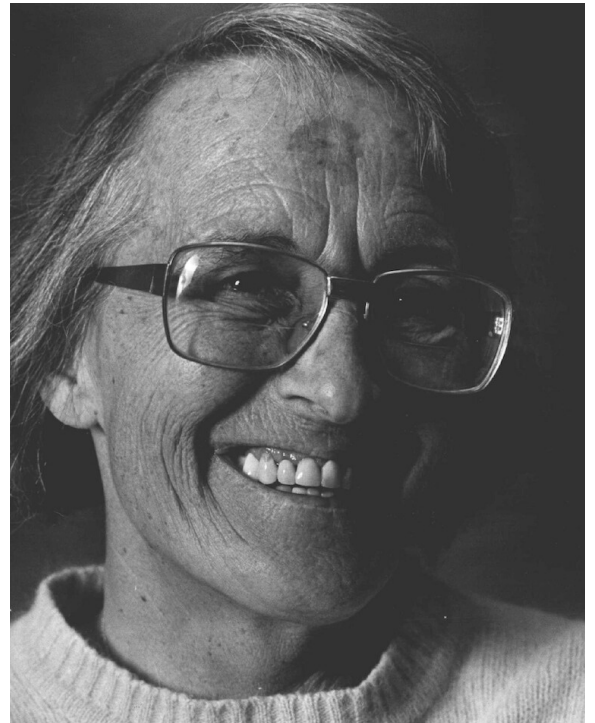




# RECLAIMING THE LEGACY OF ELISABETH KÜBLER-ROSS

INSIGHTS INTO THE ETHICS, PRACTICE,  
AND SCIENCE OF CARING





# Schedule of Events

9:00-9:10: **Continental breakfast and coffee**

9:10-9:20: **Welcome from Dr. Karl Lorenz**

9:20-9:30: **Welcome from Barbara Rothweiler**

*Introduction by Dr. Karl Lorenz*

9:30-9:40: **Welcome from Kenneth Ross**

*Introduction by Dr. Karl Lorenz*

9:40-9:50: **Stephen Connor**

*Elisabeth Kubler-Ross's contribution to the development of hospice & palliative care*

*Introduction by Dr. Karl Lorenz*

9:50-10:00: **Benjamin Stone**

*About the Elisabeth Kübler-Ross Archive*

*Introduction by Dr. Karl Lorenz*

10:00-10:30: **Dr. Mark Kuczewski**

*Elisabeth Kübler-Ross and Me: Perennial Tensions in Ethics Consultation*

10:30-10:45: *Discussion moderated by Dr. David Magnus*

10:45-11:15: **Dr. Maren Monsen**

*The Elisabeth Kubler-Ross Video Archive*

*Introduction by Dr. David Magnus*

11:15-12:00: **Dr. Chris Feudtner**

*Hope and Honesty: A Consilience*

11:45-12:00: *Discussion moderated by Dr. David Mangus*

**12:00-1:00: LUNCH**



# Schedule of Events

**1:00-1:30: Dr. Neil Wenger**

*Who, how and when should conduct advance care planning?*

1:30-1:45: *Discussion moderated by Dr. Steve Pantilat*

**1:45-2:15: Dr. Robert Arnold**

*Clinicians' feelings and identity: Internal barriers to having difficult conversations*

2:15-2:30: *Discussion moderated by Dr. Steve Pantilat*

**2:30-3:00: Dr. Katherine Shear**

*Bringing Death and Dying into the realm of medicine: Honoring Elisabeth Kubler-Ross*

