

Roundtable on Quality Care for People with Serious Illness

April 4, 2019
Washington, DC

**Improving Access to and Equity of Care
for People with Serious Illness**

A Workshop

 **#SeriousIllnessCareNAEM**

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**Keck Center of the National Academies
500 Fifth Street, NW
Room 100
Washington, DC 20001**

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ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

April 4, 2019

Dear Colleagues:

Welcome to the workshop on *Improving Access to and Equity of Care for People with Serious Illness*. This workshop is hosted by the Roundtable on Quality Care for People with Serious Illness at the National Academies of Sciences, Engineering, and Medicine.

The workshop opens with the story of an individual's personal experience with bias and discrimination in the health care system, which will provide important context for the day's presentations and highlight why addressing access and equity matters for all people, particularly those facing serious illness.

The first session of the workshop provides an overview of the challenges and opportunities related to improving access and advancing health equity for people of all ages living with serious illness, and explores the role of trauma-informed care. Subsequent workshop sessions shed light on the opportunities for improving access and equity first at the community and organizational level, then at the patients, families, and clinicians, level and finally at the policy level. The workshop closes with a solutions-focused moderated discussion of practical next steps to advance health equity and expand access to care.

We hope you will find the presentations informative, thought provoking, and inspiring, and that the suggestions made by the workshop speakers will contribute to improved practice and informed policymaking regarding this critical issue.

A major goal of the workshop is to facilitate discussion about opportunities to reduce disparities and improve care for all people with serious illness. Each session includes a question and answer/audience discussion period. We encourage you to participate actively in workshop discussions. Proceedings of this workshop will be published by the National Academies Press and may incorporate your comments and ideas. In addition, the workshop will be webcast, and a video archive will be available at:

<http://nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2019-APR-04.aspx>

We invite you to share your insights, thoughts and reactions throughout the workshop using the Twitter hashtag: **#SeriousIllnessCareNASEM**.

Sincerely,



Darci L. Graves, MPP, MA, MA
Special Assistant to the Director
Office of Minority Health
Centers for Medicare & Medicaid Services
Planning Committee Co-Chair



Peggy Maguire, JD
President
Cambia Health Foundation
Planning Committee Co-Chair

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WORKSHOP NOTES

- This workshop is being recorded. Please identify your name and affiliation prior to asking questions at the microphone.
- A live webcast of this workshop is available online at:
<http://nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2019-APR-04.aspx>
- Please use the hashtag **#SeriousIllnessCareNASEM** to tweet about the workshop.
- An archive of the video webcast and presentation slides will be available at:
<http://nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2019-APR-04.aspx>
- Proceedings of the workshop will be published following National Academies procedures. Rapporteurs will compose the proceedings from the workshop transcript and external reviewers will examine the proceedings to make sure it accurately reflects workshop discussions and conforms to institutional policies.
- Interested in receiving updates from the Roundtable on Quality Care for People with Serious Illness or the National Academies of Sciences, Engineering, and Medicine's Health and Medicine Division?

Sign up for the **Roundtable** listserv at:

<https://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable.aspx>

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We encourage you to share your thoughts, reactions, and insights about the workshop via Twitter with **#SeriousIllnessCareNASEM**



Roundtable on Quality Care for People with Serious Illness

Improving Access to and Equity of Care for People with Serious Illness: A Workshop

The Keck Center of the National Academies
500 Fifth Street, NW - Room 100
Washington, DC 20001
April 4, 2019

WORKSHOP AGENDA

April 4, 2019

April 4, 2019	
8:00 am	Registration and Breakfast
8:30 am	<p>Welcome from the Roundtable on Quality Care for People with Serious Illness Leonard D. Schaeffer, University of Southern California (Chair) and James Tulskey, MD, Harvard Medical School, Brigham and Women's Hospital, and Dana-Farber Cancer Institute (Vice Chair)</p> <p>Overview of the Workshop Darci Graves, MPP, MA, MA, Special Assistant to the Director Office of Minority Health, Centers for Medicare & Medicaid Services and Peggy Maguire, JD, President, Cambia Health Foundation Planning Committee Co-Chairs</p>
8:45 am	<p>Session 1 Overview of the Landscape for Improving Access to and Equity of Care for People with Serious Illness</p> <p><i>Moderator: Peggy Maguire, Cambia Health Foundation</i></p> <p><i>Panelists:</i></p> <ul style="list-style-type: none">▪ Bridgette Hempstead, President and Founder, Cierra Sisters▪ Marshall Chin, MD, MPH, Richard Parrillo Family Professor of Healthcare Ethics, Department of Medicine, University of Chicago Medicine

Follow the [conversation](#):

 #SeriousIllnessCareNASEM

	<ul style="list-style-type: none"> ▪ Kimberly Sherell Johnson, MD, Associate Professor of Medicine, Senior Fellow in the Center for the Study of Aging and Human Development Duke University School of Medicine ▪ Edward Machtinger, MD, Professor of Medicine, UCSF, Director, Center to Advance Trauma-informed Health Care and Women's HIV Program, UCSF <p>Panel Discussion/Audience Q&A</p>
10:30 am	Break
10:45 am	<p>Session 2 Improving Access to Care and Achieving Health Equity for People with Serious Illness: Organizational and Community Perspective</p> <p><i>Moderator: Nadine Barrett, PhD, MA, MS, Assistant Professor, Department of Community and Family Health, Duke University School of Medicine</i></p> <p><i>Panelists:</i></p> <ul style="list-style-type: none"> ▪ Sister Anne Francioni, RN, MA, SSND Executive Director, Whole Kids Outreach ▪ Adán Merecias, Community Health Worker, Patient Navigator Program Manager, Familias en Acción ▪ Sandy Chen Stokes, RN, MSN, Founder, Chinese American Coalition for Compassionate Care <p>Panel Discussion/Audience Q&A</p>
12:00 pm	Lunch
1:00 pm	<p>Session 3 Improving Access to Care and Achieving Health Equity for People with Serious Illness: Patient/Family and Clinician Perspective</p> <p><i>Moderator: Darci Graves, CMS</i></p> <p><i>Panelists:</i></p> <ul style="list-style-type: none"> ▪ <i>Video: Jay: Privilege and Discrimination in One Man's Life</i> ▪ Alice Huan-mei Chen, MD, MPH, Deputy Director and Chief Medical Officer, San Francisco Health Network, Professor of Clinical Medicine, UCSF Department of Medicine ▪ Justin J. Sanders, MD, MSc, Faculty, Serious Illness Care Program, Ariadne Labs, Attending Physician, Psychosocial Oncology and Palliative Care Department, Dana-Farber Cancer Institute and the Brigham and Women's Hospital, Instructor in Medicine, Harvard Medical School ▪ Liz Margolies, LCSW, Founder and Executive Director, National LGBT Cancer Network <p>Panel Discussion/Audience Q&A</p>



2:30 pm	Break
2:45 pm	<p>Session 4 A Policy Agenda to Improve Access to Care and Achieve Health Equity for People with Serious Illness</p> <p><i>Moderator: Sarah Downer, JD, Associate Director, Whole Person Care and Clinical Instructor on Law, Health Law and Policy Clinic, Harvard Law School</i></p> <p><i>Panelists:</i></p> <ul style="list-style-type: none"> ▪ Diane Rowland, ScD, Executive Vice President, The Henry J. Kaiser Family Foundation ▪ Andy Slavitt, MBA, Founder and General Partner, Town Hall Ventures, Former Acting Administrator, Centers for Medicare and Medicaid Services ▪ Lori Bishop, MHA, BSN, RN, CHPN, Vice President of Palliative and Advanced Care, National Hospice and Palliative Care Organization <p>Panel Discussion/Audience Q&A</p>
4:00 pm	<p>Session 5 Next Steps for Implementing Solutions to Improve Access to Care and Achieve Health Equity for People with Serious Illness</p> <p><i>Moderator: Shonta Chambers, MSW, Executive Vice President, Health Equity Initiatives and Community Engagement, Patient Advocate Foundation</i></p> <p><i>Panelists:</i></p> <ul style="list-style-type: none"> ▪ Daniel Dawes, JD, Executive Director of Health Policy & External Affairs, Morehouse School of Medicine, Principal Investigator and Co-Founder, Health Equity Leadership & Exchange Network (HELEN) ▪ Steve Clauser, PhD, MPA, Director, Healthcare Delivery and Disparities Research Program, Patient-Centered Outcomes Research Institute (PCORI) ▪ Nadine Barrett, PhD, MA, MS, Assistant Professor, Department of Family and Community Health, Duke University School of Medicine ▪ Peggy Maguire, JD, President, Cambia Health Foundation <p>Panel Discussion/Audience Q&A</p>
5:25 pm	Closing Remarks
5:30 pm	Adjourn

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TALK TO US ON TWITTER!



