair; City of Hope, Duarte, CA

Patient and Family Advisory Councils magnify their power to transform care by creating synergies with organizational priorities, as demonstrated by the impact of patient and family leaders on high-level patient experience and outpatient care re-design committees.

I4  Odets, 4th Floor

**Translating Vision Into Reality: A New Model for Cancer Care**

Joan Forte Scott, BSN, MBA, NEA-BC, Administrative Director, Patient and Community Engagement; Bev Anderson, BA, Patient/Family Partner Consultant, Chair, Cancer Center PFAC; Stanford Health Care, Palo Alto, CA

Complex disease requires new models to meet patient/family needs for coordination and comprehensive care. Embedding patient/family voice into the transformation process, from identification of problems to design and evaluation, yielded unique and effective roles and solutions.

I5  Herald/Soho, 7th Floor

**Family Bedside Orientations: Where Peer Support, Quality and Safety, and Experience of Care Meet**

Jessie Checkley, MCPM, Senior Improvement Lead; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario; Heather Mattson McCrady, BA, MThS, Manager, Family Centred Care; Nicole Lyste, BA, Patient Experience Advisor, Member, NICU Family Advisory Care Team & Family Centred Care Network; Stollery Children’s Hospital, Edmonton, Alberta

Hear how the Stollery Children’s Hospital, volunteer peer mentors and caregivers are collaboratively working to improve hand hygiene practices, use of patient bedside whiteboards, familiarity with the child’s medications, and family involvement in their child’s care.

I6  Hudson/Empire, 7th Floor

**Show Me the Impact!!! Transferrable Lessons from the Independent Evaluation of a Canadian Patient-Led Program**

Ioana Popescu, MBA, Lead, Patient Safety Improvement; Canadian Patient Safety Institute; Judy Birdsell, BScN, MSc, PhD, Chair, Membership Committee; Patients for Patient Safety Canada, Edmonton, Alberta

Results from an independent evaluation of Patients for Patient Safety Canada, a decade-old patient-led program, indicate that patient/family engagement has made an impact on patient safety at multiple system levels and offer recommendations for ways to increase impact.

I7  Brecht, 4th Floor

**Patient Engagement: Policy, Programs, and Behavior Change**

Lorna Milkovich, BSN, MBA, RN, Executive Director; Cindy Jefferies, BA, Board Member; Red Deer Primary Care Network, Red Deer, Alberta

Patient and community engagement is a priority in the Red Deer Primary Care Network. Learn about the successes and difficulties in Red Deer’s experience of engaging patients in leadership, policy development, program direction, and behavior change.

I8  Duffy, 7th Floor

**Patient Engagement in Research: How to Get it Right**

Bev Holmes, PhD, Vice President, Research & Impact; Michael Smith Foundation for Health Research; Executive Lead, British Columbia SUPPORT Unit; Colleen McGavin, EdD, Interim Lead, Patient & Stakeholder Engagement; British Columbia SUPPORT Unit, Vancouver, British Columbia

This presentation outlines a pragmatic community-based research project where we collaborated with patients and families, researchers, health care providers, administrators and research funders to develop a training program to foster meaningful and active engagement of all stakeholders in health research.

I9  Columbia, 7th floor

**Patient Family Centered Care Theatre**

Julie Newland, MFA; PFCC Theatre, Pigeon, MI

This presentation will share how Julie Newland worked with a Perioperative Department to help increase their knowledge of Patient/Family Centered Care principles using theatre to re-enact real life situations that occurred in their department, and then engaged in a discussion about the impacts of those situations on staff, patients and families.
WEDNESDAY AGENDA

WEDNESDAY, JULY 27, 2016

7:00–8:00 am Liberty, 8th Floor
SPECIAL NETWORKING BREAKFAST
Partnering with Patients and Families in Research
Join us for breakfast and network with others—patients, families, researchers, and health care professionals—who are partnering in research efforts.

8:00–9:00 am
CONCURRENT SESSIONS (J1-J10)

J1 Brecht, 4th Floor
GOOD TO GO: Partnering with Patients and Families to Improve Experience for a Smooth and Safe Transition Home After Fragility Hip Fracture
Valerie MacDonald, BSN, CNS, MS, Clinical Nurse Specialist, Orthopaedics; Fraser Health; Judy Battista, Patient Advisor; Vancouver Coastal Health and Fraser Health; Dolores Langford, MS, BScPT, Physiotherapy Practice Coordinator, Coastal Community of Care; Vancouver Coastal Health, Vancouver, British Columbia

Patients, families and health professionals collaborated in quality improvement teams at three acute orthopedic units across health authorities in Metro Vancouver, improving the patient experience of the hospital to home transition following surgery for a fragility hip fracture by 20%.

J2 Wilder, 4th Floor
Innovative Family-Centered Care Bundle: One Hospital’s Journey of Working with Family and Staff to Significantly Improve Both Family-Centered Care and Satisfaction in the NICU
Lori Chudnofsky, MN, BSN, RNC-NIC, Regional Director for Women’s and Children’s Services; Providence Everett Medical Center; Andrianna Jang, March of Dimes Parent Mentor; Swedish NICU Parent Experience Council Member; Andrew Beckstrom, MD, Neonatologist; Pediatric Medical Group, Seattle, WA

A collaborative effort involving NICU families and staff identified areas of improvement in the provision of Patient and Family Centered Care (PFCC). We subsequently implemented a targeted PFCC bundle of interventions. Consequently, we found that satisfaction scores increased significantly.

DAY AT-A-GLANCE

Wednesday, July 27, 2016
7:00 am–8:00 am Registration, Continental Breakfast
Networking Breakfast: Partnering with Patients and Families in Research
Additional Informal Networking Breakfasts
8:00 am–9:00 am Concurrent Sessions (J1–J10)
9:15 am–10:15 am Concurrent Sessions (K1–K10)
10:15 am–10:45 am Break
10:45 am –12:15 pm Spotlight on Exemplars (L1–L7)
12:15 pm–1:45 pm Lunch Break (On your own)
1:45 pm–2:45 pm Concurrent Sessions (M1–M8)
3:00 pm–4:00 pm Closing Plenary

J3 Odets, 4th Floor
How Healthy Is Your Patient and Family Advisory Council?
Deborah Sprague, BS, Patient Experience Specialist, Center for Patient Experience; Stephenie Young, BS, PMP, Patient Experience Specialist, Center for Patient Experience; Anita Jones, BA, Patient and Family Advisory Council Member; Spectrum Health, Grand Rapids, MI

Seeking to create a partnership with advisory council members and your organization’s leadership? Learn to have a mutual understanding of roles and objectives and honest and open discussions. The team from Spectrum Health will share their self evaluation tool.

J4 O’Neill, 4th Floor
Patient Led Feedback Forums: A Tool for Improving the Patient Experience
Daryl Bell, BA, MDiv, Lead, Patient- and Family-Centred Care; Angela Morin, BA, Co-chair Patient and Family Advisory Council; Kingston General Hospital, Kingston, Ontario

This session will provide a tool whereby staff learn from patients/families what the patient experience is really like. The tool encourages interprofessional education, and collaboration through the engagement of patients and families with the goal being the best patient experience.
### J5
**Duffy, 7th Floor**

**Transforming the Patient Care Experience in a Sub-Acute (Post-Acute) Setting Through Partnership, Engagement, and Co-Design During Transitions and at the Bedside**

Maria Judd, MS, BS, Senior Director, Patient Engagement and Improvement; Canadian Foundation for Healthcare Improvement; Jacqueline Tetroe, MA, Family Advisor; Sandra Schmidt, BSN, MEd, Project Lead, Transforming the Patient Care Experience; Bruyere Continuing Care; Beverley Shea, BScN, MS, PhD, Research Scientist; Bruyere Research Institute, Ottawa, Ontario

Our patients have changed to require sub-acute/post-acute care with complex medical conditions. Strategically we are committed to providing excellence in care through a coordinated person centered approach to care and are co-designing initiatives with our patients and families.

### J6
**Ziegfeld, 4th Floor**

**Improving the Quality of the Patient/Family Emergency Department Experience Through a Family Advisory Directed Ambassador Program**

Cheryl Miranda, BS, Director, Patient and Family Centered Care; Arline Riordan, BSN, Family Advisor, Patient & Family Partnership Council; Huntington Hospital, Huntington, NY

This presentation will highlight the effectiveness of an ED Ambassador program through collaboration with a Patient/Family Partnership Council. This will be demonstrated by the increase in ED patient satisfaction scores pre and post program inception.

### J7
**Herald/Soho, 7th Floor**

**Implementing a Pragmatic Framework for Authentic Patient-Researcher Partnership in Clinical Research**

Maureen Fagan, MHA, DNP, WHNP-BC, FNP, Associate Chief Nurse-OB/GYN, Executive Director, Center for Patients and Families; Martha Carnie, BA, Senior Patient Advisor; Dena Salzberg, RN, Patient Family Advisor; Brigham and Women’s Hospital, Boston, MA

A pragmatic framework for collaborative engagement with patient/family advisors and clinical researchers is described. This framework outlines the steps to create a partnership in the clinical research process with an established patient family advisory council in an academic medical center.

### J8
**Hudson/Empire, 7th Floor**

**Partnering with Patients, Families and Members to Conduct Patient-Centered Research Within a Learning Health Organization**

Jane Duncan, MPH, Strategic Programs Manager; Christine Norton, MA, Patient Research Co-Investigator; HealthPartners Institute, Minneapolis, MN

We intend to share tools and best practices to efficiently and effectively engage patients, families and members as advisors in research. A patient co-investigator of a three-year research study will share her experiences and offer guidance to build meaningful partnerships.

### J9
**Columbia, 7th Floor**

**Decolonizing Health Care: Walking the Healing Journey Together**

Scott Harrison, BScN, MA, RN, CCHNC, Director, Urban Health, HIV, Addictions; Carol Kellman, BSN, RN, Aboriginal Nurse Practice Leader; Neil Fowler, Program Assistant, HIV/AIDS & Aboriginal Health; Providence Health Care, Vancouver, British Columbia

Using both oral presentation and a traditional First Nations Talking Circle Ceremony, this presentation will address the importance of cultural safety in health care and how health care providers can walk the healing journey alongside their patients.

### J10
**Gotham/Chelsea, 7th Floor**

**Children’s PFCC Roadmap: Patients and Families as Faculty Educators**

Jill Sangha, MSW, RSW, Patient- and Family-Centred Care Specialist; Jennifer Banting, Patient Experience Associate; Children’s Hospital, London Health Sciences Centre, London, Ontario

Quality safe care and satisfaction relies on health professionals trained in patient and family-centred interprofessional team practice. A Faculty Education Program, facilitated by patients and families, was designed to educate staff, physicians and residents with this ideology in mind.

9:15–10:15 am

### CONCURRENT SESSIONS (K1-K10)

### K1
**Wilder, 4th Floor**

**Voices of Experience: Advisors Rounding on Patients in the Hospital**

Caroline Moore, MPH, Program Leader, Patient and Family Engagement; Barbara Saroff Lee, MSW, LICSW, Senior Director, Social Work and Patient/Family Engagement; Randy Gonchar, MBA, Patient/Family Advisor; Beth Israel Deaconess Medical Center, Boston, MA; Licia Berry-Berard, MSW, LICSW, Manager, Patient- and Family-Centered Care; Meg Seely, MEd, Volunteer Patient/Family Advisor; Dartmouth-Hitchcock Medical Center, Lebanon, NH

Patient/Family Engagement Leaders and Advisors from Dartmouth-Hitchcock Medical Center (DHMC) and Beth Israel Deaconess Medical Center (BIDMC) will describe two models of Advisor rounding at two different stages of development. Presentation will cover strategies, tools, benefits, challenges, and lessons learned.
**K2**  
**Engaging Patients/Families in Harm Prevention – From Board to Bedside**  
Daniel Hyman, MD, MMM, Chief Quality and Patient Safety Officer; Amy Jacquemard, Patient Family Experience Leader; Maria Hopfgarten, BA, Parent Partner; Chair, Family Advisory Council; Member, Quality and Safety Committee of the Board; Children’s Hospital Colorado, Aurora, CO

This session will describe one children’s hospital’s strategy for engaging parent partners in their safety efforts at all levels of the organization, “from board to bedside.” Successes and lessons learned will be shared, as well as tools for getting started.

