

IT'S ABOUT THE JOURNEY



PEDIATRIC PALLIATIVE CARE
WEST COAST SUMMIT



George
Mark
Children's
House

OCTOBER 28 & 29, 2019

PRESERVATION PARK
Oakland, CA



Overview of Pediatric Palliative Care Summit

The Summit is targeted for a multidisciplinary audience to highlight skills specific for providers who are interested in learning more about pediatric palliative care practice, techniques and teamwork.

There are presentations and breakout sessions for more in-depth learning opportunities in the areas of communication, symptoms management, self-care, and integrative therapeutic practices.

"We may not
be able to
change the
outcome, but
we can
change the
journey."

Day 1: Monday, October 28, 2019

7:30am–8:00am

REGISTRATION AND BREAKFAST

8:00am–8:05am

INTRODUCTION

Linda Ashcraft Hudak J.D., CEO George Mark Children's House

8:05am–9:05am

MAKING EVERY MOMENT COUNT: Pediatric Palliative Care, Enhancing the Quality of Life

Leora Kuttner Ph.D., Children's Hospital and University of British Columbia

9:05am–10:05am

FOOD, TOYS, AND LOVE: Quality of Life in Children with Cancer

Barbara Sourkes Ph.D., Stanford University School of Medicine

10:05am–10:15am

BREAK

10:15am– 11:15am

QUALITY OF LIFE IN CHILDREN WITH ADVANCED HEART DISEASE

Beth Kaufman M.D., Lucile Packard Children's Hospital Stanford, Division of Cardiology

11:15am–12:15pm

BREAKOUTS

A. THE GRIEF SPECTRUM AND THE FAMILY EXPERIENCE

Kathy Hull M.A., Psy.D., Founder, George Mark Children's House

Blyth Lord, Executive Director Courageous Parents Network

Summer Segal Ph.D., M.S., LCGC, UCSF Benioff Children's Hospital San Francisco

B. ASSESSMENT AND MANAGEMENT OF PAIN AND IRRITABILITY IN A CHILD WITH SEVERE NEUROLOGIC IMPAIRMENT

Audrey Foster-Barber M.D., Ph.D., UCSF Benioff Children's Hospital San Francisco

C. HOW TO FACILITATE DIFFICULT CONVERSATIONS AND DELIVER BAD NEWS

Joan Fisher M.D., Ph.D., Stanford University School of Medicine

Peter C. Baker M.D., UCSF Benioff Children's Hospital Oakland

D. SELF-CARE: Care for the Caregivers

Ann Ming Yeh M.D., DABMA, Stanford University School of Medicine

E. PERINATAL COUNSELING

Susan Hintz M.D., M.S., Stanford University School of Medicine

Diana Kobayashi RN, MS, CNS, NNP-BC, Lucile Packard Children's Hospital Stanford

12:15pm–1:15pm

LUNCH AND PRESENTATION

USE OF CANNABINOIDS IN PEDIATRIC PATIENTS

Jojo Yang M.D., Stanford University School of Medicine

1:15pm–2:15pm

BEREAVED PARENTS PERSPECTIVE

Facilitator: Joan Fisher M.D., Ph.D.

Panel: Reggie Cooks

Sean Eddy

Jennifer McKay Weber

Tonya Saheli

2:15pm–3:15pm

BREAKOUTS

A. THE TRANSITION FROM ADOLESCENT TO ADULT CARE

Pam Simon RN, MSN, CPNP, Lucile Packard Children's Hospital Stanford

B. CHAPLAINCY PANEL: Holding the Story, Spiritual Care

Rev. Gillian Murphy–Stephans M.Div, MPH, UCSF Benioff Children's Hospital Oakland

Rev. Dr. Carla Cheatham M.A., M.Div, Ph.D., Stephen Grafenstein MTS, Hospice by the Bay

C. INTEGRATIVE THERAPIES IN PEDIATRIC PALLIATIVE CARE

Facilitator: Nancy Ricci RN, BSN, George Mark Children's House

Palliative Aquatics: Sheila Pyatt RN, BSN; Tamara Nelson RN, George Mark Children's House