Kim Acquaviva
[@kimaacquaviva](#)

Shonta Chambers
[@Chambers_PAF](#)

Daniel Dawes
[@DanielEDawes](#)

Darci Graves
[@darcigraves](#)

Bridgette Hempstead
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Edward Machtinger
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Peggy Maguire
[@maguirepeggy](#), [@Cambia](#),
[@CambiaHealthFdn](#)

Liz Margolies
[@cancerlgbt](#)

Adán Merencias
[@familiaspdx](#)

Diane Rowland
[@dr_dianerowland](#)

Justin Sanders
[@dbljsndrs](#)

Andy Slavitt
[@ASlavitt](#)



Rosters

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Improving Access to and Equity of Care for People with Serious Illness: A Workshop

WORKSHOP PLANNING COMMITTEE

Darci Graves, MPP, MA, MA (Co-Chair)

Special Assistant to the Director
Office of Minority Health
Centers for Medicare & Medicaid Services

Peggy Maguire, JD (Co-Chair)

President and Board Chair
Cambia Health Foundation

Kimberly D. Acquaviva, PhD, MSW, CSE

Professor
The George Washington University School of
Nursing

Diane E. Meier, MD, FACP, FAAHPM

Director
Center to Advance Palliative Care
Co-Director
Patty and Jay Baker National Palliative
Care Center
Professor, Department of Geriatrics and
Palliative Medicine
Catherine Gaisman Professor of Medical
Ethics
Icahn School of Medicine of Mount Sinai

Robert A. Bergamini, MD

Medical Director, Palliative Care Services
Mercy Clinic Children's Cancer
Representing the Supportive Care
Coalition

Thomas M. Priselac, MPH

President and Chief Executive Officer
Cedars-Sinai Health System

Shonta Chambers, MSW

Executive Vice President, Health Equity
Initiatives and Community Engagement
Patient Advocate Foundation

JoAnne Reifsnyder, PhD, RN, FAAN

Executive Vice President, Clinical Operations
and Chief Nursing Officer
Genesis Healthcare
Representing the Hospice and Palliative
Nurses Association

Marshall Chin, MD, MPH

Richard Parrillo Family Professor of
Healthcare Ethics
Department of Medicine
University of Chicago Medicine

Ziad R. Haydar, MD, MBA

Senior Vice President
and Chief Clinical Officer
Ascension Health

Susan Elizabeth Wang, MD

WLA Chief, Department of Geriatrics,
Palliative & Continuing Care
Fellowship Director, Palliative Medicine
Regional Lead, Shared Decision-Making and
Advance Care Planning
Southern California Permanente Medical
Group Kaiser Permanente

Haiden Huskamp, PhD

30th Anniversary Professor of Health Care
Policy, Department of Health Care Policy
Harvard Medical School

Kimberly Sherell Johnson, MD

Associate Professor of Medicine
Senior Fellow in the Center for the Study of
Aging and Human Development
Duke University School of Medicine

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WORKSHOP SPEAKERS AND MODERATORS

Nadine Barrett, PhD, MA, MS

Assistant Professor
Department of Community and Family
Medicine, Community Health
Duke University School of Medicine

Lori Bishop, MHA, BSN, RN, CHPN

Vice President of Palliative and Advanced
Care
National Hospice and Palliative Care
Organization (NHPCO)

Shonta Chambers, MSW

Executive Vice President, Health Equity
Initiatives and Community Engagement
Patient Advocate Foundation

Alice Huan-mei Chen, MD, MPH

Deputy Director and Chief Medical Officer
San Francisco Health Network
Professor of Clinical Medicine
USCF Department of Medicine

Marshall Chin, MD, MPH

Richard Parrillo Family Professor of
Healthcare Ethics
Department of Medicine
University of Chicago Medicine

Steve Clauser, PhD, MPA

Director, Healthcare Delivery and Disparities
Research Program
Patient-Centered Outcomes Research Institute
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Morehouse School of Medicine
Principal Investigator and Co-Founder
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Sarah Downer, JD

Associate Director
Whole Person Care and Clinical Instructor on
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Health Law and Policy Clinic
Harvard Law School

Sister Anne Francioni, RN, MA, SSND

Executive Director
Whole Kids Outreach

Darci Graves, MPP, MA, MA

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Centers for Medicare & Medicaid Services

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Care (CTHC) and Women's HIV Program
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President and Board Chair
Cambia Health Foundation

Liz Margolies, LCSW

Founder and Executive Director
National LGBT Cancer Network

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Adán Merecias

Community Health Worker
Patient Navigator Program Manager
Familias en Acción

Diane Rowland, ScD

Executive Vice President
The Henry J. Kaiser Family Foundation

Justin J. Sanders, MD, MSc

Faculty, Serious Illness Care Program,
Ariadne Labs
Attending Physician, Psychosocial Oncology
and the Palliative Care Department,
Dana-Farber Cancer Institute and the
Brigham and Women's Hospital
Instructor in Medicine,
Harvard Medical School

Andy Slavitt, MBA

Founder and General Partner
Town Hall Ventures

Sandy Chen Stokes, RN, MSN

Founder
Chinese American Coalition for
Compassionate Care

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ROUNDTABLE MEMBERSHIP

- Aetna
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- American Academy of Hospice and Palliative Medicine
- American Cancer Society
- American Geriatrics Society
- Anthem
- Ascension Health
- Association of Professional Chaplains
- Association of Rehabilitation Nurses
- Blue Cross Blue Shield Association
- Blue Cross Blue Shield of MA
- Blue Cross and Blue Shield of NC
- Bristol-Myers Squibb Company
- The California State University Institute for Palliative Care
- Cambia Health Solutions
- Cedars-Sinai Health System
- Center to Advance Palliative Care
- Centers for Medicare & Medicaid Services
- Coalition to Transform Advanced Care
- Excellus BlueCross BlueShield
- Federation of American Hospitals
- The Greenwall Foundation
- The John A. Hartford Foundation
- Hospice and Palliative Nurses Association
- Kaiser Permanente
- Susan G. Komen
- Gordon and Betty Moore Foundation
- National Academy of Medicine
- National Coalition for Hospice and Palliative Care
- National Hospice and Palliative Care Organization
- National Palliative Care Research Center
- National Patient Advocate Foundation
- National Quality Forum
- New York Academy of Medicine
- Oncology Nursing Society
- Patient-Centered Outcomes Research Institute
- Social Work Hospice and Palliative Care Network
- Supportive Care Coalition

ABOUT US

THE HEALTH AND MEDICINE DIVISION

We ask and answer the nation's most pressing questions about health and health care.

The Health and Medicine Division (HMD)—an operating unit of the National Academies of Sciences, Engineering, and Medicine (National Academies)—helps those in government and the private sector make informed health decisions by providing evidence upon which they can rely.

Through our consensus studies, we offer straightforward answers to questions of national importance. Our convening activities bring together actors from across the health care spectrum to explore complex topics and work toward shared understanding on critical health issues.

Each year, more than 3,000 of the world's leading experts in industry, academia, and the health care sector volunteer their time, knowledge, and expertise with HMD. They work through committees composed to ensure the needed expertise and to avoid conflicts of interest. With the assistance of approximately 150 HMD staff members, their contributions help to advance health.

Our advice is steeped in science and led by evidence. For millions of people across the United States and around the globe, improving health is not merely an academic exercise; it is a matter of daily survival and well-being. In all we do to improve health policy and decision making, HMD is ever mindful of the impact of our work on the lives and health of individuals, families, communities, and nations.

As of March 2016, the Health and Medicine division continues the consensus studies and convening activities previously undertaken by the Institute of Medicine.

OUR WORK

From alerting the public to the widespread problem of medical errors to setting the blueprint for the future of nursing to emphasizing the importance of end-of-life care preferences, our consensus studies provide independent, evidence-based advice on pressing issues in health and health care.

Many of the studies that HMD undertakes are requested by federal agencies and independent organizations; others begin as specific mandates from Congress. Before any National Academies report is released, it undergoes extensive peer review by a second group of experts, whose identities remain anonymous to the authoring committee until the study is published. For decades, this process has resulted in sound publications providing policy makers, the health professions, and the American people with objective advice grounded in evidence.




While our consensus committees are vital to our advisory role, HMD also convenes a series of forums, roundtables, and standing committees. These activities facilitate discussion; discovery; and critical, cross-disciplinary thinking, and when required can quickly gather experts to address matters of urgent importance, such as emerging infectious diseases and health-related disaster preparedness.

OUR NAME

As of March 2016, the Health and Medicine division continues the consensus studies and convening activities previously undertaken by the Institute of Medicine. With this change, HMD is now fully integrated into the broader work of the National Academies, which is facilitating more collaborative and interdisciplinary approaches to the most pressing challenges facing the nation and the world.

Learn more at
nationalacademies.org/HMD

The National Academies are private, nonprofit institutions that provide independent, objective analysis and advice to the nation and conduct other activities to solve complex problems and inform public policy decisions related to science, technology, and medicine. The National Academies operate under an 1863 congressional charter to the National Academy of Sciences, signed by President Lincoln.

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WORKSHOP SPEAKERS, MODERATORS, AND PLANNING COMMITTEE MEMBERS

Darci Graves, MPP, MA, MA (Co-Chair of Planning Committee)

Centers for Medicare & Medicaid Services



Darci Graves serves as Special Assistant to the Director of the Office of Minority Health at the Centers for Medicare & Medicaid Services. In this role, she assists in the coordination and implementation of priority office-wide programs, policies, and products. In addition, she provides subject matter expertise in areas such as culturally and linguistically appropriate services, cancer, health disparities, and health equity.

Ms. Graves holds graduate degrees in Communications, Religion and Sociology, and Public Policy and has nearly 20 years of professional and academic experience in the fields of cultural and linguistic competence and health education. Darci began her career as a faculty member at the University of Missouri-Kansas City School of Medicine, where she aided in the development, implementation, and management of diversity, spirituality, communications, and geriatrics curricula. Since then she has continued to write and work in the area of cultural and linguistic competency as it relates to topics including public safety, disaster preparedness and response, language access, and domestic violence.