**K3**  
**Partnering with Patients and Family Faculty in Interprofessional Education: The Perspectives of Leaders**  
Steven E. Weinberger, MD, MACP, Executive Vice President and Chief Executive Officer; American College of Physicians, Philadelphia, PA; Susan Grant, MS, RN, NEA-BC, FAAN, Executive Vice President and Chief Nursing Officer; Beaumont Health, Southfield, MI; George E. Thibault, MD, President; Josiah Macy, Jr. Foundation, New York, NY; Julie Ginn Moretz, BS, Associate Vice Chancellor, Patient- and Family-Centered Care, Center for Patients and Families; University of Arkansas for Medical Sciences, Little Rock, AR; Deborah Dokken, MPA, Family Leader/Consultant; Institute for Patient- and Family-Centered Care, and formerly Associate Director; Initiative for Pediatric Palliative Care, Bethesda, MD; Amir Karimi, Certified Simulationist, Family-Centred Care Specialist; Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario

Using a practice-based model for advancing partnerships among team members, this session demonstrates how to use “courageous followership” to enhance participation and collaboration among patients, family members, and providers.

**K4**  
**Matchmaker, Matchmaker, Make Me a Match: Meaningful Engagement of Patient Family Advisors**  
Charlene VanMeter, Patient/Family Advisor; Earl Shelner, Patient/Family Advisor; Jeanne Morris, BSN, PFCC Coordinator; Matthew LeBlanc, BSN, OCN, Oncology Rehabilitation Nurse Navigator; Anne Arundel Medical Center, Annapolis, MD

See inside successful partnerships with advisors and hospital staff to explore keys to meaningful engagement. It requires good matchmaking skills and supportive staff. The payoff is meaningful work and enculturation of Patient and Family Centered Care across the organization.

**K5**  
**Courageous Followership: The Key to Patient and Provider Partnerships**  
Austin Bunch, PhD, Senior Associate Provost; East Carolina University; Wanda Bunch, PhD, Patient and Family Advisor; Vidant Health, Greenville, NC; Sue Collier, BSN, MSN, FABC, Clinical Content Development Lead; American Hospital Association/Health Research and Educational Trust (AHA/HRET), Chicago, IL

Using a practice-based model for advancing partnerships among team members, this session demonstrates how to use “courageous followership” to enhance participation and collaboration among patients, family members, and providers.

**K6**  
**Partnering with Patients and Families to Bring Shift Report to the Bedside: A Recipe for Success!**  
Dianne Gaffney, BASc, MSc, RD, Corporate Lead, Professional Practice; Donnalene Tuer-Hodes, BSN, MSN, CNE, Program Director, Surgery, Mat/Child, and Central Processing Department; Cathy Bachner, BASc, BEd, Patient Lead; Huron Perth Healthcare Alliance, Stratford, Ontario

This presentation will share the results of a patient engagement study which brought patients, family, staff and program leaders together to design and implement bedside transfer of accountability, including impact on patient satisfaction and engagement, as well as staff satisfaction.
**K7**

**Brecht, 4th Floor**

**A New Medicine for Patient Engagement: Patient/Family Advisors Play Key Role in Implementation and On-Going Assessment of Open Notes for Kaiser Permanente Northwest Region**

Jonathan Bullock, BA, Regional Program Manager, Patient and Family Centered Care Programs; Mickie Aerne-Bowe, Patient/Family Advisor; Kaiser Permanente, Portland, OR

In 2014 Kaiser Permanente Northwest launched Open Notes as a region-wide initiative. Patient/Family Advisors were key to building the will to move this initiative forward as well as playing a continued and pivotal role in on-going assessment and improvement.

**K8**

**Gotham/Chelsea, 7th Floor**

**Building Partnerships in the Research Community: Promising Practices and Future Directions**

Susan Sheridan, MIM, MBA, DHL, Director of Patient Engagement; Patient-Centered Outcomes Research Institute (PCORI), Washington, DC

PCORI will share promising practices, trends and real life examples of novel multi-stakeholder research partnerships between patients, families, PFACs and other stakeholders in the design and conduct of Patient-Centered Outcomes Research (PCOR). Preliminary data sharing the impact of patient engagement in research will be discussed as well as emerging new approaches to PCOR such as Patient Powered Research Networks.

**K9**

**Olmsted/Gramercy, 7th Floor**

**Improving Quality and Safety – Designing a New Pavilion by Engaging Patients and Families in an Experience Mapping Project**

Yasmin Yusuf, MHA, Administrator, Center for Patient Safety & Quality; Nicole Duncan, BS, Assistant Vice President, Patient Advocacy & International Services; Mary Herold, BSN, RN, CNML, Clinical Risk Manager; Steven Coffee, Patient/Family Advisor; MedStar Georgetown University Hospital, Washington, DC

A deep dive into patient experience research – engaging and observing patients and family members to develop experience maps. This presentation will share how the patient voice, and data, are critical to an AMC’s approach to the design of a new facility.

**K10**

**Duffy, 7th Floor**

**Patient Voices: Outcomes of a Brief Health Care Provider Education Intervention Featuring Persons with Disabilities as Teachers**

Ellen Hunt, Administrative Director; Autism Resource Community Hub of Lehigh Valley; Judith Sabino, MPH, CDP, Diversity/Cultural Awareness Liaison; Sweety Jain, MD, Faculty, Lehigh Valley Family Medicine Residency Program; Assistant Professor, Morsani College of Medicine, USF Director, Medical Home Project; Lehigh Valley Health Network, Allentown, PA

Educational programming, including live discussion and video vignettes, that is designed and provided by persons with disabilities can be effective in increasing health professional knowledge in caring for this patient population and ensuring equitable care delivery.

10:45 am–12:15 pm

**SPOTLIGHT ON EXEMPLARS (L1-L7)**

**L1**

**Astor Ballroom, 7th Floor**

**HASSENFELD CHILDREN’S HOSPITAL OF NEW YORK AT NYU LANGONE**

**Patient and Family Faculty in High Impact Interprofessional Education—From Classroom to Simulation Center**

Juliette Schlucter, Director, The Center for Child and Family Experience; Jeremy Donovan, BS, Family Faculty; Jennifer Daly, Family Advisor and Family Faculty; Dennis Sklenar, LCSW, Assistant Director of Social Work and Child Protection Coordinator; Lea Devins, MSN, RN, Nurse Manager, Pediatric Intensive Care Unit; Sala Institute for Child and Family-Centered Care; Michael Goonan, MD, Sala Institute for Child and Family-Centered Care and Assistant Professor of Pediatrics, NYU School of Medicine and Pediatric Hospitalist; Hassenfeld Children’s Hospital of New York at NYU Langone, New York, NY

Patient- and family-centered care is nurtured by the narratives of patients and families. This session provides strategies and tools to help patients and families learn how to harness the power of their narratives to teach healthcare professionals in a variety of educational settings.
WEDNESDAY AGENDA

L2
CHILDREN’S SPECIALIZED HOSPITAL
Wild, 4th Floor

Build a Fully Integrated Patient- and Family-Centered Care Organization Through Sustainable and Committed Family and Staff Partnerships
Donna Provenzano, BS, CTRS, Director, Family-Centered Care; Pat O’Hanlon, Family Faculty Coordinator; Children’s Specialized Hospital, New Brunswick, NJ; Josanne Pearsall, BA, MBA, Family Faculty; Children’s Specialized Hospital, Mountainside, NJ; Michele Tomaino, MSN, RN, Family Faculty; Children’s Specialized Hospital, Toms River, NJ
Provide participants with a detailed, turnkey Family Faculty and Family Advisory Council model that clearly outlines the steps necessary to initiate, compensate, embrace, and fully integrate families as partners in a Patient- and Family-Centered Care organization.

Engaging Collaborative Efforts Between Family Faculty and Strategic Improvement to Design and Implement Technology-Based Solutions to Enhance and Streamline our Patient and Family Experience
Donna Provenzano, BS, CTRS, Director, Family-Centered Care; Carrie Snyder, BA, Family Faculty; Children’s Specialized Hospital, New Brunswick, NJ; Linda Waddell, BS, Family Faculty; Nancy Panarese, Family Faculty; Children’s Specialized Hospital, Mountainside, NJ
Families and staff worked side by side in every step of the process to design, build and implement My Children’s Specialized Patient and Family Portal and Tablet Registration. These efforts have resulted in positive outcomes for our patients and families.

L3
PROVIDENCE HEALTH CARE
Liberty, 8th Floor

The PFCC Journey: Leveraging Leadership and Partnerships to Enact an Organizational Strategy
Sara-Grey Charlton, BSN, MSN, RN, Practice Consultant, Patient and Family Centred Care; Betty Murray, MA, RN, PCC, Patient Partner; Candance (Candy) Garossino, BSN, MSN, Director, Nursing and Professional Practice; Providence Health Care, Vancouver, British Columbia
Providence Health Care has committed to PFCC over the last four years by moving forward the Care Experience strategic direction. Leadership, partnerships between patients, families, and clinical staff have enabled our successes.

Patients and Families as Partners for Staff Hiring and Promotion
Sara-Grey Charlton, BSN, MSN, RN, Practice Consultant, Patient and Family Centred Care; Providence Health Care, Vancouver, British Columbia
Patient and family partners collaborated with leaders to design an interview tool to assist in hiring for Patient and Family Centred Care Values. This presentation will describe the evaluation of this new hiring process.

L4
UNIVERSITY OF WASHINGTON MEDICAL CENTER
Odets, 4th Floor

Please, I Need to Be With Her – Supporting Family Presence at Resuscitation
Katy Folk-Way, BA, ICU Patient/Family Advisor, ICU Volunteer Liaison; Carol Kummel, MSW, Palliative Care Social Worker; Patricia Kritek, BA, MD, MEd, Medical Director, Critical Care; Amy Furr, MTS, MDiv, Spiritual Care, Manager and Educator; University of Washington Medical Center, Seattle, WA
We introduce a designated Family Support Provider as a member of the Code Blue team and outline a training curriculum including: voice of the family, explanation of events of a code, guidelines for support of families, provider self-awareness and self-care.

Keep My Loved One Safe! Involving Patient and Family Advisors in Infection Prevention Helps Achieve Better Results
Katy Folk-Way, BA, ICU Patient/Family Advisor, ICU Volunteer Liaison; Robin Olsen-Scribner, BS, MPH, Infection Control Practitioner, Epidemiology; University of Washington Medical Center, Seattle, WA
We will present how at the University of Washington Medical Center we incorporated patient and family members alongside key staff for a three-year targeted infection reduction goal to reduce six different types of hospital acquired infections, and are achieving great results.

