We Can Do It!
TAking palliative care mainstream

9th Annual Palliative Care Summit
March 13-14, 2017
Sacramento, CA
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<th>TIME</th>
<th>ACTIVITY</th>
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<tr>
<td><strong>SUNDAY, MARCH 12</strong></td>
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<tr>
<td>4–6:00 p.m.</td>
<td>EARLY REGISTRATION</td>
<td>Regency Foyer</td>
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<td>5–7:30 p.m.</td>
<td>E-PATIENT DINNER AND MEETING</td>
<td>Tahoe Room</td>
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<td><strong>MONDAY, MARCH 13</strong></td>
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<td>8 a.m.–3:30 p.m.</td>
<td>EXHIBITS</td>
<td>Regency Foyer</td>
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<td>8–8:30 a.m.</td>
<td>REGISTRATION &amp; CONTINENTAL BREAKFAST</td>
<td>Regency Foyer</td>
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<td>8:30–8:45 a.m.</td>
<td>WELCOME: Setting the Stage: Making the Most of These Two Days</td>
<td>Regency ABC Ballroom</td>
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<td>Judy Thomas, JD, Coalition for Compassionate Care of California</td>
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<td>8:45–10 a.m.</td>
<td>KEYNOTE: How Palliative Care Will Heal Medicine</td>
<td>Regency ABC Ballroom</td>
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<td>Eric J. Cassell, MD, MACP, Physician &amp; Author</td>
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<td>10:15–11:30 a.m.</td>
<td>BREAKOUT SESSIONS (choose one; see Pages 6-8 for details)</td>
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<td>Grassroots Palliative Care: Fully Engaging Our Communities</td>
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<td>Prognosticating for Adverse Outcomes Using Palliative Care</td>
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<td>Improving Quality of Palliative Care: Lessons from Collaborative QI</td>
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<td>A Learning Collaborative to Improve Home-Based Care for Children</td>
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<td>Defining, Evaluating &amp; Articulating Social Work in Pediatric Palliative Care</td>
<td>(Carmel AB)</td>
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<td>11:30 a.m.–12:15 p.m.</td>
<td>NETWORKING LUNCH</td>
<td>Regency ABC Ballroom</td>
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<td>12:15–1:00 p.m.</td>
<td>GENERAL SESSION: We Can Do It! Palliative Care as a Social Movement</td>
<td>Regency ABC Ballroom</td>
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<td>Judy Thomas, JD, Coalition for Compassionate Care of California</td>
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<tr>
<td>1:00–2:15 p.m.</td>
<td>PANEL: The Road Unpaved: When Young Adults Become Engaged Patients</td>
<td>Regency ABC Ballroom</td>
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<td></td>
<td>Rachel Goldring, The Road Unpaved</td>
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<td>Charlie Blotner, CUREFORWARD</td>
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<td>Devon Dabbs, Coalition for Compassionate Care of California</td>
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<td>2:15–2:30 p.m.</td>
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<td>2:30–3:15 p.m.</td>
<td>OFFICE HOURS (see Page 9 for details)</td>
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<td>3:15–3:30 p.m.</td>
<td>BREAK</td>
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<tr>
<td>3:30–4:30 p.m.</td>
<td>GENERAL SESSION: Not Whether... But How: Reframing Our Relationship to the Inevitable</td>
<td>Regency ABC Ballroom</td>
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<td>B.J. Miller, MD, University of California, San Francisco</td>
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<td>4:30–6:00 p.m.</td>
<td>RECEPTION &amp; POSTER SESSION: Join us for cocktails, hors d’oeuvres, and a poster session featuring a showcase of the best community-based palliative care programs and projects from around the state.</td>
<td>Crest Theater</td>
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<tr>
<td>6:00–7:30 p.m.</td>
<td>SPECIAL EVENING SESSION: A New Kind of Heroism</td>
<td>Crest Theater</td>
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<td>Jessica Nutik Zitter, MD, MPH, Highland Hospital, Oakland</td>
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## SCHEDULE AT-A-GLANCE

### TUESDAY, MARCH 14

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<tr>
<th>TIME</th>
<th>ACTIVITY</th>
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<tr>
<td>7:30–8:30 a.m.</td>
<td>LOCAL COALITION BREAKFAST</td>
<td>Regency F</td>
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<td>8 a.m.–2:30 p.m.</td>
<td>EXHIBITS</td>
<td>Regency Foyer</td>
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<td>8–8:30 a.m.</td>
<td>REGISTRATION &amp; CONTINENTAL BREAKFAST</td>
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<td>8:30–9:15 a.m.</td>
<td>KEYNOTE: Public Policy &amp; Palliative Care in California</td>
<td>Regency ABC Ballroom</td>
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<td>Jennifer Kent, MPA, Director, California Department of Health Care Services</td>
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<td>9:15–10:30 a.m.</td>
<td>PANEL: How Does Palliative Care Fit into the Health Insurance Model?</td>
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<td>Assuring Palliative Care Services for People with Serious Illness</td>
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<td>N. Marcus Thygeson, MD, MPH, Blue Shield of California</td>
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<td>Judy Thomas, JD, Coalition for Compassionate Care of California</td>
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<td>Jill Mendlen, LightBridge Hospice and Palliative Care</td>
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<td>James Mittelberger, MD, MPH, Optum Center for Palliative and Supportive Care</td>
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<td>OFFICE HOURS (see Page 9 for details)</td>
<td>Regency DEF Ballroom</td>
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<td>11:30 a.m.–12:45 p.m.</td>
<td>LEADERSHIP AWARDS LUNCH CELEBRATION</td>
<td>Regency ABC Ballroom</td>
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<td>12:45–1 p.m.</td>
<td>BREAK</td>
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<tr>
<td>1–2:15 p.m.</td>
<td>BREAKOUT SESSIONS [choose one; see Pages 7-8 for details]</td>
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<td>Advancing Palliative Care Through Partnerships &amp; Community Engagement</td>
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<td>Unlocking End-of-Life Care Improvement Opportunities Using Public Data</td>
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<td>2:15–2:30 p.m.</td>
<td>BREAK</td>
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<tr>
<td>2:30–3:45 p.m.</td>
<td>GENERAL SESSION: The Relief of Suffering &amp; the “Community of Caring”</td>
<td>Regency ABC Ballroom</td>
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<td>Betty Farrell, RN, PhD, FAAN, City of Hope</td>
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<td>3:45–4:00 p.m.</td>
<td>CLOSING</td>
<td>Regency ABC Ballroom</td>
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### JOIN THE SUMMIT CONVERSATION ON TWITTER

Follow @COALITIONCCC and the speakers featured in this program. Tag your tweets with #cccc17 to join the 2017 Summit conversation.
Because we CAN do it—let’s work together to take palliative care mainstream!