As a photographer, writer, and lifelong student, Darci is committed to sharing her journey and insights. Her life philosophy is that thought-provoking and inquisitive individuals can enhance the quality of people's lives through a commitment to respectful understanding, a lifetime of learning, and a profound sense of community. This philosophy has served as the underpinning to her personal, academic, and professional careers.

Peggy Maguire, JD (Co-Chair of Planning Committee)

Cambia Health Foundation



As president of Cambia Health Foundation, Peggy works with a wide range of stakeholders to drive health care transformation that results in better experiences for people and families. Sojourns®, the Foundation's signature program, promotes palliative care to help people with serious illness and their caregivers live well. Through Healthy People, Healthy Communities, the Foundation addresses social determinants of health, improves health equity, and empowers consumers to take charge of their health and wellbeing.

Under Peggy's leadership, the Foundation has evolved from a regional grant-making organization to a purposeful investor in person-centered, economically sustainable solutions. In 2016, the

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American Academy of Hospice and Palliative Medicine recognized the Cambia Health Foundation with its highest honor, a Presidential Citation.

Peggy also oversees Corporate Social Responsibility, Ethics, Compliance and Palliative Care Solutions for Cambia Health Solutions, the Foundation's parent company. Peggy provides leadership and strategic direction over Cambia's "Personalized Care Support" program, which includes regional health insurance benefits for palliative care services, as well as specialized case management and resources for family caregivers. Peggy also advises the company on strategic investments that address aging, caregiving and coordination of care.

Peggy joined the company in 1997 as an associate general counsel and has held several posts, including chief of staff to the CEO, vice president of Legal Services, and director of Litigation & Risk Management. Previously, Peggy worked as an attorney at Garvey Schubert & Barer.

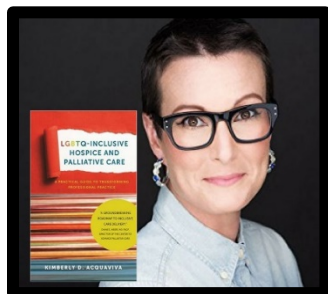
Peggy is very active in the philanthropic community. She chairs the board of directors of the Doernbecher Children's Hospital Foundation. She also serves as a member of the leadership advisory bodies for All Hands Raised, Dress for Success and Habitat for Humanity. Peggy is a senior fellow of the American Leadership Forum of Oregon. In 2017, Peggy chaired the American Heart Association's Go Red for Women campaign in Oregon and used that platform to promote health equity and palliative care awareness for people living with heart disease. She is the immediate past chair of the national board of Friends of the Children and the Oregon-based Start Making a Reader Today (SMART).

Peggy was recognized by Portland Monthly magazine as an Extraordinary Board Member in 2017 for her service to the community and leadership of the Cambia Health Foundation. She was honored by Dress for Success Oregon with its Athena Award in 2016, by the Girl Scouts of Oregon and Southwest Washington as a Woman of Distinction in 2015, and by the Portland Business Journal as a Woman of Influence in 2014.

She received her bachelor's degree in philosophy and anthropology from Lawrence University and her law degree from Northwestern School of Law of Lewis and Clark College. She has also completed the Stanford Executive Program and is a member of the Stanford Graduate School of Business Alumni Association

Kimberly D. Acquaviva, PhD, MSW, CSE

The George Washington University School of Nursing



Kimberly D. Acquaviva is a tenured professor at the George Washington University School of Nursing. On August 1, 2019, after 15 years at GW, she will be joining the University of Virginia School of Nursing in an endowed professorship. As a social worker teaching within a school of nursing, Dr. Acquaviva's scholarship is interdisciplinary and collaborative. Her scholarly work focuses on LGBTQ aging and end-of-life issues, and her clinical work has been with patients and families facing life-limiting illnesses in both hospital and hospice settings. Her

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book, *LGBTQ-Inclusive Hospice & Palliative Care: A Practical Guide to Transforming Professional Practice*, was published by Harrington Park Press and distributed by Columbia University Press. The book was awarded first place in the AJN Book of the Year Awards in the Palliative Care and Hospice Category. She's the host of *em dash* podcast, a show that explores the lived experiences of patients and healthcare professionals in the healthcare arena.

Dr. Acquaviva has a Ph.D. in Human Sexuality Education from the University of Pennsylvania Graduate School of Education, an M.S.W. from the University of Pennsylvania School of Social Policy and Practice, and a B.A. in Sociology from the University of Pennsylvania College of Arts and Sciences. She is an AASECT-Certified Sexuality Educator.

Nadine Barrett, PhD, MA, MS

Duke University School of Medicine



Nadine J. Barrett is an Assistant Professor in the Department of Community and Family Medicine at Duke University's School of Medicine. As a Medical Sociologist, Dr. Barrett applies over 20 years of health equity and stakeholder engagement expertise across several entities at Duke, regionally and nationally. She is currently the Associate Director of Community Engagement and Stakeholder Strategy for the Duke Cancer Institute and the Duke Clinical Translational Science Institute. She is also Director of Stakeholder Engagement for REACH Equity, Duke's Health Disparities Center of Excellence and the EQUAL ACP (Advanced Care Planning) study, a PCORI funded research project designed to reduce race disparities in advanced care planning among older, chronically ill patients. Dr. Barrett's work focuses on reducing health disparities across the following interrelated areas: (1) improve access to quality health care and services by linking communities and health systems, (2) Increase and diversify participation in clinical research and trials among traditionally underrepresented and marginalized populations; (3) advance the science and practice of community and stakeholder engagement, and (4), diversify the biomedical research workforce through pipeline training and programs.

For seven years, Dr. Barrett served as the inaugural director of the Duke Cancer Institute's Office of Health Equity. Together with diverse stakeholders, Dr. Barrett developed the strategic vision and direction of the office which led to an award winning health equity infrastructure that includes community facing navigation, a robust platform to facilitate community and stakeholder engagement, and mechanisms and programs to promote diverse participation in clinical research and trials, and increase diversity in the biomedical research workforce. Dr. Barrett is the Principal Investigator of an NCI funded program entitled Project PLACE (Population Level Approaches to Cancer Elimination), a community health assessment, engaging 22 community partners and reaching 2315 diverse respondents in NC. She also developed a system-level training program entitled, "Just Ask: Increasing Diverse Participation in Clinical Research and Trials," which is currently funded by the V Foundation. Nadine also works closely with North Carolina Central University as Co-

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Principal Investigator of two translational health disparities pipeline-training programs designed to diversify the biomedical research workforce.

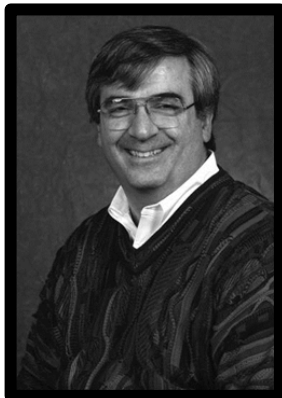
Prior to joining Duke, Dr. Barrett was Director of Community Programs at Susan G. Komen for the Cure, where she successfully engaged domestic and international affiliates to strategically identify community needs and allocate resources to improve breast cancer outcomes. During her tenure she secured over \$2 million in funding to implement health disparities research and programs, and managed a funding portfolio of \$2.5 million annually to facilitate community collaborations in the Greater Triangle and Eastern regions of NC.

Dr. Barrett is a member of several national and regional boards and committees including PCORI Health Disparities and Health Services Advisory Panel and the Association of Community Cancer Centers. She is the recipient of several national, regional, and community awards for her work in advancing health equity. She has received several awards for her work including the 2017 Association of Community Cancer Centers Innovator Award for Community Engagement, the 2017 Michelle P. Winn Diversity and Inclusive Excellence Award, Duke School of Medicine, and a 2017 NAACP Drum Major Justice Award in Community Health and Advancing Health Equity.

Robert A. Bergamini, MD

Mercy Clinic Children's Cancer

Representing the Supportive Care Coalition



Robert A. Bergamini has spent most of his 35-year career as a pediatric hematologist-oncologist, and from the beginning, included palliative care as a priority of his practice before the field was formally defined. This approach to whole person care provided a firm foundation for his current role as Mercy's ministry-level Medical Director for Palliative Care, which serves 39 hospitals and outpatient facilities/clinics across Missouri, Oklahoma, Arkansas and Kansas. He was appointed in 2013 to the Supportive Care Coalition's Board of Directors and is a member of the Coalition's Executive Committee. Following his Fellowship in Pediatric Hematology Oncology at St. Louis Children's Hospital, Washington University Department of Pediatrics, and serving as Clinical Instructor in Pediatrics at Washington University, in 1985 Dr. Bergamini entered private practice at Mercy St. Louis. Dr. Bergamini and his team established the first support group in the St. Louis area for siblings of children with cancer, and an educational support and intervention program to provide supplemental educational assistance and diagnostic testing. With the help of patients and staff, Friends of Kids with Cancer, a local charity was founded. Under Dr. Bergamini's leadership as Mercy's medical director of palliative care services, programs have started in three new communities and a pilot program is under way for palliative care and hospice care via telemedicine to meet the ministry's large rural population where density is less than six people per square mile. Mercy is in the final stages of obtaining accreditation for a palliative care fellowship and effective July 1, 2017, will have two positions available. Dr. Bergamini serves as the medical liaison to local faith-based communities. Initiatives include providing palliative care education for the Diocese of Little

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Rock and the Archdiocese of St. Louis. Dr. Bergamini is working with the Diocese of Little Rock on introduction of POLST legislation during the next session of the Arkansas legislature.