3:00-3:15: *Discussion moderated by Dr. Steve Pantilat*

**3:15-3:25: BREAK**

**3:25-3:55: Dr. LaVera Crawley**

*Revisiting Suffering*

3:55-4:10: *Discussion moderated by Dr. Barbara Koenig*

**4:10-4:40: Dr. Joanne Lynn**

*How the End of Life Has Changed in this Century*

4:40-4:55: *Discussion moderated by Dr. Barbara Koenig*

**4:55-5:00: Concluding remarks**



# About Elisabeth Kübler-Ross



Elisabeth Kübler-Ross, M.D. (July 8, 1926 – August 24, 2004) was a Swiss-born psychiatrist, a pioneer in near-death studies and the author of the groundbreaking book *On Death and Dying* (1969), where she first discussed her theory of the five stages of grief, also known as the Kübler-Ross model. Her work with dying patients helped revolutionize care of the terminally ill. She was the recipient of twenty honorary degrees and by July 1982 had taught, in her estimation, 125,000 students in death and dying courses in colleges, seminaries, medical schools, hospitals, and social-work institutions. She has also written over 20 books on death and related subjects. In 2007, she was inducted into the National Women's Hall of Fame. She was a fierce champion of the hospice movement and conducted many workshops on AIDS throughout the world. She was co-founder of the American Holistic Medical Association and founder of "Shanti Nilaya," which she intended to be a healing center for those struggling with death. This year marks the 50th anniversary of *On Death and Dying*.



# About the Speakers

**Dr. Barbara Rothweiler**, daughter of Elisabeth Kübler-Ross MD, is a license psychologist, with board certification in neuropsychology and rehabilitation psychology. In addition to conducting neuropsychological evaluations, she provides consultation liaison services, specializing in medical rehabilitation, but also hospital wide, including palliative care and hospice. She serves on the Aspirus Wausau Hospital Bioethics Committee (>20 years) and is chair of the Aspirus Medical Staff Support Committee. She is a member of the American Academy of Clinical Neuropsychology, International Neuropsychological Society, National Academy of Neuropsychology, American Psychological Association, and the Wisconsin Psychological Association. She is current secretary of the Elisabeth Kubler Ross Foundation.



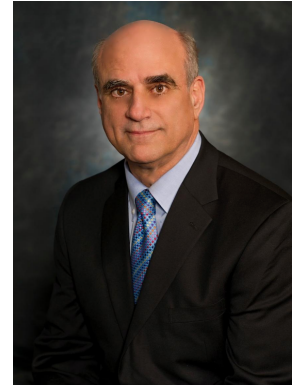
**Ken Ross**, son of Dr. Elisabeth Kübler-Ross, is the founder of the EKR Foundation (2006) and President (2006-2013 & 2018-). He also served on the board of the Elisabeth Kübler-Ross Center from 1989-2005. Ken was the principal care provider for his mother in the last 9 years of her life until her passing in 2004. His responsibilities included handling over 80 publishers of Dr. Ross's work, public relations, copyright & trademark issues, website maintenance, developing foreign EKR chapters, developing strategic partnerships, as well as preserving her research papers. While growing up, he traveled with her extensively while on her numerous foreign trips witnessing her lectures and workshops. Ken has made a series of lectures on his mother's legacy for hospices and various conferences around the USA, Argentina, Brazil, Chile, India, Japan, Mexico, The Netherlands, & Peru since 2009. A professional photographer by trade, he has photographed 100 countries towards his goal of 101.





# About the Speakers

**Dr. Stephen R. Connor** is the Executive Director of the Worldwide Hospice Palliative Care Alliance (WHPCA) with 350 organizational members in over 100 countries. Connor has worked in palliative care continuously for the past 43 years as a researcher, licensed clinical health psychologist, consultant, author, educator, advocate, & executive. For the last 16 years he has worked on global palliative care development in over 25 countries. He is a trustee of the International Children's Palliative Care Network, a board member for the Elizabeth Kubler-Ross Foundation, on the scientific advisory board of the (US) National Palliative Care Research Center and is a member of the editorial board of the Journal of Pain & Symptom Management. Connor has authored 5 books and over 125 peer reviewed journal articles, reviews, and book chapters on issues related to palliative care.