We are so excited to welcome you to this year’s Palliative Care Summit. Along with a slate of well-known thought leaders in the field, we have a number of new features for you to enjoy.

From our expanded e-Patient program that highlights the need for collaboration among not only providers but patients, to a special evening session and reception for viewing the film *Extremis* with Jessica Nutik Zitter, we hope you find the Summit a place to learn, grow and connect. Be sure to take time to see the posters and art on display from some of our e-Patients. And don’t miss the opportunities to hear from and purchase books by Steve Pantilat and Jessica Zitter.

Palliative care is based on collaboration, and that’s what we want you to see and experience at the Summit this year. Without buy-in from physicians, nurses, case workers, social workers, patients, hospitals, insurance providers, hospice and palliative care providers, and more, palliative care would never be possible. The same goes for this event. Thank you for taking the time to be here and especially for your work as advocates in each of your communities when you leave.

We hope you find inspiration, community and a renewed sense of purpose.

Enjoy!

Judy Thomas, JD  
Chief Executive Officer, Coalition for Compassionate Care of California  
@JudyThomasJD  

**Presenting Sponsors**

**Wi-Fi Sponsor:**  
Sierra Donor Services

**Summit Wi-Fi**

- Log on to:  
  @Hyatt_Meeting network
- Open an Internet browser on your computer or mobile device.
- Enter the password: CCCCCSummit

**Save the Date!**  
10th Annual Summit  
APRIL 10-11, 2018  
ANAHEIM, CA  
RESERVE YOUR SPACE TODAY!  
EMAIL KEETA SCHOLL AT KSCHOLL@COALITIONCCC.ORG

The Coalition for Compassionate Care of California promotes high-quality, compassionate care for all who are seriously ill or nearing the end of life. Our goal is to transform healthcare so that medical care is aligned with individual patient preferences—that people get the care they need and no less, and the care they want and no more.
Objectives

Over the next two days, you will:

- Understand how the history of doctoring and medicine led to the present state of how medical care is delivered
- Discuss the unique characteristics of palliative care and how its practitioners are different from other specialties
- Identify how what has been learned about the care of the dying could return medicine to its origins of caring
- Describe the provisions of the California End of Life Option Act and its relationship to advance care planning
- Reconsider the role of mortality in our lives
- Link our personal identities to our professional views on caring for the seriously ill
- Explore the elements of culture change in health care
- Identify obstacles to breaking bad news in the ICU environment, including communication challenges, medical uncertainty and navigating conflict
- Describe the negative effects that unsuccessful or delayed communication has on patients, surrogates and healthcare professionals
- Compare and contrast productive vs. problematic communication and discuss the potential use and benefits of multi-media approaches to improving communication about medical prognosis and treatment options
- Describe opportunities for interdisciplinary approaches to the relief of suffering
- Recognize the role of palliative care as a privilege and sacred work
- Describe how the palliative care social movement is impacting health care as a whole

Presentations

Slides from select presentations will be available for download after the Summit at CCCsummit.org. Please allow up to one week for all presentations to be posted.

Photos

Photos from the Summit will be posted to Facebook.com/CoalitionCCC.

The Children’s Hospice & Palliative Care Coalition, a division of the Coalition for Compassionate Care of California, is dedicated to improving children’s access to community-based palliative and hospice care services through advocacy, program development and education.
MONDAY
keynote
How Palliative Care Will Heal Medicine
ERIC CASSELL, MD, MACP, Emeritus Professor of Public Health, Weill Medical College of Cornell University
Following a heritage of two centuries, the contemporary profession of medicine is primarily focused on the diagnosis and cure of disease. And for the past century, it has been increasingly dominated by science and technology. The result of this trend is a belief that medicine is a science marked by impersonality and objectivity, with doctors trained in and devoted to both. Dr. Eric Cassell will take us on a journey to discover how doctors—and equally all caregivers—came to understand the inadequacies of the medicine they had been taught, and returned to understanding the centrality of their historically primary goal: the relief of suffering. He will explore how these lessons will effectively change and improve the contemporary profession of medicine and lead us back to the goal of relieving suffering.

breakout sessions
Grassroots Palliative Care: Fully Engaging our Communities
J. REDWING KEYSSAR, RN, BA, Jewish Family and Children’s Services of West San Francisco Bay Area; MICHAEL D. FRATKIN, MD, ResolutionCare, PC; SUSAN A. BARBER, Mission Hospice & Home Care
Our “community” includes where we live, work and play—which means community-based palliative care can be so much more than pain and symptom management outside of a hospital setting. The next frontier in palliative care is breaking down the barriers to palliative care access through education—to consumers and payers—about the meaning and importance of palliative care. Presenters in this session will share the successes and challenges of several innovative community-based palliative care programs, including advance care planning outreach initiatives, volunteer trainings, mortality discussions and palliative care lectures.

Improving the Quality of Palliative Care: Lessons from Collaborative QI
STEVEN PANTILAT, MD, FAAHPM, MHM, UCSF Palliative Care Quality Network; KARA BISCHOFF, MD, UCSF Palliative Care Quality Network; ANGELA MARKS, MSEd, UCSF Palliative Care Quality Network
Measuring quality is essential for helping palliative care programs grow, become sustainable and improve patient care—and it is increasingly necessary to meet payment reforms under the current terms of the Affordable Care Act. The Palliative Care Quality Network (PCQN) is a network of 80 hospitals developing tools and resources to help meet the needs of palliative care providers for data collection, reporting and quality improvement. In this session, presenters will discuss the lessons learned from three specific quality improvement projects and share best practices for continued quality improvement.

