

ASBH 14TH ANNUAL MEETING

REPRESENTING BIOETHICS



Washington, DC

Hyatt Regency Washington on Capitol Hill

American Society for Bioethics and Humanities

ANNUAL MEETING

Who Should Attend

The American Society of Bioethics and Humanities (ASBH) Annual Meeting is designed for physicians, nurses, attorneys, historians, philosophers, professors of literature and the humanities, members of the clergy, social workers, and others engaged in endeavors related to clinical and academic bioethics and the health-related humanities.

Purpose

The ASBH Annual Meeting will be an arena for interdisciplinary exchange among professionals in the fields of bioethics and the medical humanities.

Objectives

After participating in this meeting, attendees should be able to

- provide background education in bioethics and the medical humanities
- discuss emerging issues in bioethics and the medical humanities
- explore recent research findings related to bioethics and the medical humanities
- examine the significance of interdisciplinary and multidisciplinary approaches to issues in bioethics and the medical humanities.

Continuing Education Credit

Physicians

This live activity has been planned and implemented in accordance with the Essential Areas and Policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint sponsorship of the University of Minnesota (UMN) and ASBH. UMN is accredited by ACCME to provide continuing medical education for physicians. UMN designates this live activity for a maximum of 21.5 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Preconference event: UMN designates this live activity for a maximum of 7.0 AMA PRA Category 1

Annual meeting: UMN designates this live activity for a maximum of 14.5 AMA PRA Category 1 $Credits^{\mathsf{TM}}$.

Nurses

The UMN School of Nursing, Office of Practice, Partnerships, and Professional Development, is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation. This activity is awarded up to 21.5 contact hours.

Lawyers

UMN has applied for the Minnesota State Board of Continuing Legal Education credits. Determination of the exact number of credits is pending.

Responsible Conduct of Research credit for this activity is pending.

Social Work

This activity is pending approval from the National Association of Social Workers.

Other Attendees

Other professionals who participate in this educational activity may submit their Statements of Attendance with their specific claim for continuing education units (CEUs) to their appropriate accrediting organizations or state boards for consideration of credit. Those participants are responsible for determining whether this activity meets the requirements for acceptable CEUs.

Faculty Disclosure Statement

It is the policy of the UMN Office of Continuing Medical Education and School of Nursing to ensure balance, independence, objectivity, and scientific rigor in all of its sponsored educational activities. All participating speakers, course directors, and planning committee members are required to disclose to the program audience any financial relationships related to the subject matter of this program. Relationships of spouse/partner with proprietary entities producing healthcare goods or services should be disclosed if they are of a nature that may influence the objectivity of the individual in a position to control the content of the continuing medical education activity. Disclosure information is reviewed in advance in order to manage and resolve any possible conflicts of interest. Specific disclosure information for each speaker, course director, and planning committee member will be shared with the audience at the conference.

Program Committee Cochairs

Tom Buller, PhD Illinois State University

Eran Klein, MD PhD

Oregon Health and Science University and Portland VA Medical Center

Katie Watson, JD

Feinberg School of Medicine, Northwestern University

Members

John J. Banja, PhD

Emory University

Paula Goodman-Crews, MSW LCSW

Kaiser Permanente

Amy Haddad, PhD RN

Creighton University Medical Center

Lisa Lehmann, MD PhD

Brigham and Women's Hospital

Board Liaisons

Joseph J. Fins, MD MACP

Weill Cornell Medical College

Felicia Cohn, PhD MA

Kaiser Permanente, Orange County

About ASBH

ASBH is a multidisciplinary not-for-profit organization dedicated to promoting an exchange of ideas and fostering multidisciplinary, interdisciplinary, and interprofessional scholarship, research, teaching, policy development, professional development, and collegiality among people engaged in all of the endeavors related to clinical and academic bioethics and the health-related humanities. The more than 1,500 members of ASBH are healthcare professionals, teachers, consultants, and others who have an interest in the fields of bioethics and humanities.

Thursday, October 18

8 am-Noon

Preconference Sessions

Improving Your Skills in Empirical Ethics: From Apprentice to Artisan (001)

Nancy A. Birk, PhD, University of Michigan, Ann Arbor, MI Raymond De Vries, PhD, University of Michigan, Ann Arbor, MI Scott Y. Kim, MD PhD, University of Michigan, Ann Arbor, MI Susan D. Goold, MD MA MHSA, University of Michigan, Ann Arbor, MI Jennifer K. Walter, MD PhD, University of Michigan, Ann Arbor, MI Kevin P. Weinfurt, PhD, Duke University Medical Center, Durham, NC Renee R. Anspach, PhD, University Michigan, Ann Arbor, MI

This workshop will improve one's ability to do, and to review, empirical research on issues of ethical import. Because bioethics is a relatively new area of inquiry, bioethics professionals must ensure the scientific rigor of research in the field. The reputation and value of bioethics is diminished to the extent that it lacks rigorous research methods and careful and thorough peer review of research. Recognizing the need to improve the quality of bioethics research, ASBH sponsored a session in 2010 that provided an overview of the basic tools and skills of empirical bioethics research. Our workshop is designed to take beginners to the next level.

Participants will work in two groups so that we make the most efficient use of the time: one group will concentrate on quantitative methods, and the other, on qualitative methods. The group sessions will begin with a concise review of the most common difficulties in the application of the method and will move on to instruction in and discussion of the problems encountered by participants. Participants will reconvene to brainstorm about the ways they can continue their education in methods of research. All participants will be given both a general and an issue-specific reading list that will serve as an important resource for improving their skills as researchers.

This workshop will

- identify core topics fundamental to improving empirical ethics research skills
- explore common methodological problems in empirical ethics and learn how to surmount them
- · provide useful resources for participants to take home.

Two weeks before the workshop, the moderator will ask participants to send a description of two or three vexing problems encountered in the course of conducting empirical research. These concerns might include (but are not limited to) sampling; survey development; conducting interviews, focus groups, or observations; online data collection; and data analysis.

Registration Fee: ASBH member, \$90; nonmember, \$150; student, \$50

How to Do Things with Texts: Close Reading and **Critical Interpretation (002)**

Bernice L. Hausman, PhD, Virginia Tech, Blacksburg, VA Tod Chambers, PhD, Northwestern University, Chicago, IL Catherine Belling, PhD, Northwestern University, Feinberg School of Medicine, Chicago, IL

Kelly E. Pender, PhD, Virginia Tech, Blacksburg, VA

The workshop covers techniques of close reading and interpretation, directly addressing the conference theme of "representing bioethics" by focusing on the actual practices of analyzing textual representations. Recognized technique in this area has been established by "narrative medicine," which focuses on "recognizing, absorbing, interpreting, metabolizing, and being moved by stories of illness." However, such a definition often leaves nonliterary scholars at a loss—how does one actually approach textual analysis? How does one "do things with texts"?

This workshop aims to improve participants' technical competence with textual analysis by providing three frameworks through which actual medical humanities scholars work with texts. The target audience is medical humanists whose primary educational background is medicine or science, not the humanities. Participants who want to use such techniques in teaching will gain significant tangible skills in these areas that they can directly translate to the classroom, while those who simply want to improve their own reading practices and pleasures will also benefit. The organizers of the workshop were motivated to develop it as a result of comments made after the ASBH 2011 meeting, when participants in a preconference workshop on literary bioethics expressed a desire to have more basic, participatory instruction in textual analysis.

Narrative, rhetorical, and cultural studies approaches currently dominate close reading techniques used in the medical humanities. This topic best fits the preconference time frame because the lengthy, intensive workshop context will allow presenters to focus on each close reading framework, providing brief readings to be completed on site and guiding discussion on how the frameworks structure the reading experience and interpretative acts.

The workshop presenters are recognized experts in these areas and use these frameworks in their research and in teaching undergraduate, graduate, and medical students. Two are faculty in a medical humanities program at a medical school, and two have appointments in an English department at a major research university; one of the latter also has a secondary appointment at a medical school.

The main components of the workshop are

- reading narratologically—This two-part discussion of narrative analysis will focus attention on narrative frameworks and tropes, teaching attendees how to focus on narrative elements that condition reader expectation and move stories along in predictable or unexpected ways. Workshop attendees will learn how to identify and interpret narrative structures and their influence on textual meaning. Part 1 will focus on a fictional text, and part 2 will focus on a bioethics case.
- reading rhetorically—This discussion of rhetorical analysis will focus on the contexts and contingencies of specific bioethical

THURSDAY, OCTOBER 18: PRECONFERENCE SESSIONS

situations. Workshop attendees will practice rhetorical analysis by applying specific critical methods (metaphoric, ideographic, and neo-Aristotelian) to a few short public, scientific, and mass media texts about genetic medicine.

reading ideologically—Cultural studies frameworks often identify and analyze ideology and textual politics. This discussion of cultural studies analysis will focus on political representations and power dynamics in texts, paying special attention to gendered representations. Workshop attendees will practice ideological analysis through discussion of a short story.

Registration Fee: ASBH member, \$90; nonmember, \$150; student, \$50

Introductory Skills Workshop in Mediation: Learning the Techniques of Facilitation and Conflict Resolution for Use in Clinical Ethics Consultations (003)

Autumn Fiester, PhD, University of Pennsylvania, Philadelphia, PA Lance Wahlert, PhD, University of Pennsylvania, Philadelphia, PA Edward J. Bergman, JD, University of Pennsylvania Perelman School of Medicine, Philadelphia, PA

Professional mediators have long possessed a unique skill set needed to facilitate difficult conversations between individuals in emotionally laden situations, to generate solutions that meet the needs of all parties in a negotiation, and to resolve conflicts that seem intractable. This skill set is increasingly being recognized as invaluable to the work of clinical ethics consultants as they navigate conflicts between and among patients, families, surrogates, and providers. Moreover, given that it has long been acknowledged that communication difficulties lie at the root of many clinical ethics conflicts, the discipline of mediation has as its core area of investment for disputing parties the promotion of more effective communication of individual concerns, values, perspectives, and understandings—all of which are essential to the clinical ethics consultation process. This hands-on workshop will introduce the central techniques of mediation through the use of simulated role plays, with a focus on conflicts caused by communication breakdown, highly charged values conflicts, and disputes caused by perceived slight, offense, or insult.

The three facilitators of this workshop are experienced teachers of mediation techniques and methods. Based on their experience conducting mediation seminars and workshops for a diverse set of audiences (clinicians, nurses, clergy, hospital administrators, social workers, clinical ethics consultants) this workshop will be tailored to the needs of those who conduct bedside clinical ethics consultations or those whose professional role includes participation in a clinical ethics consultation service.

This interactive workshop session will be divided into three segments.

- In a 30-minute didactic session, mediation concepts, techniques, and an overview of the process will be introduced.
- Attendees will be divided into three small groups for two simulated mediation role plays. Each role play and assessment will feature a 60-minute simulation followed by a 30-minute debriefing and discussion session.
- The techniques learned and performed during the workshop will be reviewed, and a Q&A session will conclude the

The facilitators are three bioethicists experienced in the teaching and application of mediation techniques, each bringing a unique

and valuable skill set to the discipline of mediation. Autumn Fiester is a clinical ethicist and moral philosopher, sensitive to and mindful of the ethical and moral dilemmas at play in clinical ethics disputes and mediation interventions. Lance Wahlert is a literary scholar and medical historian who teaches mediation, paying special attention to the language used in clinical ethics disputes, the motivations of personal narratives in medical settings, and the historical legacy of ethical disputes in clinical discourse. Edward Bergman is a practicing legal mediator and director of mediation studies, proficient in the execution of mediation techniques in clinical and juridical settings.