Massage: Kerri Padget LMT

Drumming: Jana Din, Director Tao Center for Healing

D. SIBLINGS: UNIQUE CONCERNS AND OPPORTUNITIES

Emily Holl MSW, Sibling Support Project

E. AUTHORS

Facilitator: Kathy Hull M.A., Psy.D., Founder, George Mark Children's House

Amie Lands, Parent

Elisha Waldman M.D., Lurie Children's Hospital

3:15pm–3:30pm

BREAK

3:30pm–4:30pm

CULTURAL HUMILITY IN PALLIATIVE CARE

Elisha Waldman M.D., Lurie Children's Hospital

Wrap up:

Linda Ashcraft Hudak, CEO George Mark Children's House

4:30–5:30pm

NETWORKING / HOSPITALITY HOUR

Day 2: Tuesday, October 29, 2019

7:30am–8:15am

BREAKFAST

8:15am–8:30am

OPENING REMARKS

Peggy Maguire, President, Cambia Health Foundation

8:30am–9:30am

METHADONE ADMINISTRATION IN PEDIATRICS: Taming of the Shrew

Stefan Friedrichsdorf M.D., FAAP, Children's Hospital and Clinics of Minnesota

9:30am–10:30am

EXCELLENCE IN PROFESSIONAL TEAMWORK: Functions, Dynamics, Boundaries, and Conflicts, Withholding Feeds at End of Life

Facilitator: Joan Fisher M.D., Ph.D., Stanford University School of Medicine

Panel: Kyle Amsler M.S., CCLS, George Mark Children's House
Salina Patel RN, BSN, George Mark Children's House
Ruchika Mishra Ph.D., California Pacific Medical Center

10:45am–11:45am

BREAKOUTS

A. BEREAVED SIBLINGS

Alysha Lacey M.A., LPC, ATR, The Dougy Center

B. HYPNOSIS: Magic Glove and Pain Switch

Joan Fisher M.D., Ph.D., Stanford University School of Medicine

Leora Kuttner Ph.D., British Columbia Children's Hospital and University of British Columbia

C. PROVIDER AND FAMILY PERSPECTIVES OF LEGACY BUILDING IN PEDIATRIC PALLIATIVE CARE: A PANEL DISCUSSION.

Facilitator: Kyle Amsler M.S., CCLS, George Mark Children's House.

Panel: Matthew Logan M.A., MT-BC, UCSF Benioff Children's Hospital San Francisco

Amie Lands, Parent and Author

Korie Leigh Ph.D., CCLS, CT, University of Georgia

D. PEDIATRIC PALLIATIVE CARE IN A PEDIATRIC INTENSIVE CARE UNIT

David Steinhorn M.D., Children's National Medical Center

E. CURATIVE, PALLIATIVE, HOSPICE, HOSPITAL, HOME: Weaving Together Care that Addresses the Complex and Fluctuating Needs of Children

Lori Butterworth M.Ed., Jacob's Heart Children's Cancer Support Services

David Sine M.D., Hinds Hospice, Valley Children's Hospital, Pediatric Palliative Care

Trish Murphy PNP,CHPPN, Lucile Packard Children's Hospital Stanford

11:45am–12:45pm

DO AS I SAY AND AS I DO: Resilience as our Greatest Clinical Competence

Rev. Dr. Carla Cheatham M.A., M.Div., Ph.D., Certified Trauma Resolution Therapist

12:45pm

CLOSING REMARKS

Kathy Hull M.A., Psy.D., Founder, George Mark Children's House

“Be kind
whenever
possible.
It is always
possible.”

-Dali Lama

Keynote speakers

LEORA KUTTNER

PH.D., BRITISH COLUMBIA CHILDREN'S HOSPITAL AND
UNIVERSITY OF BRITISH COLUMBIA



Dr. Leora Kuttner is a Clinical Psychologist internationally recognized for her work in pediatric pain management and is Clinical Professor in the Department of Pediatrics, University of British Columbia at BC Children's Hospital in Vancouver.