Program
Prognosticating for Adverse Outcomes Using Palliative Care
DANIEL R. HOEFER, MD, Sharp Healthcare
If there is one thing on which we all agree, it’s that palliative care needs to move further upstream in the healthcare continuum, and the care we provide must be consistent with the goals of the patient and family. In this session, Dr. Hoefer will showcase how to guide elderly patients and families through decision-making processes to balance the risks and benefits of hospitalization or surgery. He will also examine how we can prognosticate for patient-centered quality metrics before adverse outcomes occur—such as hospital-induced delirium, functional decline and hospitalization associated disability.

A Learning Collaborative to Improve Home-Based Care for Children
DEBRA LOTSTEIN, MD, MPH, Children’s Hospital Los Angeles; ALLISON N. SOELLER, PhD, Loyola Marymount University
Despite increasing access to home-based palliative care services for families and children with life-threatening illnesses, community-based hospice care services are still lacking for pediatric patients. Children’s Hospital Los Angeles is filling the void and meeting the needs of their community through their Pediatric Hospice and Palliative Care Learning Collaborative. Learn how to replicate this model and discuss strategies and lessons learned to improve care for children in your community.

Defining, Evaluating & Articulating Social Work in Pediatric Palliative Care
DANIELLE JONAS, MSW, Children’s Hospital Los Angeles; JORI BOGETZ, MD, University of California, San Francisco; MARTA FRIEDMAN, LCSW, JD, ACHP-SW, UCSF Benioff Children’s Hospital Oakland; HEATHER A.F. JOLLY, LCSW, MPH, By the Bay Kids
Social workers in pediatric palliative care invest time and undivided attention to patients and families at critical moments of medical decision making. Unfortunately, the nuanced role of pediatric palliative care for social workers has yet to be defined, and many in the field are still finding their way. In this session, presenters will define the scope of practice and unique role of pediatric palliative care social work, identify the challenges faced and discuss strategies to communicate about and advocate for the need of pediatric palliative care social workers within the pediatric palliative and hospice care teams. End of life and bereavement topics will be emphasized.

Tell us how you are taking palliative care mainstream! Tweet using #CCCC17 We Can Do It!
general session
We Can Do It! Palliative Care as a Social Movement

JUDY THOMAS, JD, Coalition for Compassionate Care of California
Every major improvement in public health has been advanced by an accompanying social movement. Just think about the millions of lives positively impacted through improved maternity care, seat belt laws, smoking regulations, AIDS care, and the changing public perception about organ donation. Caring for our elders and the seriously ill is at a tipping point for action—and the time to transform our health care system to better care for these people is now. Learn how the Coalition for Compassionate Care of California is ready to spur a new phase in the palliative care movement.

panel
The Road Unpaved: When Young Adults Become Engaged Patients

Moderated by DEVON DABBS, Coalition for Compassionate Care of California. Panelists: CHARLIE BLOTNER; RACHAEL GOLDRING
This is a unique opportunity to hear from a thoughtful panel of young adults who are living with life-threatening conditions and navigating the transition into adulthood. During this interactive Q&A session, panelists will talk candidly about their personal experiences receiving medical and palliative care, share what matters most to them and what they want clinicians to know when caring for adolescents and young adults. Attendees will be able to ask questions of the panel in a safe, supportive and nonjudgmental environment.

afternoon office hours
Office hours are informal, small group discussions focused on sharing best practices on specific topics. See page 9 for details.

general session
Not Whether… But How: Reframing Our Relationship to The Inevitable

BJ MILLER, MD, UCSF Medical Center
We are all mortal, and it is inevitable that each of our lives will one day come to an end. BJ Miller, MD, has come face to face with this certainty. Dr. Miller takes us on a journey to consider how our personal and professional identities are linked to elements needed to change the culture of providing health care, and reconsider the role mortality plays in our own lives.

reception & poster session
Join us for cocktails, hors d’oeuvres and a poster session featuring a showcase of the best community-based palliative care programs and projects from around the state.
Sponsored by California Health Care Foundation

special session
A New Kind of Heroism

JESSICA NUTIK ZITTER, MD, MPH, Highland Hospital, Oakland
Dr. Jessica Zitter entered the field of critical care medicine to be a hero, to rescue people from the brink of death like a fireman rescues fire victims—calmly, swiftly and without stopping to ask questions. But early on, she realized this approach often causes more suffering than benefit, especially for those patients with life-limiting illness. In this session, Dr. Zitter will describe a new type of heroism which she encountered in the 2000’s while serendipitously brushing up against the burgeoning palliative care movement. Today, it is collaboration—between patient, family and a range of healthcare providers—that takes the place of a lone warrior-doctor.
Join us for an exclusive viewing of the Academy Award-nominated documentary Extremis with one of its featured physicians to discuss this new approach to heroism, and the transformative capabilities it could have on our treatment of the dying.

TUESDAY

general session
Public Policy & Palliative Care in California

JENNIFER KENT, MPA, California Department of Health Care Services
As the recent election has shown us—change is everywhere. Ms. Kent will help us understand the current landscape of California’s state policy on health care and how the focus on palliative care is intended to help patients receive care consistent with their values and choices.

panel
How Does Palliative Care Fit Into the Health Insurance Model? Assuring Palliative Care Services for People With Serious Illness

Moderated by N. MARCUS THYGESON, MD, Blue Shield of California and JUDY THOMAS, JD, Coalition for Compassionate Care of California. Panelists: JILL MENDLEN, LightBridge Hospice and Palliative Care; and JAMES MITTELBERGER, MD, MPH, Optum Center for Palliative Care and Supportive Care
Relieving suffering, in all its many forms, is the goal of palliative medical care. Generally, medical care is considered part of health benefit plans and insurance products. But how does palliative care fit into the health insurance model? This panel will describe how the California Advanced Illness Collaborative—a new statewide collaborative founded through a partnership between Blue Shield of California and the Coalition for Compassionate Care of California—is working to create a common language for palliative care services and to test a model of insurance payers working with palliative care providers.

morning office hours
Office hours are informal, small group discussions focused on sharing best practices on specific topics. See page 9 for details.

awards luncheon
Compassionate Care Leadership Awards

Celebrate the accomplishments of California’s leaders in palliative and end-of-life care during the Compassionate Care Leadership Award luncheon.