Registration Fee: ASBH member, \$90; nonmember, \$150; student, \$50

Advanced Skills Workshop for Clinical Ethics Consultation (004)

Jeffrey P. Spike, PhD, University of Texas–Houston, Houston, TX Sarah E. Shannon, PhD RN, University of Washington, Seattle, WA Denise M. Dudzinski, PhD MTS, University of Washington, Seattle, WA Stuart R. Sprague, PhD, Medical University of South Carolina and AnMed Health, Anderson, SC

Alexander A. Kon, MD, University of California–San Diego and Naval Medical Center San Diego, San Diego, CA

Five facilitators, experienced ethics consultants with backgrounds in the disciplines of medicine, nursing, philosophy, and religion, will focus on helping attendees develop advanced skills often called for in complex ethics consultations. We will discuss improving communication strategies, framing issues fairly, dealing with emotions, assessing decision-making capacity, encouraging shared decision making, and managing interprofessional conflict.

Topics to be covered:

- · using behavioral science skills to improve trust and communication by avoiding biased framing and ensuring a fair facilitation process
- assisting patients, families, and healthcare team members in developing a shared decision-making paradigm to avoid burdening patients and families, including a review of data that has led to this shift in our decision making away from a simplistic interpretation of the autonomy model and a discussion of when (if ever) physicians and healthcare facilities should have the power to make major treatment decisions (including the decision to limit or withdraw life-sustaining interventions), even over the objections of the patient or the family
- responding to requests for an ethics consultation when the emotional reactions of the patient, family members, or healthcare team are distracting or overwhelming. Emotion is a normal and expected part of difficult situations involving loss or contention. Yet emotions such as sorrow, guilt, frustration, hostility, intimidation, or anger sometimes distract from good decision making. How should the ethics consultant respond? Should one respond differently to emotion in a professional than to emotion in a patient or family member?
- improving interprofessional trust and communication. How should the consultant handle professional dynamics that may complicate the consultation process, such as deference to physicians? How should we approach consultations when different professionals disagree about the prognosis and plan of care? How do we ensure that all opinions are expressed, even if doing so is risky? How should we respond to the clinician who is apprehensive about talking with the attending

THURSDAY, OCTOBER 18: PRECONFERENCE SESSIONS

- physician about his or her ethical concerns? Should anonymous consultations be permitted?
- assessing decisional capacity of patients to avoid confusing families and healthcare team members about their role in decisions that belong to the patient.

ASBH's Core Competencies for Heath Care Ethics Consultation identifies the need for someone on the team to have "advanced skills" in a number of areas. Although clear standards and sources for advanced knowledge exist, (e.g., in ASBH's Improving Competencies in Clinical Ethics Consultation: An Education Guide) and they are often covered in numerous certificate and master's degree bioethics programs, it is hard to find help in learning advanced process and interpersonal skills. Unprepared consultants may simply ignore important aspects of cases that they cannot handle, leading to oversimplified case analysis and unsatisfactory resolutions.

We will identify a set of commonly needed skills and give practical hands-on training to develop those skills. Instead of didactic lectures, we will spend most of our time in small groups. Each participant will be able to choose three of the five topics. The topics will be discussed using cases and role-play to maximize interaction with the facilitators and stimulate discussion. (Note: The two texts mentioned above are highly recommended to session attendees and will be available for purchase at a discount at the registration desk. If you currently own copies of the texts, you are encouraged to bring them to the session.)

Registration Fee: ASBH member, \$90; nonmember, \$150; student, \$50

Being Present with Suffering: Wisdom from the **Humanities (005)**

Cynda H. Rushton, PhD RN FAAN, Johns Hopkins University, Potomac, MD Suzana Makowski, MD MMM FACP FAAHPM, UMass Memorial Medical Center, UMass Medical School, Grafton, MA

Sandra Bertman, PhD. National Center for Death Education, Newton, MA

As interprofessional clinicians, we have the primary obligation of relieving or reducing suffering. Many clinicians lack the skills to modulate their own emotions and responses in the face of suffering, dying, or death. Confronted with these situations, clinicians may find it difficult to remain present and may flee, abandon, withdraw, or become numb. Eventually, repeated exposures to suffering that are not modulated can threaten integrity, create chronic patterns of dysregulation, and undermine clinician well-being and the safety and quality of patient care.

Yet clinical education usually focuses on how to communicate and what information we can share, using cognitive methods for learning. Teaching the art of truly being there in these difficult moments in which we confront suffering is limited to scripts or guidelines that are often indiscriminately applied. Regardless of our primary discipline, this skill-staying present with suffering-is of vital importance in palliative care and arguably all clinical specialties.

In this experiential preconference workshop, we will explore the roles that the humanities, neuroscience, and mindfulness play in teaching us this fundamental and difficult skill of staying present in the midst of suffering. Building on the inextricable connection between body and mind, we will explore the crucial role of dissonance in music, of catharsis in literature and movies, and solitude in poetry and mindfulness. Using mindfulness practice and visual, auditory, and sensory experiences, participants will come to understand how art, music, literature, and mindfulness teach us the subtleties of authentically meeting and staying present with patients at times of crisis. Handouts will include a bibliography of resources for teaching. Participants will

- explore literature for children and adults that teaches curiosity about the cathartic moment and the intrigue of what might happen next
- listen to music and explore the meaning of dissonance and its importance in setting the precedence for resolution in classical music
- listen to poetry and experience sitting with the self as a lesson in how to be still, slow down, and explore silence and uncertainty
- have the opportunity to practice mindfulness
- consider the potential of bringing the humanities and mindfulness into their communities as a means to teach how to "be present with" a patient who is in crisis or is dying and use these tools for ongoing self-regulation.

Registration Fee: ASBH member, \$90; nonmember, \$150; student, \$50

Why the Bioethics Chart Note Is Important and How to Do It (006)

Allen S. Keller, MD, New York University School of Medicine, New York, NY Nancy N. Dubler, LLB, New York City Health and Hospitals Corporation, New York, NY

Asher Aladjem, MD, New York University School of Medicine, New York, NY James Zisfein, MD, Lincoln Hospital, Bronx, NY

In this session we will review the process of conducting and recording a clinical ethics consultation (CEC) and, in particular, effectively documenting this consultation in the medical record. We will present a model that we have developed and are disseminating for conducting CECs and specifically for writing a bioethics chart note.

The bioethics chart note has a special place in the medical record. As a documentation and reflection of the CEC, it must adhere to conventions of ethical analysis and standards for best practice in clinical medicine. It must reflect bioethics knowledge and conventions, and it must be readable, clear, and descriptive of the narrative history of the case; compelling in its identification and analysis of ethical issues; and respectful throughout to the patients, family members, and staff. Central to the consultation note is presentation and analysis of recommendations or reasonable options, including the underlying moral rationale on which they are based. Finally, the chart note should serve the crucial goal of education.

Specific information to be presented and discussed in this session:

- · brief overview of our CEC model and its implementation at several hospitals
- review of a stepwise approach to conducting bioethics consultations, including clarification of the ethical question; presentation of relevant facts to the case, including what is and is not known; application of relevant ethical principles to the bioethics consultation; and recommendations, including reasonable options and their moral justification.
- presentation of a model for writing bioethics chart notes and the relevant information that should be included
- discussion and review of ethics consultations, including those conducted by participants, and deidentified chart notes that

THURSDAY, OCTOBER 18: PRECONFERENCE SESSIONS

were written. We will come prepared with cases and chart notes, and, if possible, we will contact registered participants in advance of the session, share materials with them, and encourage them to come to the session with cases and notes

utilization of a quality improvement instrument developed in evaluating the quality of the note (as a surrogate marker for the quality of the consultation itself).

Registration Fee: ASBH member, \$90; nonmember, \$150; student, \$50

Building Your Bioethics Program: Strategies and Resources for Visioning, Programming, Academics, and Fundraising (007)

Paul Root Wolpe, PhD, director, Center for Ethics, Emory University, Atlanta,

David Magnus, PhD, director, Center for Bioethics, Emory University, Atlanta, GA

Susan Dorr Goold, MD MA MHSA, former director, Center for Bioethics and Social Sciences in Medicine, University of Michigan, Ann Arbor, MI

Mildred Solomon, EdD, president, Hastings Center, Garrison, NY

Holly Fernandez, JD M.Bioethics, executive director, Petrie-Flom Center of Law, Biotechnology, and Bioethics at Harvard Law School, Boston, MA

Many ASBH members will be called upon to establish, build, direct, and develop a bioethics center or simply to contribute to its growth and flourishing. Bioethics centers are strange and unique entities in most universities, and certain strategies, tricks, and wisdom about problem-solving, finding resources, and creating coherence are applicable to most of them. Bioethics centers also have some unique challenges. Five center directors will share their experiences and ideas on building a successful program. The directors are from different kinds of centers and will bring a diverse set of experiences and expertise.

The presentation will cover an overview of the considerations a bioethics center should weigh in determining its future: its core identity; its balance of scholarship, education, clinical work, and internal and external programming; its balance of staff and faculty needs and participation; and the role of local and university politics. Resource needs and solutions will be particularly highlighted.

We will also discuss the nuts and bolts of creating or maintaining a thriving bioethics center, including creating diversified funding streams to support the center and to support and develop the faculty (especially the junior faculty). We will discuss strategies for increasing publication rates and presentations at national bioethics meetings and developing a model that better integrates the various aspects of the center's mission. We will discuss bioethics centers that are largely research centers only; those that are teaching and research centers, and those that integrate other components of bioethics, such as clinical ethics, research ethics consultation, and policy and oversight roles.

We will also explore ways to balance aspects of mission (education, research, outreach, and service), necessary resources and budget stability, faculty appointments and responsibilities, and tricks for success and recipes for failure.

After a break, attendees in smaller working groups will discuss particular challenges at their institution and brainstorm solutions. Finally, the group will reconvene to share creative ideas and strategies generated in the breakout groups.

Registration Fee: ASBH member, \$90; nonmember, \$150; student, \$50

National Library of Medicine Tour (008)

ASBH is pleased to offer meeting attendees the opportunity to take a personalized tour of the National Library of Medicine. Buses will take registrants from the meeting hotel to the library, and a member of the library staff will lead the tour of rotating exhibits and portions of the research facilities. For more information on the library, please visit www.nlm.nih.gov/about/visitor.html.

Please be sure to bring a government-issued photo ID in order to gain entrance to the library. Buses will leave from in front of the meeting hotel at approximately 8:15 am. You will return to the meeting hotel at approximately 12:30 pm.

Registration Fee: ASBH member, \$40; nonmember, \$40; student, \$40

10-10:30 am

Preconference Workshop Break

Noon-1 pm Lunch (on your own)

1-2:30 pm

Concurrent Sessions

Workshop Session (101)

Re-Presenting the Doing of Ethics Consultation and **Peer Review**

Stuart G. Finder, PhD, Cedars-Sinai Medical Center, Los Angeles, CA Mark J. Bliton, PhD, Los Angeles Medical Center, Los Angeles, CA Andrea N. Frolic, PhD, Hamilton Health Sciences, Hamilton, ON, Canada Susan Rubin, PhD, The Ethics Practice, Oakland, CA

Workshop Session (102)

What Priority for Prevention Can Be Ethically Justified?