L5
UNIVERSITY OF MICHIGAN HEALTH SYSTEM
O’Neill, 4th Floor

Think Disruptively! #LeadershipMatters: Two Case Studies Highlighting the Integration of PFCC into an Outpatient Audiology Clinic and Congenital Heart Center
Stefanie Peters, LMSW, MPA, Director of Clinical Operations; Mary Shaw, PFCC Coordinator; University of Michigan C.S. Mott Children’s Hospital Congenital Heart Center; Ann Green-Ramsey, MS, Member, University of Michigan, C.S. Mott Congenital Heart Center National Advisory Board; Ann Arbor, MI; Jennifer Wilcox, PFCC Coordinator; Jaynee Handelsman, PhD, CCC-A, Director, Pediatric Audiology; Angeline Boerst, MA, CCC-A, Audiologist; University of Michigan C.S. Mott Children’s Hospital Pediatric Audiology Clinic, Ann Arbor, MI
Leaders in the Congenital Heart Center and Pediatric Audiology clinic have pioneered an infrastructure that elevates PFCC practices creating a strategic ripple of change. In both areas a paid PFCC Coordinator position has been created to ensure a sustainable program.
THE CHILDREN’S HOSPITAL OF PHILADELPHIA

Engaging Parents in Research: Creation of a Parent Research Advisory Board in a Pediatric PBRN
Amy Kratchman, BA, Family Consultant; Erica Evans, MS, Patient/Family Advisor; The Children’s Hospital of Philadelphia, Philadelphia, PA

Engaging families, caregivers, clinicians, and other stakeholders throughout the research process is critical to successfully performing research in practice settings. This presentation details the creation, governance, use, and utility of the Research Parent Advisory Board as integral to a PBRN.

Family Partners in Research: A System for Enabling Authentic Family Engagement in Pediatric Health Research
Amy Kratchman, BA, Family Consultant; Anne Marie Richards, Family Centered Care Program Coordinator; Katherine Bevans, PhD, Assistant Professor of Pediatrics, The Children’s Hospital of Philadelphia, Philadelphia, PA

Child and family-centered pediatric healthcare systems authentically and equitably involve children and caregivers in research that meaningfully impacts their health outcomes. We will describe an institution-wide approach to establishing research partnerships and supporting the implementation of best-practice patient/family-centered research strategies.

LUNCH

Lunch on your own. Enjoy lunch in one of the culinary capitals of the world. A list of nearby New York City restaurants is available at the IPFCC registration desk.

CONCURRENT SESSIONS (M1-M8)

M1
Patient Partnership in Quality Improvement of Healthcare Services: Patient Input and Challenges Faced
Marie-Pascale Pomey, MD, PhD, Professor; Edith Morin, Patient/Family Advisor; University of Montréal, Montréal, Quebec

This study focuses on the perception of patients who participated in Continuous Quality Improvement (CIC) committees regarding their contributions, lessons learned, and challenges encountered.

M2
The Reality of Real Time Patient Experience Measurement: Cancer Treatment Questionnaire
Sarah Benn, MA, Lead, Patient Experience Measurement, Person-Centred Care; Patricia Pottie, BS, Patient and Family Partner; Cancer Care Ontario, Toronto, Ontario

This presentation will share the reality of real time patient experience measurement based on a recent cancer treatment questionnaire validation pilot.

M3
Bridging the Gap: Finding Meaning Through Collaboration Between Families and Medical Staff in a Developing Pediatric Complex Care Clinic
Rebecca Barkhuizen, Patient/Family Advisor; Aide Benson, Patient/Family Advisor; Kendra Koch, MA, Research Scientist; Kim Wirth, BSN, Staff Nurse Day Surgery; Children’s Comprehensive Care Clinic, Austin, TX

This abstract aims to inform healthcare providers and family advocates about the meaningful roles and experiences of parent members in the creation and implementation of a clinic designed to provide care for children with complex medical needs and their families.

M4
Patient Family Advisor Rounding with Leaders and Independently for Patient Safety, Experience, and Engagement
Sherrill Beaman, BS, CPHQ, MPH, Director, Quality Programs; Terry Martin, BSN, RN, Coordinator, Quality Improvement; Barbara Haymon, Patient Family Advisor, Vidant Edgecombe Hospital, Tarboro, NC

To expedite goals related to patient safety and exceptional experiences, the Vidant Health System developed models of patient and family rounding. Patient family advisors’ roles now include rounding with leaders and independently in the hospital and ambulatory clinic settings.
Creating Capacity for Sustainable Partnerships with Patient and Family Advisory Councils in Research

Kelly Parent, BS, Program Specialist for Patient and Family Partnerships; Institute for Patient- and Family-Centered Care, Bethesda, MD; Catherine McCarty, PhD, MPH, Principal Research Scientist; Essentia Institute of Rural Health; Jeane Riese, BBA; Patient Advisor; Wade Roseth, MA, MHES, Patient Advisor; Essentia Health, Duluth, MN; Kimly Blanton, MIS, MLS, Patient Family Advisor; Dorothea Handron, EdD, RN, APRN, Patient Advisor; Kathy Dutton, MSN, NEA-BC, RN, FABC, Senior Administrator, Office of Patient and Family Experience; Vidant Health, Greenville, NC

This panel presentation will discuss the experiences of two health care systems that are engaging Patient and Family Advisory Councils in research projects. Essentia Health’s project focuses on leveraging technology to improve communication among advisors over a large geographic region. Vidant Health’s project explores a model of communication and interprofessional care based on the Compassionate, Collaborative Care framework. Both organizations will discuss their challenges and successes as well as key strategies for engaging advisors in research and preparing researchers, staff, and PFACs to partner.

Patient/Family Partnership in Designing the Environment of Care

Katie Abbott, MHA, Senior Program Manager, Business Operations; Linda Toeniskoetter, BA, RYT, Patient/Family Partner, South Bay Patient and Family Advisory Council; Stanford Health Care, Palo Alto, CA

At Stanford’s new cancer center, the Patient and Family Advisory Council comprised of local cancer survivors directly impacted every aspect of design, workflow planning, staff selection and training, and was key to building partnerships with the local community.

Using Simulation to Teach Family-Centred Care in an Interprofessional Environment

Amir Karmali, Certified Simulationist, Family-Centred Care Specialist; Rebecca Quinlan, MEd, RECE, Family Partner/Family-Centred Care Specialist; Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario

This dynamic session will describe and demonstrate the process of developing simulations (video and live) through storytelling between clinicians and families to experientially teach family-centred care behaviours and best practices in an interprofessional environment.

Real-Time Intentional Patient and Family Check-Ins: A Catalyst for Cultural Change

Kathryn Conaboy, BA, Manager, Patient & Family Experience; Danielle Flynn, BSN, CPN, MS, RN, Nurse Manager; Karen Ross, BSN, MA, RN, Nurse Manager; The Children’s Hospital of Philadelphia, Philadelphia, PA

Real-Time Intentional Rounds yield actionable feedback at the point of care that staff can use, share and respond to in order to improve the patient/family experience. Results have shown increased staff engagement and early gains in patient/family satisfaction scores.

The Pursuit of Equity in Health and Healthcare: Creating the Climate for Change and Partnerships

B. Lee Green, Phd, MEd, BS, Vice President of Diversity and Community Relations; Faculty Member, Health Outcomes and Behavior Department; Moffitt Cancer Center, Tampa, FL

There is a clear momentum to engage together to create ideal health care systems, and yet, a challenge remains to embrace all cultures and honor the rich diversity of our populations. Join B. Lee Green for this inspirational closing session to explore the various initiatives and approaches that seek to reduce and eliminate health disparities, invite all to the conversation, build genuine partnerships, and improve the overall health of all our communities.
A Design in Time: The Architectural Project that Established a Patient- and Family-Centered Culture
Jane Lasdow, MEd, Chair and Founding Member, Cancer Patient Care Advisory Council; Marianne Clark, MA, Founding Member, Former Chair, Cancer Patient Care Advisory Council; Marian Gilmore, OCN, RN, Nurse Navigator; Dana Farber/Brigham and Women’s Cancer Center in Clinical Affiliation with South Shore Hospital, South Weymouth, MA

This poster tells the story of patients participating in the design of the cancer center. We spotlight the Cancer Patient Council and its Rounding program, which symbolizes the heart and soul of the patient-centered care experience.

A Grass Roots Approach to Creating a Patient and Family/Caregiver Advisory Council at a Comprehensive Cancer Center
Katherine Pisano, BA, Patient Advisor; Gail Zephyr, BSN, OCN, Nurse Clinician III; Colleen Apostol, BSN, CHPN, MSN, OCN, Nurse Manager; Sharon Krumer, BSN, MS, PhD, Clinical Administrator and Director of Nursing; karla Viloria, BSN, RN, Nurse Clinician IIE; The Sidney Kimmel Comprehensive Cancer Center at the Johns Hopkins Hospital, Baltimore, MD

A bedside nursing initiative created an alliance with oncology leadership to partner with patients, their families and caregivers to create, develop and sustain a Patient and Family/Caregiver Advisory Council (PFAC) in a National Cancer Institute (NCI) Cancer Center.

A Quality Initiative Endorsed by Cancer Care Ontario in Partnership with the Program in Evidence-Based Care: The Person-Centred Care Guideline
Brett Nicholls, BScN, MBA, Specialist, Person-Centred Care; Cancer Care Ontario, Toronto, Ontario

The Person-Centred Care Guideline outlines the level of care delivery that any person accessing adult oncology services in Ontario should expect to receive. Although cancer-specific, many principles in the Guideline are relevant to all healthcare professionals and staff.

A Strategic Approach for Prioritizing and Implementing Patient and Family Centered Care Principles in a Comprehensive Healthcare Delivery System
Marylynn Kelts, MS, Executive Leadership Team, Care Experience Leader, Excellence Journey; Kaiser Permanente San Diego, San Diego, CA

Use of a national, validated instrument for strategic planning to assess, identify, and develop and integrate effective Patient and Family Centered Care (PFCC) Principles across the care continuum in a comprehensive healthcare delivery system.

A Vital Voice in Healthcare: Partnering with Teenage Patients as Advisors and Teachers for the Best Care
Erin Lauinger, LCSW, MSW, Senior Pediatric Social Worker; Hassenfeld Children’s Hospital of New York at NYU Langone, New York, NY

The Youth Advisory Council was established to bring the critical voice of youth to the forefront of healthcare design and to advance a family-centered culture. We present our model with young advisors prepared to share their perspectives.

Advance Primary Care: Spectrum Health Transforms the Culture to Meet the Needs of the Patient
Stephanie Young, BS, PMP, Program Manager, Patient Experience Specialist, Center for Patient Experiences; Deborah Sprague, BS, Program Manager, Patient Experience Specialist, Center for Patient Experiences; Spectrum Health, Grand Rapids, MI

Join the leadership of Spectrum Health and learn about their journey to transform the Primary Care model by identifying alternative resources and meeting the patients’ needs more closely.

Advancing Awareness of Young Adult Issues: Reviewing the Benefits and Deliverables Created by a Young Adult Advisory Council Following Implementation of a New Goal-Setting Model
Wendy Griffith, MSSW, Senior Social Work Counselor; Mark Gardner, BS, EIT, Member, Young Adult Advisory Council; MD Anderson Cancer Center, Houston, TX

This poster will review the positive outcomes and interprofessional educational curricula that resulted following the implementation of a new structure and goal setting model within an oncology young adult patient advisory council.

CONFERENCE POSTER SCHEDULE
Monday, July 25, 2016
7:00 am–8:00 am Poster Displays
9:45 am–10:30 am Poster presenters available for questions and discussion
11:45 am–1:15 pm Poster presenters available for questions and discussion

Tuesday, July 26, 2016
7:00 am–8:00 am Poster Displays
9:30 am–10:00 am Poster Displays
12:15 pm–1:45 pm Poster Displays

Poster sessions sponsored by American College of Radiology

REFER TO ON-SITE HANDOUT FOR MAP WITH POSTER NUMBERS AND LOCATIONS.
Advancing Family Advisors Into State and National Leaders
Kara Adams, Immediate Past President, Family Advisory Council; Monroe Carell Jr. Children’s Hospital at Vanderbilt; Program Coordinator/Family Consultant; Family Voices of Tennessee; Tennessee Disability Coalition, Nashville, TN; Belinda Hotchkiss, BS, Family Advisor; NICU Clinical Advisory Group; Monroe Carell Jr. Children’s Hospital at Vanderbilt; Director, Family Voices of Tennessee; Tennessee Disability Coalition, Nashville, TN; Janet Cross, BS, MEd, CCLS, Administrative Director, Patient and Family-Centered Care; Monroe Carell Jr. Children’s Hospital at Vanderbilt, Nashville, TN

This poster will share strategies for leadership development in health system family advisors. Effective screening, training and ongoing coaching for family advisors can reap successful family advisors for health systems, and maximize partnership opportunities with local, state and federal organizations.