Sponsored by California Health Care Foundation
**breakout sessions**

Advancing Palliative Care Through Partnerships & Community Engagement

CHRISTINE KNUTSON, RN, MSN, San Diego Coalition for Compassionate Care; RYAN HAZLEY, RN, BSN, San Diego Coalition for Compassionate Care; JOHN W. TASTAD, MA, San Diego Coalition for Compassionate Care; JENNIFER MOORE BALLENTINE, MA, The Iris Project

Learn from the San Diego Coalition for Compassionate Care (SDCC) as they share their experience and insights in engaging community partners and local stakeholders to advance palliative care across a multidisciplinary spectrum and multi-modal platform. The SDCCC will describe the journey of a developing local coalition within the landscape of palliative care in San Diego including: how to identify key players and stakeholders in palliative care innovation and quality improvement within a local community; how to establish partnerships to promote best practices and create a larger impact; and how to build and strengthen bridges for success, develop plans for future growth and form a strategic plan for coalition sustainability.

Improving the Last Year of Life: Telephonic Palliative Care with Registered Nurse Case Managers

BECKY YAMARIK, MD, MPH, FAAHPM, SCAN HealthPlan of California; ROMILLA BATRA, MD, MBA, SCAN HealthPlan of California; JEANETTE DESPAL, MPH, RN, CCM, SCAN HealthPlan of California

In 2013, SCAN HealthPlan—a Medicare Advantage Plan in California and Arizona—launched their Program for Advanced Illness (PAI), a unique case management program to assist patients with multiple, chronic health conditions to manage their symptoms and medications. The program is designed to manage the sickest patients in the last months to years of life. In this session, you will get an inside look at the background data from the PAI, including: the characteristics and qualities of the RN case managers who were hired, the initial training received in palliative care, ongoing training and support, a detailed description of the case manager work, program graduation goals, outcome measures and data, success stories and failures, and lessons learned along the way.

Unlocking End-of-Life Care Improvement Opportunities Using Public Data

MICHAEL KERSTEN, MPH, Hill Physicians Medical Group; TERRY HILL, MD, FACP, Hill Physicians Medical Group; ANNE KINDERMAN, MD, Zuckerberg San Francisco General Hospital; HEATHER A. HARRIS, MD, Zuckerberg San Francisco General Hospital; KATHLEEN KERR, Kerr Healthcare Analytics

Optimizing care towards the end of life is a critical component of many population health initiatives. In order to measure and improve its end-of-life outcomes (e.g., the quality, cost and appropriateness of care), an organization must first know who died, when and where. In 2016, the California Department of Public Health (CDPH) modified the process for releasing California’s Public Use Death Data Files. In this session, presenters will describe how Hill Physicians Medical Group and the San Francisco Health Network use CDPH data to evaluate aspects of end-of-life care quality, demonstrate how other organizations can replicate this process to describe their own patients and practices, and use such data to inform strategic planning and quality improvement efforts.

Reaching the Most Vulnerable in Your Community Using Home-Based Palliative Care

JEANINE ELINWOOD, MD, Snowline Hospice & Supportive Care; VICTORIA CARDING, LCSW, Snowline Hospice & Supportive Care; RACHELLE PALM, RN, CHPN, Snowline Hospice & Supportive Care

Community-based palliative care delivered in the home reaches the most vulnerable patients in the community—patients who are frequently too ill to drive to a clinic, are in need of a palliative care consultation and are often hospice-appropriate. After first addressing the physical and emotional pain of advanced cancer, COPD and end-stage cardiac disease, a home-visit allows for a gentle exploration of a patient’s goals for end-of-life treatment and care. This session provides an overview of how the Snowline Hospice & Supportive Care program is able to provide services to vulnerable, often rural, patients and their families through donations and support from the local community, including physicians, the health community and county partners.

Harnessing the Power of Telemedicine in Pediatric Palliative Care

AMI DOSHI, MD, FAAP, Rady Children’s Hospital; ROBIN SHORT, RN, BSN, Rady Children’s Hospital; TOLUWALASE AJAYI, MD, Rady Children’s Hospital and Scripps Health; KIMBERLEY BOWER, MD, Rady Children’s Hospital and Scripps Health

Transporting seriously ill and medically fragile children from home to medical appointments or the hospital results in stressors that adversely affect quality of life. This barrier significantly limits access to specialist palliative care for home-based patients. Learn how Rady Children’s Hospital Home Supportive Care program is using telemedicine to improve access to palliative care physicians for home-based pediatric patients. Presenters will describe the rationale for incorporating telemedicine into palliative care, its proven benefits, expected challenges, and key steps for integrating a successful and sustainable telemedicine program into existing palliative care programs.

closing session

The Relief of Suffering and the “Community of Caring”

BETTY FERRELL, RN, PHD, FAAN, City of Hope

Suffering is a human response to serious illness, and it is the shared responsibility—and privilege—of the entire healthcare team to respond to suffering. It is only through collaboration and interdisciplinary work that the team can best meet the physical, psychological, social and spiritual needs of patients and their families.

In this session, Dr. Ferrell delivers a vision for how a “community of caring” can transcend the needs of all patients and families, and how palliative care team members weave together the person-centered response needed to provide the best care.

Tell us how you are taking palliative care mainstream! Tweet using #CCCC17
OFFICE HOURS

Bring questions. Get answers. Consult with experts on a variety of topics.

Take advantage of this unique opportunity for small group discussions with experts and get answers to your most pressing questions.