Paul T. Menzel, PhD, Pacific Lutheran University, Coupeville, WA Kenneth Kipnis, PhD, University of Hawaii–Manoa, Honolulu, HI Ruth R. Faden, PhD MPH, Johns Hopkins University, Baltimore, MD Halley S. Faust, MD MPH MA, American College of Preventive Medicine, Santa Fe, NM

Sarah Kliff, BA, The Washington Post, Washington, DC

Workshop Session (103): Clinical Research **Ethics Key Function Committee**

Establishing a Research Ethics Consultation Service: Core Features and Tailored Approaches

Benjamin Wilfond, MD, Seattle Children's Institute, University of Washington Seattle, WA

Mildred Cho, PhD, Stanford University, Palo Alto, CA

Marion Danis, MD, National Institutes of Health Clinical Center, Bethesda,

Elizabeth Heitman, PhD, Vanderbilt University, Nashville, TN Walter Limehouse MD, Medical University of South Carolina, Charleston, SC Holly Taylor, PhD, Johns Hopkins University, Baltimore, MD

Workshop Session (104)

Conundrums of Conscience: How Should Bioethics Represent and Accommodate the Conscientious Beliefs of Individual and Institutional Healthcare **Providers?**

Joseph C. Parker, MD PhD, East Carolina University Brody School of Medicine, Grimesland, NC

John C. Moskop, PhD, Wake Forest School of Medicine, Winston-Salem, NC Diane S. Behar, MBA, Wake Forest Baptist Health, Winston-Salem, NC

Panel Session (105)

Legal Update 2012: Top 10 Legal Developments in **Bioethics**

Amy T. Campbell, JD MBE, State University of New York Upstate Medical University, Syracuse, NY

Arthur Derse, MD JD, Medical College of Wisconsin, Milwaukee, WI Alicia Ouellette, JD, Albany Law School, Albany, NY

Thaddeus M. Pope, PhD JD, Hamline University, St. Paul, MN

Paper Session (106): Neonatal and Family Issues

Emerging Ethical Issues in Genetic Testing for Sudden Cardiac Death Syndromes: Challenges Facing Health Providers, Patients, and Families

Michelle A. Mullen, PhD MHP, Children's Hospital of Eastern Ontario, Ottawa, ON, Canada

Robert M. Gow, MD, Children's Hospital of Eastern Ontario, Ottawa, ON, Canada

What Is in Children's Best Interest? Genetic **Susceptibility Testing in Minors for Adult-Onset Disease**

Kathleen M. O'Connor, MBA MSW, Arizona State University, Tempe, AZ

"It Runs in the Family": Grappling with Addiction **Genetics**

Molly Dingel, PhD, University of Minnesota-Rochester, Rochester, MN Jenny E. Ostergren, MPH, Mayo Clinic, Rochester, MN Rachel R. Hammer, BS, Mayo Clinic College of Medicine, Rochester, MN Jennifer B. McCormick, PhD MPP, Mayo Clinic, Rochester, MN Barbara A. Koenig, PhD, University of California–San Francisco, San Francisco, CA

What Do We Owe Our Patient's Family? An Ethical Inquiry

Piroska K. Kopar, MD, Dartmouth-Hitchcock Medical Center, Lebanon, NH Danielle N. Ko, MD JD, Massachusetts General Hospital, Boston, MA Lisa Lehmann, MD PhD, Brigham and Women's Hospital, Boston, MA

Workshop Session (107)

Moving Beyond Words: An Embodied Narrative for the End of Life

Gretchen M. Spars, MDiv MA, Cone Health, Greensboro, NC Jo Nygard Owens, MDiv, Holy Trinity Episcopal Church, Greensboro, NC Megan E. Bell, BS, Bethel University, St. Paul, MN

2:45-3:45 pm

Concurrent Sessions

Paper Session (108): Ethics Consultation

Against Personal Experience

Allyson L. Robichaud, PhD, Cleveland State University, Cleveland, OH

"We'd Like to Get Ethics Involved": Clarifying **What Clinical Ethics Consultation Represents to Requestors and Patients**

Joshua Crites, PhD, Cleveland Clinic, Cleveland, OH

Are Minority Patients Less Likely to Be Allowed a Support Person in the Hospital? An Analysis of **Patient Survey Data**

Andrew J. Jager, MA, American Medical Association, Chicago, IL Matthew Wynia, MD MPH, American Medical Association, Chicago, IL

Panel Session (109)

Reusing Pacemakers in the Developing World: Moral Imperative or Conflict of Values?

James N. Kirkpatrick, MD, University of Pennsylvania, Philadelphia, PA Krishna G. Aragam, MD MS, University of Pennsylvania, Philadelphia, PA Thomas C. Crawford, MD, University of Michigan, Ann Arbor, MI Cdr. Brian Lewis, MD, U.S. Public Health Service, U.S. Food and Drug Administration, Center for Devices and Radiological Health, Silver Spring, MD

Panel Session (110): Clinical Research Ethics **Key Function Committee**

Who Are We to Say? Lessons on the Road to **Biobanking Policy and Governance**

Gail Henderson, University of North Carolina, Chapel Hill, NC Aaron Goldenberg, Case Western Reserve University, Cleveland, OH David Kaufman, PhD, Johns Hopkins University, Washington, DC Eric Juengst, University of North Carolina, Chapel Hill, NC

Paper Session (111): Sex, Gender, and **Pregnancy**

Research Involving Pregnant Women

Francoise Baylis, PhD, Dalhousie University, Halifax, NS, Canada

"She Walked Out of the Room and Never Came **Back": Is Provider Refusal to Treat Transgender Patients a Legitimate Case of Conscientious Objection or a Betrayal of the Patient-Provider** Relationship?

Alison C. Reiheld, PhD, Southern Illinois University-Edwardsville, Edwardsville, IL

Sex, Conceptual Change, and Ethics: How Changing What We Think Might Change What We Think We **Should Do**

Jill R. Oliver, PhD, University of Toronto, Toronto, ON, Canada

Paper Session (112): History

Representing Nursing Ethics

Thomas L. Long, PhD, University of Connecticut, Storrs, CT

Representing Ethics and Action: How the Tuskegee **Study of Untreated Syphilis Almost Never Came to** Liaht

Merle Lenihan, MD FACOG, University of Texas Medical Branch, Galveston, TX

Use of Visual Representations of the Fit and Unfit in the U.S. Eugenics Movement

Mary D. Lagerwey, PhD RN, Western Michigan University, Kalamazoo, MI

Panel Session (113)

"Living on the Edge": Patient, Family, and Clinician "Representations" of Benefit and Burden During and After a Life-Threatening Event

Gail Geller, ScD MHS, Johns Hopkins University Berman Institute of Bioethics, Baltimore, MD

Jo Rivers, Lexington Park, MD

Thomas Crawford, MD, Johns Hopkins University, Baltimore, MD Cynda H. Rushton, PhD RN FAAN, Johns Hopkins University, Potomac, MD

Paper Session (114): Professionalism

Attitudes Toward Professionalism Among First-Year Medical Students: Bridging the Generation Gap as a **Challenge in Professionalism Education**

Ashley K. Fernandes, MD PhD, Wright State University Boonshoft School of Medicine, Dayton, OH

Gloria Han, MD, Wright State University Boonshoft School of Medicine, Dayton, OH

Nicole J. Borges, PhD, Wright State University Boonshoft School of Medicine, Dayton, OH

Professionalism Endangered: Critical Reflections on Work, Relationships, and Responsibility in Science **Production**

Ashok Kumbamu, PhD, Mayo Clinic, Rochester, MN Yichen Chiu, MA, Mayo Clinic, Rochester, MN Jennifer B. McCormick, PhD MPP, Mayo Clinic, Rochester, MN

Who's a Professional?

Abraham P. Schwab, PhD IPFW, Fort Wayne, IN

4-5:15 pm **Welcome and Plenary Session**



Representing Bioethics and Freedom of Speech

John Harris, DPhil BA FMedSci FRSA FSB, Institute for Science, Ethics and Innovation, University of Manchester, Manchester, United Kingdom

This presentation will address the dilemmas and paradoxes of "representing bioethics globally" and

indeed of "doing" bioethics in a global village. The accountability of bioethicists for what they do and say will be considered, as will their responsibilities to facilitate the public good that medical science represents. These responsibilities may include reminding both patients and citizens that they do not have just rights and interests but considerable responsibilities to contribute to the public good nationally and globally.

5:30-7 pm

Opening Reception in the Exhibit Hall

7-8 pm

President's Meeting with Students

Friday, October 19

6:30-7:45 am **Affinity Group Meeting**

Disability and Rehabilitation Ethics (200)

7-9 am

Continental Breakfast in the Exhibit Hall

7:30-9 am **Meet-the-Professor Session**

8-9 am

Concurrent Sessions

Panel Session (201)

Biomarkers and Disease Susceptibility: Ethical and Legal Challenges in Diagnosing, Treating, and **Categorizing Premorbid or Prodromal Conditions**

Paul R. Wolpe, PhD, Emory University, Atlanta, GA Jason S. Robert, PhD, Arizona State University, Tempe, AZ Jason Karlawish, MD, University of Pennsylvania, Philadelphia, PA

Jalayne Arias, JD, Cleveland Clinic, Cleveland, OH

Panel Session (202)

Responsible Stewardship: The Role of National Commissions in Shaping the Public Discourse of

Kayte Spector-Bagdady, JD M. Bioethics, Presidential Commission for the Study of Bioethical Issues, Washington, DC

Valerie H. Bonham, JD, Presidential Commission for the Study of Bioethical Issues, Washington, DC

Paul A. Lombardo, PhD JD, Georgia State University, Decatur, GA Jason L. Schwartz, MBE AM, University of Pennsylvania, Philadelphia, PA

Panel Session (203)

Rethinking the Placebo Effect in Bioethics

Jon C. Tilburt, MD MPH, Mayo Clinic, Rochester, MN Luana Colloca, MD PhD, National Institutes of Health, Bethesda, MD Howard Brody, MD PhD, University of Texas Medical Branch, Galveston, TX Franklin Miller, PhD, National Institutes of Health, Bethesda, MD

Panel Session (204)

Controlling In Vitro Fertilization: Representing Women and Children

Annie Janvier, MD PhD BSc, University of Montreal, Montreal, QC, Canada Anne D. D. Lyerly, MD MA, University of North Carolina, Chapel Hill, NC Elena Gates, MD, University of California-San Francisco, San Francisco, CA Josephine Johnston, LLB MBHL, The Hastings Center, Garrison, NY

Paper Session (205): Religion and Trust

"Empiricizing" the Things of God: The Misrepresentation of Religion and Spirituality in **Research on Health**

Cory Andrew Labrecque, Emory University, Atlanta, GA

Changing Expectations in Public Health: Trust and Trustworthiness

Karen M. Meagher, Michigan State University, Lansing, MI

Bioethics in Israel: Religion and Medicine, Rabbis and Doctors

Michal Raucher, MA, Northwestern University, Evanston, IL

Panel Session (206)

What Is "Normal"? Bioethics and Dramatic Representations of Neurological and **Neuropsychiatric Disorders**

Karen H. Rothenberg, JD MPA, University of Maryland Francis King Carey School of Law, Baltimore, MD

Lynn W. Bush, PhD MA, Columbia University, New York, NY

Ruth L. Fischbach, PhD MPE, Columbia University College of Physicians and Surgeons, New York, NY

Jeffrey Seltzer, PhD JD, Montgomery County Public Schools, Rockville, MD

Panel Session (207)

Medicine and Nursing After the Holocaust: Developing a Curriculum

Howard Brody, MD PhD, University of Texas Medical Branch, Galveston, TX Judy Smith, PhD RN, BJC HealthCare, St. Louis, MO

Michaela R. Shafer, PhD MSN RN, Uniformed Services University, Bethesda, MD

Edward H. Livingston, MD, UT Southwestern Medical Center, Dallas, TX

9:15-10:15 am **Plenary Session**



Black Swans, Zebras, and the Strangeness of the Everyday: Low-**Probability Events in Biomedicine**

David B. Morris, PhD, Emeritus Professor, University of Virginia, Charlottesville, VA

Medical teaching famously focuses on norms and regularities. When you hear hoofbeats, don't think

zebras. Health and illness occur, however, in a biological world that contains large irregularities in defiance of all experience, expectation, probability, and logic: black swans. British headline: "Woman with two wombs gives birth to a one-in-a-million baby girl" (Mail Online, 15 July 2009). This lecture explores the place of such outliers as they challenge us, in and outside medicine, to recognize and to account for the strangeness of the everyday.

10:15-10:30 am Break in the Exhibit Hall

10:30-11:30 am

Concurrent Sessions

Paper Session (208): Clinical Ethics

Learning from Requestors' Retrospective Reports: Re-Presenting the Reason for Requesting Ethics Consultation (and What Is Said to Be Most Important)

Stuart G. Finder, PhD, Cedars-Sinai Medical Center, Los Angeles, CA Virginia L. Bartlett, PhD, Cedars-Sinai Medical Center, Los Angeles, CA

Four Models for the Physician-Family Relationship

George E. Hardart, MD MPH, Columbia University, New York, NY

Developing and Tracking Metrics for Ethics Consultation Services

Kelly Armstrong, PhD, Southern Illinois University School of Medicine, Springfield, IL

Panel Session (209)

Vaccination in Historical and Cultural Context

Bernice L. Hausman, PhD, Virginia Tech, Blacksburg, VA Elena Conis, PhD MS, Emory University, Atlanta, GA Andrea Kitta, PhD, East Carolina University, Greenville, NC Heidi Y. Lawrence, Virginia Tech, Blacksburg, VA

Paper Session (210): Research Ethics

How "Representative" Are Institutional Review **Boards?**

Patricia M. Alt, PhD, Towson University, Towson, MD

The Ethics of Research in the Global Health **Environment**

Joanna Weinberg, JD LLM, University of California–San Francisco, San Francisco, CA

Observational Research in Medically Indigent Hospice Patients: A New Tuskegee?