“Agents of Little Acts of Human Kindness”: The Powerful Role of Family Resource Center (FRC) Volunteers in Advancing Family-Centered Care Within a Children’s Hospital
Mary Delaney, MSW, LCSW-R, Director, Family Support and Family Resource Center; Anmarie Shisler, RN, BSN, Member, MFCH Family Advisory Council; RN in Adult Pulmonology/Cardiology; Northern Westchester Hospital; Carol Havlin, BA, MA, Volunteer, Family Resource Center; Maddy Yeager, Volunteer, Family Resource Center; Maria Fareri Children’s Hospital at Westchester Medical Center, Valhalla, NY

As non-clinical members of the hospital team, volunteers have a unique role in assisting families in coping with their child’s hospitalization. Vignettes will be shared highlighting FRC volunteers’ unique roles and their impact on advancing family-centered care.

All Teach All Learn: A Collaborative Strategy for Spread of Family Engagement in Safety and Quality Across Children’s Hospitals in New York State
Jennie Donovan, BA, MEd, Family Advisor; Jeremy Donovan, Volunteer, Family Resource Center; Sala Institute for Child and Family Centered Care; Hassenfeld Children’s Hospital of New York at NYU Langone, New York, NY

This poster highlights the work of an innovative collaboration between 8 Children’s Hospitals across New York state united in a mission to advance family engagement in safety and quality using a philosophy of “All Teach All Learn.”

Ask the Experts: How to Make Your Patients and Families Active Members of Your Facility Design Team
Rachel Knox, AIA, ACHA, EDAC, LEED AP, Pediatric Practice Leader; HKS Inc, Dallas, TX

Innovative role of patients and families in the design process of the new Kay Jewelers Pavilion at Akron Children’s Hospital.

Beyond the Bedside: Patient and Family Engagement in Key Organizational Priorities
John Trotsky, Patient/Family Advisor, Volunteer; Valerie Leatherman, MSN, RN, CMSRN, Charge Nurse; Mary Flaherty, CHPN, MS, OCN, RN-BC, CNML, SCRN, Clinical Nurse Manager; University of Maryland Upper Chesapeake Health, Bel Air, MD

This poster presents a strategy to engage a Patient and Family Advisor in the facilitation of a key organizational priority. Interdisciplinary Bedside Rounding enhances the partnership of patients and families by encouraging participation and decision-making in their plan of care.

Beyond the Patient Handout: How Patients and Families Have Transformed Health Education
Liza Cooper, MSW, Coordinator, Child and Family Education; Jennie Donovan, BA, MEd, Family Advisor; Jeremy Donovan, BS, Senior Family Advisor; Sala Institute for Child and Family Centered Care, Hassenfeld Children’s Hospital of New York at NYU Langone, New York, NY

At Hassenfeld Children’s Hospital of New York at NYU Langone, partnering with patients and families in the development of educational materials has revolutionized our patient education work, leading to the creation of interactive, engaging resources that enhance shared decision-making, safety and partnership.

Building Better: Partnering with Families from Ground Breaking to Ribbon Cutting and Beyond
Amy Kratchman, BS, Family Consultant, Patricia Richards, Senior Director, Ambulatory Services; The Children’s Hospital of Philadelphia, Philadelphia, PA

CHOP will discuss how the hospital actively involved the patient and family voice from inception to completion in the design, planning, patient flow layout and construction of the Buerger Center, the hospital’s new ambulatory care center on CHOP’s main campus.

Building Community for Dialysis Patients
Cynthia Bryson, BScN, Clinical Manager, Outpatient Kidney Care Program; Anna Cobian, Web & New Media Coordinator; Elaina Orlando, MPH, BPH PhD(c), Quality & Patient Safety Advisor; Kirsten Emesaks, Patient Moderator; Niagra Health System, St. Catharines, Ontario

The NHS has partnered with patients to launch an online community for dialysis patients. With the goals of enhancing sense of community and identifying opportunities for service improvement, the online community is a novel approach to patient engagement.
Children and Young People’s Voices: Using Child-Friendly Surveys to Obtain Feedback from Young Inpatients to Move Towards Improving Patient-Centred Paediatric Care
Sarah-Ann Burger, MSc, Senior Project Manager; Picker Institute Europe, Oxford, United Kingdom

Few tools exist to robustly measure children and young people’s experience of healthcare. This poster focuses on using a tested, age-appropriate tool, and presents results of 70 NHS trusts who participated in a national children’s inpatient and day case survey.

Choosing Words Wisely: Communication Tools During and Immediately Following the Delivery of a Baby with Hypoxic-Ischemic Encephalopathy
Joan Smith, BSN, MSN, NNP, PhD, RN, Advanced Practice Clinical Scientist; St. Louis Children’s Hospital and Goldfarb School of Nursing at Barnes-Jewish College, Saint Louis, MO; Maggie Wolf, BSN, MSN, NNP, RN, Director, Newborn Intensive Services; Karin Jackson, MS, CCC-SLP, Lead Partner, Family Care Initiatives; St. Louis Children’s Hospital, Saint Louis, MO

Members of our Family Partner program collaborated with neonatal, neurology and obstetrical providers to develop and implement a training module for an interdisciplinary research project on effective communication strategies for physicians and nurses during highly stressful and vulnerable situations.

Chronicling Childhood Cancer: Illuminating the Illness Experience Through Narrative
Trisha Paul, BS, Lead Investigator, Chronicling Childhood Cancer Research Project, Medical Student; University of Michigan, Ann Arbor, MI

At the University of Michigan C.S. Mott Children’s Hospital, pediatric oncology patients explored writing, drawing, and/or speaking about cancer and published a book for providers, caregivers, and other patients. This PFCC-based research illuminates childhood cancer from a patient-centered perspective.

Clinical Practices that Increase Active Patient and Family Involvement in Care: Are These Being Utilized at Your Institution? How Do You Know?
Lynn Ferguson, Chair, Patient and Family Advisory Council; Pam James, Chair, Patient and Family Advisory Council; Vanderbilt University Medical Center, Nashville, TN

This poster focuses primarily on the creation of an infrastructure to prioritize and implement the Elements of the Patient + Family Engagement Roadmap and describe a process that established a baseline inventory for clinician and leadership training.

Code Help – A Mixed Methods Evaluation of a Patient and Family Activated Safety System
Sara-Grey Charlton, BScN, MSN, RN, Practice Consultant, Patient and Family Centred Care; Betty Murray, MA, RN, Patient and Family Partner; Providence Health Care; Vancouver, British Columbia

Patient and family partners helped design a patient and family activated safety system. An evaluation explored the nature of calls, participants’ experience of the system, and the details of the impact of making the calls.

Collaboration with the Mass General Cancer Center’s Patient and Family Advisory Council Evolves Patient Education in Changing Times
Theodore Groves, BFA, Principal; Myriad Inc.; Ann Buckley, BA, Independent Consultant; Arbonne, Inc., Boston, MA

This poster focuses on the role of PFAC in the decentralization of the Cancer Center Resource Room, including the development of resource pods, programming, use of technology, space plans, input on communication, and lessons learned.

Community Collaborations Foster Successful Health Care Partnerships
Ellen Hunt, Mother, Child with Autism, Parent Trainer, P-DAT(Patients with Disabilities as Teachers), Member, Program Steering Committee Medical Home Project, Administrative Director; Elwyn/Autism Resource Community Hub of Lehigh Valley, Allentown, PA; Sweety Jain, MD, Assistant Professor, Morsani School of Medicine Faculty, Family Medicine Residency Program Director; Medical Home Project; Douglas Wells, BS, Research Scholar; Lehigh Valley Health Network, Allentown, PA

In today’s changing health care arena, community partnerships are becoming important for patient centered and cost effective care. One such effective partnership serves as a model for others who wish to establish and maintain similar partnerships for improving population health.

Developing a System-Level Approach to Measure the Delivery of Person-Centred Care in Ontario
Sarah Benn, MA, Lead, Patient Experience Measurement, Person-Centred Care; Naomi Peek, BA, Engagement Specialist; Saurabh Ingle, BS, MHA, Analyst, Person-Centred Care; Cancer Care Ontario, Toronto, Ontario

This poster summarizes the involvement of Patient and Family Advisors to evaluate the current Person-Centred Care (PCC) practice in Ontario and identify areas of improvement to develop strategies that will lead to standardize delivery of PCC and improve patient experience.
Engaging Families in the Journey to Becoming a High Reliability Organization
Julie Kirby, MBA, Program Manager, Patient Care Services; Serena Hadsell, MA, LMHC, Member, Family Advisory Council; William O’Donnell, BS, Co-Chair, Family Advisory Council; Boston Children’s Hospital, Boston, MA

Boston Children’s Hospital is on a journey to become a High Reliability Organization, an organization that aims for ZERO preventable harm to its patients and employees. This poster discusses the crucial role our parent advisors are playing on this journey.

Engaging Patient and Family Partners in the Governance Structure for Significant Strategic Initiatives
Ann Cullen, MSN, RN, Clinical Director, Transition Strategy; Cynthia Parke, BSN, MS, RN, Assistant Patient Care Manager; Nerissa Ambers, MPH, Program Manager; Susan Ganz, Administrative Director, Transition Strategy; Lovester Law, Patient and Family Partner; Joan Forte Scott, BSN, MBA, CNE-BC, Administrative Director, Patient and Community Engagement; Stanford Health Care, Palo Alto, CA

A major academic medical center (AMC) is paving the way for patient and family volunteers to take the next step in engagement: from partnering to governing in a healthcare setting.

Engaging Patients and Families as Partners: Transforming the Out-Patient Cancer Center Experience
Deborah Panetta, BS, Director, Radiation Oncology; Brian Byrne, AB, Patient Advisor; The Valley Hospital, Paramus, NJ

This poster reviews how staff and patient/family advisors came together to develop strategies and transformational enhancements to optimize the cancer patient journey. Case examples inclusive of environmental improvements, educational material development, optimized communication efforts and valued outcomes will be shared.

Engaging Patients and Families in Leading Research to Inform and Advance Patient and Family Centred Care in Critical Care
Jessica Lamb, BSc, MScOT, Senior Patient Engagement Advisor, Strategic Clinical Networks; Alberta Health Services, Calgary, Alberta

This poster shares how Alberta Health Services use of a novel patient and community engagement research method has helped to understand patient and family experiences with Critical Care, and is leading to prioritized evidence-informed improvements in patient and family care.

Engaging Patients and Families in Patient-Centered Outcomes Research on Care Transitions
Jaye Bea Smalley, MPA, Engagement Officer; Patient-Centered Outcomes Research Institute (PCORI), Washington, DC; Peter W Thomas, JD, Principal, Powers, Pyles, Sutter & Verville, Washington, DC; Carol Levine, Director, Families and Health Care Project; United Hospital Fund, New York, NY; Sari Siegel, PhD, MA, CPHQ, Senior Study Director; Westat, Rockville, MD

This poster describes the broad range of roles played by patients and families within the 19 PCORI-funded studies that comprise PCORI’s Transitional Care Evidence to Action Network (TC-E2AN).

Engaging Patients in Practice Transformation
Lucia Angel, MHA(c), Lead, Care Experience; Amy Petersen, MPH, Healthcare Analyst, Care Experience; Catherine James, MD, Medical Director for Primary Care; Olushade Unger, Performance Improvement Coordinator; Sofia Solorzano, BA, Coordinator, Patient Advisory Council; San Francisco Health Network-Department of Public Health; San Francisco, CA

Patient advisory councils across a large, safety net system, collaborate to improve care delivery processes. Trained together to facilitate change, advisors and health leaders identify mutually beneficial objectives resulting in better overall experience for patients, staff and the larger community.