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<th>DATE/TIME</th>
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<th>LOCATION</th>
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<tbody>
<tr>
<td>March 13</td>
<td>Suffering and Healing</td>
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<td>2:30–3:15p.m.</td>
<td>Pediatric Patients as Engaged Young Adults</td>
<td>Charlie Blotner &amp; Rachel Goldring, ePatient Scholars</td>
<td>Regency ABC</td>
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<td>Thoughts on the California End of Life Option Act: The first year</td>
<td>Lael Duncan, MD, Coalition for Compassionate Care of California Alicia Wagnon, JD, California Medical Association</td>
<td>Regency ABC</td>
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<td>DeathEd: Using Interactive Media to Transform the Taboo</td>
<td>Jessica Nutik Zitter, MD, Highland Hospital Dawn Gross, MD, PhD, University of California, San Francisco</td>
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<td>POLST eRegistry</td>
<td>Kelley Queale, Coalition for Compassionate Care of California</td>
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<td>TelePalliative Care</td>
<td>Michael Fratkin, MD, Resolution Care</td>
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<td>Engaging the Chinese-American Community</td>
<td>Sandy Chen Stokes, RN, MSN, Chinese American Coalition for Compassionate Care</td>
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<td>Community-Based Palliative Care and Hospice for Pediatric Patients</td>
<td>Terri Warren, Providence TrinityCare Hospice Sandee Wishon, RN, MS, CHPN, Hospice by the Bay</td>
<td>Regency DEF</td>
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<td>March 14</td>
<td>Reframing Mortality…What’s Next</td>
<td>BJ Miller, MD, University of California, San Francisco</td>
<td>Regency DEF</td>
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<td>10:45–11:30a.m.</td>
<td>The Road Ahead: A local engagement toolkit</td>
<td>Julie Boudreau, Independent Healthcare Consultant</td>
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<td>Pediatric Concurrent Care</td>
<td>Terri Warren, Providence TrinityCare Hospice Sandee Wishon, RN, MS, CHPN, Hospice by the Bay</td>
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<td>Communication Skills for Speaking with Seriously Ill Patients</td>
<td>Lael Duncan, MD, Coalition for Compassionate Care of California</td>
<td>Regency DEF</td>
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<td>Leveraging Engagement with the Patient Voice</td>
<td>Q &amp; A with ePatient Scholars</td>
<td>Regency DEF</td>
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**Book Signings on Monday, March 13th:**

**REGENCY FOYER**

*Life After the Diagnosis: Expert Advice on Living Well with Serious Illness for Patients and Caregivers* by Dr. Steven Pantilat. Signing available immediately following his session.

**CREST THEATER**

*Extreme Measures* by Dr. Jessica Zitter. Signing available immediately following her session.

**Patient & Caregiver Artists:**

*Be sure to see the art presented during the Summit. More details on page 13.*

**BALLROOM CORRIDOR, VIDEO AT BREAKFAST**

Richard Beckermeyer
Elizabeth Jameson
Selene Seltzer
Cathy Speck
MONDAY,  
MARCH 13

Eric J. Cassell,  
MD, MACP  
Physician & Author  
As one of the early pioneers of palliative care, Eric J. Cassell is well known for authoring The Nature of Suffering and the Goals of Medicine, a book considered by many as the founding cornerstone of the palliative care movement. Dr. Cassell retired from active practice in 1998 after 37 years in internal medicine, and has spent the last several years writing, speaking and lecturing around the world. Now at the age of 88, Dr. Cassell is passing the torch and looks forward to addressing the changemakers of today who are taking palliative care mainstream.

BJ Miller, MD  
University of California, San Francisco Medical Center  
BJ Miller is a hospice and palliative medicine physician who sees patients and families at the UCSF Helen Diller Family Comprehensive Cancer Center where he also teaches and serves on the faculty. His TED Talk, Not Whether But How (aka “What Matters Most at the End of Life”), a reflection of his vision to make empathic palliative care available to all, ranked among the Top 15 Most Viewed TED Talks of 2015. He speaks internationally on the topics of perspective making, aesthetics and palliative care.

Jessica Nutik Zitter, MD, MPH  
Highland Hospital, Oakland  
Jessica Zitter is committed to changing the current paradigm of end-of-life medical decision-making. A critical care and palliative care physician at Highland Hospital in Oakland, CA, Dr. Zitter is dedicated to the ideals and delivery of patient-centered medicine. She believes we must reorient our care of the dying from default medicalization to a process where the patient, not their organ or disease, is the primary focus of care. She is an essayist for The New York Times and Huffington Post. Her first book, Extreme Measures, will be available for purchase at her session.

TUESDAY,  
MARCH 14

Jennifer Kent,  
MPA  
California Department of Health Care Services  
Jennifer Kent was appointed as director of the California Department of Health Care Services (DHCS) by Gov. Jerry Brown in January 2015. As director, Ms. Kent oversees a staff of 3,700, who are responsible for the operation of Medi-Cal, the state’s Medicaid program. DHCS manages the annual spending of more than $93 billion in public funds that support the health of more than 13.3 million Californians. Ms. Kent is supportive of programs to expand access to palliative care, including the Partner’s For Children (PFC) program and Senate Bill 1004.

Betty Ferrell, RN, PhD, FAAN  
City of Hope  
Betty Ferrell has been working in the field of nursing for 39 years and has focused her clinical expertise and research in pain management, quality of life and palliative care. She is Director of Nursing Research & Education and a Professor at the City of Hope Medical Center in Duarte, CA, and a Fellow of the American Academy of Nursing. In 2013, Dr. Ferrell was named one of the 30 Visionaries by the American Academy of Hospice and Palliative Medicine.

