

# Hastening Death by Voluntarily Stopping Eating and Drinking: Clinical, Legal, Ethical, Religious, and Family Perspectives

October 13-15, 2016

# Agenda

# Friday, October 14

8:45 a.m. Welcome & Introductions: Annette Clark, MD, JD, Dean, Seattle University School of

Law

9 a.m. Keynote Addresses:

Chair: Annette Clark, MD, JD, Dean, Seattle University School of Law

Clinical: Timothy Quill, MD, University of Rochester School of Medicine

Legal: Thaddeus Pope , JD, PhD, Mitchell Hamline School of Law

Ethical: Robert Truog, MD, Medical Ethics & Anaesthesiology, Harvard Medical

School

10:30 a.m. Break

10:45 a.m. Clinical Findings panel (comfort/distress, duration, who uses, etc.)

Chair: Linda Ganzini, MD MPH, Geriatric Psychiatry, Oregon Health Sciences

University

Eva Bolt, MD, Center for Palliative Care, VU Medical Center, Amsterdam

Judith Schwarz, RN, PhD, Clinical Coordinator, End of Life Choices NY

Peter Reagan, MD, Family Practice (Portland)

Joan Teno, MD, MS, Gerontology & Geriatrics, School of Medicine, University of

Washington

12:10 p.m. Overview: "A Journalist's Take: what people don't know about VSED, what the media haven't

reported, and how the public might respond"

Chair: Judith Schwarz, RN, PhD, Clinical Coordinator, End of Life Choices NY

Paula Span, NY Times, New Old Age blog, author

12:50 p.m. Lunch (included)

# 2:00 p.m. Family Perspectives

Chair: Paul Menzel, PhD, Professor Emeritus, Philosophy, Pacific Lutheran University

2:00 Diane Rehm (via live video feed), Diane Rehm Show (NPR, APR), author

2:20 Phyllis Shacter, Bellingham WA, TEDx talk "Not Here By Choice"

2:40 Katherine Hammond, daughter of Margot Bentley (BC Court of Appeals case)

3:00 Audience Q&A

3:30 p.m. Break

3:45 p.m. Religious and Ethical Perspectives

Chair: Sergia Hay, PhD, Philosophy, Pacific Lutheran University

Michael Jaycox, PhD, Department of Theology & Religious Studies, Seattle University

Trudy James, MRE, multi-faith chaplain, Seattle, "Speaking of Dying" (film)
Paulette Kidder, PhD, Philosophy and Acting Dean, Matteo Ricci College, Seattle
University

Anson Laytner, Rabbi (retired, Seattle) and author

5:15 p.m. Evaluations and Adjourn

5:30 p.m. Reception

# Saturday, October 15, 2016

8:00 a.m. Coffee and gathering 8:30 a.m. Legal and Ethical Issues

Chair: Patricia Kuszler, MD JD, Professor of Law, U of Washington School of Law

Norman L. Cantor, JD, Professor of Law & Justice (emeritus), Rutgers University Annette Clark, MD, JD, Professor and Dean, Seattle University School of Law Margaret Battin, PhD, Professor of Philosophy, University of Utah Carla Calogero, JD, Reed Longyear Malnati & Ahrens, PLLC, Seattle

10:00 a.m. Break

10:15 a.m. Dementia, Depression and Capacity Determination

Chair: Sarah Shannon, RN, PhD, Biobehavioral Nursing & Health Systems, Oregon Health Sciences University

Linda Ganzini, MD, MPH, Geriatric Psychiatry, Oregon Health Sciences University

11:00 a.m. VSED by Advance Directive (dementia, etc.)