**Mark G. Kuczewski, PhD**, is the Fr. Michael I. English, S.J., Professor of Medical Ethics. He is also the director of the Neiswanger Institute for Bioethics and Health Policy and chair of the Department of Medical Education at the Loyola University Chicago Stritch School of Medicine. Mark is a past president of the American Society for Bioethics and Humanities (ASBH). He has been engaged in bedside clinical ethics issues for more than 25 years. For the last decade, he has been an articulate spokesperson for the just and equitable treatment of immigrant patients including creating with Drs. Johana Mejias-Beck and Amy Blair the Sanctuary Doctor website to assist clinicians in supporting immigrant patients. He also led the effort to make the Stritch School of Medicine the first medical school in the nation to openly welcome applicants who are DACA recipients.



# About the Speakers



**Maren Monsen**, Founding Director of the Program in Bioethics and Film at Stanford University Center for Biomedical Ethics and Filmmaker in Residence Emerita, is a physician and clinical ethicist who uses film to share patient stories. Her films have been released theatrically and broadcast nationally and internationally, screened at Sundance, Cannes, the Skoll World Forum in Oxford, and several TEDx events run by Melinda Gates. She co-directed the Emmy-nominated *The Revolutionary Optimists*, which was translated into 6 languages, broadcast on PBS, won the Hilton Sustainability award at Sundance, and went on to a theatrical release with policy screenings at UNICEF and USAID. Previous films include *Rare*, *Worlds Apart*, *Hold Your Breath*, *the Vanishing Line* and *Where the Highway Ends*. Dr. Monsen received her Bachelors in Art History at Stanford University, studied film at the London International Film School, received her Medical Doctorate from the University of Washington, and returned to Stanford to complete her residency in Emergency Medicine and a fellowship in Palliative Care. She has worked clinically seeing patients as an emergency physician, palliative care physician and clinical ethicist, and taught clinical and research ethics. She founded and directed the Program in Bioethics and Film at the Stanford University School of Medicine for 21 years and was the co-director of the Biomedical Ethics and Medical Humanities Scholarly Concentration. Dr. Monsen lives in a floating home in Seattle with her husband, son, and 110 pound Labrador. She is currently working on a film on Elizabeth Kubler Ross.

**Chris Feudtner** is a pediatrician, clinical investigator, and ethicist at The Children's Hospital of Philadelphia and the University of Pennsylvania who focuses on improving the lives of children with complex chronic conditions and their families. Over the years, he has conducted a wide variety of research projects and been involved in developing clinical programs while also taking care of complex pediatric patients, including providing palliative care, as well as providing clinical ethics consultations. He lives outside of Philadelphia with his wife (a family physician), three children, and a small sassy dog.





# About the Speakers



**Neil Wenger MD, MPH** is a Professor in the Division of General Internal Medicine and Health Services Research at UCLA. He directs the UCLA Advance Care Planning program and is chair of the Ronald Reagan-UCLA Medical Center ethics committee. His research focuses on measuring and improving medical care for vulnerable older people and implementation of advance care planning. Dr. Wenger is a active general interest focusing on caring for patients with complex medical conditions.

**Robert M. Arnold, MD**, is a Professor in the Division of General Internal Medicine, Department of Medicine at the University of Pittsburgh and in the University of Pittsburgh Center for Bioethics and Health Law. In 2000, Dr. Arnold was named the first Leo H. Creip Chair of Patient Care. The chair emphasizes the importance of the doctor-patient relationship, particularly at the end of life. He is the Director of the Institute for Doctor-Patient Communication and the Medical Director of the UPMC Palliative and Supportive Institute. He is clinically active in palliative care, and has published on end-of-life care, hospice and palliative care, doctor-patient communication and ethics education. He also is working with the UPMC Health System to develop system-wide, integrative palliative services throughout the health system. He is the Past-President of the American Society of Bioethics and Humanities as well as the American Academy of Hospice and Palliative Medicine.