Susan D. McCammon, MD MFA, University of Texas Medical Branch, Galveston, TX

Paper Session (211): Clinicians' Responsibilities

Representing Conscience and Abortion Provision: Toward a Standard of Care for Conscientious Objection

Lisa H. Harris, MD PhD, University of Michigan, Ann Arbor, MI

Undiagnosing MS: A Physician Survey Exploring the Ethical Challenges in Correcting a Misdiagnosis of Multiple Sclerosis

Andrew J. Solomon, MD, University of Vermont and Fletcher Allen Healthcare, Burlington, VT

Too Close for Words: Ethical Issues That Arise When Certified Healthcare Interpreters Share the Patient's or Family's Cultural or Ethnic Beliefs

Melissa J. Kurtz, MSN MA RN, Montefiore Medical Center, Bronx, NY

Panel Session (212)

To Gain a Voice in Bioethics and Medicine: Toward a New Dialogue Between Social Sciences, History, and Bioethics

Michele Rivkin-Fish, PhD, University of North Carolina-Chapel Hill, Chapel Hill, NC

Brooke Cunningham, MD PhD, Johns Hopkins University, Baltimore, MD Dan O'Connor, PhD MA, Johns Hopkins University, Baltimore, MD Eric T. Juengst, PhD, University of North Carolina-Chapel Hill, Chapel Hill, NC

Paper Session (213): Pediatrics

Extreme Caregiving: Unrecognized Ethical Concerns in the Parenting of Medically Complex Children

Lisa C. Freitag, MD, University of Minnesota, Minneapolis, MN

Nondonor Siblings of Children Undergoing Allogeneic Stem Cell Transfers: Not Represented

Rebecca D. Pentz, PhD, Emory University School of Medicine, Atlanta, GA Wendy Pelletier, MSW RSW, Alberta Children's Hospital, Calgary, AB, Canada Kristin Stegenga, PhD RN, Children's Mercy Hospital, Kansas City, MO Melissa A. Alderfer, PhD, University of Pennsylvania Perelman School of Medicine and Children's Hospital of Philadelphia, Philadelphia, PA Louisa K. Wall, Emory University, Atlanta, GA

Are Medically Complex Children at Risk for **Underutilization of Advanced Extracorporeal Life** Support?

Jessica M. Turnbull, MD, Seattle Children's Hospital, Seattle, WA Douglas S. Diekema, MD MPH, Seattle Children's Research Institute, Seattle,

Mithya Lewis-Newby, MD MPH, Seattle Children's Hospital-University of Washington, Seattle, WA

Jonna D. Clark, MD, Seattle Children's Hospital, Seattle, WA

Panel Session (214)

Envisioning the Future of Medical Ethics and Humanities Education

David J. Doukas, MD, University of Louisville, Louisville, KY Clarence Braddock, MD MPH, Stanford Center for Biomedical Ethics, Palo Alto, CA

Stephanie Brown-Clark, PhD, University of Rochester, Rochester, NY Joseph J. Fins, MD MACP, Weill Cornell Medical College, New York, NY

11:30 am-12:45 pm Lunch (on your own)

Affinity Group Meetings Jewish Bioethics (215)

Literature and Medicine (216) Neuroethics (217) Pediatric Ethics (232) Environmental Bioethics (233) Law and Bioethics (234)

FRIDAY, OCTOBER 19: EDUCATIONAL SESSIONS

1-2:30 pm

Concurrent Sessions

Workshop Session (218)

Developing a Code of Ethics for Healthcare Ethics Consultants

Anita J. Tarzian, PhD RN, University of Maryland School of Nursing and School of Law, Baltimore, MD

Robert Baker, PhD, Bioethics Program of Union Graduate College and Mount Sinai School of Medicine, Schenectady, NY

Martha Jurchak, PhD RN, Brigham and Women's Hospital, Boston, MA

Workshop Session (219)

Draft Guidance on Allocating Scarce Federal Resources in Disaster Situations: A Framework for **Ethical Decision Making**

Virginia A. Sharpe, PhD, National Center for Ethics in Health Care, Washington, DC

Marion Danis, MD, National Institutes of Health, Bethesda, MD Ann Knebel, DNSc RN FAAN, U.S. Department of Health and Human Services, Washington, DC

Paper Session (220): Civic Engagement

Healthcare Providers Opting Out of, or Not Participating in, Medicare—Who Represents the **Elderly in this Ethical Dilemma?**

G. Richard Holt, MD MSE MPH MABE, University of Texas Health Science Center at San Antonio, San Antonio, TX

Grassroots Engagement: Representing the Public Voice in Bioethics

Valarie Blake, JD MA, American Medical Association, Chicago, IL Thomas D. Harter, PhD, Gundersen Lutheran Medical Foundation, La Crosse, WI

Aaron J. Goldenberg, PhD MPH, Case Western Reserve University, Cleveland, OH

Ethics Engagement in Citizen Panel Deliberations: A **New Organizational Ethics Role for Bioethicists**

Jeffrey C. Kirby, MD MA, Dalhousie University, Halifax, NS, Canada Christy Simpson, PhD, Dalhousie University, Halifax, NS, Canada

Workshop Session (221)

Mandating Ultrasound Viewing Before Abortion: The Ethics and Politics of Fetal Representation

Rebecca Kukla, PhD, Georgetown University, Washington, DC Anne D. D. Lyerly, MD MA, University of North Carolina, Chapel Hill, NC Lisa M. Mitchell, PhD, University of Victoria, Victoria, BC, Canada James Rocha, PhD MA, Louisiana State University, Baton Rouge, LA

Paper Session (222): Media

Bioethics Representation in Today's Media: The Trouble with Sound Bites

Ilene F. Wilets, PhD, Mount Sinai School of Medicine, New York, NY

Ethics and the Healthcare Administrator in Popular Culture

Michael D. Dahnke, PhD, Drexel University, Philadelphia, PA

Social Media and Medicine: (Mis)Representing **Physicians and Patients Online?**

Matthew DeCamp, MD PhD, Johns Hopkins University and School of Medicine, Baltimore, MD

The Want Ads: Representation, Ethics, and the **Presentation of Foster Care Children**

Laurie Zoloth, PhD, Northwestern University, Evanston, IL

Meet-the-Author Session (223)

The Program Committee's Special Session: The **Reading Game**

Hosts: Katie Watson, Eran Klein, Tom Buller

Authors: Catherine Belling, Jeff Bishop, Marion Danis, Rebecca Dresser, Lisa Eckenwiler, Paul Lombardo, Max Mehlman, Alicia Ouellette, Sylvia Pamboukin, Jeremy Sugarman and Dan Sulmasy, Tom Tomlinson, Mark Wicclair

Workshop Session (224)

Readers' Theater: An Innovative Method for Ethics Education

K. Jane Lee, MD MA, Medical College of Wisconsin, Milwaukee, WI Brenda M. Schiltz, MD MS MA FAAP, Mayo Clinic, Rochester, MN Ellen L. Blank, MD MA, Medical College of Wisconsin, Milwaukee, WI Nancy King, JD, Wake Forest School of Medicine, Winston-Salem, NC

2:30-2:45 pm Break in the Exhibit Hall

2:45-3:45 pm

Concurrent Sessions

Panel Session (225)

Futility in the Intensive Care Unit: What Every Clinical Ethicist Needs to Know About the American College of Critical Care Medicine and American Thoracic Society's National Guidelines

Alexander A. Kon, MD, University of California–San Diego and Naval Medical Center San Diego, San Diego, CA

Marion Danis, MD, National Institutes of Health, Bethesda, MD Douglas White, MD MAS, University of Pittsburgh, Pittsburgh, PA Anita J. Catlin, DNSc FNP FAAN, Kaiser Permanente, Pope Valley, CA

Panel Session (226)

Ethical Challenges in Designing a Systemwide Approach to Dealing with Critical Drug Shortages

Carol Taylor, PhD RN, Georgetown University, Falls Church, VA Robert J. Barnet, MD MA, Georgetown University, Falls Church, VA Bonnie Levin, PharmD MBA, MedStar Health, Silver Spring, MD Johan Suyderhoud, MD, Georgetown University, Washington, DC

FRIDAY, OCTOBER 19: EDUCATIONAL SESSIONS: EDUCATIONAL SESSIONS

Panel Session (227)

The Wild West of Incidental Findings

Judy Illes, PhD, University of British Columbia, Vancouver, BC, Canada Emily L. Borgelt, MA, University of British Columbia, Vancouver, British Columbia Nina DiPietro, University of British Columbia, Vancouver, BC, Canada James Anderson, PhD, University of British Columbia, Vancouver, BC, Canada

Panel Session (228)

Spaces for Suffering at the End of Life: Learning through Living and Dying

Susan D. McCammon, MD MFA, University of Texas Medical Branch, Galveston, TX

Nicole M. Piemonte, MA, University of Texas Medical Branch, Galveston, TX Julie E. Kutac, MA, University of Texas Medical Branch, Galveston, TX Andrew Childress, MA, University of Texas Medical Branch, Galveston, TX

Panel Session (229)

"The Life Worth Living": Theological Borderlands in **Islamic Bioethics**

Ahsan Arozullah, MD MPH, Astellas Pharma Global Development, Northbrook, IL

Afshan Mohiuddin, University of Chicago, Chicago, IL Katherine M. Klima, MS CNM, Henry Ford Health System, Dearborn, MI Mohammed Amin Kholwadia, Darul Kasim, Glen Ellyn, IL Aasim I. Padela, MD MSc, University of Chicago, Chicago, IL

Panel Session (230)

Representing Death, Anticipating the Corpse

Lydia S. Dugdale, MD, Yale School of Medicine, New Haven, CT Farr Curlin, MD, University of Chicago, Chicago, IL Franklin Miller, PhD, National Institutes of Health, Bethesda, MD Jeffrey P. Bishop, MD PhD, St. Louis University, St. Louis, MO

Panel Session (231)

Disability and Do-Not-Resuscitate: Teaching Difficult Conversations

Debjani Mukherjee, PhD, Rehabilitation Institute of Chicago, Chicago, IL Gayle R. Spill, MD, Rehabilitation Institute of Chicago, Chicago, IL Preya Tarsney, JD, Rehabilitation Institute of Chicago, Chicago, IL Joshua Hauser, MD, Northwestern University, Evanston, IL

4-5:15 pm

President's Address and Members' Meeting **Awards Presentation**



Distinguished Service Award

Doris Goldstein, MLS MA, Kennedy Institute of Ethics, Georgetown University, Washington, DC

Doris Goldstein, MLS MA, is Senior Library Advisor for International Initiatives at the Bioethics Research Library, Kennedy Institute of Ethics, Georgetown University, Washington, DC. A recipient of the

Georgetown University President's Medal in 2005, Goldstein has been at the institute since the founding of the library in 1973 and served as director until 2011. Under the leadership of LeRoy Walters,

she managed several federal grants, including those for the National Reference Center for Bioethics Literature (1985-2009) and the National Information Resource on Ethics and Human Genetics (1994-2010). She has lectured widely on bioethics information resources and management, most recently at the Founders of Bioethics Conference, Edinboro University, Edinboro, PA, and at the Third International Islamic Bioethics Conference, in Antalya, Turkey. She served as coeditor of the annual Bibliography of Bioethics, Volumes 28-35. Other publications include the reference work Bioethics: A Guide to Information Sources and contributions to the three editions of the Encyclopedia of Bioethics. She is currently principal investigator on a 3-year Qatar National Research Foundation grant to develop a research collection and bibliographic database on Islamic medical and scientific ethics. She was recently awarded a grant from Georgetown University's "Engaging India" initiative to build relationships and explore possible joint ventures on behalf of the institute and library and a second from the German Reference Centre for Ethics in the Life Sciences (Bonn) to collaborate on merging online resources to support global access to bioethics research via the European Commission's ETHICSWEB database.