Chair: Lisa Brodoff, JD, Director, Ronald A. Peterson Law Clinic, Seattle University School of Law

Norman L. Cantor, JD, Professor of Law & Justice (emeritus), Rutgers University School of Law

Stanley Terman, MD, PhD, Medical Director, Caring Advocates, Carlsbad CA Paul Menzel, PhD, Professor of Philosophy (emeritus), Pacific Lutheran University

12:15 p.m. Lunch (on your own)

1:30 p.m. Institutional Considerations (hospice, palliative care, nursing homes)

Chair: David Gruenewald, MD, Medical Director, Palliative Care & Hospice, VA Puget Sound

Hope Wechkin, MD, Evergreen Health Hospice, Kirkland Patricia Hunter, Washington State Long Term Care Ombudman Amy Freeman, JD, Attorney, Washington State Long Term Care Ombudsman Program

Tresa Mariotto, CDMHT, Social Services Supervisor, Skilled Nursing Homes, State of Washington; former Executive Director, Woodway Senior Living, Bellingham

3:00 p.m. Capstone Panel: brief observations, in light of the conference, toward a comprehensive comparative assessment of VSED

Chair: Sara Goering, PhD, Associate Professor of Philosophy, University of Washington

Thaddeus Pope, JD, PhD, Mitchell Hamline School of Law Timothy Quill, MD, University of Rochester School of Medicine Sarah Shannon, RN, PhD, Biobehavioral Nursing & Health Systems, Oregon Health Sciences University Paula Span, NY Times, New Old Age blog, author

**Audience Comments & Questions** 

4:00 p.m. Adjourn

# **Faculty Biographies**

# **Margaret Pabst Battin**

Margaret Pabst Battin, M.F.A., PhD., (nicknamed Peggy) is Distinguished Professor of philosophy and medical ethics at the University of Utah. She has authored, co-authored, edited, or co-edited some twenty books, including Drugs and Justice and The Patient as Victim and Vector: Ethics and Infectious Disease. She has worked on end-of-life issues throughout her academic career, and has published fiction, articles, and essays in two collections, The Least Worst Death and Ending Life, as well as a comprehensive historical sourcebook coupled with an online Digital Archive, The Ethics of Suicide: Historical Sources <a href="http://ethicsofsuicide.lib.utah.edu">http://ethicsofsuicide.lib.utah.edu</a>. Her current projects include a book, Sex & Consequences, on the large-scale reproductive problems of the globe, and work on challenging assumptions in urban design.

## Eva E. Bolt

Eva Bolt is a family physician in training, as well as a PhD student at the VU medical center in Amsterdam, the Netherlands. Her PhD focusses on end-of-life decisions which aim to hasten death, such as physician-assisted death and voluntary stopping of eating and drinking. In the Netherlands, family physicians are regularly asked to play a role in hastening death, which can put them in a difficult ethical dilemma. Eva plans to defend her PhD thesis in 2017. In Seattle, she will describe the experiences of Dutch family physicians with patients who voluntarily stop eating and drinking.

#### **Lisa Brodoff**

Professor Brodoff served as chief review judge in the Office of Appeals for the Washington Department of Social and Health Services and was appointed chief administrative law judge for the Office of Administrative Hearings. She has also worked as an attorney for the Puget Sound Legal Assistance Foundation and as legislative staff counsel to the Washington Senate. She joined the faculty in 1997.

Professor Brodoff has engaged in both scholarly work and impact litigation/legislative advocacy while teaching at Seattle University. Her areas of expertise are in the rights of sexual minorities, people with disabilities, the elderly, and public assistance beneficiaries; and in clinical law teaching theory. She is a frequent speaker at conferences and continuing legal education programs on topics including the right to counsel in civil matters, end-of-life and disability planning, and the administrative hearing process. Professor Brodoff was instrumental in the passage of legislation in Washington State creating the Mental Health Advance Directive, a planning document for people with mental illness. Washington's statute is now considered model legislation for states seeking to expand the rights and planning options for people with mental illness. She also created a new and innovative planning document for people with Alzheimer's Disease and other types of dementia - the Alzheimer's/Dementia Mental Health Advance Directive.

In addition to her scholarship, speaking, and impact work, Professor Brodoff has served on a number of committees and boards including the Coalition for Indigent Representation and Civil Legal Equality (CIRCLE), the Access to Justice Board Impediments Committee, and the Street Youth Legal Advocates of Washington Board. She is also a tribal court appellate judge for the Northwest Intertribal Court System.