Lori Bishop, MHA, BSN, RN, CHPN

National Hospice and Palliative Care Organization



Lori Bishop is a healthcare nurse executive focused on innovative and transformational interdisciplinary care delivery models for the vulnerable seriously ill population. Lori has an extensive clinical background in hospice and palliative care. Her current position is Vice President of Palliative and Advanced Care at NHPCO. Previously, Lori was the Chief Advanced Illness Management (AIM) Executive for Sutter Health serving an average daily census of 2500 seriously ill patients across Northern California. Under her leadership, the Sutter Health AIM program reduced total program cost by 13% two consecutive years while achieving full performance for quality metrics. In 2017, she restructured the program including widespread implementation of primary palliative care in home health; implemented a standard palliative care patient satisfaction survey through a national vendor; implemented daily huddle, bi-weekly case conference, and monthly care conference leveraging patient level data to drive performance and care coordination. AIM received the inaugural Vanguard Award from the California Hospital Quality Institute in 2016. In her previous executive role at UnityPoint Health, Lori facilitated the creation of a system-wide palliative care program across care settings by developing standard clinical, operational, satisfaction, and financial metrics across sites of service. The system-wide integrated Palliative Care program received the prestigious Circle of Life Award in 2013. The team enhanced and optimized the electronic health record to pull clinical data for metric reporting and shared their build with other Epic users.

Shonta Chambers, MSW

Patient Advocate Foundation



Shonta Chambers is a seasoned non-profit executive and public health professional whose career spans more than 20 years' experience in chronic disease prevention, health promotion, community engagement and women's health. Currently, she serves as Executive Vice President-Health Equity and Community Engagement for Patient Advocate Foundation. Shonta is responsible for the development and execution of the Foundation's national strategy to address health equity, with a specific focus on persons with chronic, life threatening and debilitating diseases residing in low income communities with high chronic disease mortality. She specifically drives program initiatives that support minority populations with limited basic and/or health literacy. As the staff lead for PAF's health equity work promoting person-centered care, Ms. Chambers strategically engages with community stakeholders to align resources in collaborative efforts which mitigate as many health care barriers as possible for limited resourced populations.

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Additionally, Shonta is the Principal Investigator on record as part of DP18-1808 Networking2Save: CDC's National Network Approach to Preventing and Controlling Tobacco related Cancers in Special Populations Cooperative Agreement. In this role, she oversees PAF's SelfMade Health Network, a national network focused on reducing cancer and tobacco-related disparities among populations with low socio-economic characteristics.

As a caregiver of her mother who lives with progressive multiple sclerosis, Shonta understands firsthand the challenges that patients with chronic conditions experience and the emotional and physical isolation experienced by caregivers that often goes unnoticed and untreated.

Alice Huan-mei Chen, MD, MPH

San Francisco Health Network and UCSF



Alice Chen is the chief medical officer and deputy director for the San Francisco Health Network (SFHN), and professor of medicine at the University of California San Francisco (UCSF). She has dedicated her career to improving the health of underserved individuals and communities through direct patient care, teaching, policy and advocacy, and administrative leadership across a variety of settings, including public health, philanthropy, academia, and government.

In her role at SFHN, Dr. Chen is responsible for providing clinical and operational leadership, vision, and direction for the San Francisco Department of Public Health's nearly \$2 billion a year publicly funded delivery system that encompasses primary, specialty, maternal and child health, mental health, substance use, acute care, trauma, long term, jail health, and homeless health care services. She has led the Network's work responding to value-based payments, addressing patient-level social determinants of health, and creating an integrated system of care.

Known for her work with vulnerable populations and delivery system innovations to improve access and quality of care for safety net systems, Dr. Chen has published over 50 book chapters, research and peer-reviewed articles, including in the *New England Journal of Medicine* and *Health Affairs*. She has served on the board of several non-profits and foundations as well as on expert advisory committees, and currently serves as board president for Health Access Foundation and The Health Initiative.

A graduate of Yale University, Stanford University Medical School, and the Harvard School of Public Health, Dr. Chen's training includes a primary care internal medicine residency and chief residency at Brigham and Women's Hospital. She is an alumna of the Commonwealth Fund Fellowship in Minority Health Policy at Harvard, the Soros Physician Advocacy Fellowship, the California HealthCare Foundation Leadership Program and the Aspen Institute's Health.

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Marshall Chin, MD, MPH

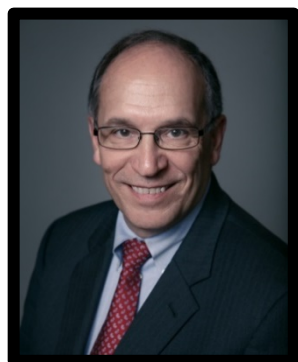
University of Chicago Medicine



Marshall Chin Richard Parrillo Family Professor of Healthcare Ethics in the Department of Medicine at the University of Chicago, is a general internist and health services researcher with extensive experience improving the care of vulnerable patients with chronic disease. He co-directs the Robert Wood Johnson Foundation Advancing Health Equity: Leading Care, Payment, and Systems Transformation National Program Office and the Merck Foundation Bridging the Gap: Reducing Disparities in Diabetes Care National Program Office. Dr. Chin serves on the National Advisory Council to the National Institute on Minority Health and Health Disparities and the Families USA Health Equity and Value Task Force Advisory Council. He co-chairs the National Quality Forum Disparities Standing Committee and is a former President of the Society of General Internal Medicine. Dr. Chin was elected to the National Academy of Medicine in 2017.

Steve Clauser, PhD, MPA

Patient-Centered Outcomes Research Institute (PCORI)



Steve Clauser is the Program Director of the Healthcare Delivery and Disparities Research program at the Patient-Centered Outcomes Research Institute (PCORI). He is responsible for developing PCORI's research program that evaluates comparisons among alternative health system strategies to improve patient outcomes in a broad range of clinical and organizational domains.

Clauser is a health services and outcomes researcher with over 25 years of research management experience. His past research has focused on developing measures of patient reported outcomes, care experiences, and clinical effectiveness for use by health care organizations to track, assess, and improve the quality of care they provide to adults with cancer and other chronic diseases. Before coming to PCORI, Clauser held the positions of associate director for the National Cancer Institute's (NCI) Community Oncology Research Program, as well as chief of NCI's Outcomes Research Branch. He also was co-director of NCI's Community Cancer Centers Program, where he developed and managed a variety of research projects related to system strategies to improve cancer care delivery, including methods to increase adherence to evidence based practice and models of multidisciplinary treatment planning for patients requiring multi-modal cancer treatment. He has expertise in a broad range of research methodologies used for assessing patient reported outcomes and quality improvement programs.

Before NCI, Clauser served in a number of senior research management positions at the Centers for Medicare and Medicaid Services. His most recent position was director of the Quality Measurement and Health Assessment Group in the Office of Clinical Standards and Quality, where he directed

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CMS quality measurement research initiatives in support of Medicare's consumer quality reporting programs in managed care organizations, hospitals, nursing homes, home health agencies, and renal dialysis centers. He also served as director, operations policy directorate, in the Office of the Assistant Secretary for Health Affairs, where he directed the CHAMPUS Reform program to improve primary care for military dependents and retirees. Clauser received his BA from Michigan State University, PhD from the University of Minnesota, and MPA from the Hubert H. Humphrey Institute in Minneapolis.

Daniel Dawes, JD

Morehouse School of Medicine and Health Equity Leadership and Exchange Network (HELEN)



Daniel E. Dawes is a nationally recognized leader in the movement to advance health equity among under-resourced, vulnerable and marginalized communities. An attorney, scholar and health policy expert, Dawes brings a forward-thinking, inclusive and multidisciplinary approach to the law and public policy, and has been at the forefront of recent major federal health policy negotiations in the United States. Among his many achievements, he was an instrumental figure in shaping the *Mental Health Parity Act*, the *Genetic Information Nondiscrimination Act*, the *Americans with Disabilities Act Amendments Act*, and the *Affordable Care Act* ("ObamaCare").

Dawes is the Executive Director of Health Policy at Morehouse School of Medicine, Associate Professor in the Department of Community Health and Preventive Medicine, Senior Advisor and General Counsel to the Satcher Health Leadership Institute at Morehouse School of Medicine and an Associate Professor of complex health systems at Nova Southeastern University in Ft. Lauderdale, Florida. In addition, he is the co-founder of the Health Equity Leadership & Exchange Network (HELEN), which is a nationwide network of over 1500 governmental and non-governmental leaders and scholars focused on bolstering leadership and the exchange of research, information, and solutions relative to the advancement of evidence-based health equity-focused policies and programs.

A published expert on health reform, health equity, and the social determinants of health, Dawes is the author of the groundbreaking book, *150 Years of Obamacare*, published by Johns Hopkins University Press, which has received critical acclaim and endorsements from a bipartisan group of national leaders. He is currently the editor of the Johns Hopkins University Press special book series, *Health Equity in America*, and the author of a forthcoming book, *The Political Determinants of Health*, which will also be published by Johns Hopkins University Press.

Dawes has served as an Attorney & Manager of Federal Affairs and Grassroots Network for Premier healthcare alliance and Senior Legislative and Federal Affairs Officer at the American Psychological Association (APA). Prior to working for the APA, he worked on the United States Senate Health, Education, Labor, and Pensions (HELP) Committee under the leadership of Senator Edward M. Kennedy where he advised the Senator and members of the committee on an array of issues related to health care, public health, employment, education, and disability law and policy.