Lifetime Achievement Award



Kathryn Montgomery, PhD, Feinberg School of Medicine, Northwestern University, Chicago, IL

Kathryn Montgomery, PhD, is Julia and David Uihlein Professor of Medicine Humanities and Bioethics and professor of medicine at Northwestern University's Feinberg School of Medicine. She is the author of *Doctors' Stories: The*

Narrative Structure of Medical Knowledge (Princeton University Press, 1991) and How Doctors Think: Clinical Judgment and the Practice of Medicine (Oxford University Press, 2006).

Long interested in medical education, Montgomery was part of the faculty that founded the Morehouse School of Medicine, Atlanta, GA. At the University of Rochester School of Medicine she began the Division of the Medical Humanities and took part in the school's landmark curriculum reform. Her participation in the Association of American Medical Colleges' revisionist Physicians for the Twenty-First Century Project and the Kaiser-AAMC Site Visit Committee to Harvard's New Pathway was put to use in helping to design a third "new" curriculum, this one at Northwestern. Two decades of committee work in three institutions produced half a dozen needlepoint pillows and her favorite essay, "Eating the Curriculum" (Academic Medicine, 1997, 72, 167-72), a look at the metaphors wielded by all parties to curricular reform

A member of the Fellows Council of the Hastings Center for Bioethics, she served as president of the American Society for Bioethics and Humanities in 2001-2002. She has served on the editorial boards of Literature and Medicine, Second Opinion, and Medical Humanities Review. She is currently on the editorial boards of the Journal of Evaluation in Clinical Practice; Biophilosophy, Bioethics, and Biohumanities; and Narrative Inquiry in Bioethics and is at work on a project called "Knowledge Needed to Treat."

Cornerstone Award

Institute for the Medical Humanities at the University of Texas Medical Branch in Galveston

Founded in 1973, the Institute for the Medical Humanities at the University of Texas Medical Branch in Galveston is an interdisciplinary group studying and teaching the history of medicine, bioethics,

FRIDAY, OCTOBER 19-SATURDAY, OCTOBER 20: EDUCATIONAL SESSIONS

literature and medicine, religion and health, visual arts in medicine, social medicine, and health law and policy. The institute awards the only PhD degree in the United States in interdisciplinary medical humanities. It is responsible for teaching medical students about humanities, ethics, and professionalism and provides ethics consultation for both clinicians and research investigators.

5:45-7 pm

Affinity Group Meetings

Rural Bioethics (235) Dental Ethics (236)

Philosophy (237)

Bioethics and Christian Theology (238) Race and Culture/Ethnicity (239)

Research (240)

Hospice and Palliative Care/Social Work (241)

8-9 pm **Special Performance**



The Mind and Music of George Gershwin (REC)

Richard Kogan, MD PhD, Weill Cornell Music and Medicine Program, New York, NY

A concert and lecture by Juilliard-trained virtuoso pianist and Harvard-trained psychiatrist Richard Kogan

Registration Fee: ASBH member, \$0; nonmember, \$25

Saturday, October 20

6:30-7:45 am **Affinity Group Meeting Organizational Ethics (300)**

7-9 am

Continental Breakfast in the Exhibit Hall

8-9 am

Concurrent Sessions

Panel Session (301)

Great Expectations—Representing Ethics at the Bedside: A Critical Exploration of Client **Expectations of Ethics Consultation: Their Nature,** Cause, Legitimacy, and Practical Reasonableness

Katherine A. Brown-Saltzman, MA RN, UCLA Health System, Los Angeles, CA

James A. Hynds, LLB PhD, University of California-Los Angeles, Los Angeles, CA

Ellen M. Robinson, PhD RN, Massachusetts General Hospital, Boston, MA Kevin M. Dirksen, MDiv MSc, UCLA Health System, Los Angeles, CA

Paper Session (302): Health Policy

Public Health Surveillance, Privacy, and **Representations of Autonomy**

Alan P. Rubel, PhD JD, University of Wisconsin-Madison, Madison, WI

Professional License?

Daniel Brudney, PhD, University of Chicago, Chicago, IL

Repeat Triage for the Underrepresented: Questions for Bioethicists from a Haiti Disaster Relief Team

Nir Eyal, DPhil, Harvard Medical School and Harvard University, Boston, MA Paul G. Firth, MBChB, Harvard University, Boston, MA

MGH Disaster Relief Ethics Group, Massachusetts General Hospital, Boston, MA

Panel Session (303)

Moral Science: Protecting Participants in Human Subjects Research

Michelle A. Groman, JD, Presidential Commission for the Study of Bioethical Issues, Washington, DC

Sergio G. Litewka, MD MPH, University of Miami, Miami, FL

James W. Wagner, PhD, Emory University, Atlanta, GA

Jeremy Sugarman, MD MPH MA, Johns Hopkins University, Baltimore, MD

Paper Session (304): The Intensive Care Unit and the End of Life

Treatment Decisions in the Context of Acute Traumatic Injury

Joshua Crites, PhD, Cleveland Clinic, Cleveland, OH

Bearing Witness to the Dying Body: How Paul Ricoeur's Narrative Method Can Be Expanded to Include Care for Nonverbal Patients at the End of Life

Tara E. Flanagan, Loyola University Chicago, Chicago, IL

Tangled Up in Blue: Conflict over Code Status in the **Setting of Anticipatory Futility and Harm**

Jason Morrow, MD PhD, University of Texas Health Science Center, San Antonio, TX

Paper Session (305): Philosophy and **Neuroscience**

Enhancing for Virtue? Toward Holistic Moral Enhancement

William P. Kabasenche, PhD, Washington State University, Pullman, WA

On the Ethical Implications of Social Neuroscience

Arleen L. Salles, PhD, Centro de Investigaciones Filosoficas, Buenos Aires, Argentina

Two Agendas for Bioethics: Critique and Integration

Jeremy R. Garrett, PhD, Children's Mercy Hospital, Kansas City, MO

Paper Session (306): Family and Addiction

Bringing Unrepresented Voices into the Discussion: Parental Regret, Survivor Distress, and Practitioner Ambivalence in Neonatal Circumcision

Ryan McAllister, PhD, Georgetown University, Washington, DC

Representing the Ethics of Behavior Change: **Perspectives of Patients in Substance-Use Treatment**

Jenny E. Ostergren, MPH, Mayo Clinic, Rochester, MN Molly Dingel, PhD, University of Minnesota, Rochester, MN Rachel R. Hammer, BS, Mayo Clinic College of Medicine, Rochester, MN Marguerite E. Robinson, MAR MA, Mayo Clinic, Rochester, MN Jennifer B. McCormick, PhD MPP, Mayo Clinic, Rochester, MN Barbara A. Koenig, PhD, University of California-San Francisco, San Francisco, CA

Not Without My Family: How Bioethics Has Gotten **End-of-Life Decisions All Wrong.**

Michael B. Bevins, MD PhD, Scott and White Healthcare, Texas A&M University Health Science Center, Round Rock, TX

Panel Session (307)

Representing Surgical Ethics: Conceptual, **Empirical, and Clinical Challenges in the Practice of Modern Surgery**

Ryan M. Antiel, MD MA, Mayo Clinic, Rochester, MN Peter Angelos, MD PhD, University of Chicago, Chicago, IL Anji E. Wall, MD PhD, Vanderbilt University, Nashville, TN Daniel E. Hall, MD MDiv MHSc, University of Pittsburgh, Pittsburgh, PA

9:15-10:15 am **Plenary Session**



The Health Care System in Uncertain Times

Julie Rovner, Health Policy Correspondent for National Public Radio

Julie Rovner will provide an overview of what has transpired since the Supreme Court ruled on the Affordable Care Act and discuss how the issue

of health care has been dealt with in the 2012 presidential and Congressional campaign and what is likely to happen after the election.

10:15-10:30 am Break in Exhibit Hall

10:30-11:30 am

Concurrent Sessions

Paper Session (308): Issues at the End of Life **Identifying and Implementing Best-Practice End-of-**Life Care in an Academic Medical Center

Gerardo R. Maradiaga, MA, Wake Forest Baptist Health, Winston-Salem, NC

The First Amendment, Expressive Association, and **Physicians Involved in Killing**

Lawrence J. Nelson, PhD JD, Santa Clara University, Santa Clara, CA

Representation for Advanced Illness Patients: An **Innovative Approach to Improve Communication** and Decision-Making Processes at End of Life Helen D. Blank, PhD, Vital Decisions, LLC, Edison, NJ

Panel Session (309)

How the Healthcare Ombudsperson/Mediator Can Transform Clinical Ethics Practice: Building Capacity, Bridges, and Relationships

Mathew D. Pauley, JD MA MDR, Kaiser Permanente, Fontana, CA David Richardson, PhD, Fontana, CA

Lauren Edelstein, MA, Washington Hospital Center, Washington, DC Sandra Silva, JD, Center for Practical Bioethics, Kansas City, MO

Paper Session (310): Genetics

Is There a Right to Know One's Genetic Origins?

Inmaculada De Melo-Martin, PhD, Weill Cornell Medical College, Cornell University, New York, NY

When Genetic Makeup Determines Inclusion in Clinical Trials. Is There a Need to Represent the Excluded?

Hamid Reza Raziee, MD, University of Toronto, Toronto, ON, Canada Trudo Lemmens, LLM DCL, University of Toronto, Toronto, ON, Canada Jonathan Kimmelman, PhD, McGill University, Montreal, QB, Canada

Social Networking-Based Genetic Testing: The Shifting Role of Participants in the Evolving **Research Model**

Valerie Gutmann Koch, JD, New York State Task Force on Life and the Law, New York NY

Panel Session (311)

Physician-Assisted Suicide: Are We Asking the **Right Questions?**

Ryan Spellecy, PhD, Medical College of Wisconsin, Milwaukee, WI Marshall Beckman, MD, Medical College of Wisconsin, Milwaukee, WI Darren M. Henson, STL, Marquette University, Milwaukee, WI David C. Clark, PhD, Medical College of Wisconsin, Milwaukee, WI

Paper Session (312): Transplant Ethics

The Ethics of Private Versus Public Cord Blood Banking

Victoria K. Seavilleklein, PhD, Alberta Health Services, Red Deer, AB, Canada

A Donor-Intent-Driven Policy for Directed Donation of Deceased Donor Organs

Aviva M. Goldberg, MD MA FRCPC, University of Manitoba, Winnipeg, MB, Canada

Ethical Codes and Procedural Tools for Communicating with Patients Through an Interpreter

Lisa Bradford, PhD, Medical College of Wisconsin, Milwaukee, WI

Paper Session (313): Humanities

Medicine's Favorite Doctor: "Oslermania," **Bioethics, and the Medical Humanities**

Rimma Osipov, BA, University of Texas Medical Branch, Galveston, TX

A Genealogy of Persistent Vegetative State

Tyler S. Gibb, JD, St. Louis University, St. Louis, MO

Who Speaks for Whom? Representation, the Medical Humanities, and the Social Context of Health

Rebecca E. Garden, PhD, State University of New York Upstate Medical University, Syracuse, NY

Paper Session (314): Research Ethics

Research with the Newly Dead: Creation of an **Ethics Advisory Panel for Genetic Projects at** the Crossroads of Research Participation, Organ **Donation, and Anatomical Gifts for Research**

Arlene M. Davis, JD, University of North Carolina School of Medicine, Chapel Hill, NC