# **Carla Calogero**

Carla Calogero is an attorney at Reed, Longyear, Malnati & Ahrens, PLLC in Seattle. Ms. Calogero's practice is limited to the representation of persons involved in guardianships, vulnerable adult

protective actions, probates, and trusts, and to advance care, end of life, and estate planning. In addition, Ms. Calogero is regularly appointed by the King County Superior Court as Guardian ad Litem or Special Representative for incapacitated persons in guardianship, trust, probate and litigation matters. She the immediate past Chair of the Elder Law Section of the Washington State Bar Association and a past Chair of the King County Bar Association Guardianship and Elder Law Section. Ms. Calogero received her J.D. from Seattle University School of Law, as well as an M.A. in Bioethics from the University of Washington, and an M.A. in Education from Western Washington University.

## Norman L. Cantor

Norman L. Cantor is Distinguished Professor of Law, Emeritus, at Rutgers University Law School, Newark. There, he taught in several fields, most notably "Death, Dying, and the Law." On that topic he has published dozens of articles in medical and legal journals as well as 4 books: *After We Die: The Life and Times of the Human Cadaver* (2010); *Making Medical Decisions for the Profoundly Mentally Disabled* (2005); *Advance Directives and the Pursuit of Death with Dignity* (1993); and *Legal Frontiers of Death and Dying* (1986). Professor Cantor is a cum laude graduate of Princeton University and a magna cum laude graduate of Columbia Law School where he was notes and comments editor of the Columbia Law Review. Professor Cantor has served as a visiting professor at Columbia University, Seton Hall University, Hebrew University of Jerusalem, and Tel Aviv University.

## **Annette Clark**

After receiving an M.D. with Honors from the University of Washington's School of Medicine and her J.D. summa cum laude from the Seattle University School of Law, Dean Clark joined the School of Law faculty in 1989. In addition to her duties as a faculty member, she is a long-time administrator, having served for ten years as Associate Dean and then Vice Dean, overseeing the academic program, including the curriculum and centers and institutes, as well as the faculty. She was the Interim Dean at Seattle University School of Law from 2009-2010, a Visiting Scholar at The George Washington University Law School for Fall 2010, and Dean and Professor of Law at the Saint Louis University School of Law from 2011-12.

While on the SU faculty, Dean Clark received the Seattle Journal for Social Justice Faculty Award in 2005, the Dean's Medal in 2006, and the Outstanding Teacher Award from the graduating class in December 2007 and December 2011. She was also named the James B. McGoldrick, S.J., Fellow in 2008-09 by President Stephen V. Sundborg, S.J. This annual award is given to the faculty member or administrator who best exemplifies commitment to students and to the values of a Jesuit education. Dean Clark counts teaching law students as one of her greatest joys.

Her areas of expertise include civil procedure, medical liability, bioethics, and legal education and she is a frequent regional and national lecturer on these topics. Her scholarship operates at the interface of health care, law, and health policy, with a particular emphasis on end-of-life issues. She has published articles in the New York University Law Review, the Georgetown Law Journal, and the Tulane Law Review, among others.

Throughout her professional career, Dean Clark has been active in various community and professional organizations, including serving on the MultiCare Institutional Review Board and the Safe Crossings Foundation Board.

#### **Amy Freeman**

Amy Freeman is an attorney with experience in federal and state litigation, legislative advocacy, and administrative law in both California and Washington. Currently a solo attorney in private practice, Ms. Freeman represents the Washington State Long-Term Care Ombudsman, a nonprofit-based program established under federal law to advocate for the rights of individuals living in long-term care facilities. Ms. Freeman is also an adjunct professor at Seattle University School of Law, where she teaches Introduction to Elder Law. An active volunteer, Ms. Freeman has served as chair, and continues to serve on the executive committees, of the elder law sections for both the Washington State and the King County Bar Associations. From 2008-12, Ms. Freeman worked as an elder law attorney in the Seattle Office of Columbia Legal Services, a statewide nonprofit organization that advocates for people who face injustice and poverty. Before relocating to Seattle, she practiced employment law and class action litigation with O'Melveny & Myers, an international law firm based in Los Angeles. Prior to law school, Ms. Freeman worked for a variety of non-profit organizations that serve low-income elderly individuals.