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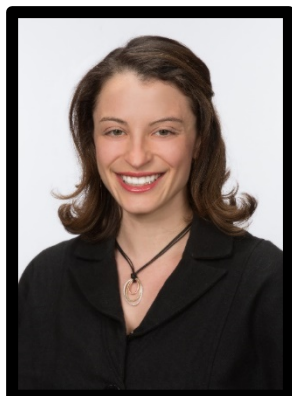
Prior to his work with the Senate HELP Committee, Dawes received the prestigious Louis Stokes Health Policy Fellowship and worked for the CBC Health Braintrust under the leadership of Congresswoman Donna M. Christensen, M.D. on legislative efforts related to health system transformation, health disparities, disability, and emergency preparedness/bioterrorism.

Dawes is an elected fellow of the New York Academy of Medicine and serves on several boards, commissions, and councils focused on improving health outcomes and elevating health equity in the United States, including the Centers for Disease Control and Prevention (CDC) Federal Advisory Committee on Health Disparities, Robert Wood Johnson Foundation's National Advisory Committee, Association of American Medical Colleges Health Equity Advisory Board, the National League of Cities National Advisory Board, the National Urban League's Advisory Panel, The White House National HIV/AIDS Strategy Committee, the Better Medicare Alliance's Council of Scholars, the Aetna Foundation's Healthiest Cities & Counties Challenge Advisory Council, National Health IT Collaborative for the Underserved National Advisory Board, the Hogg Foundation for Mental Health National Advisory Council, the Healthcare Georgia Foundation Board of Directors, the Alliance for Strong Families and Communities Board of Directors, the New York City Department of Health & Mental Hygiene Mental Health Advisory Group, and the Children's Mental Health Network National Advisory Council.

He is the recipient of several national awards and recognition, including the American Public Health Association's Medical Care Section Award for Significant Contribution to Public Health, the American Psychological Association's Exceptional Leadership in Advocacy Award, the Centers for Disease Control and Prevention's Health Equity Champion Award, Families USA Health Equity Advocate Award, the National Medical Association's Louis Stokes Health Policy Award, Honorary Doctor of Humane Letters from Nova Southeastern University, NMQF Minority Health Leader Award, the CBC Leadership in Advocacy Award, the University of Nebraska Master Alumni Award, Gift of Life Healthcare Vanguard Award, and the SHIRE Health Reform Champion Award. In addition, he was the 2019 Southern Illinois University School of Medicine's Ted LeBlang Distinguished Lecturer, the 2019 Creighton University School of Law TePoel Distinguished Lecturer, 2019 Union College George Gibson Distinguished Lecturer, 2018 Howard University School of Medicine Distinguished W. Montague Cobb Lecturer, 2017 Saint Louis University School of Law Distinguished Lecturer, 2016 Harvard University HEAL Lecturer, the 2016 Distinguished Speaker Series Lecturer at Nova Southeastern University, the 2013 Distinguished Bowman Lecturer at the University of Chicago Pritzker School of Medicine, and the 2012 Distinguished Bellos Lecturer at Yale University. Daniel holds a Bachelor of Science degree in business administration and psychology and a Juris Doctor degree from the University of Nebraska.

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Sarah Downer, JD
Harvard Law School



Sarah Downer is the Associate Director of the Center for Health Law and Policy Innovation of Harvard Law School and leads the Center's Whole Person Care Initiative, which seeks to improve care for underserved individuals at every point of interaction with the healthcare system. She works with clients and partners to nurture innovations in healthcare delivery and financing, scale successful interventions, convene effective coalitions, translate emerging research into comprehensive and compelling resources for policy-makers, and to explore the short and long-term implications of healthcare trends. Ms. Downer also leads the Center's Social Determinants of Health Law Lab, a special project dedicated to analyzing novel legal issues that arise when the healthcare system interacts with patients in new ways. Ms. Downer has a BA from Harvard College and JD from Harvard Law School.

Sister Anne Francioni, SSND, RN, MA
Whole Kids Outreach



Sr. Anne Francioni, SSND, RN, MA, is the Executive Director and founder of Whole Kids Outreach (WKO). She has worked in the field of children's health and development for 40 years as a nurse and administrator. Sr. Anne holds degrees in Nursing, Special Education and a Nonprofit Management.

Sr. Anne sits on the boards of the Ozark Foothills Community Foundation, the Ozark Regional Planning Commission and the Black River Medical Foundation. She is also a member of the Ellington Chamber of Commerce and Community Intergenerational Day Care Committee. She is the recipient of the Dr. Corinne Walentic Leadership in Health Award; the Women's Justice Award for Citizenship; the American Academy of Pediatrics, Child Advocate of the Year and the Women of the Well Award.

When Sr. Anne Francioni, SSND, RN, MA moved to Missouri from her home in New Orleans, she pursued her dream of being a pediatric nurse in two of St. Louis's children's hospitals. From there she accepted the role of director of St. Mary's Special School in St. Louis where she worked with children who had significant and varied physical and developmental challenges. Later came her call to serve God as a School Sister of Notre Dame. It was then she was led to southeast Missouri to assist other Sisters who were working in the area and received permission to start Whole Kids Outreach in 1999. She has continued to be an agent of change in the region, helping families to work toward better futures for their children.

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Bridgette Hempstead

Cierra Sisters



Cierra Sisters, Inc. is an African American Breast Cancer organization which uniquely provides education and advocacy about women's breast and health issues. Bridgette's personal, hands on approach, has and is changing the lives of women all across the country. Her determination to educate and empower others comes out of her own experience with breast cancer. Bridgette is a 23 year three time breast cancer survivor and she received her diagnosis on her 35th birthday.

At that time, she Bridgette is a 23 year three time breast cancer survivor and she received her diagnosis on her 35th birthday. At that time, she found no resources for African American women. Therefore, she became the solution, and Cierra Sisters, Inc. was born. She found that women's fear of breast cancer was due largely to the lack of knowledge. As the late author and entertainer, Earl Nightingale once stated, "Whenever we're afraid, it's because we don't know enough. If we understood enough, we would never be afraid." Inspired by Ms. Nightingale's words, Bridgette chose the African word "Cierra" which means "knowing" to identify and share community resource and to create educational opportunities as an organization which she launched on February 23, 1996. Cierra Sisters is helping to change the way members of our local and global community, think about cancer by taking the fear out of the word cancer and replacing it with knowledge which ultimately leads to personal empowerment.

As Bridgette's reputation grew in the health community, more and more patients were being referred to her by doctors, family members, LGBT, and religious institutions for her assistance in navigating individuals through the health care system. Her efforts helped many to connect with the proper resources, support networks and casting down the fears that come with a cancer diagnosis. Over the years Bridgette has been featured on, City Stream, Channel 9 KCTS Connects; Channel 4 KOMO Fisher Broadcasting, The Good News about Breast Cancer; King 5 News with Jean Enerson featuring a unique door-to-door outreach; K.R.I.Z. Radio with Barbara Laners, Community Potpourri; The Seattle Times; A National Health Care forum along with Teresa Heinz Kerry; Everyday Health News (a leading provider in health solutions); a documentary on Bridgette's story through Seattle Theater Group and Seattle Cancer Care Alliance.

Her most recent conference poster session presentation was at the American Society of Preventative Oncology Conference in Seattle March 2017 titled Community Empowerment Partners: Examining the use of peer education to empower African American Women to improve breast health.

Bridgette recently published an article in the Journal of Community Health "Community Empowerment Partners (CEPs): A Breast Health Education Program for African-American Women." This work includes the development of an evidence-based breast health curriculum tool kit; CEPs Cierra Empowerment Partners for community members who can then share it within their own networks to empower the underserved community. CEPs breast health has become a model for other peer education structures. The CEPs model has recently been adapted to educate those effected by endometrial cancer in African American woman. With the launch of the first national training of ten CEPs EC ambassadors. The ECANA Conference was held in Honolulu March 2019, with the hope

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of saving the lives of African American Women diagnosed with Endometrial Cancer. CEPs EC is on the ground running.

Bridgette is an engaging and effective speaker, a songwriter, and a soul piercing singer. Her single, “Sista Don’t You Know,” will encourage you through your cancer journey.

Ziad R. Haydar, MD, MBA

Ascension Health



Ziad Haydar, MD, MBA, is Ascension Healthcare’s Senior Vice President and Chief Clinical Officer. Dr. Haydar leads the organization’s Care Excellence efforts advancing exceptional care for all. In his role, Dr. Haydar works with individual market leaders to advance the quadruple aim of exceptional health outcomes, exceptional experience for those we serve, and exceptional provider experience at an affordable and sustainable cost. Dr. Haydar joined Ascension in 2010 as Vice President, Clinical Excellence and Physician Integration. He previously was an executive with Baylor Health Care System in Dallas, Texas, where he served as the Vice President for Health Care Improvement and Director of the Center for Health Care Improvement.

Dr. Haydar received his medical degree from American University of Beirut, trained in Family Medicine at the Medical University of South Carolina, Charleston, and completed a fellowship in Geriatrics and Gerontology at Johns Hopkins University School of Medicine, Baltimore. As an executive, Dr. Haydar obtained a Master of Business Administration from the Cox School of Business at Southern Methodist University, Dallas.