Enhancing Family-Centered Care Within Pediatric Practices: A Quality Improvement Approach
Michelle Esquivel, MPH, Director; AAP Division of Children with Special Needs; Alexandra Kuznetsov, RD, Program Manager; American Academy of Pediatrics/National Center for Medical Home Implementation, Elk Grove Village, IL

The Family Centered Care Quality Improvement Project was a collaboration among six teams of three pediatricians per team to plan, test, and implement strategies to improve the quality of family-centered care in primary care practice.

Every Birth an Extraordinary Birth
Jill Smitley, BSN, RN, Clinical Director, Labor and Delivery; Lisa Davis, MSN, RNC, RNC-OB, Unit Charge Nurse, Labor and Delivery; Kristen DeBoy Caminiti, MSW, LSCW-C, Patient Family Advisor; Anne Arundel Medical Center, Annapolis, MD

Women giving birth by Cesarean Sections are often disappointed with not having the same experience as mothers having vaginal deliveries. The contrast between the two is stark. The time has come to make surgical births a positive patient and family experience.
Experience Is the Best Teacher: Patient/Family Advisors at the Forefront of Provider Education
Barbara Samoff Lee, MSW, LICSW, Senior Director, Social Work and Patient/Family Engagement; Caroline Moore, MPH, Program Leader, Patient/Family Engagement; Kristin O'Reilly, RN, MPH, Manager, Critical Care Quality; Kathryn Zieja, BS, Project Manager, Critical Care Quality; Beth Israel Deaconess Medical Center, Boston, MA

The role of advisors is ever-evolving. Advisors are increasingly being invited to participate as educators of providers, enriching didactic instruction and changing the paradigm of who is the expert. This poster describes successful examples of advisors as teachers.

Extending the Culture of Patient-Centered Care in Physician Practices at Vidant Health
Melissa Thomason, BS, Patient Family Advisor; Paige Irons, MHA, Program Manager; Vidant Health, Greenville, NC

There are approximately 500,000 encounters that occur each year within Vidant Health’s physician practices. Ensuring that each encounter is focused on what’s most important to the patient and family is essential to ensuring the provision of quality care.

Families Influencing Safety Initiatives: Partnering to Prevent Patient Falls at The Children’s Hospital of Philadelphia
Amy Kratchman, BA, Family Consultant; The Children’s Hospital of Philadelphia, Philadelphia, PA

The Children’s Hospital of Philadelphia shares their Family Centered Care approach in partnering with families to influence and promote safe care environments around patient falls.

Family Presence in Hospital: The Results from a Rapid Evidence Assessment and Policy Implementation
Sara-Grey Charlton, BSN, MSN, RN, Practice Consultant, Patient and Family Centred Care; Providence Health Care, Vancouver, British Columbia

A rapid evidence assessment shows that hospitalized patients and their loved ones desire proximity to one another. The results of an REA and the lessons learned from a real life organization-wide family presence policy implementation will be shared.

Family-Centered Collaborative Care for Children with Undiagnosed Complex Conditions
Angel Mitchell, CPN, MSN, RN, Nurse Coordinator, Declan Donoghue Collaborative Care Program; Nicole Donoghue; Brenner Children’s Hospital of Wake Forest Baptist Health, Winston-Salem, NC

Collaboration among healthcare providers, families and patients is vital in providing safe and high-quality care. The Declan Donoghue Collaborative Care Program was developed to help make diagnoses in children with undiagnosed complex chronic conditions.

From Concepts to Actions: Patients, Family Members and Physicians Describe Patient- and Family-Centered Care
Lauren Murray, Director, Consumer Engagement and Community Outreach, National Partnership for Women & Families; Washington, DC; Wendy Nickel, MPH, Director, Center for Patient Partnership in Healthcare, American College of Physicians; Philadelphia, PA

An interdisciplinary team undertook an effort to assess the practice of patient- and family-centered care in ambulatory primary care settings across the US. We conducted focus groups with patients, family members and physicians to elicit rich descriptions of what constitutes PFCC in ambulatory care and identify specific, concrete actions associated with PFCC.

Lisa Affatato, MSN, RN-BC, Nurse Manager, Family Centered Care; Huntington Hospital, Huntington, NY

This poster will demonstrate how project management techniques were applied by a Patient/Family Workgroup in planning and motivating the community and organization to meet the goals and objectives of partnership. The result was the formation of a Patient/Family Partnership Council.

From Patient to Partner: How Truly Partnering with Parents/Patients Can Improve Care
Lindy Moake, CPNP, MSN, RN, Manager, Advanced Practice Service, Heart Center; Children’s Medical Center Dallas, Dallas, TX

A Family Advisory Council parent lead and a Healthcare manager discuss their role in this partnership; review their journey, including startup, family selection and meeting agendas as they work to improve the patient family experience.

Getting Excellent Advice Isn’t Enough, Getting that Advice Implemented is Key: Optimizing the Implementation of Patient and Family Advisory Council Advice – Newton-Wellesley Hospital’s Story
Bert Thurlo-Walsh, CPHQ, RN, MM, Vice President, Quality and Patient Safety; Gloria Plottel, MBA, MS, Patient and Family Lead; Brian O’Dea, BS, Director, Public Affairs & Marketing; Newton-Wellesley Hospital, Newton, MA

Newton-Wellesley Hospital’s Patient and Family Advisory Council (PFAC) gives excellent patient-and-family-centered advice to hospital departments and staff, but that advice wasn’t consistently implemented. A 5-Stage Process Flow was developed to optimize implementing these patient-and-family-centered ideas to improve care and quality.
Getting It Right From the Start: The Transformation of ICU Clerical Front Desk Staff into Patient and Family Advocates
Katy Folk-Way, BS, Patient and Family Advisor, Co-Lead, ICU Volunteer Liaison; Kristen Killian, BSN, ICU RN, Patient and Family Advisory Council Co-Lead, ICU Volunteer Coordinator; University of Washington Medical Center, Seattle, WA

Patients and families partner with ICU teams for transition to comfort care by engaging patients in discerning goals of care, involving families in creating patient specific personal space and providing staff with specialized training in facilitating compassionate end-of-life care.

Going Beyond the Advisory Council – An Innovative Approach to Engaging and Sustaining Family and Patient Partnership in Outcomes Improvement
Jennifer Chamberlin, Family & Patient Engagement Specialist; Cincinnati Children’s Hospital, Cincinnati, OH

Family and Patient participation in quality improvement has evolved to uniquely partner families with clinical teams at Cincinnati Children’s Hospital. Parents and sometime patients, are embedded as partners with the team, working toward meaningful and measureable outcomes improvements.

Honing America’s Heroes: A Veteran-Centered Design Chronicle
Susan Bower, BSN, MBA, EDAC, Principal; NBBJ, Columbus, OH

The collaborative partnership, developed with Veterans and their families, uncovered deep insights leading to transformational results in both patient care and the environment for the new VAMC in New Orleans. This poster will share unique tools, methods and results.

Implementation of Patient and Family-Centered Care in a Children’s Hospital in the Netherlands: The Dutch Experience
Barbara Sibbles, MD, MSc, Pediatrician-Developmental and Genetic Pediatrics; Vivi Buijs, MA, Nurse Manager, Coordinator, PFCC Steering Committee; Patricia Kalkman, MD, MSc, Pediatrician; Maik Koster, MA, Project Manager; Inge van’t Wout, MBA, Nurse Manager; Erasmus Medical Centre, Rotterdam, Netherlands

Erasmus MC Sophia is a tertiary care children’s hospital in Rotterdam, the Netherlands, and is currently engaged in implementation of PFCC. PFCC is relatively new in this country, which gives this process an extra dimension; the Dutch experience.

Implementing the S.M.A.R.T Transition Always Event® to Engage Patients and Families in Their Health Care
Kimly Blanton, MIS, MLS, Patient/Family Advisor; Rose Ann Simmons, MPH, Administrator, Patient Family Engagement; Vidant Health, Greenville, NC

Patients and families partner with Vidant Health leaders to implement the S.M.A.R.T. Transition Always Event. This includes S.M.A.R.T. tools and a new discharge instruction format that incorporates easy to read guidelines to help patients and families transition between care settings.

Improving Interdisciplinary Rounds: Patient and Family Advisors Partner with Unit-Based Clinical Leaders to Strengthen Patient and Family Presence and Participation
Anita McGinn Natali, Co-Chair, Patient and Family Advisory Committee; Karen Anderson, MSN, RN, PMHCNS BC, Clinical Nurse Specialist for Patient- and Family-Centered Care; Jeff Greenblatt, MD, Medical Director; Michael Newcomb, BSN, Nurse Manager; Patricia Macolino, MSN, RN, Patient Safety Consultant; The Hospital of the University of Pennsylvania, Philadelphia, PA

The purpose of this poster is to describe the successful partnership between Unit-based Clinical Leaders and Patient and Family Advisors to improve interdisciplinary rounds. Outcomes of this collaboration will be described including a novel approach to physician education.

Improving the Lives of Alzheimer’s Patients and Their Caregivers: A Patient-Centered Statewide Approach
Holly Garcia, BS, Research Coordinator; Billings Clinic, Billings, MT

As the number of cases of Alzheimer’s disease and other related dementias threaten to overtake the United States healthcare system, states, in conjunction with the Alzheimer’s Association, are taking action. Montana has joined this effort using a statewide patient-centered approach.

Improving with Our Patients: Tools from Kaiser Permanente for Involving Patients in CoDesign for Performance Improvement
Jean Ingram, MPA, Principal Consultant; Kaiser Permanente, Oakland, CA

Patients and families are key partners in designing and improving healthcare services. This poster will share strategies, approaches, and tools from Kaiser Permanente for integrating patients and family members in Performance Improvement and CoDesign.
Learning from and Engaging Patients/Families During the Implementation of a New Medical Record System

Kathleen Horvath, BA, Program Manager, Patient/Family Relations; Patricia Jahoda Stahl, MED, Manager, Volunteer Programs & Services, Staff Liaison, Patient/Family Advisory Councils; Tony Serge, BS, Co-Chair, Adult Patient and Family Advisory Council; Dana-Farber Cancer Institute, Boston, MA

Dana-Farber Cancer Institute (DFCI) implemented a new medical record system. Through involvement of our Adult Patient Family Advisory Council, together we designed, implemented and evaluated a plan which was patient/family-centered.

Lessons Learned from Creating a Member Advisory Group for a Large, Non-Profit Insurer

Maureen Maurer, MPH, Principal Researcher; American Institutes for Research, Chapel Hill, NC; Dawn Porter, MPH, Healthcare Program Developer; Blue Cross and Blue Shield of North Carolina, Durham, NC

The purpose of our poster is to share lessons learned from the creation of a patient and family advisory committee, called the Member Advisory Group, for a non-profit insurer in North Carolina.

#MakeTheTransition: Building an Interprofessional Curriculum on Youth with Special Healthcare Needs Entering Adulthood Through Partnerships with Patients and Families

Eduardo Del Rosario, MSN, FNP-BC; Megan Strong Conklin, PT, DPT, PCS; Michelle Romano-Shami, LCSW; Hospital for Joint Diseases, Hassenfeld Children’s Hospital of New York at NYU Langone, New York, NY

Our poster shares our process developing a Transition Program for youth with special healthcare needs entering adulthood. We partnered with patients and families to incorporate their perspective and motivate them to embrace transition, including practical, emotional and psychosocial elements.

MHS Patient and Family Advisory’s Community Outreach Education Initiative: PFCC on the Road!