#### Linda Ganzini

Professor of Psychiatry and Medicine, OHSU; Staff Psychiatrist, Consult-Liaison Psychiatry Service and Outpatient Mental Health, VA Portland HCS; Director of Geriatric Psychiatry Fellowship Program, OHSU; Director of the Division of Geriatric Psychiatry, OHSU; Project on Death in America, Faculty Scholars Award, 1998-2000; Research Award, Academy of Psychosomatic Medicine, 2005 Clinical and Research Interests Dr. Ganzini joined the OHSU Department of Psychiatry faculty immediately upon completion of a gerontology fellowship at the Portland VA Medical Center (PVAMC) in 1989. She also joined the psychiatry staff at the Portland VA as Director of Consult-Liaison Psychiatry (1989-98, 2015-current). From 1994-97, she was director of the OHSU Medical Student Clerkship in Psychiatry, and from 1996-2001, she was Associate Director of the OHSU Psychiatry Residency Training Program. The department honored her with the Psychiatry Residency Teaching Award in 1991 and the Distinguished Service Award in 1996 in recognition of her contributions to the residency training program. She was awarded the Nancy C.A. Roeske, M.D., Certificate of Recognition for Excellence in Medical Student Education by the American Psychiatric Association in 1997 and the Faculty Development Award, in 2003. She was Director of the Health Services Research and Development Enhancement Award Program at the Portland VAMC between 2006 and 2013. She is currently the Associate Director of the HSR&D Center of Innovation. Dr. Ganzini's research interests are centered in the areas of geriatric mental health, end-of-life care issues, and suicide. Dr. Ganzini has published extensively in peer-reviewed journals, invited articles, book chapters, editorials and commentaries on the topics of Oregon's Death with Dignity Act, physician aidin-dying, assessing mental health in the terminally ill, and medical ethics among psychiatrists and health care providers.

# **Erin Crisman Glass**

Erin Crisman Glass is an estate planning, elder law, and adoption attorney at Barron Smith Daugert PLLC in Bellingham, Washington. Erin believes every person deserves to have an estate plan that is shaped by their own set of unique circumstances, whatever those may be. Erin is especially dedicated to ensuring that her client's end of life wishes are thoughtfully considered and documented so that their values can be honored at the end of life. Additionally, Erin prepares special needs trusts to assist families as they navigate the often complex legal and financial issues that are raised when a loved one has a cognitive or physical impairment. Erin advises clients on the myriad of issues encountered regarding access to public benefits, particularly long-term care Medicaid and veterans' benefits planning. Many times, these issues require the appointment of a guardian, as well as trust creation and administration. Erin is a frequent speaker on these and other issues. Erin graduated cum laude from Seattle University School of Law where she served as editor-in-chief of the Seattle Journal for Social Justice.

#### **Sara Goering**

Sara Goering is Associate Professor of Philosophy at the University of Washington, with affiliations with the Program on Values in Society, the Disability Studies Program, and the Department of Bioethics & Humanities.

#### **David Gruenewald**

David Gruenewald M.D. is Medical Director of the Palliative Care & Hospice Service at VA Puget Sound Health Care System (2004-current), and Associate Director of the Palliative Medicine Fellowship at the University of Washington School of Medicine. He is board-certified in Hospice and Palliative Medicine, Geriatric Medicine, and Internal Medicine. He published peer-reviewed articles in palliative care for people with multiple sclerosis and palliative care for older adults, as well as a quality improvement curriculum for improving family meetings in intensive care units. He is local site investigator for a project to identify barriers and facilitators of end of life care for homeless Veterans, and leads a project to improve palliative care in intensive care units throughout the Department of Veterans Affairs.

