

CHILDREN'S MERCY HOSPITAL CERTIFICATE PROGRAM IN PEDIATRIC BIOETHICS

--- 2012-13 Program Syllabus ---

INITIAL ON-SITE TRAINING CONFERENCE (September 7-9)

Friday, September 7

3:00-3:30 **Welcome and Introductions**

3:30-4:45 **What is Special about Pediatric Bioethics?** (John Lantos)

- Lantos. [Does pediatrics need its own bioethics?](#) *Persp Biol Med*, 2010.
- *Encyclopedia of Bioethics*, "Children"
- Robinson & Unruh. The hepatitis experiments at the Willowbrook State School. In: Emanuel, et al. (eds.), *The Oxford Textbook of Clinical Research Ethics*.

5:00-6:30 **Narrative and Pediatrics** (John Lantos and Martha Montello)

- Williams. [The use of force](#).
- Janvier. [I'm only punching in](#). *Arch Pediatr Adolesc Med*, 2007.
- Forman, [This Lovely Life](#), pp. 1-84.

7:00-9:00 Group Dinner (Pierpont's at Union Station)

Saturday, September 8

8:00-8:30 Breakfast (On-site)

8:30-10:00 **Moral Philosophy and Pediatrics** (Jeremy Garrett and Wayne Vaught)

- Donovan & Pellegrino. Virtues and goals in pediatrics. In: Miller (ed.), *Pediatric Bioethics* (pp. 3-10).
- McCullough. Contributions of ethical theory to pediatric ethics. In: Miller (ed.), *Pediatric Bioethics* (pp. 11-21).
- Kopelman. Using the best-interests standard in treatment decisions for young children. In: Miller (ed.), *Pediatric Bioethics* (pp. 22-37).

10:30-12:00 **The Law and Pediatrics** (June Carbone and Mary Kay Kisthardt)

- Sayeed. The moral and legal status of children and parents. In: Miller (ed.), *Pediatric Bioethics* (pp. 38-53).
- Supreme Judicial Court of Massachusetts, Plymouth. Custody of a Minor. 375 Mass. 733, 379 N.E.2d 1053. (Chad Green case).
- [Miller v. HCA](#)

12:00-1:00 Lunch (On-site)

- 1:00-2:30 **Public Policy, Hospital Administration, and Pediatrics** (Rand O'Donnell)
• Readings TBD.
- 3:00-4:30 **Small Group Breakout Sessions**
- 6:00-8:00 Group Dinner (Fiorella's Jack Stack Barbecue)

Sunday, September 9

- 8:00-8:30 Breakfast (On-site)
- 8:30-10:00 **IRBs and Pediatric Research Ethics** (Rebecca Ballard)
• Moreno & Kravitt. The ethics of pediatric research. In: Miller (ed.), *Pediatric Bioethics* (pp. 54-72).
• Ramsey. The enforcement of morals: nontherapeutic research on children. *Hastings Center Report*, 1976.
• McCormick. Experimentation in children: sharing in sociality. *Hastings Center Report*, 1976.
- 10:30-12:00 **Ethics Committees and Pediatric Clinical Ethics** (Lynne Covitz, Drew Lasky, Doug Myers, and Diane Plantz)
• Mercurio. Pediatric ethics committees. In: Miller (ed.), *Pediatric Bioethics* (pp. 87-108).
• AAP Statement on Institutional Ethics Committees. *Pediatrics*, 2001.
• Kesselheim et al. [Ethics consultation in children's hospitals: results from a survey of pediatric clinical ethicists](#). *Pediatrics*, 2010.
- 12:00-1:00 **Working Lunch - Small Group Breakout Sessions** (On-site)
• Work through ethics consultation case in small groups
- 1:00-2:00 **Mock Ethics Committee Consultation Meeting** (John Lantos)
• Re-gather as large group for mock ethics committee meeting
- 2:15-3:00 **Introduction to Course Technology** (Jeremy Garrett and John Lantos)
- 3:00 – Conference ends; Dinner on your own

FALL
(September 10 – November 16)

Weeks 1-3: Futility and Moral Distress

Week #1 → Week of September 10 – (June Carbone and John Lantos)

- Lantos et al. [The illusion of futility in clinical practice](#). *Am J Med*, 1989
- Helft et al. [The rise and fall of the futility movement](#). *NEJM*, 2000
- Fine. [The Texas Advance Directive](#). *Chest*, 2009
- Truog. [The Texas AD Act is flawed](#). *Chest*, 2009

Week #2 → Week of September 17 – (Lynne Covitz and Angie Knackstedt)

- Jameton. [Dilemmas of moral distress: moral responsibility and nursing practice](#). *AWHONNS Clin Issues Perinat Womens Health Nurs*, 1993.
- Repenshek. [Moral distress: inability to act or discomfort with moral subjectivity?](#) *Nurs Ethics*, 2009.
- McCarthy et al. [Moral distress reconsidered](#). *Nurs Ethics*, 2008.

Week #3 → Week of September 24 – (Rosemary Hubble and Dane Sommer)

- Truog. [Is it always wrong to perform futile CPR](#). *NEJM*, 2010.
- Feudtner. [The breadth of hopes](#). *NEJM*, 2009.
- Frader. [Symbolic resuscitation and futility](#). *Pediatrics*, 2010.
- Pope. Involuntary passive euthanasia in U.S. courts: reassessing the judicial treatment of medical futility cases. *Marquette Elder's Advisor*, 2009.