Proactive Ethics in Translational Research

Evelyn McKinney, PhD, University of Texas Medical Branch, Galveston, TX

The Tangled Web: The Rare Disease Biobank and the Internet Age

Leah R. Eisenberg, JD MA, Mayo Clinic, Rochester, MN Devin Oglesbee, PhD, Mayo Clinic, Rochester, MN W. Edward Highsmith, PhD, Mayo Clinic, Rochester, MN Jennifer L. Hesemann, MS, Mayo Clinic, Rochester, MN Claire Anderson, MS, Mayo Clinic, Rochester, MN

11:45 am-1:30 pm Lunch (on your own)

1:45-2:45 pm

Concurrent Sessions

Panel Session (315)

Authors (Editors) Meet Critics: Guidance for Healthcare Ethics Committees

Toby Schonfeld, PhD, Emory University, Atlanta, GA Jessica Berg, JD MPH, Case Western Reserve University, Cleveland, OH Sarah E. Shannon, PhD RN, University of Washington, Seattle, WA Ann Mongoven, PhD MPH, Michigan State University College of Human Medicine, East Lansing, MI

Panel Session (316)

Caring for the Hidden and Misrepresented: Toward an Ethical Approach to Health Care for **Undocumented Immigrants**

Mark G. Kuczewski, PhD, Loyola University Chicago, Maywood, IL Nancy Berlinger, PhD MDiv, Hastings Center, Garrison, NY Katherine W. Wasson, PhD MPH, Loyola University Chicago, Maywood, IL Michael K. Gusmano, PhD, Hastings Center, Garrison, NY

Paper Session (317): Research Ethics

Researched to Death: Diabetes and the Akimel O'odham

Mary Drago, MA, Arizona State University, Tempe, AZ

Is It Really All About the Money? Reconsidering Nonfinancial Interests in Medical Research Regulation

Richard S. Saver, JD, University of North Carolina, Chapel Hill, NC

Advocates as Investigators: Conflicts of Interest in Rare Disease Research

Rugayyah Abdul-Karim, BA, National Institutes of Health, Bethesda, MD Benjamin Berkman, JD MPH, National Institutes of Health, Bethesda, MD Sara C. Hull, PhD, National Institutes of Health, Bethesda, MD

Panel Session (318)

Is It Time to Revisit Medicaid Policy on Sterilization?

Lisa H. Harris, MD PhD, University of Michigan, Ann Arbor, MI Taida J. Wolfe, MD, Rutgers University, New Brunswick, NJ Talcott Camp, JD, American Civil Liberties Union, New York, NY Sonya Borrero, MD MS, University of Pittsburgh, Pittsburgh, PA

Paper Session (319): Philosophy

Forced Ethics: From Old Moral Theory to New Moral Reality

Ben E. Rosenstein, BBmE, University of Minnesota, Minneapolis, MN

Evidence-Based Medicine: Representation or Misrepresentation of Medicine?

Wayne S. Rosen, MD MSc, University of Calgary, Calgary, AB, Canada

Patients, Practitioners, and Conscience: A Fresh **Approach to Representing Moral Pluralism in Medicine**

Nathaniel J. Brown, MD PhD, University of Colorado School of Medicine, Denver, CO

Paper Session (320): Narrative Ethics

Narrative Ethics: Making It Practical

Martha Montello, PhD, University of Kansas, Kansas City, KS

The Overreaching of Narrative Medicine: A **Dialogical Response**

Paul Burcher, MD PhD, Albany Medical College, Albany, NY

On Narrative Ethics for the End of Life: Selzer's **Mercy Narratives**

Alvan A. Ikoku, MD, Albert Einstein College of Medicine, Bronx, NY

Paper Session (321): Public Health

Saying What No One Else Will Say: The Bioethicist as Translator, Interpreter, and Advocate in the **Public Sphere**

Syd M. Johnson, PhD MA, Michigan Technological University, Houghton, MI

Critical Concepts in Representing Public Opinion on Biobanks: Choice, Control, and Consent

Christian M. Simon, PhD, University of Iowa, Iowa City, IA

Representing the Public: A Deliberative Community **Engagement to Establish Governance of Population-Based Medical Records Research**

J. Eline Garrett, JD, Minnesota Center for Health Care Ethics, Minneapolis, MN

Caroline Barnhill, MPH, TCB Health, Arlington, VA Leona Han, BA, Mayo Clinic, Rochester, MN

Jennifer B. McCormick, PhD MPP, Mayo Clinic, Rochester, MN

Angela Witt Prehn, PhD, Walden University, Apple Valley, MN

Marguerite E. Robinson, MAR MA, Mayo Clinic, Rochester, MN

Walter Rocca, MD MPH, Mayo Clinic College of Medicine, Rochester, MN

Jennifer St. Sauver, PhD, Mayo Clinic, Rochester, MN

Barbara Yawn, MD MSc FAAFP, Olmsted Medical Center, Rochester, MN Barbara A. Koenig, PhD, University of California–San Francisco, San

Francisco, CA

2:45-3 pm **Break**

3-4 pm

Concurrent Sessions

Panel Session (322)

Contours of Ethics Consultation: Are They Different in Rural and Urban Cultures?

Thomas D. Harter, PhD, Gundersen Lutheran Medical Foundation, La Crosse, WI

Lisa Anderson-Shaw, DPH MA MSN, University of Illinois-Chicago, Chicago, IL Olubukunola Tawose, JD MA, Cleveland Clinic, Cleveland, OH

Rachel Phetteplace, MSSA MA LSW, Case Western Reserve University, Cleveland, OH

Paper Session (323): Justice and Health Policy Moral Panic, Moral Monsters, and Justice in Health Care

Mary Faith Marshall, PhD, University of Minnesota, Minneapolis, MN Joan Liaschenko, PhD, University of Minnesota, Minneapolis, MN Michael H. Miner, PhD, University of Minnesota, Minneapolis, MN Christopher W. Barbey, Grinnell College, Hastings-on-Hudson, NY

Social Justice, Health Inequalities, and Methodological Individualism in U.S. Health **Promotion**

Daniel S. Goldberg, PhD JD, Brody School of Medicine, East Carolina University, Greenville, NC

The Duty to Buy Health Insurance

Tina Rulli, PhD, National Institutes of Health, Bethesda, MD

Panel Session (324)

Representing Patient Groups: Situating Patient Expertise Within Biomedicine

Richard R. Sharp, PhD, Cleveland Clinic, Cleveland, OH Pei Koay, PhD, Case Western Reserve University, Cleveland, OH Susannah L. Rose, PhD MS MSW, Cleveland Clinic, Cleveland, OH Paul J. Ford. PhD. Cleveland Clinic. Cleveland. OH

Panel Session (325)

What Is Progress for Lesbian-Gav-Bisexual-**Transgendered Health in Bioethics? Engaging the Controversies of Marginalized Groups Responsibly**

Cameron R. Waldman, BA, Hastings Center, Garrison, NY Jacob D. Moses, AB, Hastings Center, Garrison, NY Hilde Lindemann, PhD, Michigan State University, East Lansing, MI Kristen Hessler, PhD, State University of New York-Albany, Albany, NY

Panel Session (326)

Social Work and Bioethics: A Call for Collaboration

Tracy Brazg, MSW MPH, University of Washington, Seattle, WA Danae Dotolo, MSW, University of Washington, Seattle, WA Erika Blacksher, PhD, University of Washington, Seattle, WA Benjamin S. Wilfond, MD, Seattle Children's Hospital, Seattle, WA

Paper Session (327): Contraception and **Neonatology**

Clinical Ethics and Coordination of Care: An Added Dimension?

Ruchika Mishra, PhD, California Pacific Medical Center, San Francisco, CA

Where Google Searches Take You: Information **About Neonatology in Parent Blogs**

Jessica T. Fry, MD, Children's Memorial Hospital, Northwestern University, Chicago, IL

Joel Frader, MD, Children's Memorial Hospital, Chicago, IL

Contraception and Prevention of HIV Transmission: Resolving the Ethical Conflict in Public Health Principles

Sean Philpott, PhD MS, Union Graduate College, Schenectady, NY Toby Schonfeld, PhD, Emory University, Atlanta, GA Lisa B. Haddad, MD MS MPH, Emory University, Atlanta, GA

SATURDAY, OCTOBER 20: EDUCATIONAL SESSIONS

Paper Session (328): Genetics

Hope in Sight: Ocular Gene Transfer Risk Communication

Shelly Benjaminy, BSc, University of Alberta, Edmonton, AB, Canada Tania M. Bubela, PhD JD BSc, University of Alberta, Edmonton, AB, Canada

Representing the Views of Patients Enrolled in **Emergency Research Using the Exception from Informed Consent**

Neal W. Dickert, MD PhD, Emory University School of Medicine, Atlanta, GA Victoria A. Mah, MPH, Emory University, Atlanta, GA

Rebecca D. Pentz, PhD, Emory University School of Medicine, Atlanta, GA

How Informed Are Surrogate Decision Makers About the Principles of Surrogate Decision Making? Preliminary Data from Intensive Care Unit Family Conferences

Thomas V. Cunningham, MS, University of Pittsburgh, Pittsburgh, PA Leslie P. Scheunemann, MD MPH, University of Pittsburgh, Pittsburgh, PA Madeline Crankovich, University of Pittsburgh, Pittsburgh, PA Douglas White, MD MAS, University of Pittsburgh, Pittsburgh, PA

4:15-5:15 pm

Concurrent Sessions Panel Session (329)

The Ethical Challenges of Ventricular Assist **Devices: Proposals and Frameworks for Addressing** the Challenges

Martin L. Smith, STD, Cleveland Clinic, Cleveland, OH Denise M. Dudzinski, PhD MTS, University of Washington, Seattle, WA Courtenay R. Bruce, JD MA, Baylor College of Medicine, Houston, TX Daniel P. Sulmasy, MD PhD, University of Chicago, Chicago, IL

Panel Session (331)

The Ethics of Biomedical Research on Chimpanzees

Hope R. Ferdowsian, MD MPH, George Washington University, Washington, DC

Tom L. Beauchamp, PhD, Georgetown University, Washington, DC Jeffrey Kahn, PhD MPH, Johns Hopkins University, Baltimore, MD R. Alta Charo, JD, University of Wisconsin, Madison, WI

Panel Session (332)

De-Closeting Clinical Ethics: Lesbian-Gay-Bisexual-Transgendered Ethical Dilemmas and the Queering of the Field

Autumn Fiester, PhD, University of Pennsylvania, Philadelphia, PA Lance Wahlert, PhD, University of Pennsylvania, Philadelphia, PA Mary K. Walton, MSN MBE RN, Hospital of the University of Pennsylvania, Philadelphia, PA

Tod Chambers, PhD, Northwestern University, Chicago, IL

Panel Session (333)

A Tribute to Bernard Gert and His Work

Loretta M. Kopelman, PhD, East Carolina University, Greenville, NC, and Georgetown University, Washington, DC

Rosamond Rhodes, PhD, Mount Sinai School of Medicine, New York, NY Dan W. Brock, PhD, Harvard Medical School, Boston, MA Tom L. Beauchamp, PhD, Georgetown University, Washington, DC

Paper Session (334): Strategies for Health and Wellness

Enhancing Communication and Understanding in Healthcare Settings Using the Daily Spiritual **Experience Scale**

Lynn Underwood, PhD, Cleveland State University, Chagrin Falls, OH

How to Keep Well: W. A. Evans and the Invention of **Medical Journalism**

Paul A. Lombardo, PhD JD, Georgia State University, Decatur, GA

Charles Dickens: (Mis)Representing Modern Medicine?

Sylvia A. Pamboukian, PhD, Robert Morris University, Moon, PA

Panel Session (335)

Organizational Ethics: Speaking the Wrong Language or Lost In Translation?