As a clinician in palliative care and geriatric care, Dr. Gruenewald has cared for and counseled patients who have considered voluntary cessation of eating and drinking. He is well versed in "options of last resort" for patients who are facing the end of their lives and considering their options.

## **Katherine Hammond**

Katherine Hammond, longtime resident of British Columbia and registered nurse, has taught at Fraser Valley College. She now manages a log and timber frame construction company that she helped to develop, is raising three sons, and is a consultant in vocational rehabilitation.

She became involved in issues around dying with dignity and provision of food and water when her mother, Margot Bentley, became extremely debilitated in the final stages of Alzheimer's. She and her family are involved in a 5-year legal struggle to have her mother's wishes honored.

# Sergia Hay

Sergia Hay is Assistant Professor of Philosophy at Pacific Lutheran University in Tacoma, Washington where she teaches courses in the history of philosophy and ethics, including biomedical ethics this fall. Prof. Hay studied philosophy at Wellesley College, Cambridge University, and Columbia University. Her research focuses on the Christian ethics of Søren Kierkegaard.

#### **Patricia Hunter**

Under the 1965 Older American's Act, the Long-Term Care Ombudsman Program is mandated to promote and protect the civil and legal rights, dignity and well-being of individuals living in licensed long-term care settings. Since 2011, Patricia has served as the State Long-Term Care Ombuds for Washington. She leads a statewide effort of paid staff, subcontractors and volunteer ombudsmen to actively receive, investigate and resolve approximately 4800 complaints annually, filed by, or on behalf of, long-term care residents. Ms. Hunter also works on systemic issues, collaborating with consumers, community leaders, state agencies, and legislators to improve the quality of care and life in long-term care settings. Patricia started her 28 year-career in the "aging" field, working in a nursing home. She earned a Master's in Social Work in 1996 from the University of Washington, in Seattle. Currently, she is an appointed to serve on the Washington State Joint Legislative and Executive Committee on Aging and Disability and she is a subcommittee member of the Washington State Dementia Action Coalition. The State Long-Term Care Ombudsman Program is administered by the Multi-Service Center, a private not-for-profit organization located in Federal Way, Washington.

#### **Trudy James**

Trudy James is a seminary graduate and retired interfaith hospital chaplain. She learned hands-on lessons about death, dying and grief in the early days of the AIDS epidemic in the South. Her ground-breaking work with AIDS was honored at the Clinton White House. Later, she developed an AIDS Care Team program in Seattle and served as a chaplain at the Seattle Cancer Care Alliance. After retiring, she spent four years pioneering community-based end-of-life planning workshops and two years producing a 30-minute documentary film based on those groups. The film, *Speaking of Dying*, is useful for individuals, groups and families who wish to become more comfortable discussing the choices and resources involved in planning for good endings. She has also trained ten Heartwork facilitators who conduct end-of-life planning workshops throughout the Puget Sound area and in other states. Learn more at www.speakingofdying.com

# Michael Jaycox

Dr. Jaycox received his Ph.D. in theological ethics from Boston College in 2014. In his dissertation, he proposed a virtue-based ethic of social anger, considering this emotion as a form of moral agency that motivates groups to pursue prophetic political resistance and institutional reform in response to systemic injustice.

Operating within the Catholic moral tradition, his scholarship is generally concerned with the question of how critical perspectives on class, race, gender, and sexuality might offer a basis for reconstructing the natural law methodologies that characterize this tradition. More specifically, he investigates the extent to which the "preferential option for the poor" can offer an accurate and powerful moral lens helpful for addressing justice issues in bioethics, violations of human rights, inequitable institutional participation, and other traditional concerns of Catholic social ethics.

He is published in the journals Developing World Bioethics and Horizons, and he has authored reviews for Political Theology and the Journal of the Society of Christian Ethics. He is an active member of the Society of Christian Ethics, the Catholic Theological Society of America, and the College Theology Society. Currently, he teaches undergraduate courses in Christian theology and ethics at SU, and he is preparing a book proposal for his research on anger and social justice.