She pioneered treatments in pain relief, implemented pain management programs for children and parents and has taught pediatric professionals throughout the US, UK, Italy, France, Switzerland, Germany, Finland, Australia, Turkey, New Zealand and in the Middle East.

Dr. Kuttner has published over 50 journal articles and written two books, the latest, *A Child in Pain: What Health Professionals Can Do to Help* is translated in Italian, French and Mandarin. Her collaboration with colleagues at WHO and IASP (International Association for the Study of Pain) resulted in *Cancer Pain Relief and Palliative Care in Children* (1998) Geneva.

Her first career was as a documentary film-maker. She integrated this into her clinical work, and directed five documentaries including the acclaimed **No Fears, No Tears – 13 Years Later, Making Every Moment Count on Pediatric Palliative Care** with David Suzuki and the NFB, and **Dancing with Pain**, on Youth dealing with Chronic Pain.

Since 1987, Dr. Kuttner has taught pediatric professionals all over the world and has won many awards for her writings, film and work -- notably in 1998 she was honored as a "Woman of Distinction" in Vancouver and in 2007, she received The American Pain Society's Jeffrey Lawson Award for Pediatric Pain Advocacy.

www.drleorakuttner.com

Keynote speakers

BARBARA SOURKES

PH.D., STANFORD UNIVERSITY SCHOOL OF MEDICINE



Barbara Sourkes Ph.D. is the first John Kriewall and Elizabeth Haehl Director of the Pediatric Palliative Care Program at Lucile Packard Children's Hospital Stanford, and Professor of Pediatrics at Stanford University. Her previous affiliations were with the Montreal Children's Hospital (McGill University) and the Dana-Farber Cancer Institute / Boston Children's Hospital (Harvard University).

In addition to many articles and chapters, Dr. Sourkes has published three books: *The Deepening Shade: Psychological Aspects of Life-threatening Illness* (1982), *Armfuls of Time: The Child's Psychological Experience of Life-Threatening Illness* (1995), and (with Michel Hanus, M.D.) *Les Enfants en Deuil: Portraits du Chagrin* [Bereaved Children, Portraits of Grief] (1997). She also co-edited (with Drs. Joanne Wolfe and Pamela Hinds) *Textbook of Interdisciplinary Pediatric Palliative Care* (2011).

Dr. Sourkes served as a member of the United States Institute of Medicine Committee on Palliative and End-of-Life Care for Children and their Families. She has won several awards, including the Outstanding Clinical Care award from the American Psychosocial Oncology Society (2011), the Humanities Award from the American Academy of Hospice and Palliative Medicine (2014), and the Compassion in Action Award from Hospice of the Valley (2016).

Keynote speakers

BETH KAUFMAN

M.D., LUCILLE PACKARD CHILDREN'S HOSPITAL STANFORD



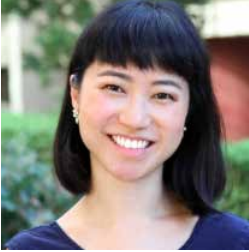
Dr. Beth Kaufman is currently the Director of the Pediatric Cardiomyopathy Program and Attending Physician in the Pediatric Advanced Cardiac Therapies Program at Lucile Packard Children's Hospital Stanford and Clinical Associate Professor of Pediatrics at Stanford University. She has been practicing pediatric cardiomyopathy,

heart failure, and heart transplantation for 15 years, initially at Children's Hospital of Philadelphia for 8 years prior to her current appointment at Stanford in 2013. She has held leadership positions in the International Society of Heart and Lung Transplant and has been an active member of collaborative research projects related to pediatric cardiomyopathy, mechanical support and heart transplant. Dr. Kaufman current research interests are in palliative care, shared decision-making, and ethics related to caring for children with heart failure.

Keynote speakers

JOJO YANG

M.D., STANFORD UNIVERSITY SCHOOL OF MEDICINE



JoJo Yang M.D. is a Fellow in Pediatric Epilepsy at Stanford University, Lucile Packard Children's Hospital Stanford. She attended medical school at UC San Francisco and completed a Child Neurology residency at Stanford. She is interested in medical education at the resident level and pioneering integrative medicine approaches

to pediatric neurology, incorporating complimentary and alternative practices. She is also interested specifically in gene therapies for early onset pediatric epilepsies.