David T. Ozar, PhD, Loyola University Chicago, Chicago, IL Ruth Mickelsen, JD MPH MA, University of Minnesota, Minneapolis, MN J. Michael Stebbins, PhD, Avera Health, Sioux Falls, SD Donald E. Patthoff, DDS, American College of Dentists, Martinsburg, WV

5:30-6:45 pm

Affinity Group Meetings

Mental Health Ethics and Policy (115) Conflict Resolution and Bioethics (336) ELSI (Ethical, Legal, and Social Implications) (337) **Ethics and Humanities Educators in the Health Professions (338) Student Interest and Residency Interest (339)**

Religion, Spirituality, and Bioethics (340) Nursing (341)

7-8:15 pm

Affinity Group Meetings

Visual Arts and Cultural Representations (342) Sexuality and Gender Identity (343) Student Interest and Residency Interest (344) **History of Medical Ethics (345)** Philosophy of Medicine (346) **Reproduction (347)**

8:30-9:45 pm

Affinity Group Meeting

Clinical Ethics Consultation (348)

Sunday, October 21

7:30-8:30 am **Continental Breakfast**

8:30-9:30 am

Concurrent Sessions

Panel Session (401)

Preserving Hope: When Treatments Are "Hopeless"

Deborah Kasman, MD MA, Kaiser Permanente, Baldwin Park, CA Mathew D. Pauley, JD MA MDR, Kaiser Permanente, Fontana, CA Felicia G. Cohn, PhD, Kaiser Permanente Orange County, Tustin, CA Paula Goodman-Crews, LCSW, Kaiser Permanente, San Diego, CA

Panel Session (402)

Representing the Underrepresented in Allocating Scarce Resources in a Public Health Emergency: **Ethical and Legal Considerations**

Beth E. Roxland, JD M.Bioethics, New York State Task Force on Life and the Law, New York, NY

Valerie Gutmann Koch, JD, New York State Task Force on Life and the Law, New York, NY

Susie A. Han, MA, New York State Task Force on Life and the Law, New York, NY

Carrie S. Zoubul, JD MA, New York, NY

Panel Session (403)

Representing Whole Exome and Whole Genome Sequencing to Research Participants and Patients: Considerations for Informed Consent

Joon-Ho Yu, PhD MPH, University of Washington, Seattle, WA Paul S. Appelbaum, MD, Columbia University, New York, NY Ingrid A. Holm, MD MPH, Children's Hospital Boston, Boston, MA Laura M. Beskow, PhD MPH, Duke University, Durham, NC

Panel Session (404)

(Mis)Representations of an Ethical Narrative: Realizing the Potential of Induced Pluripotent Stem Cells

Justin I. Lowenthal, BS, National Institutes of Health Clinical Center, Bethesda, MD

Insoo Hyun, PhD, Case Western Reserve University School of Medicine, Cleveland, OH

Debra Mathews, PhD MA, Johns Hopkins University, Baltimore, MD Rosario Isasi, JD MPH, McGill University, Montreal, QB, Canada

Panel Session (405)

The Organ Shortage: Tacit Assumptions, Policy **Failures, and New Directions**

Elisa J. Gordon, PhD MPH, Northwestern University, Chicago, IL Benjamin E. Hippen, MD, Metrolina Nephrology Associates, PA, Charlotte, NC

James M. DuBois, PhD DSc, St. Louis University, St. Louis, MO Douglas White, MD MAS, University of Pittsburgh, Pittsburgh, PA

Panel Session (406)

Momentary Anesthesia of the Heart

Julie M. Aultman, PhD, Northeast Ohio Medical University, Rootstown, OH Tom Tomlinson, PhD, Michigan State University, East Lansing, MI Joseph Zarconi, MD, Summa Health System, Akron, OH Elizabeth Menefee, MD, Northeast Ohio Medical University, Akron, OH

Paper Session (407): Genetics

Driving Research Forward, But in What Direction? Scientist Perspectives on Goals and Stakeholders in Autism Genetics Research

Lauren C. Milner, PhD, Stanford University, Stanford, CA

A Study of Willingness to Pay for Whole-Genome Sequencing

Matthew R. Fickie, MD MA, Baystate Health System, Springfield, MA Jane L. Garb, MS, Baystate Health System, Springfield, MA Lisa Lehmann, MD PhD, Brigham and Women's Hospital, Boston, MA

Military Genomics

Maxwell Mehlman, JD, Case Western Reserve University, Cleveland, OH

9:30-9:45 am

Break

9:45-10:45 am

Concurrent Sessions

Panel Session (408)

Representing Patient Preferences in the Electronic Medical Record

Felicia G. Cohn, PhD, Kaiser Permanente Orange County, Tustin, CA D. Malcolm Shaner, MD, Kaiser Permanente, Southern California, Los Angeles, CA

Paula Goodman-Crews, MSW LCSW, Kaiser Permanente, San Diego, CA Mark J. Bliton, PhD, Los Angeles Medical Center, Los Angeles, CA

Paper Session (409): Public Health

A Public Health Ethics Analysis of the Mandatory **Immunization of Healthcare Personnel: Minimizing Burdens and Increasing Fairness**

Armand H. Antommaria, MD PhD, University of Utah, Salt Lake City, UT

"Informed Consent Is Protecting Patients to Their **Death": The Perceived Harms of Informed Consent** for Newborn Screening in Ontario

Erica J. Sutton, MA, University of Toronto, Toronto, ON, Canada

Priority Setting in Public Health: Linkages Between Public Health Ethics and Practice

J. P. Leider, BA BS, Johns Hopkins University, Baltimore, MD

SUNDAY, OCTOBER 21: EDUCATIONAL SESSIONS

Paper Session (410): Biobanks and Research

Is More Always Better? The Impact of Simplified **Informed Consent on Response Rates and Comprehension in a Clinic-Based Biobank**

Leona Han, BA, Mayo Clinic, Rochester, MN

Barbara A. Koenig, PhD, University of California–San Francisco, San Francisco, CA

Jeanette Y. Ziegenfuss, PhD, Mayo Clinic, Rochester, MN

Jennifer L. Ridgeway, MPP, Mayo Clinic, Rochester, MN

Janet E. Olson, PhD, Mayo Clinic, Rochester, MN

Marguerite E. Robinson, MAR MA, Mayo Clinic, Rochester, MN

Kandace A. Lackore, BA, Mayo Clinic, Rochester, MN

Methodological Necessity and the Justification of **Placebo-Controlled Trials**

Joseph Millum, PhD, National Institutes of Health, Bethesda, MD

What Can Biobanks Learn from Advanced **Directives in Clinical Medicine?**

Stephanie R. Solomon, PhD, St. Louis University, St. Louis, MO Ann Mongoven, PhD MPH, Michigan State University College of Human Medicine, East Lansing, MI

Paper Session (411): Sentience, the Mind-Body Problem, and Mental Illness

The Fetal Body in Pain: From the Science of Sentience to the Ethics of Representation

Sarah K. Hansen, PhD, Rhodes College, Memphis, TN

Addressing Mental Illness and Suicide in Asian **American Women Through Performance Art**

Stephen Murphy-Shigematsu, PhD , Stanford University, Stanford, CA Audrey Shafer, MD, Stanford University and VA Palo Alto Health Care System, Palo Alto, CA

A New Look at Medicine and the Mind-Body **Problem: Can Dewey's Pragmatism Reconnect Medicine with Its Mission?**

Wayne N. Shelton, PhD, Albany Medical College, Albany, NY Joseph J. Fins, MD MACP, Weill Cornell Medical College, New York, NY

Paper Session (412): Law

More Than Fentanyl: Rethinking the Moscow Theater Crisis in the Wake of Finogenov v. Russia (European Court of Human Rights, 2011)

Jonathan H. Marks, MA BCL, Pennsylvania State University, University Park,

The Panopticon Revisited: Addressing Unauthorized **Patient and Family Member Use of Covert Video Surveillance (CVS) to Monitor Healthcare Providers**

Sally Bean, JD MA, University of Toronto, Joint Centre for Bioethics, Toronto, ON, Canada

Graphic Imagery: Prejudice and Persuasion in Medicine, Public Health, and the Law

Nadia N. Sawicki, JD MBioeth, Loyola University Chicago School of Law, Chicago, IL

Panel Session (414)

Voices of Chaos: Narrative Application in Medical Student Education Concerning Mental Illness

Stephanie L. Darrow, BA, University of Texas Medical Branch, Galveston, TX Erica H. Fletcher, BS, University of Texas Medical Branch, Galveston, TX Sarah E. Baker, BA, University of Texas Medical Branch, Galveston, TX Anne Hudson Jones, PhD, University of Texas Medical Branch, Galveston, TX

11 am-Noon

Concurrent Sessions

Paper Session (415): Ethics and Education

What Reflection Says About Our Future Doctors

Abigale L. Ottenberg, MA, Mayo Clinic, Rochester, MN

The Hidden Curriculum and Ethical Erosion: Exposure to Role Modeling and the Disclosure of Medical Errors

William Martinez, MD, MS, Brigham and Women's Hospital, Boston, MA Lisa Lehmann, MD PhD, Brigham and Women's Hospital, Boston, MA

Teaching Bioethics to High School Science and Religion Students

Terry S. Maksymowych, MS MA, Academy of Notre Dame de Namur, Villanova, PA

Paper Session (416): Humanities

Nonconsensual Ties: Why Practical Reasons in Families Are So Odd

Hilde Lindemann, PhD, Michigan State University, East Lansing, MI James L. Nelson, PhD, Michigan State University, East Lansing, MI

The Ethics of Cultivated Gratitude

Robert C. Macauley, MD, University of Vermont College of Medicine, Burlington, VT

Representing the Silence: Poetry on the Other Side of Illness

Anna Gotlib, PhD JD, Brooklyn College, City University of New York, Brooklyn, NY

Panel Session (417)

Personalized Genomic Medicine: Representation, Reality, and Implications

Eric T. Juengst, PhD, University of North Carolina-Chapel Hill, Chapel Hill, NC

Shawneegua Callier, JD MA, George Washington University, Washington, DC

Charmaine D. Royal, PhD, Duke University, Durham, NC Debra Mathews, PhD MA, Johns Hopkins University, Baltimore, MD

SUNDAY, OCTOBER 21: EDUCATIONAL SESSIONS

Panel Session (418)

Medicine Across the Curriculum: Medical Humanities in Undergraduate Education

Erin G. Lamb, PhD, Hiram College, Hiram, OH Michael Blackie, PhD, Hiram College, Hiram, OH Sally Shigley, PhD, Weber State University, Ogden, UT Marilyn C. McEntyre, PhD, University of California-Berkeley, Berkeley, CA, and University of California-San Francisco, San Francisco, CA

Paper Session (419): Transplant Ethics

Organ Donation After Determination of Death by Neurologic Criteria: Facilitating Cooperation **Between Organ Procurement Organizations and** Intensivists—One Hospital's Experience

Jessica P. Miller, PhD, University of Maine and Eastern Maine Medical Center, Orono, ME

Transplantation Listing Decisions and Parental Refusal of Vaccination: A Nationwide Survey of Pediatric Solid Organ Transplantation Programs

Jennifer M. Ladd, BS, Stanford University School of Medicine, Stanford, CA Katrina E. Karkazis, PhD MPH, Stanford University, Stanford, CA David Magnus, PhD, Stanford University, Stanford, CA

Representing Bioethics in Living Organ Donor Advocacy

Rosamond Rhodes, PhD, Mount Sinai School of Medicine, New York, NY

Paper Session (420): Commodities and **Brokering**

Discussing Costs in the Clinical Encounter: Patient Perspectives

Roseanna Sommers, BA, National Institutes of Health Clinical Center, Bethesda, MD

The Inclusion and Representation of Industry in **Bioethics and Bioethics in Industry**

Jenny Dyck Brian, PhD, Asian University for Women, Chittagong, Bangladesh

Egg Brokers: An Analysis of Egg Donation Agency Versus In Vitro Fertilization Clinic Websites

Jason C. Keehn, MS, Columbia University, New York, NY Eve B. Holwell, BA, Columbia University, New York, NY Robert Klitzman, MD, Columbia University, New York, NY

Panel Session (421)

Military Medical Ethics: Standing at the Medico-**Military Intersection**

Sheena M. Eagan Chamberlin, MPH, University of Texas Medical Branch, Galveston, TX

Rimma Osipov, BA, University of Texas Medical Branch, Galveston, TX Alina Bennett, MA, University of Texas Medical Branch, Galveston, TX Jacqueline M. Genovese, BA, University of Texas Medical Branch, Galveston, TX



Hotel

ASBH has selected the Hyatt Regency Washington on Capitol Hill as the headquarters hotel and has secured a limited number of sleeping rooms at a special negotiated room rate. To obtain the special rate, make your reservation early and be sure to mention that you are attending the ASBH meeting.