# **Paulette Kidder**

Paulette Kidder is an Associate Professor of Philosophy at Seattle University. She received her PhD from Boston College in 1989. Dr. Kidder teaches courses in Health Care Ethics, Ethics of Food, 19th Century Thought, Feminist Moral Theory, and the philosophy of Martha Nussbaum. Her research interests and publications focus on bioethics, philosophy and literature/film, contemporary Continental philosophy, and the dialogue between Catholic thought and contemporary philosophical movements. Dr. Kidder serves as a community member of the Institutional Review Board at Fred Hutchinson Cancer Research Center in Seattle. She has served as Associate Dean for Faculty and Interim Dean in SU's College of Arts and Sciences and as Acting Dean of the Matteo Ricci College.

#### Patricia C. Kuszler

Patricia C. Kuszler is a graduate of Mayo Medical School (MD, 1978) and Yale Law School (JD, 1991). She joined the faculty of the School of Law at the University of Washington in 1994 and is currently the Charles I Stone Professor of Law. She is the Director of the School of Law's Center for Law, Science and Global Health, and is an Adjunct Professor in the UW School of Medicine (Department of Bioethics and Humanities), the School of Public Health (Department of Health Services). Professor Kuszler 's teaching and research interests include the impact of law and regulation on health care delivery, health care

finance, research standards and misconduct, health and human rights, disability law, public health law in the age of bioterrorism, global and comparative health law, and the legal, ethical and policy issues presented by genetic information and the biotechnology industry.

Most recently, Professor Kuszler has been integrally involved in launching UW School of Law's Health Law LL.M, its Masters of Jurisprudence program for non-attorneys, and its joint venture with the Washington State Bar Association to train Limited License Legal Technicians. The latter is the first such program in the nation and is serving as a model for other states seeking to improve access to legal services.

# **Anson Laytner**

Rabbi Anson Laytner retired in 2015 from his position as program manager of the Interreligious Initiative at Seattle University's School of Theology and Ministry. Currently he is writing a study of god-concepts and the meaning of suffering entitled "Cold Comfort: I Know There Is A God; I Just Don't Know What S/He Does" and co-editing a volume of scholarly essays on the Jews of Kaifeng, China. As a volunteer, he is past president of the Sino-Judaic Institute and edits its journal, Points East. He also serves on the advisory boards of End of Life (Washington) and the New Israel Fund (Pacific Northwest).

Previously he worked as grants and contracts coordinator for the Jewish Family Service of Seattle, a bereavement chaplain with Kline Galland Hospice, interim rabbi at Congregation Kol HaNeshamah in West Seattle, and as executive director of the Seattle Chapter of the American Jewish Committee and of Multifaith Works, a Seattle non-profit agency that served people with AIDS. He also directed the Seattle Jewish Federation's Community Relations Council.

Laytner is the author of the cult classic "Arguing with God" (Jason Aronson, 1998) and, with Dan Bridge, of "The Animals' Lawsuit Against Humanity" (Fons Vitae, 2005). He has authored over sixty articles on subjects ranging from Jewish theology to the Arab-Israel conflict to the Chinese Jews. Laytner has a BA, summa cum laude, from York University in Toronto, a Masters of Hebrew Letters (MHL) and rabbinic ordination from Hebrew Union College, a Masters in Not-for-Profit Leadership (MNPL) from Seattle University, and an honorary Doctorate in Divinity from Hebrew Union College.

# **Tresa Mariotto**

Tresa Mariotto is the former Executive Director of Woodway Senior Living. She currently works for DSHS Home and Community Services as the Region 2 Social Services Director for the Skilled Nursing Facility Unit. Tresa is a certified Mental Health and Dementia trainer, educating and training caregivers how to redirect and support the cognitively impaired. Tresa is on a mission to advocate for resident's rights especially the cognitively impaired in life and in death.

# **Paul Menzel**

Paul T. Menzel, PhD, is Professor of Philosophy emeritus at Pacific Lutheran University. He has published widely on moral questions in health economics and health policy, including several books. Most recently he has written on end of life issues, including advance directives for dementia and VSED. In recent years he has also been a visiting scholar at the Brocher Foundation (Geneva) and the Chinese University of Hong Kong.