Haiden Huskamp, PhD

Harvard Medical School



Haiden Huskamp is a health economist and 30th Anniversary Professor of Health Care Policy at Harvard Medical School. Dr. Huskamp has three primary areas of research: 1) the financing and utilization of end-of-life care services; 2) mental health and substance use disorder policy; and 3) prescription drug policy. Dr. Huskamp’s research on end-of-life care has examined the changing characteristics of the hospice industry and the effects of industry changes on the provision of end-of-life care, the timing of discussions about hospice care that occur between physicians and patients, and patient-level variation in hospice costs. She served on the Centers for Medicare and Medicaid Services Technical Expert Panel for Hospice Payment Reform and on the Institute of Medicine Committee on Care for Children Who Die and Their Families. Dr. Huskamp recently authored a paper on the financing of end-of-life care services published in the Institute of Medicine report “Dying in America.”

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Kimberly Sherell Johnson, MD

Duke University School of Medicine



Dr. Kimberly S. Johnson is an Associate Professor with Tenure in the Department of Medicine, Division of Geriatrics, Center for Aging, and Center for Palliative Care at Duke University Medical Center in Durham, North Carolina. Her research focuses on understanding and eliminating racial disparities in palliative and end-of-life care.

She has published widely and is nationally recognized for her work investigating how cultural beliefs and preferences and organizational practices and policies may influence the use of hospice care by older African Americans. Dr. Johnson is the Director of the Duke Center for Research to Advance Health Care Equity (REACH Equity). The Center focuses on developing and testing interventions to reduce racial disparities by improving the quality of patient-centered care in the clinical encounter.

Edward Machtinger, MD

UCSF



Edward Machtinger is a Professor of Medicine and Director of the Women's HIV Program (WHP) and the Center to Advance Trauma-informed Health Care (CTHC) at the University of California, San Francisco (UCSF). The current focus of Dr. Machtinger's research, advocacy, and clinical innovation is implementing and evaluating a scalable model of trauma-informed health care. Dr. Machtinger convened, with Positive Women's Network-USA, a national strategy group to develop a model of trauma-informed health care to guide national implementation and evaluation efforts.

His latest publications include: a conceptual framework for trauma-informed health care, practical guidance for inquiry about recent and past trauma in health care settings, a meta-analysis describing high rates of trauma and PTSD among US HIV-positive woman, and a study demonstrating a significant association of recent trauma and HIV antiretroviral treatment failure. Dr. Machtinger is also interested in the healing power of peer-led trauma interventions. He recently published a studies describing the positive impacts of an expressive therapy intervention using theater for women living with HIV and histories of trauma as well as of a group intervention for co-occurring substance use disorder and PTSD.

In partnership with the Robert Wood Johnson Foundation, he now leads a national demonstration site of trauma-informed health care at UCSF. His team is conducting one of the first prospective implementation studies of this model, with the goal of publishing an evidence-based blueprint to guide future research and facilitate implementation in a variety of clinical settings.

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Dr. Machtinger is a respected thought leader and advocate nationally for policy pertaining to trauma-informed care. He serves on the NIH prioritization committee for women and girls with HIV across all institutes and helped lead the effort to include addressing trauma as a national research priority. He has been a consultant and technical expert about trauma-informed health care for the Substance Abuse and Mental Health Administration (SAMHSA) and Health Resources and Services Administration (HRSA). In addition, he advised the Presidential Federal Working Group on the Intersection of HIV/AIDS, Violence Against Women and Gender-related Health Disparities and was a keynote speaker at the White House release of their final report. He serves on the Executive Committee of the AIDS Research Institute (ARI) at UCSF and the Executive Committee for the oversight of Congressional Ryan White funds to women and children in San Francisco.

Dr. Machtinger is also a respected clinician, teacher and mentor and was the recipient of the UCSF School of Medicine 2013 Osler Distinguished Teaching Award. He is a graduate of Harvard Medical School and performed his residency in internal medicine at UCSF. Dr. Machtinger's other interests include the well-being of animals and the environment and the relationship between human health, animal welfare, and environmental stewardship.

Liz Margolies, LCSW

National LGBT Cancer Network



Liz Margolies, LCSW, is the founder and executive director of the National LGBT Cancer Network, the first and only national program addressing the needs of LGBT people with cancer and those at risk. Based in NYC, the Network focuses on education, training, advocacy and support. Liz is also a psychotherapist in private practice, specializing in trauma, loss, health disparities and sexuality.

In 2014 Liz was chosen as one of the OUT100 for her work in the LGBT community.

Diane E. Meier, MD, FACP

Center to Advance Palliative Care



Diane E. Meier is Director of the Center to Advance Palliative Care (CAPC), a national organization devoted to increasing the number and quality of palliative care programs in the United States. Under her leadership the number of palliative care programs in U.S. hospitals has more than tripled in the last 10 years. She is also Vice-Chair for Public Policy and Professor of Geriatrics and Palliative Medicine; Catherine Gaisman Professor of Medical Ethics; and was the founder and Director of the Hertzberg Palliative Care Institute from 1997-2011, all at the Icahn School of Medicine at Mount Sinai in New York City. Dr. Meier is the recipient of numerous awards, including the 2008 MacArthur Fellowship. She was named one of 20 People Who Make Healthcare Better in the U.S. by *HealthLeaders Media* 2010 and received an Honorary Doctorate of Science from Oberlin College in 2010. In 2012, she was awarded

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American Cancer Society's Medal of Honor for Cancer Control in recognition of her pioneering leadership of the effort to bring non-hospice palliative care into mainstream medicine. Other honors include the Open Society Institute Faculty Scholar's Award of the Project on Death in America, the Founders Award of the National Hospice and Palliative Care Organization 2007, AARP's 50th Anniversary Social Impact Award 2008, Castle Connolly's Physician of the Year Award 2009 and the American Academy of Hospice and Palliative Medicine Lifetime Achievement Award 2009. Dr. Meier served as one of Columbia University's Health and Aging Policy Fellows in Washington, DC during the 2009-2010 academic year, working both on the Senate's HELP Committee and the Department of Health and Human Services. Dr. Meier has published more than 200 original peer review papers, and several books. Her most recent book, *Meeting the Needs of Older Adults with Serious Illness: Challenges and Opportunities in the Age of Health Care Reform*, was published by Humana in 2014. She edited the first textbook on geriatric palliative care, as well as four editions of *Geriatric Medicine*. Diane E. Meier received her BA from Oberlin College and her MD from Northwestern University Medical School. She completed her residency and fellowship training at Oregon Health Sciences University in Portland. She has been on the faculty of the Department of Geriatrics and Palliative Medicine and Department of Medicine at Mount Sinai since 1983. She lives in New York City.

Adán Merecias

Familias en Acción



Adán Merecias works as a Community Health Worker for Familias en Acción. He provides services to insured and uninsured Latino members who have chronic condition. He graduated in 2009 from Portland State University with a BS in Community Health Education. Adán is a certified Leader for a number of classes such as Diabetes Self-Management Class, Chronic Disease Management, Walk With Ease, Seed to Supper and Un Abrazo. He is a certified Community Assister and a certified Community Health Worker who currently helps Latino Families apply for medical coverage. Adán's current role is to help Latino families understand how to use the health system and to address any social barrier that families are facing. When Adam is not at work, he enjoys spending time with his wonderful wife and daughter Ita.

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Thomas M. Priselac, MPH

Cedars-Sinai Health System



Thomas M. Priselac, also known as Tom, has been the Chief Executive Officer and President of Cedars-Sinai Medical Center since January 1994. Mr. Priselac has been associated with Cedars-Sinai since 1979. He served as an Executive Vice President of Cedars-Sinai Medical from 1988 to 1993. Before joining Cedars-Sinai, Mr. Priselac was on the executive staff at Montefiore Hospital. He serves as Chairman of the American Hospital Association Board of Trustees. Mr. Priselac has been a Director of California Regional Health Information Organization since December 2005. He serves as a Director of Cedars-Sinai Medical Center. He serves as Term Trustee at Washington & Jefferson College. He serves as Member of Board of Directors of Summation Health Ventures. He serves on the Los Angeles Chamber of Commerce Board. He served as a Director of VHA Inc. until April 2003. Mr. Priselac was Chair of the Association of American Medical Colleges. Mr. Priselac chaired the Hospital Association of Southern California, the California Healthcare Association, and the Association of American Medical Colleges Council of Teaching Hospitals. He is the holder of the Warschaw/Law endowed Chair in Healthcare Leadership at Cedars-Sinai Medical Center. Mr. Priselac is an author and invited speaker on a variety of contemporary issues facing the health care field today including policy issues related to the delivery and financing of health care, health care quality and safety and the adoption and implementation of information technology. He obtained Master's in public health, health services administration and planning, from the University of Pittsburgh and Bachelor's Degree in biology from Washington and Jefferson College in Pennsylvania.

JoAnne Reifsnyder, PhD, RN, FAAN

Genesis Healthcare

Representing the Hospice and Palliative Nurses Association



JoAnne Reifsnyder has been the Chief Nursing Officer of Genesis Healthcare, Inc. since July 2012 and also serves as its Executive Vice President of Clinical Operations. Dr. Reifsnyder has held executive and leadership roles in both for profit and not for profit health care settings. Prior to joining Genesis, Dr. Reifsnyder was Senior Vice President, Care Transitions, with Moorestown, NJ-based Care Kinesis, LLC. In this role, she served as a consultant to Genesis HealthCare and to Bayada Nurses, working with executives and clinical team members to develop a skilled nursing facility to home transitional care model for vulnerable older adults.