# About the Speakers

**Dr. M. Katherine Shear** is the Marion E. Kenworthy Professor of Psychiatry and the founding Director of the Center for Complicated Grief at Columbia School of Social Work. Dr. Shear is a clinical researcher who first worked in anxiety and depression. For the last two decades she has focused on understanding and treating people who experience persistent intense grief. She developed and tested complicated grief treatment (CGT) a short-term targeted intervention and confirmed its efficacy in three large NIMH-funded studies. CGT is strength-based and focused on fostering adaptation to loss. Dr. Shear is widely recognized for her work in bereavement, including both research and clinical awards from the Association for Death Education and Counseling and invited authorship of articles for Uptodate and the New England Journal of Medicine.



**LaVera Crawley, MD, MPH**, describes her professional path as a dedication to “Radical Servanthood”—first as a Board-Certified Family Physician on the Navajo Indian Reservation; as an at-home mom; an empirical bioethicist at Stanford focusing on health inequities; and as hospital chaplain practicing the art of spiritual companionship. She now serves as Director of Spiritual Care and Clinical Pastoral Education at the California Pacific Medical Center in San Francisco. Her academic, theological and spiritual preparation includes her MD from Meharry Medical College; her Family Medicine residency and chief residency training at USCF; an MPH from UC Berkeley focusing on epidemiology and biostatistics; an Ethics Fellowship at the Stanford School of Medicine Center for Biomedical Ethics; and a Palliative Care Education Fellowship at Harvard. She completed her chaplaincy and ACPE Certified Educator training at the Alta Bates Summit Medical Center CPE program in Berkeley and Oakland and her Masters of Divinity Equivalency coursework through the Pacific School of Religion (Graduate Theological Union), the Catholic Distance University, and the Franciscan-based Living School of Action and Contemplation founded by Fr. Richard Rohr.



# About the Speakers

**Joanne Lynn, MD, MA, MS** is the director of the Program to Improve Eldercare at Altarum. One of the first hospice physicians in the US, Dr. Lynn is author of 300 peer-reviewed journal articles and 80 books and chapters on geriatrics, palliative care, and end of life care. She has been medical director of hospice, long-term care facilities, and home care, as well as the Chair of the geriatrics program at George Washington University School of Medicine. She has led the team that has developed the MediCaring Communities reform model for eldercare and is actively working to build the elements needed for integrating management of comprehensive care planning for geographic communities. She is an elected member of the Institute of Medicine, a Master in the American College of Physicians, a Fellow of both the American Geriatrics Society (which awarded her the Nascher/Manning Award for lifetime achievement in geriatrics) and the Hastings Center (which awarded her the Henry Knowles Beecher Award for lifetime achievement in ethics and life sciences), and a former faculty member of the Institute for Healthcare Improvement. Dr. Lynn has been a tenured professor in Medicine at both George Washington University and Dartmouth College School of Medicine.





# About the Moderators

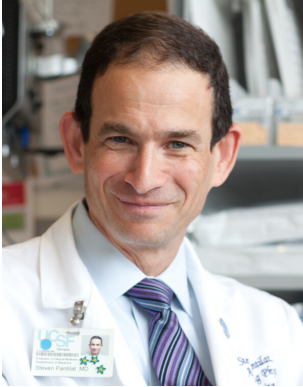
**Dr. Karl Lorenz, MD MSHS** is a general internal medicine and palliative care physician, and Section chief of the VA Palo Alto-Stanford Palliative Care Program. Formerly at the VA Greater Los Angeles, Dr. Lorenz directed palliative care research at the VA Center for Innovation to Implementation and served on the faculty at the UCLA School of Medicine. Dr. Lorenz is a member of the VA's national Hospice and Palliative Care Program (HPC) leadership team, director of the operational palliative care Quality Improvement Resource Center (QuIRC), and adjunct faculty staff member at RAND. Under Dr. Lorenz's leadership, since 2009 the Quality Improvement Resource Center (QuIRC) has served as one of three national leadership Centers responsible for strategic and operational support of the VA's national hospice and palliative care programs. In that role, Dr. Lorenz participates with the national leadership team in strategic planning, policy development, and providing resources to support operational efforts. Dr. Lorenz has contributed to the field of global palliative care, serving the World Health Organization in its development of Palliative Care for Older People and leading methods for Palliative Care Essential Medications.