The special rate expires August 21, 2012, or when the ASBH room block has been filled. After that time, higher rates may apply.

Hyatt Regency Washington on Capitol Hill

400 New Jersey Ave., NW Washington, DC 20001 **Reservations: 202.737.1234 Hotel:** 202.737.1234 Rate: \$199 single/double Cutoff date: August 21, 2012

Airlines

AmericanAirlines[®]

To take advantage of a 5% discount on American Airlines, American Eagle, AmericanConnections, oneworld Alliance, and codeshare partners, book your reservation at www.aa.com. Select your flights under the "Enter Passenger Details" tab, go to the "AA. com Promotion Code" field, and enter authorization code 2912SS.

To book reservations by phone, call (or have your travel professional call) 800.433.1790 from anywhere in the United States or Canada, 7 days a week, from 6 am to midnight (Central Time), and refer to authorization code A2912SS. Reservations for the hearing and speech impaired are available at 800.543.1586. A \$25 USD reservations service fee is charged for tickets issued through AA reservations, and a \$35 USD ticketing fee is charged for tickets issued at the airport.

Earn AAdvantage miles for your trip. Enroll online at www.aa.com.



United Airlines is offering special discounts to ASBH meeting attendees. Simply call (or have your travel agent call) United Meeting Reservation Desk at 800.521.4041 and refer to Meeting ID 550KO to receive a 5% discount on applicable fares. Discounts also apply to United codeshare flights operated by Continental Airlines, Continental Express, Lufthansa, and All Nippon Airways.

Transportation

The Hyatt Regency Washington on Capitol Hill is located less than 20 minutes from Ronald Reagan National Airport. Taxis are available outside the baggage claim area for an average fare of \$14-\$18. Super shuttles are also available 7 days a week for \$14 each way; advanced reservations can be made by calling 800.BLUEVAN. Try the local Metro Subway with stops just blocks from the Hyatt Regency for less than \$2. The Metro also provides a great way for you to get around the city and see the sites. Please contact the hotel concierge or visit www.wmata.com to plan your trip. Valet parking is also available for \$45 per night at the hotel. For more information, visit http://washingtonregency.hyatt.com.

ASBH Membership

Categories

Individual: Individual membership in ASBH is open to all individuals with an interest in health care from disciplines such as philosophy, medicine, nursing, health policy, history, law, literature, and religion. Individual members receive all privileges and benefits of membership, including the right to vote and hold office in the society.

Student: Full-time undergraduate and graduate students may apply for student membership in ASBH. Proof of fulltime student status is required. Student members receive all the privileges and benefits of regular members.

Affiliate (institutional or organizational):

Eligible organizations for affiliate membership are institutions, organizations, associations, departments, networks, or companies (such as publishers) that are interested in bioethics and health-related humanities. Affiliate membership includes annual meeting registration for one person and discount opportunities for advertising and exhibiting through ASBH.

Benefits

- · Discount on Annual Meeting registration
- Discounts on scholarly journals
- Participation in affinity groups
- Opportunities for networking
- Online membership directory
- ASBH e-mail discussion groups
- Discount on members' mailing labels

Application

An ASBH membership application form can be obtained through the ASBH website at www.asbh.org. Direct questions to Member Services at info@asbh.org or 847.375.4745.

Exhibit Schedule

Thursday, October 18

Exhibit Hall Open 5-7 pm

Friday, October 19

Exhibit Hall Open 7 am-5 pm

Saturday, October 20

Exhibit Hall Open 7 am-1:30 pm

Registration

The full registration fee includes

- · the Thursday evening reception
- all educational sessions (excluding preconference workshops)
- continental breakfasts
- refreshment breaks
- the complete program book with abstracts

Member Registration

You must be an ASBH member in good standing at the time you register to take advantage of the discounted member rate.

Join and Register

You can become an ASBH member and register for the conference at the reduced member rate. Check the join-and-register option and the appropriate membership category on the registration form.

Student Registration

If you are enrolled full time in a degree program, you may register at the student rate. A letter from a university department confirming full-time status must accompany your registration.

Guest Pass

Any spouse or domestic partner can take advantage of a reduced registration fee. Guests will have access to all general sessions, the exhibit hall, and networking events.

Deadlines

The early registration deadline is September 18, 2012. You are encouraged to register by this date to take advantage of the early registration discount. The final registration deadline is October 9, 2012. After that date, you must call ASBH Member Services at 847.375.4745 to register. Please keep a copy of your registration form for your records.

Deductibility of Expenses

Consult your tax adviser for information regarding the deductibility of registration fees

Exhibitors (as of June 20)

Albany Medical College

The Bioethics Program of Union Graduate College and Mount Sinai School of Medicine

Case Western Reserve University

Center for Bioethics, Health and Society

Center for Practical Bioethics

Columbia University School of Continuing Education

Emory University Center for Ethics

EthicShare—University of Minnesota

Georgetown University Press

The Hastings Center

Johns Hopkins University Press

The Journal of Clinical Ethics

Kennedy Institute of Ethics/Bioethics Research Library

Loyola University—Neiswanger Institute for Bioethics and Health Policy

The MIT Press

Montefiore-Finstein Center for **Bioethics**

Oxford University Press

Saint Louis University Center for Health Care Ethics

Springer Science and Business Media

Taylor and Francis

University of Louisville

University of Pennsylvania Center for Bioethics

Wiley-Blackwell

2012 Conference Sponsors

The American Journal of **BIOETHICS**

AJOB

AJOB Primary Research



ASBH 14th Annual Meeting Registration

October 18-21, 2012 • Hyatt Regency Washington on Capitol Hill • Washington, DC

Please print or type clearly. Use a separate form for o	each registrant and duplicate as necessary.	
Complete name First name for badge		
Title		Credentials (Limit to 8 characters)
Employer	Em _l	ployer's city/state
Mailing address (☐home ☐work)		
-		E-mail address (required*)
*Confirmation of your registration will only be sent v	ia e-mail to the e-mail address that you provide here	2.
Home phone ()	Work phone ()	(FTA) This will be my first ASBH Annual Meeting.
Emergency contact		
(SA) \square I will be using a wheelchair at the conference.	Information needed to project space accomodation for meeting	ng rooms and other functions.) (SDV) 🔲 I will need a vegetarian meal. (OTH) 🔲 I have other needs. Please contact me.
To register, make your selec	tions in the boxes below. Ac	dd the subtotals and indicate the total amount in Box H.
Full Meeting Registration—Octo		A Preconference Sessions—Thursday, October 18
(Be sure to complete Boxes E an Registration Rates	On or Before After	(See pages 3–6 for descriptions and codes.)
	9/18/2012 9/18/2012	8 am-Noon 0 0 Member \$90 Nonmember \$150 Student* \$50
ASBH Member Nonmember	□\$350 □\$400 □\$650 □\$700	8 am-Noon 0 0 8 Member \$40 Nonmember \$40 Student* \$40
Student*	\$050 \$700 \$75 \$125	*Full-time student in a degree program (see page 22 for details). Subtotal D \$
Join and Register (regular member)	□\$350 □\$400	Educational Cossions and Affinity Cycum Mastings
Join and Register (student)	□\$75 □\$125	Educational Sessions and Affinity Group Meetings (See session descriptions on pages 7–20 for codes.)
Membership Rates	Meeting Fee Subtotal \$	Thursday, October 18
Annual Income	Dues	10 1 200 20 2 2 2
Less than \$35,000	□\$50 □\$05	Friday, October 19 (continued) 1–2:30 pm 2:45–3:45 pm 5:45–7 pm
\$35,000-\$64,999 \$65,000-\$79,999	□\$95 □\$125	2 2 2 2 2
\$80,000-\$99,999	□\$160	Saturday, October 20
\$100,000-\$149,999	\$200	6:30-7:45 am 8-9 am 10:30-11:30 am 1:45-2:45 pm
\$150,000 and up	\$250	3–4 pm 4:15–5:15 pm 5:30–6:45 pm 7–8:15 pm
Student* *Full-time student in a degree program	□\$30 Membership Dues Subtotal \$	3 2 3 3 4
(See page 22 for details.)	Subtotal A \$	— Sunday, October 21 8:30-9:30 am 9:45-10:45 am 11 am-Noon
(See page 22 for details.)	oubtotul A ψ	
1-Day Meeting Registration (for registrants attending 1 day of the meeting only) Ghealt the day way will attend		
Check the day you will attend. ☐ Thursday ☐ Friday ☐ Sat	urday Sunday	Name Subtotal F \$
	On or Before After	Ontional Event
Marka Ball	9/18/2012 9/18/2012	optional Event
Member Daily Nonmember Daily	□\$200 □\$250 □\$350 □\$400	The Mind and Music of George Gershwin (REC)—Friday, October 19, 8–9 pm
Student Daily*	□\$40 □\$90	☐ Member \$0 ☐ Nonmember \$25 Subtotal G \$
*Full-time student in a degree program		
(See page 22 for details.) Subtotal B \$ Total Amount Due (A or B) + C + D + F + G \$		
Continuing Education Credit Individuals seeking credit must select:		Payment
(CME) ☐ Continuing Medical Education, (CNE) ☐ Continuing Nursing Education, or		□ Check (enclosed)
(CLE) ☐ Continuing Legal Education		Make check payable to ASBH.
There is a \$100 (CME) or \$50 (CNE & CLE) processing fee to receive CE credit.		A charge of \$25 will apply to checks returned for insufficient funds.
	Cubiatal C ft	Checks not in U.S. funds will be returned.
	Subtotal C \$	
4 easy ways to register		Mascreac UISA Discover
Online www.asbh.org	Fax 847.375.6482	 If rebilling of a credit card charge is necessary, a \$25 pr^essing fee will be charged.
credit card payment only	credit card payment only	Account number Expiration date
Mail ASBH Conference	Phone 847.375.4745	
PO Box 839	credit card payment only	Signature
Glenview, IL 60025-0839		Cardholder's name (Please print.)
Cancellation policy: All cancellation requests must be made in writing. A \$75 processing fee applies to all cancellations. No refunds will be made on cancellations postmarked after September 28, 2012. All refunds will be processed after the meeting.		
ASBH reserves the right to substitute faculty or cancel or i	eschedule sessions because of low enrollment or other unfores nts will receive a full credit for or refund of their paid registration	een



4700 W. Lake Avenue Glenview, IL 60025-1485

PRSRT STD U.S. Postage PAID Glenview. IL Permit No. 62

American Society for Bioethics and Humanities

14TH ANNUAL MEETING

October 18-21, 2012 • Washington, DC

Schedule at a Glance

THURSDAY, OCTOBER 18

Preconference Sessions 8 am-Noon

Concurrent Sessions

1-2:30 pm 2:45-3:45 pm

Plenary Session

4-5:15 pm

Opening Reception 5:30-7 pm

FRIDAY, OCTOBER 19

Affinity Group Meeting 6:30-7:45 am

Concurrent Sessions

Plenary Session

9:15-10:15 am

Concurrent Sessions

10:30-11:30 am

Affinity Group Meetings

11:30 am-12:45 pm

Concurrent Sessions

1-2:30 pm

2:45-3:45 pm

President's Address and

Members' Meeting

4-5:15 pm

Affinity Group Meetings

5:45-7 pm

Special Performance

8-9 pm

SATURDAY, OCTOBER 20

Affinity Group Meeting

6:30-7:45 am

Concurrent Sessions

8-9 am

Plenary Session

9:15-10:15 am

Concurrent Sessions

10:30-11:30 am

1:45-2:45 pm

3-4 pm

4:15-5:15 pm

Affinity Group Meetings

5:30-6:45 pm

7-8:15 pm

8:30-9:45 pm

SUNDAY, OCTOBER 21

Concurrent Sessions

8:30-9:30 am

9:45-10:45 am

11 am-Noon