# **Thaddeus Pope**

Thaddeus Mason Pope is Director of the Health Law Institute and Professor of Law and at Mitchell Hamline School of Law. He is also an Adjunct Professor with the Australian Centre for Health Law

Research at Queensland University of Technology; Adjunct Associate Professor with the Alden March Bioethics Institute at Albany Medical College; and Visiting Professor of Medical Jurisprudence at St. Georges University. Professor Pope has over 1 25 publications in: leading medical journals, law reviews, bar journals, nursing journals, bioethics journals, and book chapters. He also coauthors the definitive treatise The Right to Die: The Law of End -of- Life Decisionmaking, and runs the Medical Futility Blog (with over two million page views). Professor Pope works to calibrate the balance between individual liberty and public health in the end -of-life medical treatment context. Specific research topics have included: medical futility, ethics committees, brain death, advance directives, surrogate decision making, aid in dying, and VSED. More recently, Pope has been innovating new legal tools to better assure adequate informed consent and fair internal dispute resolution mechanisms. Prior to joining academia, Professor Pope practiced at Arnold & Porter LLP and clerked on the U.S. Court of Appeals for the Seventh Circuit. Pope earned a JD and PhD in philosophy and bioethics from Georgetown University.

# **Timothy Quill**

Timothy E. Quill, MD is the Thomas and Georgia Gosnell Distinguished Professor in Palliative Care at the University of Rochester Medical Center (URMC) where his is also Professor of Medicine, Psychiatry, Medical Humanities and Nursing. He was the Founding Director of the URMC Palliative Care Division and a Past President of the American Academy of Hospice and Palliative Medicine.

Dr. Quill has published and lectured widely about various aspects of the doctor-patient relationship, with special focus on end-of-life decision making, including delivering bad news, nonabandonment, discussing palliative care earlier, and exploring last-resort options. He is the author of several books on end-of life care and over 150 articles published in major medical journals. Dr. Quill was the lead physician plaintiff in the New York State legal case challenging the law prohibiting physician-assisted death that was heard in 1997 by the U.S. Supreme Court (Quill v. Vacco).

Dr. Quill received his undergraduate degree from Amherst College (1971), and his M.D. from the University of Rochester (1976). He completed his Internal Medicine Residency in 1979 and a Fellowship in Medicine/Psychiatry Liaison in 1981, both from the University of Rochester School of Medicine and Dentistry. Dr. Quill is a Fellow in the American Academy of Hospice and Palliative Medicine, a Fellow

# **Peter Reagan**

Dr. Reagan attended Haverford College in Philadelphia and Reed College in Portland, and was a 1977 OHSU medical school graduate before completing our family medicine residency in 1983. Pete has been the recipient of the OHSU Family Medicine Lewis Carpenter Award for Excellence in Student Teaching. Students nominating him for this award described him as, "a teacher at heart, both to patients and students."

# **Diane Rehm**

Host since 1979 of *The Diane Rehm Show* distributed by National Public Radio, Diane Rehm is also the author of *Finding My Voice* (1999) and *On My Own* (2016). She has become a prominent spokesperson in the national discussion of end-of-life options. In 2014 her husband, John, died by voluntarily stopping eating and drinking. She received the Peabody Award in 2009 and National Humanities Medal in 2013.

## **Judith Schwarz**

Judith Schwarz has been the Clinical Director of End of Life Choices New York (EOLCNY) and its predecessor organization Compassion & Choices of New York since 2002. EOLCNY is a not-for-profit

organization that provides information, advocacy and support to incurably and terminally ill patients and their families who seek control of the circumstances and timing of death.

She is a nationally recognized clinical expert on the option of voluntarily stopping eating and drinking (VSED) as a means for capacitated and suffering patients to hasten death. She has published six articles addressing clinical and ethical aspects of VSED, and frequently lectures about this option to professional and lay audiences. She was recently invited by a hospice ethics committee to explore the benefits of developing organizational policies regarding support of hospice patients who choose VSED. She provides consultation about VSED to clinicians across the country.