Michelle Barone, Director, Patient & Family Centered Care; Memorial HealthCare System; Joe DiMaggio Children’s Hospital; Elise Bloch, EdD, Associate Professor, Occupational Therapy Department; Nova Southeastern University; Secretary, Patient and Family Advisory Council; Memorial HealthCare System; Joe DiMaggio Children’s Hospital, Hollywood, FL

This poster will discuss the creation and execution of a System wide PFAC directed community education project. This was undertaken to improve health literacy and access to health systems of residents in our local community.

Moving Toward Truly Family-Centered Bedside Rounds: Changes in Parental Perceptions of Patient- and Family-Centered Care During Bedside Rounds Following a Healthcare Provider Workshop

Chantelle Barnard, MDFRCP, Hospital Pediatrician; Alberta Children’s Hospital, Calgary, Alberta

Family-centered bedside rounds (FBR) can enhance communication and partnerships between healthcare providers (HCP) and families. We evaluated whether a HCP workshop can transcend HCP education and promote change in parental perceptions of patient and family centered care during FBR.

NICU Parent Education: Using Parents to Help Develop a Comprehensive, Standardized Educational Program

Jessamyn Ressler Maerlender, MPH, Manager, NICU Family Support; Lori Goser, MScEd, NICU Family Support Specialist/ Site Manager; March of Dimes, White Plains, NY

A not-for-profit foundation providing direct services to families in the neonatal intensive care unit (NICU) implemented a nationwide initiative to determine best practices in NICU parent education by incorporating parent guidance, feedback, and evaluations throughout the project.

NICU University – CHKD’s College of NICU Knowledge

Rachel Houck, LCSW, NICU, Clinical Social Worker; Marnie Dyer, Parent Support Coordinator; Elizabeth Moll, BSN, CPNP, MSN, RN, Developmental Care Specialist; Children’s Hospital of the King’s Daughters, Norfolk, VA

While I was in NICU, my mommy and daddy enrolled in a University designed by staff and family advisors. They majored in Education to learn the skills needed to care for me at the hospital and home. We graduated together!

Nurturing Authentic Parent Engagement: Families Leading the Development of a Transition Portal

Scott Wilson, Coordinator, Family Centered Care; Catherine Jones, BSW, RSW, Manager, Social Work; Alberta Health Services, Glenrose Rehabilitation Hospital, Edmonton, Alberta

The Glenrose Rehabilitation Hospital is committed to family participation in critical decision-making. This poster describes how parent perspectives were used as the foundation for the development of a portal for youth with disabilities transitioning to adulthood.

Our Journey: Patient Family Advisory Council and Research at a Community Based Hospital

Nancy Goodwin, MLS, AHIP, Director, Library & Knowledge Services; Donna Drouin, PFAC Co-Chair; Stephanie Garvey, PFAC Member; Middlesex Hospital, Middletown, CT

This poster details the progress made at a community hospital to introduce Patient Family Advisory Council (PFAC) members to research concepts and process. We describe lessons learned and next steps to engage our PFAC members in research at Middlesex Hospital.
Once in a Lifetime – Changing the ICU Culture at the End of Life
Carol Kummet, LCSW, LICSW, MTS, Palliative Care Social Worker; Kristen Killian, BSN, ICU RN, Patient and Family Advisory Council Co-Lead, ICU Volunteer Coordinator; University of Washington Medical Center, Seattle, WA
The first point of contact for ICU families was the front desk staff who were typically overloaded with patient administration. With the help of volunteer liaisons, we encouraged them to be the more welcoming first point of contact for families.

Parent and a Family-to-Family Information Series: Providing Families with a Peer-to-Peer Support Program
Jill Sangha, MSW, RSW, Patient and Family-Centred Care Specialist; Jennifer Bantering, Patient Experience Associate; London Health Sciences Centre, London, Ontario
A Peer-to-Peer Support Program was developed by Advisors to improve the family experience, build on the families’ strengths and promote patients and families as partners in their care.

Parents Co-Facilitating Staff Helpfulness Trainings at Mass General Hospital for Children
Sharon Badgett-Lichten, LCSW, Graduate Certified Executive Coach, Senior Organizational Development Specialist; Mass General Hospital, Boston, MA; Darcy Daniels, Member, Family Advisory Council; Lisa Cimino, Co-Chair, Family Advisory Council; Mass General Hospital for Children, Boston, MA
This poster demonstrates the value of parent participation in staff trainings on helpfulness to improve CGCAHP scores. We outline the process of collaboration with the Quality and Safety team to develop the program, parent participation and high staff ratings.

Partnering with Family Advisors for High-Quality Video Monitoring
Deborah Mulloy, PhD, RN, CNOR, Associate Chief Nurse, Quality and Center for Nursing Excellence; Brigham and Women’s Hospital, Boston, MA
Acutely confused hospital patients present safety challenges such as falls, dislodging devices, and restraints. In this PI project, we partnered with patient and family advisors to design, implement, and evaluate the use of an emerging technology to keep patients safe.

Partnership with Patients – A Guide to Effective Onboarding
Malori Keller, BA, MPA, Kaizen Specialist-Patient Engagement; Saskatchewan Health Quality Council, Saskatoon, Saskatchewan; Laura Marshall, BHSc, Quality Improvement Consultant; Ken Wiest, Patient Family Advisor; Prince Albert Parkland Health Region, Prince Albert, Saskatchewan
The Saskatchewan health system currently engages 300+ patient and family advisors in improvement processes. When asked, they revealed that they felt unprepared and unsure of their role, spurring the development of this comprehensive guide to onboarding and orienting advisors.

Partnersing with Patients for Quality Improvement – Results of Pan-Canadian Collaborative
Maria Judd, MS, BS, Senior Director, Patient Engagement and Improvement; Canadian Foundation for Healthcare Improvement, Ottawa, Ontario; Patricia O’Connor, RN, MSN, CHE, FCOIHI, Senior Advisor, Patient Engagement and the McGill Nursing Collaborative; McGill University Health Center, Montréal, Quebec
The Canadian Foundation for Healthcare Improvement established a pan-Canadian learning collaborative to support 22 organizations in building capacity to co-design quality improvement initiatives in partnership with patients. Hear key program elements, outcomes and learnings advancing the evidence on co-design mechanisms.

Partnering with Patients to Improve Quality and Patient Satisfaction Results in a Canadian Academic Ambulatory Care Hospital
Jennifer Sawyer, Specialist, Patient Relations and Quality Improvement; Adriana Storm, Patient Experience Advisor; Elizabeth Bardon, BA, MA, CHE, Chief of Public Relations & Community Engagement; Adriana Storm, Patient Experience Advisor; Hotel Dieu Hospital, Kingston, Ontario
A Canadian academic ambulatory care hospital engaged Patient Experience Advisors and staff in a low cost initiative to improve specific patient satisfaction metrics on standardized surveys administered to patients who attend the hospital’s busy Orthopedic and Ophthalmology clinics.

Patient and Family Advisors...Frontline Engagement Opportunities
Liz Tortorella, MSW, CAVS, Director, Volunteer Resources; Claudia Allocco, MS, Director, Library Services; Janet Weis, BS, MS; The Valley Hospital, Ridgewood, NJ
This poster explores the progression of patient and family advisors (PFAs) from committee/council involvement to bedside engagement. Successful implementation of the Consumer Health Ambassador Program served as the model for replicative programs and expansion of PFA roles, focusing on collaboration and information sharing.

Patient Experiences as Drivers of Change: A Unique Model for Reducing Transgender Health Care Disparities at an Academic Medical Center
Aron Janssen, MD, Assistant Professor of Child and Adolescent Psychiatry, Clinical Director, NYU Gender and Sexuality Service; Hassenfeld Children’s Hospital of New York at NYU Langone; Oscar Dimant, First Year Medical Student; NYU School of Medicine, New York, NY
Transgender individuals face stark health disparities including frequent maltreatment in healthcare settings. From experiences culled from a focus group of transgender-identified individuals, we will be designing and evaluating standardized patient experiences to teach medical students about optimal transgender healthcare.
Patient Organizations as Drivers of Research: Where Are We Now? What Can We Learn from “Research-Engaged” Groups?
Barbara Norton, BS, MBA, MPH, PhD, Assistant Professor, Research; University of Oklahoma Health Sciences Center Department of Family & Preventive Services, Oklahoma City, OK

There is little known about how to sustain patient engagement in research and elevate patient-centered research priorities, especially those in primary healthcare. The experience of exemplar patient groups, community organizations, and clinician networks can help point the way.

PFAs, Emory Healthcare’s Most Powerful Partners
Michelle Gray, BSN, CCRN, MSN, NEA-BC, RN, Corporate Director, Care Transformation; Don Boykin, Patient and Family Advisor; Emory Healthcare, Atlanta, GA

Emory Healthcare's Patient and Family Advisor Program involves more than 150 patient and family advisors (PFAs), in all aspects of the organization. Hear a PFA's journey as a family member that led to service on the Emory Healthcare Board, including risk prevention and disclosure.

PFCC in the ED: A Bundle Approach
Andrea Ennis, MSN, Clinical Team Manager, Emergency Services Program; Ann Shook, BScN, Clinical Coordinator, Emergency Services Program; Helen Kelly, MSN, Clinical Nurse Educator, Emergency Services Program; Jennifer Page, BScN, Clinical Nurse Educator; North York General Hospital, Toronto, Ontario


Profile of a Model Peer-to-Peer Program
Anne Heideck, LCSW, Program Manager, Peer 2 Peer; Lovester Law, MA, Patient Partner, Peer 2 Peer Mentor; Stanford Health Care, Palo Alto, CA

This program has been in place for three years. Established and monitored by a team that includes patients, families, clinical staff and administrators, it showcases many best practices and standard work. It serves as a model for new programs.

Replicating AHRQ Health Care Innovations Exchange Strategies to Advance the Practice of PFCC in Florida Hospitals
Sari Siegel, PhD, MA, CPHQ, Senior Study Director and AHRQ Health Care Innovations Exchange’s (HCIE) Patient- and Family-Centered Care Learning Community (PFCC LC) Facilitator; Susan Hassell, MS, MPH, Senior Study Director and PFCC LC Knowledge Integrator; Westat, Rockville, MD

The Health Care Innovations Exchange, sponsored by the Agency for Healthcare Research and Quality (AHRQ), developed and is currently sponsoring a Patient- and Family-Centered Care (PFCC) Learning Community (LC). This poster will describe the LC’s operation (i.e., webinars, monthly “coaching calls” with individual hospital teams), highlight the strategies adopted, offer lessons learned, and identify free, publicly-available resources for replication.

Research Priorities of Women At Risk for Preterm Birth
Linda S. Franck, RN, PhD, Professor, UCSF School of Nursing; San Francisco, CA

This poster describes a novel method for engaging patients and families in identifying research questions of most interest to them and then developing a priority agenda to influence funders and researchers.

Responding to the Education Needs of Our Patients through Mobile Technology
Amy Wainwright, MSc.PT, Physiotherapist; Lucy Pereira, Project Manager; Holland Orthopaedic & Arthritic Centre of Sunnybrook Health Sciences Centre, Toronto, Ontario

Responding to feedback obtained in a qualitative study, we partnered with our patients to co-design an interactive Mobile App. Patients complete a daily health questionnaire and receive personalized feedback that helps track recovery and addresses common concerns and questions.

S.Q.U.A.S.H. (Smart Choices, Quality Ingredients, Unique, Appetizing, Simple & Healthy): How Patients and Families are Partnering to Transform Nutrition Education Programs
Jacqueline Bailou Erdos, MS, RD, Pediatric Nutrition Coordinator; Beth Silber, Family Consultant; Fiona Levy, MBA, MD, Inaugural Executive Director of the Sala Institute for Child and Family Centered Care; Hassenfeld Children’s Hospital of New York at NYU Langone, New York, NY

Nutrition significantly impacts health, and is especially important for patients with chronic illnesses. Though nutrition is critical for growth, development and healing, few patient and family centered pediatric nutrition education programs exist that are tailored to a chronically ill population.
Strategically Speaking: Patient and Family Advisors as Allies Within Interdisciplinary Shared Governance
Patricia Kenney, DNP, MN, APRN, FNP, Executive Director; Patient-Centered Care; Linda Reiser, MS, BSN, CPNP; Director of Patient Advocacy; Barbara Alford, MSN, BSN, VP & CCO/CNO; Alexandra Copeland, Chair, Patient and Family Advisory Committee; Tallahassee Memorial HealthCare, Tallahassee, FL
A pilot program successfully launched Patient and Family Advisors (PFAs) as essential allies within the Interdisciplinary Shared Governance structure. Aligned with the organizational strategic plan, PFAs were infused into councils and committees resulting in improved patient- and family-centered care.