See bios for all 35+ presenters at ccccsummit.org/speakers
**General Session Panelists**

Charlie Blotner, Precision Medicine Advocate, CURE-FORWARD, Student at Arizona State University  
Devon Dabbs, Vice President of Pediatric Programming and Education, Coalition for Compassionate Care of California  
Rachael Goldring, Blogger, *The Road Unpaved*, Student at Arizona State University  
Jill Mendlen, Founder & President/CEO, LightBridge Hospice and Palliative Care  
James Mittelberger, MD, Director & CMO, Optum Center for Palliative and Supportive Care  
Judy Thomas, JD, CEO, Coalition for Compassionate Care of California  
N. Marcus Thygeson, MD, MPH, Chief Health Officer, Blue Shield of California

**Breakout Session Presenters**

Tuluwalase Ajayi, MD, Assistant Clinical Professor of Pediatrics, University of California San Diego  
Jennifer Ballentine, MA, President, The Iris Project  
Susan A. Barber, Community Education and Volunteer Coordinator, Mission Hospice & Home Care  
Romilla Batra, MD, MBA, Chief Medical Executive, SCAN HealthPlan  
Kara Bischoff, MD, Director of Quality Improvement for the Palliative Care Service, University of California, San Francisco  
Victoria Carding LCSW, Snowline Hospice & Supportive Care  
Jori Bogetz, MD, Clinical Assistant Professor of Pediatrics, University of California, San Francisco  
Kimberly Bower, MD, Chief of Palliative Medicine, Rady Children’s Hospital-San Diego  
Jeanette Despal, MPH, RN, CCM, Director, Program for Advanced Illness, SCAN HealthPlan  
Ami Doshi, MD, FAAP, Director of Inpatient Palliative Care, Rady Children’s Hospital-San Diego  
Jeanine Ellinwood, MD, Medical Director, Snowline Hospice & Supportive Care  
Michael D. Fratkin, MD, Founder/Director, Resolution-Care  
Marta Friedman, LCSW, JD, ACHP-SW, UCSF Benioff Children’s Hospital, Oakland

**Breakout Session Presenters, continued**

Heather A. Harris, MD, Associate Professor of Clinical Medicine, University of California, San Francisco  
Ryan Hazley, RN, BSN, San Diego Coalition for Compassionate Care  
Terry Hill, MD, FACP, Vice President for Performance Strategy, Hill Physicians Medical Group  
Daniel R. Hoefer, MD, Chief Medical Officer, Sharp HealthCare Outpatient Palliative Care Program  
Heather A.F. Jolly, MSW, MPH, Hospice and Palliative Care Social Worker, By the Bay Kids  
Danielle Jonas, MSW, Pediatric Palliative Care Social Worker, Children’s Hospital Los Angeles  
Kathleen Kerr, Founder, Kerr Healthcare Analytics  
Michael Kerston, MPH, Manager of Clinical Innovations and Program Manager for Serious Illness Management and the Virtual Care Team, Hill Physicians  
J. Redwing Keyssar, RN, BA, Director, Palliative Care Program at Jewish Family and Children’s Services San Francisco Bay  
Anne Kinderman, MD, Director, Supportive & Palliative Care Service at San Francisco General Hospital  
Christine Knutson, RN, MSN, San Diego Coalition for Compassionate Care  
Debra Lotstein, MD, MPH, Director of the Division of Palliative Care, Children’s Hospital Los Angeles  
Angela Marks, MSED, Deputy Director, Palliative Care Quality Network University of California, San Francisco  
Rachelle Palm, RN, CHPN, Palliative In-Home Clinical Nurse, Snowline Hospice & Supportive Care  
Steven Pantilat, MD, FAAHPM, MHM, Founding Director, University of California, San Francisco Palliative Care Program  
Robin Short, RN, BSN, Home Supportive Care Coordinator, Rady Children’s Hospital  
Allison N. Soeller, PhD, Assistant Professor of Organizational Communication, Loyola Marymount University  
John W. Tastad, MA, Coordinator for the Advance Care Planning Program, Sharp HealthCare  
Becky Yamarik, MD, MPH, FAAHPM, Fellow, American Academy of Hospice and Palliative Medicine

*Purple lettering = pediatric focus*
Leadership Awards

The Coalition for Compassionate Care of California is proud to present the 2017 Compassionate Care Leadership Awards and the 2017 Compassionate Care Innovator Award. These awards recognize individuals and an organization that are changing the way we care for people who are seriously ill or approaching the end of life.

Organization Award

UCSF Benioff Children’s Hospital Oakland Pediatric Palliative Care Program

When it comes to pediatric palliative care, one program stands out as the standard-bearer and trailblazer. Formally established in 2011, the Pediatric Palliative Care (PPC) Program of UCSF Benioff Children’s Hospital Oakland (Children’s) continues to lead the field.

Building their program specifically to decrease fragmentation and increase cooperation among the patient’s family and medical team, the PPC Program team works diligently to create partnerships that support a patient in multiple settings, including primary care, specialty clinics, the hospital and at home. This is all done with respect to the child, his or her family, and their collective wishes and needs.

The PPC Program’s mission is to provide expert pain and symptom management, psycho-social and spiritual support, assistance with advance care planning and access to community resources. Using a specialized interdisciplinary team of a physician, nurse and social worker, the program provides this extra layer of support for the child, family and the treating teams. This is done using telephone support, as well as in-person meetings. The team works to facilitate continuity of care among the hospital and the community partners, to best ensure the comfort of the child and family.

At the outset of the program, much education and groundwork had to be done to prepare community organizations and providers to care for child patients. As such, education and training for colleagues across all disciplines and the community was, and continues to be, a large part of the work of the PPC Program. From their End-of-Life Nursing Education Curriculum for Pediatric Palliative Care Course (ELNEC-PPC) to organizing two conferences with national renown, the program continues to lead the conversation on pediatric palliative care. Today the palliative care team has an average census of 18-20 inpatients and close to 300 outpatients all at different stages of their journey. Patients are increasingly being referred earlier in their disease trajectory, allowing for stronger relationship building, the ability to help families identify goals of care and assistance with traversing the complicated health care system—all to provide the best possible care for every child and family.

Individual Award

Susan Keller, MA, MLIS

It would be hard to find a more tireless, long-serving advocate for palliative care, advance care planning and better end-of-life care in her community than Susan Keller. For nearly 40 years, Susan has dedicated herself both personally and professionally to advancing high quality, compassionate care for serious illness as an essential element of community health and health care improvement. For these reasons and many more, the committee selected Susan as the 2017 recipient of our Compassionate Care Leadership Award.