Dr. Reifsnyder was Chief Quality Outcomes officer for excelleRx, Inc., a Philadelphia-based medication management therapy company. She was also co-founder and partner in Ethos Consulting Group, LLC, a company focused on program development, education/training and research/evaluation to advance end of life care. She was formerly the Director of the Hospice Program for the VNA of Greater Philadelphia and was Director of Patient Services for Samaritan Hospice in Marlton, NJ. Dr. Reifsnyder served as President of the Board of Directors for the Hospice and Palliative Nurses Association, Pennsylvania Hospice Network, and LifeChoice Hospice and

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currently serves on the Board of Hospice Foundation of America. She is a member of the American Nurses Association, the American Academy of Nursing, American Organization of Nurse Executives (AONE), the National Gerontological Nurses Association (NGNA) and Sigma Theta Tau International, the Honor Society of Nursing. In 2002, Dr. Reifsnnyder co-developed and was the coordinator of a palliative care minor at the University of Pennsylvania School of Nursing, where she taught both core courses to nursing, social work and medical students. In 2009, she led the development of the first Masters' program in Chronic Care Management at Jefferson School of Population Health (JSPH), Thomas Jefferson University in Philadelphia, PA. Dr. Reifsnnyder completed a postdoctoral fellowship in psychosocial oncology at the University of Pennsylvania School of Nursing, and holds a PhD in nursing from the University of Maryland, a Master's Degree in nursing from Thomas Jefferson University, and a BSN from Holy Family College. She will complete the requirements for a Master's in Business Administration from George Washington University in December, 2016.

Diane Rowland, ScD

The Henry J. Kaiser Family Foundation



Diane Rowland, Executive Vice President of the Kaiser Family Foundation, is a nationally recognized health policy expert with a distinguished career in public policy and research focusing on health insurance coverage, access to care, and health financing for low-income, elderly, and disabled populations. She oversees the Foundation's health policy analytic work on Medicaid, Medicare, private health insurance, HIV and global health policy, women's Health Policy, and disparities. Dr. Rowland is also an Adjunct Professor in the Department of Health Policy and Management at the Bloomberg School of Public Health of the Johns Hopkins University.

An expert on Medicaid policy, from 1991-2016, Dr. Rowland served as Executive Director of the Foundation's Kaiser Commission on Medicaid and the Uninsured, now the Kaiser Program on Medicaid and the Uninsured. From 2009-2015, she served as the inaugural Chair of the congressionally-authorized Medicaid and CHIP Payment and Access Commission (MACPAC) established to advise Congress on issues related to Medicaid and the Children's Health Insurance Program (CHIP).

A noted authority on health policy, Medicare and Medicaid, and health care for poor and disadvantaged populations, Dr. Rowland frequently testifies as an expert witness before the United States Congress on health policy issues. She has also published widely on these subjects and is the editor of several books, including *Financing Home Care* and *The Medicaid Financing Crisis: Balancing Responsibilities, Policies, and Dollars*, and is a co-author of *Medicare Policy: New Directions for Health and Long-Term Care of the Elderly* and *Health Care Cost Containment: Lessons from the Past and a Policy Proposal for the Future*. Her federal health policy experience includes service on the staff of the Committee on Energy and Commerce in the House of Representatives of the U.S. Congress, as well as senior health policy positions in the Department of Health and Human Services.

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Dr. Rowland is an elected member of the National Academy of Medicine (NAM) formerly known as the Institute of Medicine, a founding member of the National Academy for Social Insurance, and Past President and Fellow of the Association for Health Services Research (now Academy Health). She has previously served on the Boards of Grantmakers in Health, the Association for Health Services Research, and Academy Health and as a member of numerous commissions and task forces. She holds a bachelor's degree from Wellesley College, a Master's in Public Administration from the University of California at Los Angeles and a Doctor of Science in health policy and management from the Bloomberg School of Public Health at the Johns Hopkins University.

Justin Sanders, MD, MSc

Ariadne Labs, Dana-Farber Cancer Institute, Brigham and Women's Hospital, and Harvard Medical School



Justin Sanders is a Family Medicine-trained Palliative Care physician at Dana-Farber Cancer Institute and Brigham and Women's Hospital in Boston, Massachusetts. He is an Instructor of Medicine at Harvard Medical School and a faculty member in the Serious Illness Care Program at Ariadne Labs. The Serious Illness Care Program focuses on implementation of a system-level approach for increasing clinician capacity to ensure high-quality discussions about patients' goals, values, and priorities. Dr. Sanders' research and implementation work focuses on understanding and ameliorating communication-driven disparities in care for the seriously ill through system-level interventions and social science-informed research. Dr. Sanders has a master's degree in Medical Anthropology. He was recognized in 2016 as an emerging leader in the field of Palliative Care with a Sojourns Scholar Leadership Award from the Cambia Health Foundation.

Andy Slavitt, MBA

Town Hall Ventures and Former CMS Administrator



Andy has shaped some of the country's most significant health care initiatives that impact millions of Americans. From 2015 to 2017, he served as the Acting Administrator for the Centers for Medicare & Medicaid Services (CMS) under President Obama, overseeing the Medicaid, Medicare, the Children's Health Insurance Program, and the Health Insurance Marketplace. Prior to that, Andy oversaw the successful turnaround of healthcare.gov and served as a Group Executive Vice President of Optum, which he grew from its inception to \$35 billion in revenues. Andy is currently Board Chair of United States of Care, a national non-profit health think-tank and advocacy organization he founded to achieve full, sustainable access to health care for all American families. Andy co-chairs The Future of Healthcare initiative at the Bipartisan Policy Center and chairs the Medicaid Transformation Project which aims to transform care for the most vulnerable. He is also the founder and General Partner of Town Hall Ventures, which invests in health care innovations in vulnerable communities. Andy was named top

ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

Politico 50; was recognized by Modern Healthcare as one of the 10 most influential people in health care; and was named the Most Influential Healthcare Tweeter by Healthcare Dive. Andy is a graduate of the University of Pennsylvania, (BA and BS) and Harvard University, (MBA).

Sandy Chen Stokes, RN, MSN

Chinese American Coalition for Compassionate Care



Sandy Chen Stokes founder and former ED of the Chinese American Coalition for Compassionate Care (CACCC), is an internationally recognized speaker. She has been providing end of life education and training for the Chinese community and health professionals since 2005. Under Sandy's leadership, the CACCC produced end of life DVDs, books, and other educational materials in Chinese, where none existed before. Sandy created CACCC's Heart to Heart® cards and developed the Heart to Heart® Café, where the cards are used to facilitate end of life conversations that lead to Advanced Care Planning. CACCC workshops and training have focused on Advance Care Planning, hospice and palliative care, respite and spiritual care, Chinese cultural beliefs and practices, and the role of medical interpreters. In 2009, Sandy received the American Cancer Society's National Lane Adams Quality of Life Award for her work with the CACCC. In 2011, she received the AARP's Inspire Award. In 2017, she received the Compassionate Care Innovator Award from Coalition for Compassionate Care of California. Sandy is a member of the advisory board for the Chinese Health Initiative at El Camino Hospital in Mountain View, CA and a member of the National Hospice and Palliative Care Organization's (NHPCO) Diversity Advisory Council.

Susan Elizabeth Wang, MD

Southern California Permanente Medical Group Kaiser Permanente



Susan Elizabeth Wang is the medical director for the Kaiser Permanente (KP) National Quality Initiatives in Shared Decision Making and Life Care Planning for KP Southern California. In this role, she has implemented a centralized advance care planning tab in an EPIC-based EMR including an E-POLST, developed a primary palliative care curriculum for physicians and other health disciplines, and expanded advance care planning to 60k members in the past year. Dr. Wang is Chief of the Department of Geriatrics & Palliative Medicine at KP West Los Angeles which includes the operation of a hospital consult service, two outpatient clinics, SNF rounding and a Hospice and Community-Based Palliative Care agency. She is director emeritus of the KP LA Hospice & Palliative Medicine fellowship, a program she started in 2008. She is an assistant clinical professor at UCLA and triple board-certified in Internal, Geriatric and Palliative Medicine. She is also Co-Investigator on the PCORI Technology-Enabled Home-Based Palliative Care study.

DONATIONS TO HELP CIERRA SISTERS

Name _____

Address _____

Phone _____

Email _____

I would like to donate:

- ☐ Volunteer time
- ☐ Tax-deductible donation of: _____

Please mail this form to:
PO Box 1634
Renton, WA 98057

FOR MORE INFORMATION, PLEASE CONTACT
CIERRA SISTERS AT (206) 505-9194.
WWW.CIERRASISTERS.ORG



CIERRA SISTERS, INC. is a 501(c)3 nonprofit organization dedicated to African-American breast cancer support that was founded by cancer survivor Bridgette Hempstead who was diagnosed February 21, 1996 on her 35th birthday.

Our mission is to “break the cycle of fear” and increase knowledge concerning breast cancer in the African-American and underserved communities. Cierra Sisters is committed to increasing local, state, nationwide, and global attention to the devastating impact of breast cancer.

We are dedicated to promoting the importance of education and advocacy through our Each-One-Teach-One program, community collaborations, and outreach projects. Cierra Sisters provides one-on-one and group support to both newly diagnosed women and cancer survivors who are in need of strong social, emotional, and spiritual support.