Keynote speakers

ELISHA WALDMAN

M.D., LURIE CHILDREN'S HOSPITAL OF CHICAGO



Dr. Waldman was born in New York City and raised in Connecticut. After earning a B.A. in Religious Studies at Yale University he went on to get his M.D. in Tel Aviv. He trained in General Pediatrics at Mount Sinai Medical Center and Pediatric Hematology–Oncology at Memorial Sloan Kettering Cancer Center. In 2007 he moved to Israel, where he assumed responsibility for the pediatric sarcoma service at Hadassah Medical Center

in Jerusalem. Through his work in Jerusalem he developed an increasing interest in pediatric palliative care. In 2012, he returned to Boston to complete an additional fellowship in Pediatric Hospice and Palliative Medicine at Dana Farber Cancer Institute/ Children's Hospital Boston. In September 2013, he returned to Hadassah for a year to help develop pediatric palliative care services for the greater Jerusalem area.

Dr. Waldman currently is the Chief of the Division of Palliative Care at Lurie Children's Hospital of Chicago.

Dr. Waldman has interests in a number of areas within palliative care, including spiritual needs of children facing life-limiting illness, palliative care for children with cancer, program development, and palliative care in the setting of limited resources, in particular in the context of humanitarian crises.

Dr. Waldman has published in a number of medical journals as well as national media outlets. He is the author of the nonfiction book, *This Narrow Space* about his experiences working in the Middle East, recently released by Random House. His writing has appeared in **The Hill, The New York Times, The Washington Post, Time** and elsewhere.

Keynote speakers

STEFAN FRIEDRICHSDORF

M.D., FAAP, CHILDREN'S HOSPITAL AND CLINICS OF MINNESOTA



Stefan Friedrichsdorf is the medical director of the Department of Pain Medicine, Palliative Care and Integrative Medicine at Children's Minnesota – one of the largest and most comprehensive programs of its kind in the country. He is president-elect of the Special Interest Group on Pain in Childhood of the International Association for the Study of Pain (IASP).

Dr. Friedrichsdorf received the 2016 “Elizabeth Narcessian Award for Outstanding Educational Achievements in the Field of Pain” by the American Pain Society and the 2011 “Hastings Center Cunniff– Dixon Physician Award”. The Department received the “Circle of Life Award” by the American Hospital Association in 2008 and was the 2013 recipient of the “Clinical Centers of Excellence in Pain Management Award” by the American Pain Society. In 2016, Children's Minnesota received the prestigious ChildKind International pain relief certification, and, in 2018, the Albert Bandura Influencer Award from VitalSmarts.

Dr. Friedrichsdorf received his M.D. from the Medical University of Lübeck, Germany, completed his pediatric residency at the University of Witten/Herdecke, Germany (Children's Hospital Datteln), and undertook his fellowship in Pediatric Pain Medicine & Palliative Care at the University of Sydney, Australia (Children's Hospital at Westmead). He is a Diplomate of the American Board of Pediatrics, double-boarded in Pediatrics (Germany, USA), and is trained in teaching pediatric hypnosis.