Nominated by the Steering Committee for My Care, My Plan: Speak Up Sonoma County (MCMP), an advance care planning community initiative that she helped to found and on which she still serves, we can see how Susan continues to dedicate her time and vast expertise to her passionate causes.

Beginning in 1978, Susan founded the Community Network for Appropriate Technologies (CNAT), where she serves as the Executive Director and works as a public interest planner, network developer, consumer advocate and educator. In the early 1990s, Susan launched the Community Network Journey Project to develop important programs in response to the lack of palliative care and community-based long-term care, and authored Journey to Life’s End: A Traveler’s Guide. In the past, Susan worked as a UCSF Clinical Instructor teaching advance care planning and palliative care for the Santa Rosa Family Medicine Residency Program from 2010-2015.

Susan has been working in collaboration with the Coalition for Compassionate Care of California since the late 1990s on numerous projects including work with RWJF Rallying Points Program and the Sonoma County POLST Coalition. She also serves as a consumer advocate on the California POLST Task Force and is currently spearheading a project to improve advance care planning and palliative care for people living with serious mental health challenges.
Compassionate Care Innovator Award
Sandy Chen Stokes, RN, PHN, MSN

Thanks to Sandy Chen Stokes, Chinese Americans in California are able to face the end of life with dignity, respect and culturally congruent care they may not otherwise have. For more than 11 years, Sandy has dedicated her time and love to building the Chinese American Coalition for Compassionate Care (CACCC - the only network in the U.S. devoted to addressing the end-of-life concerns of the Chinese-American Community). A long-time advocate for advance care planning and compassionate end-of-life care, Sandy provides workshops and seminars nationwide for health providers (physicians, nurses, social workers, chaplains and medical interpreters), hospice and palliative care volunteers, and for the Chinese community. For this reason, she is the recipient of the 2017 Compassionate Care Innovator Award.

Sandy founded CACCC in 2005, motivated to help Chinese Americans to talk about and prepare for death, which is considered bad luck for most Chinese. Since then, the organization has continued to grow and serve thousands of Chinese Americans. CACCC’s workshops and seminars focus on Chinese American end-of-life issues, including advance care planning, spiritual care at the end of life, cultural beliefs and practices regarding end of life, and the role of medical interpreters in hospice and palliative care. CACCC now has more than 1,300 individual members and 80 organizational members working to improve end-of-life care services and resources for Chinese Americans. From developing and translating numerous end-of-life resources like the Heart to Heart® cards and Chinese POLST forms, to recruiting and training an army of hospice and palliative care volunteers, to giving hundreds of trainings to educate healthcare professionals who serve Chinese Americans, Sandy’s efforts, and those of the CACCC under her direction, have impacted many lives across the state.

Sandy has focused on end-of-life care, elder care and mental health issues in the Chinese-American community for much of her career. In 2008, Sandy received the American Cancer Society’s Lane Adams Award for her work with the CACCC. Three years later, she received the 2011 AARP Inspire Award. She sits on the Advisory Board for the Chinese Health Initiative at El Camino Hospital in Mountain View and the Diversity Advisory Council for the National Hospice and Palliative Care Organization.

e-Patient Program

Thanks to a Eugene Washington PCORI Engagement Award, the e-Patient Program for the 2017 Summit is larger than ever before. By involving a new cohort of engaged and empowered patients, caregivers, and patient advocates in the Summit, we will create a unique experience allowing patients to work as partners with clinicians to advance a shared vision for palliative care.

As part of this Engagement Award, 15 patients have been selected as “e-Patient Scholars” and received full or partial scholarships to support their participation in the CCCC Summit. Scholars have the opportunity to inform Summit content, submit posters, showcase artwork, develop and conduct and/or participate in specific sessions, serve as presenters, and broadly share information learned about palliative care with their networks. Clinicians and other attendees will have numerous opportunities to interact and dialogue with the Scholars and develop new research, projects or practices based on patient-informed palliative care questions or priorities.

In addition to expanding the number of Scholars, we are thrilled to be able to further integrate the patient/caregiver/advocate voice into all aspects of the Summit. Some Scholars will present art, some will have posters, and others will be panelists or conduct Office Hours. All of these modalities will give Summit participants numerous ways to access and understand the lives of the critically ill. In addition, general sessions and panels will be live streamed to encourage broad participation in the movement for palliative care.

e-Patient Scholars will be wearing ribbons, and artwork and posters will be featured in the Ballroom Corridor. In addition, patient and caregiver-produced videos will be screened during breakfast both days of the Summit.

About PCORI

The Patient-Centered Outcomes Research Institute (PCORI) is an independent, nonprofit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, their caregivers and clinicians with the evidence-based information needed to make better-informed healthcare decisions. PCORI is committed to continually seeking input from a broad range of stakeholders to guide its work.
Aleksandra Kizior  Lodz, Poland
Aleksandra is a patient advocate working at PRO ARS nonprofit foundation for cancer control and prevention. Her goal is to reduce the suffering of seriously ill patients by educating them with healthy coping skills to improve their quality of life. As a patient advocate and a person who has experienced multiple life-threatening illnesses, Aleksandra is dedicated to raising public awareness of prevention in all stages of serious illness.

Amy Pickard  Los Angeles, CA
Amy is a former freelance TV producer and broadcaster living in Los Angeles. She is the creator and CEO of Good To Go!, an unconventional advance planning company changing the cultural narrative on how we view death preparedness, dying and the aftermath - by having a party! Amy is proud to be part of the Death Positive community.

Charlie Blotner  Tempe, AZ
Charlie is a pediatric/young adult patient advocate dedicated to helping patients become better informed about not only their tumors, but also policy, side effects and future implications of their disease. Charlie is also social worker in training, Cure Forward precision medicine team member, Stanford Medicine X Student Advisor, and co-founder and co-moderator of #BTSM (Brain Tumor Social Media) Chats. LGBTQ+ health is a special interest of Charlie’s as well.