Dr. Schwarz earned a PhD in nursing research from New York University, a MSN from Lehman College, a BS from Fordham College, and an RN degree from St. Luke's School of Nursing in Denver.

# **Phyllis Shacter**

Phyllis Shacter has been a teacher, business consultant, life coach, and public speaker, including her TEDx Talk, "Not Here By Choice". She has a detailed website about VSED and her personal story at PhyllisShacter.com. She uses all her skills today to share her personal story to educate others about end of life choices

## **Sarah Shannon**

Dr. Shannon's area of scholarship has focused on improving the health care team's communication with patients and their families around end-of-life care and disclosure of medical errors to patients. Dr. Shannon has expertise on the ethical issues of caring for seriously-ill and dying adults including end-of-life decision-making, clinicians' knowledge of the legal guidelines for abating life-sustaining therapy, care of families of dying ICU patients, and interdisciplinary conflict. She currently is an investigator on two NIH funded grants focused on improving communication between health care teams and seriously-ill patients and their families and one foundation-funded study focused on integrating interprofessional skills in professional education. Dr. Shannon is a long time member of several local hospital ethics committees. She is a regular faculty member of the annual Summer Seminar in Health Care Ethics course and a frequent local and national speaker on ethic

# Paula Span

Paula Span, a veteran journalist, anchored the New Old Age blog for the New York Times from 2009 through 2014. She now writes a twice-monthly column on aging and caregiving, also called the New Old Age, which appears on the New York Times website and in the print Science Times section. Her book, "When the Time Comes: Families With Aging Parents Share Their Struggles and Solutions," was published in 2009 by Hachette. A former staff writer for the Washington Post, and a freelance contributor to many magazines and newspapers, she has helped train the next generation of journalists at the Columbia University Graduate School of Journalism since 1999. She gives talks about aging and caregiving to groups nationwide.

#### Joan Teno

Dr. Teno led the effort in the design of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) intervention analysis and was lead author in twelve publications from that research effort, which ranged from the role of advance directives to describing the dying experience of seriously ill and older adults. Both as a researcher and clinician,. Dr. Teno has devoted her career to understanding how to measure and improve the quality of end of life care for vulnerable populations. She was the lead investigator in a research effort to create a Toolkit of

Instruments to Measure Care at the End of Life (TIME). In this grant effort, she created the Brown University Family Evaluation of Hospice Care, that was in part adapted into CAHPS Hospice Survey. She has led a state wide effort to improve pain management in nursing homes, for which she has received an award from the American Cancer Society

#### Robert D. Truog, MD

Robert D. Truog, MD, is the Frances Glessner Lee Professor of Medical Ethics, Anaesthesia and Pediatrics at Harvard Medical School, where he serves as Director of the Center for Bioethics, leading teaching and academic initiatives across the medical school, including an undergraduate curriculum, Master's degree and Fellowship programs, and a post-doctoral program for Research Scholars.

He has practiced pediatric intensive care medicine at Boston Children's Hospital for more than 30 years, including serving as Chief of the Division for more than a decade. He has published more than 250 articles and books in bioethics and related disciplines, including "Talking with patients and families about medical error" (2010, Hopkins) and Death, dying, and organ transplantation (2012, Oxford). In 2013 he was honored with the Spinoza Chair at the University of Amsterdam.

# **Hope Wechkin**

Hope Wechkin, MD has been the medical director of EvergreenHealth's Hospice and Palliative Care programs since 2007. A graduate of Yale University and the University of Washington School of Medicine, Dr. Wechkin is a frequent guest speaker on clinical, ethical, and programmatic aspects of providing care to patients with serious illness. In 2015, she was the first palliative care physician to be featured as one Seattle Magazine's "Top Docs." A recipient of EvergreenHealth's Physician Innovation and Leadership award, Dr. Wechkin sees patients and families at EvergreenHealth's Palliative Medicine clinic in Kirkland, Washington.