Keynote speakers

REV. DR. CARLA CHEATHAM

M.A., M.DIV., PH.D., CERTIFIED TRAUMA RESOLUTION THERAPIST



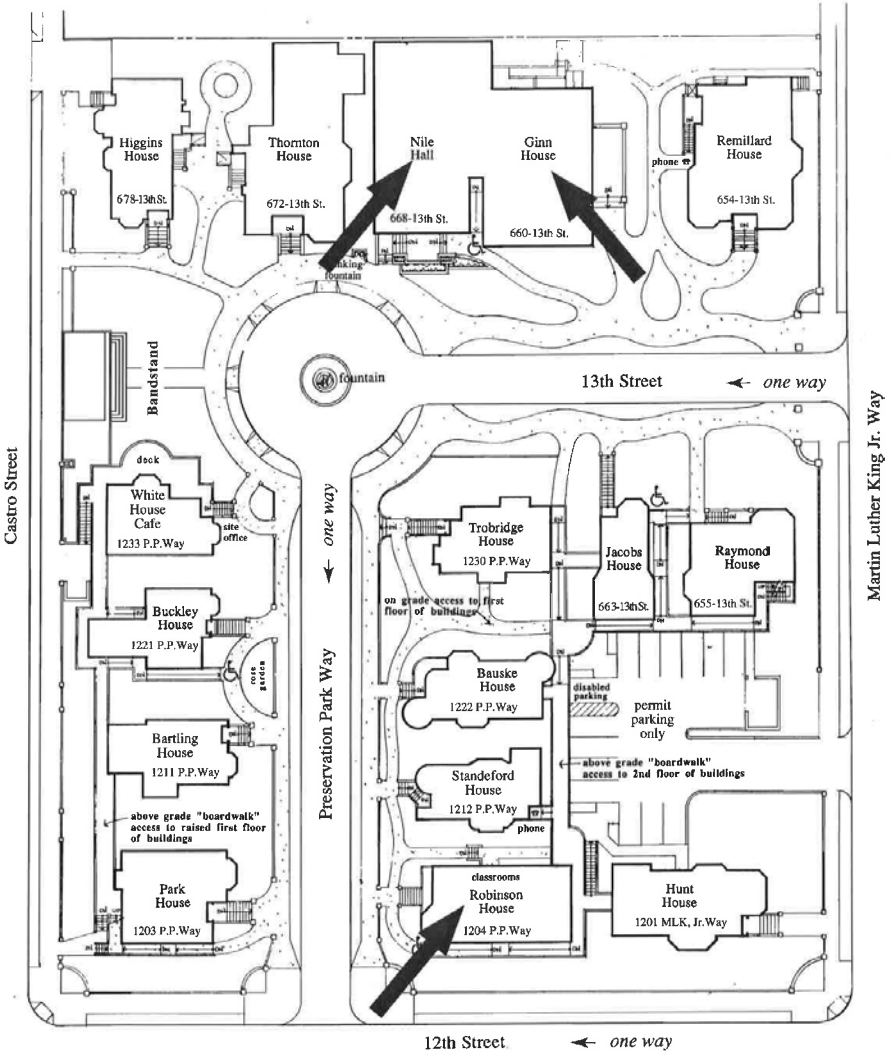
Rev. Dr. Carla Cheatham began her career in social services with an M.A. in Psychology, certification in trauma counseling, Ph.D. in Health & Kinesiology, and Masters of Divinity. After serving faith communities and an interfaith non-profit, Carla worked 10 years as a hospice chaplain and bereavement coordinator.

She is the Lead Trainer for Carla Cheatham Consulting Group, LLC, based in Austin, Texas, and a national keynote speaker and consultant focusing on emotional competencies for professionals and resilient organizations.

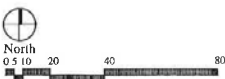
Carla is Section Leader for the National Hospice and Palliative Care Organization's (NHPCO) Spiritual Caregivers Section, Chair of NHPCO's Ethics Advisory Council and serves on NHPCO's Trauma-Informed End of Life Care Work Group. Carla is an Adjunct Professor at Seminary of the Southwest, and Affiliate Assistant Professor at University of Maryland for its Masters of Science in Palliative Care.

Carla is the author of *Hospice Whispers: Stories of Life* and *Sharing Our Stories: A Hospice Whispers Grief Support Workbook*, and her books on grief and the art of presence will publish late 2019.

Map of property



Site Plan



Preservation Park is a project of Preservation Park, Inc., a nonprofit partnership between East Bay Asian Local Development Corporation and Tenants of Preservation Park.

The five room Conference Center and outdoor bandstand and fountain circle provide meeting and social event spaces for businesses, nonprofit organizations, and private citizens throughout the greater Bay Area.

CONTINUING MEDICAL EDUCATION ACCREDITATION

CME ACCREDITATION

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of Stanford University School of Medicine and George Mark Childrens House. The Stanford University School of Medicine is accredited by the ACCME to provide continuing medical education for physicians.