**David Magnus, PhD** is Thomas A. Raffin Professor of Medicine and Biomedical Ethics and Professor of Pediatrics and Medicine at Stanford University, where he is Director of the Stanford Center for Biomedical Ethics and member of the Ethics Committee for the Stanford Hospital. He is currently the Vice-Chair of the IRB for the NIH Precision Medicine Initiative ("All of Us"), and is the Editor in Chief of the American Journal of Bioethics. He has published articles on a wide range of topics in bioethics. He was a member of the Secretary of Agriculture's Advisory Committee on Biotechnology in the 21st Century and currently serves on the California Human Stem Cell Research Advisory Committee. His publications have appeared in New England Journal of Medicine, Science, Nature Biotechnology, and the British Medical Journal. He has appeared on many radio and television shows including 60 Minutes, Good Morning America, The Today Show, CBS This Morning, FOX news Sunday, and ABC World News and NPR. In addition to his scholarly work, he has published Opinion pieces in the Philadelphia Inquirer, the Chicago Tribune, the San Jose Mercury News, and the New Jersey Star Ledger.



# About the Moderators



**Steven Pantilat, MD** is the Kates-Burnard and Hellman Distinguished Professor in Palliative Care and the inaugural Chief of the Division of Palliative Medicine at UCSF. Dr. Pantilat is the founding Director of the Palliative Care Quality Network, a national collaboration of over 130 Palliative Care teams dedicated to improving the quality of care provided to seriously ill people and their families. He also serves as Chair of the Advisory Board for the Cambia Health Foundation's Sojourns Scholar Leadership Award program and is a co-director of the UCSF Palliative Care Leadership Center. Dr. Pantilat has published over 100 peer-reviewed scientific papers, authored two dozen book chapters, and co-edited with two textbooks on palliative care. In 2011 he received a James Irvine Foundation Leadership Award in recognition of his work to improve the lives of Californians and in 2014 Dr. Pantilat received the Ritz E. Heerman Award from the California Hospital Association in recognition of his work to improve the quality of palliative care. He has received five teaching awards from the medical students at UCSF for outstanding lectures and lecture series and the excellence in teaching award from the Society of Hospital Medicine.

**Barbara A. Koenig, Ph.D.**, is Professor of Bioethics and Medical Anthropology, based at the Institute for Health & Aging, University of California, San Francisco. She is the Director of "UCSF Bioethics," a program that spans ethics research, clinical ethics, and ethics education across the university's four professional schools. Prof. Koenig pioneered the use of empirical methods in the study of ethical questions in science, medicine, and health. She has long-standing interests in palliative care and technology use near the end of life. In San Francisco in the early 1980s, she was one of the first anthropologists to work on the then emerging epidemic of HIV/AIDS, focusing on the impact of the disease on clinicians' care for dying patients. Koenig also led the first NIH-funded study of the dynamics of end-of-life decision making and patient choice in a public hospital cancer clinic serving patients from varied ethno-cultural backgrounds; her work revealed the limitations of traditional bioethics practices in a diverse society. Koenig's research led to her being named a Soros Faculty Scholar in the Open Society Institute's "Project on Death in America." With the passage of California's physician aid-in-dying legislation, she convened a state-wide conference to bring together the law's opponents and proponents to reflect on implementation challenges.





# Thank you

**Please visit <http://med.stanford.edu/bioethics/events/elisabeth-kubler-ross-archive.html> for updates about the Elisabeth Kübler-Ross Archives.**

**Be sure to read December's issue of the American Journal of Bioethics, which celebrates the 50th anniversary of *On Death and Dying*.**

**Thank you for joining us at *Reclaiming the Legacy of Elisabeth Kübler-Ross: Insights into the Ethics, Practice, and Science of Caring*.**