Surveying a National Sample of Ambulatory Primary Care Practices About Patient- and Family-Centered Care
Wendy Nickel, MPH, Director, Center for Patient Partnership in Healthcare, American College of Physicians; Philadelphia, PA; Mary Minniti, BS, CPHQ, Senior Policy and Program Specialist, Institute for Patient- and Family-Centered Care; Bethesda, MD
The poster describes a survey that was developed to assess the current state of patient- and family-centered care in ambulatory primary care practices across the United States and preliminary results. It was informed by the experiences of patients, caregivers/family members, and clinicians.

The 5Ps: Promoting the Power of Proactive Partnership with Patient and Family Advisors
Marilynne Kelts, BA, MS, Director, Care Experience; Susan Mahler, PhD, Patient & Family Centered Care Advisor; Kaiser Permanente San Diego, San Diego, CA
Partnering with the Patient and Family Centered Care Advisory Council, Kaiser Permanente San Diego Blood Donor Center (KPSD-BDC) revised promotional materials designed to raise awareness about life-saving BDC services, increasing collections and decreasing requirements to procure blood products externally.

The Hospital for Sick Children (SickKids) Annual Child and Family-Centred Care (CFCC) Week: An Authentic Partnership in Action
Sitara de Gagne, BA, MFA, Family Advisor; The Hospital for Sick Children (SickKids), Toronto, Ontario
The Family-Centred Care Advisory Council (FCCAC) at SickKids embodies the organization’s commitment to authentic partnership with our patients and families. They lead and support many initiatives. Family advisors lead the success of our annual CFCC Week in June.

The Off-Treatment Initiative: The Development and Implementation of a Road Map Towards Survivorship
Karen Rossman, BS, MHA, RD, Co-Chair, Pediatric Patient Family Advisory Council; Dana-Farber Cancer Institute, Boston, MA
The Off Treatment Initiative Assists assists parents in the transition of their children from cancer treatment back into an off-treatment world. The project origins, development and implementation will be outlined and described.

The Voice of the Patient in Leadership Rounds
Donald Ford, MBA, MD, Vice President, Medical Operations; Becky Streem, MSW, Ombudsman; Cleveland Clinic/Hillcrest Hospital, Mayfield Hts., OH
Leadership at Hillcrest Hospital, a Cleveland Clinic Regional Hospital, has included in-depth sessions with recently discharged patients as part of monthly Enterprise Leadership Rounding. This has brought insights, opportunities and best practices to our entire hospital, from patients and families.

Tools and Training for Engagement: Increasing Reliability of Engagement Between Interprofessional Team and Patients and Families During Rounds
Juliette Schlucter, BS, Director, The Center for Child and Family Experience, Sala Institute for Child and Family Centered Care; Gabrielle Gold-von Simson, MD, MS, NYU School of Medicine, Associate Professor, Pediatrics; Lea Devins, MSN, RN, Nurse Manager, Pediatric Intensive Care Unit; Arun Chopra, MD, Attending Physician, Division Director, Pediatric Critical Care Medicine; Hasenfeld Children’s Hospital of New York at NYU Langone, New York, NY
Patients and families collaborated with an interprofessional team to develop training, co-taught by families, and create mirror image tools to prepare everyone for effective engagement on rounds. Sharing a quality improvement model to increase reliability, communication and coordination on rounds.

Using Co-Creation Sessions to Collaborate with Residents and Families to Redesign the Care Experience
Margo Wilson, MSN, Director, Chronic Disease Management; Providence Health Care, Vancouver, British Columbia
Co-creation sessions are one method out of human-centred design used to collaborate with patients and families to make change. Learn about co-creation activities used by Providence Health Care and learn how to run your own co-creation sessions.
Using Technology to Transform Care: Engaging and Activating Families in the Implementation of a Health Portal
Amir Karmali, Family-Centred Care Specialist, Client and Family Integrated Care; Becky Quinlan, MEd, RECE, Family Centred Care Specialist; Gideon Sheps, Patient Family Advisor; Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario

Web-based portals are making it easier for patients and families to access health information and can promote activation and improve outcomes. Engagement strategies that supported the successful implementation of a consumer health portal at a pediatric rehabilitation hospital are described.

Utilizing Patient Shadowing to Enhance the Patient and Family Experience
Melissa Ruffito, RN, Clinical Nurse, Emergency Department; Paul Redfield, Patient/Family Advisor; The Valley Hospital, Ridgewood, NJ

In the emergency department's attempt to improve the overall patient experience, the ED utilized an innovative patient shadowing initiative to gain a better understanding of the patient experience.

We Don't Just Meet to Eat – Sustaining a Successful Patient and Family Advisory Council in a Comprehensive Cancer Center
Sue Holick-Bade, Patient and Family Advisor; Chesley Cheatham, MEd, MCHES, Manager, Community Outreach; Wendy Miano, MSN, DNP, AOCN, Director of Nursing; University Hospitals Seidman Cancer Center, Cleveland, OH

The Seidman Cancer Center is innovative in its approach to creating a successful Patient and Family Advisory Council (PFAC). Learn about how to recruit, engage and evaluate a PFAC and share best practices that support Patient Centered Care.

We Need PFCC STAT: An Interprofessional Patient- and Family-Centered Approach to Overhauling Emergency Department Care
Valerie Chism, BSN, RN, APRN CNP ACNP-BC; Julie Moretz, BS, Family Leader/Associate Vice Chancellor for Patient- and Family-Centered Care; Lindsay Hale-Bender; University of Arkansas for Medical Sciences, Little Rock, AR

The emergency department has unique challenges in patient- and family-centered care. An interprofessional team representing nurses, chaplains, physicians, security, patients, and others, designed and are implementing a five pillar plan. Already, a number of valuable lessons have emerged.

Whānau/Family Centred Care “Nothing About Me Without Me and My Whānau and Family” Guided by Indigenous Māori Concepts and Model of Care – New Zealand
Rowena Kui, Kaiiringi, Director Maori Health; Julie Patterson, Kaihautu Hauora, Chief Executive; Whanganui District Health Board, Whanganui, New Zealand

Whanganui District Health Board (New Zealand) is on a journey to embed patient and whānau (family) centred care as the foundation in our work and all that we do, guided by the indigenous Māori framework of Whānau Ora (healthy families).

What Do Maternity Providers Believe Patient and Family-Centered Care Is and How Is It Provided Differently for Vulnerable Women?
Dana Samak, MPA, Senior Research Associate; The Commonwealth Fund, New York, NY

What do providers of maternity services see as the main tenets of PFCC? We discovered that building relationships and providing individually appropriate care were important. Vulnerable women had additional needs that needed to be met before shared-decision making was possible.

Youth, Caregiver, and Physician Perspectives on Important Factors in the Transition from Pediatric to Adult Healthcare
Kerry Reynolds, PhD, Social/Behavioral Scientist; RAND, Pittsburgh, PA

We used concept mapping, an innovative participatory process, to solicit perspectives of youth, caregivers, and physicians on the transition from pediatric to adult healthcare. Results highlight the importance of recognizing and bridging varied expectations and perspectives to achieve person-centered transitions.
AUTHENTIC PARTNERSHIPS

Moving Forward with Patient- and Family-Centered Care
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with patients and families are essential as hospitals, health systems, primary care practices, and community organizations seek to improve the patient experience, the health of populations, and the cost of care.
IPFCC, a non-profit organization, provides essential leadership to advance the understanding and practice of patient-and family-centered care. By promoting collaborative, empowering relationships among patients, families, and health care professionals, IPFCC facilitates patient- and family-centered change in all settings where individuals and families receive care and support.

IPFCC serves as a central resource for policy makers, administrators, program planners, direct service providers, educators of health care professionals, design professionals, researchers, patients, and family members. IPFCC promotes change and improvement in health care through development of print and audiovisual resources, information dissemination, policy and research initiatives, training, and technical assistance.

Receive 10% off IPFCC Resources when purchased at our 7th International Conference and online until September 30th!

Please visit www.ipfcc.org/resources to purchase materials through our simple and secure online marketplace. Use discount code “newyork” for a 10% discount, valid until September 30, 2016.

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Must See!
• Getting Started with Patient-and Family-Centered Care (Online/Download)
• Essential Allies—Patient, Resident, and Family Advisors: A Guide for Staff Liaisons
• Words of Advice: A Guide for Patient, Resident, and Family Advisors
• Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities
• Partnerships with Patients, Residents, and Families: Leading the Journey (DVD)
• Developing Patient- and Family-Centered Vision, Mission, and Philosophy of Care Statements
GUIDANCE PUBLICATIONS

Advancing the Practice of Patient- and Family-Centered Geriatric Care
This publication serves as a guide to using a collaborative process to advance patient- and family-centered geriatric care in hospitals and long-term care settings. This resource contains a set of self-assessment tools for geriatric care in hospitals and long-term care facilities. Tools for geriatric medical education and design planning are also included.

Item No. 32083  $40
Item No. 32183, 12 copies  (Save $40) $440

Collaborative Design Planning
This publication guides organizations through the process of collaborative design planning. It will stimulate thinking about ways to collaborate with patients, families, and staff to create more supportive environments for all types of health care facilities.

Item No. 32099  $30
Item No. 32199, 12 copies  (Save $30) $330

Creating Children’s Advisory Councils
This publication offers practical guidance and strategies for creating and sustaining councils that involve children and youth. This resource profiles ten advisory councils and includes sample advisory council materials.

Item No. 32087  $30
Item No. 32187, 12 copies  (Save $30) $330

Creating Patient and Family Faculty Programs
This publication can help organizations create ways for patients and families to be educators in graduate and undergraduate programs, and to be actively involved in staff orientation and development programs. Includes recommendations for recruitment, training, and support for patient and family faculty. Over 50 programs are highlighted.

Item No. 32088  $50
Item No. 32188, 12 copies  (Save $50) $550

Developing and Sustaining a Patient and Family Advisory Council
This resource profiles a variety of advisory councils, their structures, and activities. Guidance on establishing a new council and sustaining the momentum of an existing council is included. Descriptions include council responsibilities and the potential impact a council can have on an organization. Sample materials and forms from established councils across North America and an annotated bibliography are also included.

Item No. 32085  $40
Item No. 32185, 12 copies  (Save $40) $440

Developing Patient- and Family-Centered Vision, Mission, and Philosophy of Care Statements
This second edition is a practical resource to guide health care organizations, hospitals, departments, units, long-term care communities, and clinics through the process of developing vision, mission, and philosophy of care statements that support and advance the practice of patient- and family-centered care. Designed for administrative leaders, as well as clinicians, staff, and patient and family advisors who are interested in transforming organizational culture. Sample statements from a variety of organizations are included.

Item No. 32098  $40
Item No. 32198, 12 copies  (Save $40) $440

MUST SEE! Essential Allies—Patient, Resident, and Family Advisors: A Guide for Staff Liaisons
This completely updated publication is a practical, how-to-guide for clinicians and staff who are responsible for coordinating partnership endeavors with patient, resident, and family advisors. It includes advice, strategies, resources, and a wealth of examples from organizations. A flash drive containing over 200 tools, materials, and templates accompanies the written guide.