CIERRA IS AN AFRICAN WORD THAT MEANS “KNOWING.” WHEN WE HAVE KNOWLEDGE, WE HAVE THE POWER TO FIGHT AGAINST THE EFFECTS OF BREAST CANCER.

MEETINGS

- Every fourth Thursday of the month
- 6:15 pm – 8:15 pm

Rainier Beach Community Center
8825 Rainier Ave S, Seattle, WA 98118

Cierra Sisters



AN AFRICAN-AMERICAN
BREAST CANCER
SURVIVOR & SUPPORT
ORGANIZATION

WWW.CIERRASISTERS.ORG • 206.505.9194

WHAT SHOULD YOU DO?

WHAT ARE THE WARNING SIGNS?

WHAT ARE THE RISK FACTORS?

You are the best defense against breast cancer!

We recommend these steps for early detection:

- **Breast self exam (BSE)**
Every month, starting at age 20
- **Clinical breast examination by a trained medical professional**
Every 2-3 years, beginning at age 20
Each year, after age 40
- **Mammogram**
Each year, after age 35

If your mother or sister has had breast cancer, you may need to get a mammogram earlier and more frequently.

Breast self-exam should be done just as your period ends, or for post-menopausal women, the same day each month. This simple technique allows a woman to become more familiar with her breasts, making it easier to detect subtle—but important—changes or abnormalities.

Breast ultrasound is frequently useful in evaluating breast and mammography abnormalities, especially in young women.

- Lump, hard knot, or thickening in the breast
- Swelling, redness, or increased warmth in the breast
- Change in the size of shape of the breast
- Itchy, sore or scaling area on the nipple or areola
- Nipple discharge (particularly if bloody) that starts suddenly
- Pulling in of the nipple
- Dimpling or puckering of the side of the breast
- Unusual pain in an area of the breast

EARLY DETECTION IS THE BEST PROTECTION AGAINST BREAST CANCER.



Breast cancer is one of the most common cancers to occur in African-American women. It ranks second in all cancer-related deaths among African-American women.

Breast cancer is most responsive to treatment during its early stages. However, research shows that African-American women are more likely to receive a diagnosis in the later stages of the disease. With the use of mammograms, self breast examinations, and self-advocacy, these numbers will change.

RISK FACTORS FOR BREAST CANCER INCLUDE:

- Gender
- Age
- Heredity/ genetic factors
- Long menstrual cycles
- Never having children
- Personal history of breast or ovarian cancer
- Environmental factors

WOMEN RECEIVING ANNUAL MAMMOGRAPHY SCREENING ARE 30% LESS LIKELY TO DIE FROM BREAST CANCER COMPARED TO UNSCREENED WOMEN.

OVER 74% OF BREAST CANCERS ARE DIAGNOSED IN WOMEN WITH NO IDENTIFIABLE RISK FACTORS.



62143 MO-21, Ellington, MO 63638
(573) 663-3257
(800)760-3259
info@wholekidsoutreach.org

For over 20 years, Whole Kids Outreach (WKO) has demonstrated its commitment to developing programs to meet the unmet health and developmental needs of expectant families and those with young children in the Missouri Ozarks. Using the Social Determinant definition of health, WKO's interventions help to create healthy families and communities by addressing not only medical needs, but also things such as safe access/transportation to services and jobs, housing, education and skill building, and risk factors for abuse and neglect.

Whole Kids Outreach's (WKO) target population includes impoverished pregnant women/teens, parents, infants, and children residing in the remote, rural areas of southeast Missouri. Currently, Whole Kids Outreach's service area includes seven counties—approximately 5,000 square miles.

Although Whole Kids Outreach's approach focuses predominately on prevention strategies, the critical shortage of health and social services in the area necessitates directing extensive energy and resources to developing and sustaining partnerships with local and regional individuals, organizations, service providers and universities to meet the families' healthcare needs.

For service delivery, WKO utilizes the Nurses for Newborns model for its Maternal-Child Nursing Program, staffed by experienced pediatric and labor and delivery RNs, to provide home visits. Complementing the nursing program, WKO has a two evidence-based home visiting programs, Healthy Families America and Parents as Teachers programs staffed by lay health advisors and parent educators. These home visiting programs have shown to reduce factors such as poverty, inadequate prenatal care, lack of supportive relationships, absence of knowledge and skills about child development that contribute to the high infant mortality/morbidity, poor health outcomes and child maltreatment rates in the service area.

Whole Kids Outreach also offers a wide array of center-based programs for children, teens and parents including a five-week summer health and wellness day camp, a Riding program and community/parent gatherings—all aimed at decreasing the negative impact of social and geographic isolation and improving health outcomes for children, their families and the community.

Building a community in which Chinese Americans are able to face end of life with dignity and respect

FAST FACTS

A coalition model, the Chinese American Coalition for Compassionate Care (CACCC) is the first coalition devoted to addressing end-of-life care issues in the Chinese American community

Our Mission

- Encourage dialogue among Chinese Americans about end of life issues so that it is viewed as a natural part of life.
- Enhance advanced illness and end of life care by improving advance care planning and decision-making for Chinese Americans through community outreach education and volunteer, caregiver, and health professional training.
- Empower Chinese Americans by improving access to end of life resources: producing original Chinese language materials or translating existing materials into Chinese and providing referrals to appropriate agencies.
- Use a coalition model, where expertise and resources are shared, to insure Chinese Americans receive exceptional end of life care and services that address physical, psychosocial, emotional and spiritual needs.

Our Vision

Building a community in which Chinese Americans are able to face end of life with dignity and respect

Our Coalition Model

The active coalition consists of 150 local, state, and national partner organizations, including organizations in Taiwan and China. Approximately 1,400 individual members are dedicated to the mission.

Partners: Partner organizations include, but not limited to, hospitals, medical centers, hospices, nursing homes, senior community centers, schools, and churches.

Who We Serve

Chinese American community and the healthcare professionals who serve them by collaborating with partner organizations in the U.S., Taiwan and China.

Operating Budget: \$100,000

Donations are graciously accepted. Donate through PayPal at <http://www.caccc-usa.org/en/donate.html>

Products & Services

Developed and produced:

- Heart to Heart® Cards
- Heart to Heart® Cafés
- DVDs: Kathy & Windy; Loving Life: Understanding Hospice; Advance Care Planning short films
- Books: *Learning to Let Go: Saying Goodbye Peacefully*, *Advance Care Planning and Hospice & Palliative Care*

Provides compassionate care, community service, education and outreach to Chinese Americans and to the healthcare professionals who serve them.

Social Media

<https://www.facebook.com/CACforCC>

<https://www.youtube.com/channel/UCHPZ2zXzcr-iDX5A71ax-nA>

Website: caccc-usa.org

Founded and Incorporated

December 2005

California nonprofit corporation since 2007, is tax-exempt under Internal Revenue Code section 501(c)(3)

Number of Employees: Three (3) part time staff

Number of Volunteers: 400

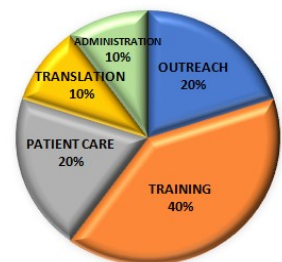
Annual Average Volunteer Hours: 11,000

Board of Directors: (11-15 members)

Volunteer board is comprised of health and medical professionals, community leaders, and individuals with a passion for advance care planning and end-of-life care issues.



Heart to Heart® Café



Fund Distribution

Programs

- Advance Care Planning workshops
- Heart to Heart® Cafés
- Caregiver and volunteer trainings
- Community education and outreach
- Professional healthcare forums, seminars, workshops
- Produce and translate English and Chinese end of life resources and materials
- Hospital Volunteer Ambassador program
- Patient and family visits with partner organizations
- Toll free Warm Line: (866) 661-5687

Contact CACCC

PO Box 276

Cupertino CA 95015

info@caccc-usa.org

Toll free: (866) 661-5687 [leave message]



Familias en Acción (Familias) was founded in 1998 in response to the need for a culturally specific organization to promote health for Latinos. Our mission is to promote holistic family well-being for Latinos through community engagement, education, research and advocacy for social justice. Our primary constituency is low-income Latinos who live in the Portland metropolitan region.

As a Latino serving health promotion organization in Oregon, we provide Community Health Worker services to insured Latinos and those who remain uninsured. Our programs serve 200 clients and their families per year, in navigating a complex health system, building their health literacy skills and addressing barriers to their health such as underemployment, sub-standard housing and immigration issues amongst others.

Our Programs Include:

- ✓ Community Health Worker services for Latinos diagnosed with chronic diseases including cancer, diabetes, end stage renal disease and cardiovascular disease.
- ✓ Community health education, cancer support group and chronic disease self-management classes; and
- ✓ Health professional cultural competence training including our annual Latino Health Equity Conference and online/in person health professional training.

Familias is the first culturally specific organization in Oregon to partner with a health system to embed a Community Health Work as a member of the patient care team. Our model linked the community resources of Familias with the health resources of Kaiser Permanente in order to provide culturally competent patient and family centered care for Latinos using the Pathways to Care model for payment.

The Latino Health Equity Conference examines the unique health issues faced by Latino immigrant communities in the United States. In our 2019 conference, we will explore topics that address food equity for Latinos, with specific emphasis on how colonization has and continues to have an impact on food choice, availability, and cultural identity. By hearing from experts and practitioners in the field, we will leave inspired, informed, and prepared to affect policy, programs, and initiatives that aim to improve Latino health.