Danielle Edges  Gilbert, AZ
Danielle is an educator, mother and wife who is passionate about health care advocacy for medically complex children. Inspired by her 9-year-old daughter born with a rare medical condition, she has worked with nonprofit organizations to raise awareness, support and empowerment for new families diagnosed with the same condition as her daughter.

Danny van Leeuwen  Arlington, MA
Danny is an e-Patient living with Multiple Sclerosis, avid blogger, co-chair of PCORI’s Communication and Dissemination Advisory Panel, and a member of several expert panels for AHRQ. He’s also a caregiver, nurse, informaticist, leader, sax player, Opa and husband. Danny is an action catalyst empowering people traveling together toward best health.

Elizabeth Bailey  New York, NY
Elizabeth Bailey is a Patient Advocate and the author of The Patient’s Checklist: 10 Simple Checklists to Keep You Safe, Sane and Organized. She is a writer, patient advocate, wife, mother and caregiver – and a producer, director and vice president of video production for several record labels.

Elizabeth Jameson  Lafayette, CA
Elizabeth is an artist specializing in the intersection of art and science. As a person living with Multiple Sclerosis, she transforms her brain scans to celebrate the imperfect body and brain, collaborating with scientists, healthcare providers, and those living with illness to spark conversations and deepen the complex narrative of disability and disease.

Julie Flygare  Los Angeles, CA
Julie is the founder of Project Sleep, a narcolepsy spokesperson, award-winning author and runner who was diagnosed with narcolepsy with cataplexy in 2007. She is the creator of the international NARCOLEPSY: NOT ALONE campaign and the co-founder of the first-ever national scholarship for students with narcolepsy, the Jack & Julie Narcolepsy Scholarship.

Kate Riley  Hailey, ID
Kate Riley is an author, educator and advocate for end-of-life compassionate care. She is a strong proponent for change in how people die, and recently published a book about her mother’s choice to die a conscious death, Launching Vee’s Chariot: An End-of-Life Tale. Despite the diagnosis of an auto-immune disorder, Kate lives life passionately.

Kathy Kastner  Toronto, Ontario
Kathy is a leading e-Patient ‘voice’ doing a deep-dive into the end-of-life health space with BestEndings.com and her eBook, Death Kills… and Other Things I’ve learned on the internet. An ardent tweeter, Kathy founded a hospice and palliative medicine tweetchat and instantly became a Palliative Care ‘evangelist’.

MarlaJan Wexler  Marlton, NJ
MarlaJan is a certified pediatric nurse, patient advocate, MedX Scholar, public speaker and coffee enthusiast. She is the creator and author of the blog, Luck Fupus, which began as a means to cope living with chronic illnesses, and has become a platform for her to educate and advocate for patients across the globe.

MaryAnne Sterling  Ashburn, VA
MaryAnne is a fierce activist for healthcare transformation, family caregiver empowerment and a cure for Alzheimer’s. She has been an advocate for family caregivers and Alzheimer’s families for 20 years, with 3-out-of-4 parents impacted by dementia. She currently serves as a Patient Research Partner and Ambassador for PCORI and Advisory Council member for the National Alzheimer’s & Dementia Patient & Caregiver-Powered Research Network.

Peter Kafka  Haiku, HI
Peter was diagnosed with aggressive prostate cancer in 2014 and treated at UCSF. He now moderates live, interactive support calls for the Answer Cancer Foundation. Peter lives in Maui where he acts as an advocate for other men diagnosed with prostate cancer, exploring options for treatment and management of their disease. He is a strong advocate for the importance of healthy living, exercising and staying engaged in life’s adventures.

Rachel Goldring  Clovis, CA
Rachel is a student at Arizona State University. She maintains a blog, The Road Unpaved, about her experiences living with congenital heart disease, common variable immunodeficiency, COPD and PTSD – among other life experiences. She hopes to be an encouragement to other young people living with serious illness.

Selene Seltzer  Ashland, OR
Selene is an integrative patient advocate, palliative care activist, passionate community organizer and ardent optimizer of quality of life. She has had two cancer events, a severe injury and a multiplicity of serious illnesses all of which inform her perspective. As an Integrative Care provider and a Clinical Healthcare Chaplain specializing in palliative and end-of-life care, Selene advocates for and provides “whole person” care to ease pain and suffering in the body, heart/mind and spirit.
CONTINUING EDUCATION

Full attendance in its entirety is required at all education sessions in order to receive professional continuing education credits (CMEs/CEs). Continuing education is provided for full-day attendance. Partial day credit is not available. All attendees must sign in with their professional license numbers in the morning of each day of the Summit. In order to receive credit, participants must complete an online survey within 30 days following the Summit in order to receive a CME/CE certificate. Continuing education certificates will be sent via email. Certificates of attendance will be available at the end of the Summit in the afternoon of Tuesday, March 14, 2017. Note: A 50-minute minimum of uninterrupted time is required to qualify for one hour of CME/CE credit. Continuing education excludes lunch and break periods.

| PHYSICIANS & PHYSICIAN ASSISTANTS | Application for CME credit has been filed with the American Academy of Family Physicians. Determination of credit is pending. CME credits are sponsored by Partnership HealthPlan of California. |
| NURSES | This course meets the qualifications for approximately 12 contact hours. This provider is approved by the California Board of Registered Nursing, Provider #CEP 15403. |
| SOCIAL WORKERS | This course meets the qualifications for an estimated 12 hours of continuing education credit for LMFTs, LCSWs, LPCCs and/or LEPs as required by the California Board of Behavioral Sciences. CCCC is approved by the California Association of Marriage and Family Therapists to sponsor continuing education for LCSWs and LMFTs, Provider #91987. |
| NURSING HOME ADMINISTRATORS | An application has been made to the California Nursing Home Administration program (NHAP# CEP 1735) for an estimated 12 NHAP/P credits. Determination is pending. |
| CHAPLAINS | This program may be used for continuing education credit for chaplains certified with the Board of Chaplaincy Certification, Inc. |

Summit Map:
Hyatt Regency
Sacramento

1st Floor

2nd Floor
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