Item No. 32063  $65
Item No. 32163, 3 copies  (Save $20) $175

Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: Recommendations and Promising Practices
This publication, with funding support from the California HealthCare Foundation, is based on the deliberations and key recommendations that emerged from a unique meeting convened by the IPFCC in collaboration with the Institute for Healthcare Improvement and funded by the Robert Wood Johnson Foundation. Highlighted are examples of best practices drawn from hospitals, ambulatory programs, medical and nursing schools, funders of health care, patient- and family-led organizations, and other health care entities that are partnering with patients and families to enhance quality and safety and to improve the experience of care. (For more information on the meeting, see Partnering with Patients and Families...A Roadmap for the Future, available for download at www.ipfcc.org/tools/downloads.html)

Item No. 3212  $60
Item No. 3213, 5 copies  (Save $25) $275
Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities

This groundbreaking resource shows how partnerships with patients, residents living in long-term care communities, and families have been essential to organizational change in many different health care settings. The guide provides a framework for senior leaders to create and sustain such partnerships and offers specific steps that leaders can take to develop partnerships to redesign and improve health care. Best practices from over 130 exemplary organizations provide concrete and real-world examples. Several practical tools and a detailed list of helpful written, audiovisual, and online resources are included.

Item No. 3215 $65
Item No. 3218, 5 copies (Save $25) $300

See also the companion video, “Partnerships with Patients, Residents, and Families: Leading the Journey” (Item No. 32108)

Privileged Presence: Personal Stories of Connections in Health Care, 2nd Edition

Privileged Presence: Personal Stories of Connections in Health Care is a collection of over 65 stories that reflect people’s health care experiences from the points of view of compassion, communication, collaboration, respect, and dignity...or their absence. This new edition uses real-world experiences recounted by patients and their families, nurses, doctors, and other health care professionals to illustrate what works and what doesn’t, what increases or diminishes people’s sense of confidence and well-being. Tools for improving care and creating partnerships are included in the book.

Item No. 3221 $16.95

Words of Advice: A Guide for Patient, Resident, and Family Advisors

This workbook is for patients, residents in long-term care communities, and families who are new to advisory roles. Many self-assessment tools and exercises to help identify skills and interests are included, as well as “words of advice” from expert patient, resident, and family advisors.

Item No. 32061 $20
Item No. 32161, 12 copies (Save $20) $220

VIDEOS/DVDS

Bedside Nurse Change of Shift Report (5 minutes)
This video presents two nurses and an adult patient participating in an actual bedside nurse change of shift report at Perham Memorial Hospital in Perham, MN.

Item No. 32106, Online/Download $35
Item No. 32107, DVD $3

Collaborative Rounds in Adult Cardiology (10 minutes) and Patient Advisors for Cardiology (6 minutes)
The first video portrays a model for rounds that is non-hierarchical, encourages the participation of the patient, family, and all other members of the team, and provides the opportunity to discuss problems in care and identify solutions. The structured communications protocol for rounds featured in this video received the John M. Eisenberg Patient Safety Award in 2002. In the second video, an adult cardiac patient and other cardiology team members discuss the improvements and benefits of having patients serve as peer mentors and advisors.

Item No. 32104 $85

Getting Started with Patient- and Family-Centered Care (11:30 minutes and 10:32 minutes)
These two videos, Patient- and Family-Centered Care: The Valley Hospital’s Journey and Patient- and Family-Centered Care: Building the Foundation, along with the Video Discussion Guide are an educational resource for hospitals or health systems that are considering implementation of patient- and family-centered concepts and strategies in their organizations or are in the early stages of their journey to advance PFCC.

Item No. 32111 Online/Download $120

Parent Participation in Rounds: The Reflections of a Pediatric Intensivist (8 minutes)
This video presents an interview with Daniel L. Levin, MD, former Medical Director of Pediatric Critical Care at Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire, describing a process of conducting rounds in a PICU with families as an integral part of the process. He discusses potential benefits, the importance of parent observations, valuable insights learned from parents about their children and the children’s conditions, and the role of collaboration with families in creating the “accurate story.”

Item No. 32103 $55

Partnerships with Families in Newborn Intensive Care...Enhancing Quality and Safety (11 minutes)
This video highlights how family-centered concepts can be integrated within a NICU, beginning with a philosophy of care developed collaboratively by families, staff, and faculty. Family participation in rounds is featured. A physician leader, various staff, and families offer their perspectives on family-centered care. This video won first place in the “Working Together” category of the 2003 Dartmouth Clinical Microsystem Film Festival.

Item No. 32102 $85
Resources

**MUST SEE!** Partnerships with Patients, Residents, and Families: Leading the Journey (20 minutes)
This video focuses on the accomplishments and ongoing activities of key leaders who have created exemplary partnerships in two health care organizations representing very different types of care settings—an urban academic center with a large ambulatory program and a rural, critical access hospital with a long-term care community. The video captures the experiences of leaders in these organizations and shares their insights regarding the benefits of collaborating with patient, resident, and family advisors in a variety of advisory roles.

Item No. 32108 $95

See also the publication, “Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities” (Item No. 3215)

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The Birth of Jacob...Honoring the Gift of Jacob (20 minutes)
In this video, a mother shares her compelling story about the birth of her first child, and twelve years later, his death. This powerful teaching tool illustrates two very different experiences—a negative experience and its impact on a child and family, and then a more positive family-centered experience with emergency services.

Item No. 3210 $75

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**RESOURCE PACKAGES**

**Executive Leadership Team Resource Package**
This package includes the following resources:
- Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities (10 copies)
- Partnerships with Patients, Residents, and Families: Leading the Journey (Video with Discussion Guide) (1 copy)
- Developing Patient- and Family-Centered Vision, Mission, and Philosophy of Care Statements (1 copy)
- Essential Allies—Patient, Resident, and Family Advisors: A Guide for Staff Liaisons (1 copy)
- Words of Advice: A Guide for Patients, Residents, and Family Advisors (3 copies)

Item No. 3209A (Save $90) $820

**Facility Design Package**
This package includes the following publications:
- Collaborative Design Planning (1 copy)
- Essential Allies—Patient, Resident, and Family Advisors: A Guide for Staff Liaisons (1 copy)
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Item No. 3208A (Save $30) $265

**Geriatric Resource Package**
This package includes the following publications:
- Advancing the Practice of Patient- and Family-Centered Geriatric Care (1 copy)
- Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities (1 copy)
- Partnerships with Patients, Residents, and Families: Leading the Journey (Video with Discussion Guide) (1 copy)
- Developing Patient- and Family-Centered Vision, Mission, and Philosophy of Care Statements (1 copy)
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Item No. 3207A (Save $35) $345

**Newborn Intensive Care Package**
This package includes the following publications:
- Partnering with Families in Newborn Intensive Care: Enhancing Quality and Safety (Video) (1 copy)
- Essential Allies—Patient, Resident, and Family Advisors: A Guide for Staff Liaisons (1 copy)
- Words of Advice: A Guide for Patients, Residents, and Family Advisors (5 copies)

Item No. 3204A (Save $25) $225

**Patient and Family Leadership Package**
This package includes the following publications:
- Essential Allies—Patient, Resident, and Family Advisors: A Guide for Staff Liaisons (1 copy)
- Words of Advice: A Guide for Patients, Residents, and Family Advisors (1 copy)
- Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities (1 copy)

Item No. 3206A (Save $10) $140
SELF-ASSESSMENT TOOLS FOR EVALUATING PATIENT- AND FAMILY-CENTERED PRACTICES

These in-depth self-assessment inventories provide detailed questions for interdisciplinary patient/family teams in hospitals and outpatient settings. These tools can help to assess patient- and family-centered care in a hospital, clinical area, unit, or outpatient clinic or practice, and to develop a plan to advance the practice of patient- and family-centered care. (PDF downloads)

**PATIENT AND FAMILY-CENTERED CARE**

**Patient- and Family-Centered Adult Intensive Care: A Self-Assessment Inventory**  
Item No. SAT14  $10

**Patient- and Family-Centered Ambulatory Care: A Self-Assessment Inventory**  
Item No. SAT12  $10

**Patient- and Family-Centered Care in the Emergency Department: A Self-Assessment Inventory**  
Item No. SAT03  $10

**Patient- and Family-Centered Hospital Design: A Self-Assessment Inventory**  
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**Patient- and Family-Centered Medical Education: A Self-Assessment Inventory for Medical Schools**  
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**Personnel Practices to Advance the Practice of Patient- and Family-Centered Care: A Self-Assessment Inventory**  
Item No. SAT05  $10

**PATIENT AND FAMILY-CENTERED GERIATRIC CARE**

**Patient- and Family-Centered Geriatric Care: The Short Tool**  
Item No. SAT15  $10

**PATIENT AND FAMILY-CENTERED MATERNITY CARE**

**Patient- and Family-Centered Maternity Care: A Self-Assessment Inventory**  
Item No. SAT09  $10

**Patient- and Family-Centered Outpatient Maternity Care: A Self-Assessment Inventory**  
Item No. SAT09a  $10

**PATIENT AND FAMILY-CENTERED NEWBORN INTENSIVE CARE**

**Advancing Family-Centered Newborn Intensive Care: A Self-Assessment Inventory**  
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**PATIENT AND FAMILY-CENTERED PEDIATRIC CARE**

**Patient- and Family-Centered Pediatric Ambulatory Care: A Self-Assessment Inventory**  
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**Patient- and Family-Centered Pediatric Care in Hospitals: A Self-Assessment Inventory**  
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**Patient- and Family-Centered Pediatric Intensive Care: A Self-Assessment Inventory**  
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**PINWHEEL RESOURCES**

**Pinwheel Lapel Pin**

The Pinwheel symbol is the official emblem of IPFCC. This Pinwheel lapel pin is a perfect way to recognize patient and family advisors and other patient- and family-centered care champions. The .75” cloisonné lapel pin is two-tone blue, encased in polished silver, with an 8mm post and butterfly clutch.

Item No. 33001  $10
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SEMIFAN AND CONFERENCE MATERIALS

Previous seminar and conference materials are available for purchase upon request.

The 6th International Conference on Patient- and Family-Centered Care (Vancouver, BC, 2014)
This MP3 CD includes all recorded sessions of The 6th International Conference on Patient- and Family-Centered Care convened in August 2014, in Vancouver, British Columbia. Purchase the entire set or select individual sessions.

MP3 Audio CD
Visit www.ipfcc.org/6th-conf-recordings.html
Conference Syllabus (PDF download)
Item No. IC2014 $30

Moving Forward with Patient- and Family-Centered Care Intensive Training Seminar Flash Drive
Fall 2015
The flash drive includes all presentation handouts from our Fall 2015 (Tampa, Florida) Moving Forward with Patient- and Family-Centered Care Seminar. The flash drive includes over 200 resources - organized both by seminar session as well as by subject - such as Changing the Concept of Families as Visitors, Leadership Strategies and Tools, and Patient and Family Advisors. Also included is the video, Patient- and Family-Centered Care: Partnerships for Quality and Safety, produced by the American Hospital Association and IPFCC.

Seminar Flash Drive
Item No. 32431 (Fall 2015, Tampa, FL) $150
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About the Institute for Patient- and Family-Centered Care

Since 1992, the Institute for Patient- and Family-Centered Care (IPFCC) has provided national and international leadership to advance the understanding and practice of patient- and family-centered care. By promoting collaborative, empowering relationships, IPFCC facilitates patient- and family-centered change in all settings where individuals and families receive care and support.

IPFCC also serves as a central resource for policy makers, administrators, program planners, direct service providers, educators of health care professionals, researchers, design professionals, and patient and family leaders. IPFCC accomplishes its mission through education, consultation, and technical assistance; materials development and information dissemination; and strategic partnerships.

For more information about IPFCC, its consultation and training services, seminars, webinars, publications, or to receive the monthly e-newsletter, visit www.ipfcc.org.