The Stanford University School of Medicine designates this live activity for a maximum of 12.5 *AMA PRA Category 1 Credits*[™]. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

The California Board of Registered Nursing recognizes that Continuing Medical Education (CME) is acceptable for meeting RN continuing education requirements as long as the course is certified for *AMA PRA Category 1 Credits*[™] (rn.ca.gov). Nurses will receive a Certificate of Participation following this activity that may be used for license renewal.

FACULTY DISCLOSURE

The Stanford University School of Medicine adheres to ACCME Criteria, Standards and Policies regarding industry support of continuing medical education.

There are no relevant financial relationships with ACCME-defined commercial interests for anyone who was in control of the content of this activity.

CLAIM CREDIT | COMPLETE EVALUATION

An online course evaluation with instructions will be emailed to all learners for completion. Upon completing the evaluation, the learner may access their credit transcript to obtain proof of participation. For questions about your credit 30 days following this activity, please contact the appropriate crediting body.

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CONTINUING EDUCATION UNITS ACCREDITATION

SOCIAL WORK: Course meets the qualifications for an estimated 12 hours of continuing education credit for LMFT's, LCSW's, LPCC's and/or LEP's and 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 LCSW's and LMFT's, Provider #91987.



COALITION FOR
COMPASSIONATE CARE
OF CALIFORNIA

"Life isn't a
matter of
milestones,
but of
moments."

-Rose Kennedy

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FOR PALLIATIVE CARE**



SPECIAL THANKS

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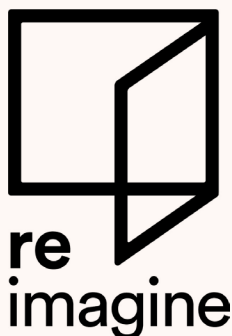
SALT AND HONEY

PRESERVATION PARK

440 DESIGN

OAKLAND AUDIO-VISUAL SERVICE

COURTYARD BY MARRIOTT



George Mark Children's House is thrilled to partner with Reimagine End of Life on this exciting new program.

A LOVE THAT NEVER DIES

Monday, October 28, 7:00 pm
New Parkway Theater, Oakland

Tickets: \$12 general admission/\$10 students and seniors

George Mark Children's House and The Good Grief Project are proud to co-present the North American premier of the film **A LOVE THAT NEVER DIES**, the personal journey of two bereaved parents, Jane Harris and Jimmy Edmonds, and a love letter to their son Josh. Their son died in a road accident in South East Asia seven years ago and they now honor him with their own journeys: to Vietnam the place where he died, to Varanasi, India and a road trip across the USA, where they meet with other families who have also lost a child, all of whom have found grief variously isolating, transformative yet ultimately life enhancing.

For ticket information:

<https://letsreimagine.org/1754/film-a-love-that-never-dies-finding-a-voice-for-grief>

The **Good Grief Project** & **George Mark Children's House** present

A LOVE THAT NEVER DIES

A BEYOND GOODBYE MEDIA PRODUCTION 75 MINS

REIMAGINE end of life Festival
Monday, October 28
7:00pm-9:00pm

New Parkway Theatre
474 24th Street
Oakland, CA 94612

SCREENING followed by Q & A with the directors





A culture of caring

Pediatric palliative care is an important area of medicine—one that's decidedly different from adult palliative care. We need to do better for our children, ensuring pediatric palliative care is readily accessible to patients and their families. Helping spur innovation, Cambia Health Foundation invests in solutions that build meaningful relationships with children and their families, and help them make every day the best it can be.

IT'S ABOUT THE JOURNEY



PEDIATRIC PALLIATIVE CARE
WEST COAST SUMMIT

THANK YOU
FOR YOUR ATTENDANCE AND PARTICIPATION
IN THE FIRST WEST COAST PEDIATRIC
PALLIATIVE CARE SUMMIT.



George
Mark
Children's
House

QUESTIONS?

Shannon Beatty • sbeatty@georgemark.org • 925.785.3941
Salina Patel • spatel@georgemark.org • 510.862.6011
Katie Peña • kpena@georgemark.org • 925.209.4966