Weeks 4-7: End-of-Life Decisions and Pediatric Palliative Care

Week #4 → Week of October 1 – Palliative Care (Lynne Covitz, Rosemary Hubble)

- IOM. Summary of [When Children Die: Improving Palliative and End-Of-Life Care for Children and Their Families](#).
- [AAP statement](#) on palliative care
- Feudtner et al. [Pediatric palliative care patients: a prospective multicenter cohort study](#). *Pediatrics*, 2011.

Week #5 → Week of October 8 – Ethics and End of Life/Palliative Care (Rebecca Ballard, Rosemary Hubble, Doug Myers)

- Lantos. The interface of ethics and palliative care. Chapter 13 from *Textbook of Interdisciplinary Pediatric Palliative Care*.
- Sayeed & Miller. The forgoing of life-sustaining treatment for children. In: Miller (ed.), *Pediatric Bioethics* (pp. 262-283).
- Solomon et al. New and lingering controversies in pediatric end of life care. *Pediatrics*, 2005.

Week #6 → Week of October 15 – Child and Parent Understanding and Perceptions

(Rosemary Hubble, Doug Myers)

- *Textbook of Interdisciplinary Pediatric Palliative Care*
 - Chapter 1: The Language of Pediatric Palliative Care
 - Chapter 3: Children's Voices: The Experience of Patients and Their Siblings
 - Chapter 4: Understanding the Illness Experience and Providing Anticipatory Guidance
- [Parental Preference or Child Well-Being: An Ethical Dilemma](#), *J Pediatr Nurs*, 2010 Feb;25(1):58-63
- [Preschool as Palliative Care](#), *J Clin Oncol*, 2008 Aug 1;26(22):3797-9
- ["Trying to be a Good Parent" as Defined by Interviews with Parents Who Made Phase I, Terminal Care, and Resuscitation Decisions for their Children](#), *J Clin Oncol*, 2009 Dec 10;27(35):5979-85

Week #7 → Week of October 22 – Brain Death, Minimal Consciousness, and Vegetative States in Children (Diane Plantz, Dane Sommer)

- Miller & Ashwal. Brain death, minimal consciousness, and vegetative states in children. In: Miller (ed.), *Pediatric Bioethics*, (pp. 247-261).
- AAP Clinical Report: ["Guidelines for the Determination of Brain Death in Infants and Children: An update of the 1987 Task Force Recommendations"](#)
- American Academy of Pediatrics, [Task Force on Brain Death in Children. Report of Special Task Force: guidelines for determination of brain death in children.](#) *Pediatrics*. 1987;80(2):298 –300
- [Controversies in the Determination of Death, A White Paper by the President's Council of Bioethics](#), Chapters 4-6
- Monti, MM, et al. [Willful Modulation of Brain Activity in Disorders of Consciousness.](#) *NEJM*. 2010;362(7):579-589
- Diekema, DS. [What is left of futility? The convergence of anencephaly and the emergency medical treatment and active labor act.](#) *Arch Pediatrics and Adolescent Medicine*. 1995;149:1156-1159

Weeks 8-10: Pediatric Research Ethics

Week #8 → Week of October 29 – (Rebecca Ballard, Doug Myers, Dane Sommer)

- Selections from Kodish, [Ethics and Research with Children: A Case-Based Approach.](#)

Week #9 → Week of November 5 – (Dane Sommer and Rebecca Ballard)

- Selections from Ross, [Children in Medical Research.](#)

Week #10 → Week of November 12 – (Rebecca Ballard and John Lantos)

- Lantos et al. [Extracorporeal membrane oxygenation and the ethics of clinical research in pediatrics.](#) *NEJM*, 1990.
- Lantos et al. [Hot debate about a cool therapy.](#) *NeoReviews*, 2009.

Fall Break → November 17-25

WINTER
(November 26 – December 14)

Weeks 11-13: Newborn Screening and Pediatric Genetic Research

Week #11 → Week of November 26 – (Jeremy Garrett)

- [The Changing Moral Focus of Newborn Screening: An Ethical Analysis by the President's Council on Bioethics](#)

Week #12 → Week of December 3 – (Jeremy Garrett and Felix Okah)

- Selections from Baily et al., [Ethics and Newborn Genetic Screening: New Technologies, New Challenges](#).

Week #13 → Week of December 10 – (Rebecca Ballard and Jeremy Garrett)

- Selections from Buchanan et al., [From Chance to Choice: Genetics and Justice](#)
- Ross. [Ethical and policy issues in pediatric genetics](#). *Am J Med Genet Part C Semin Med Genet*, 2008.
- Gurwitz et al. [Children and population biobanks](#). *Science*, 2009.

Winter Break → December 17 – January 27

SPRING
(January 28 – April 30)

Weeks 14-22: Specific Topics in Pediatric Bioethics

Week #14 → Conscience (Week of January 28) – (Diane Plantz and Dane Sommer)

- Curlin et al. [Religion, conscience, and controversial clinical practices](#). *NEJM*, 2007.
- Curlin. [Conscience and clinical practice: medical ethics in the face of moral controversy](#). *Theor Med Bioeth*, 2008.
- Sulmasy. [What is conscience and why is respect for it so important?](#) *Theor Med Bioeth*, 2008.
- Savulescu. [Conscientious objection in medicine](#). *BMJ*, 2006.

Week #15 → Cultural and Religious Issues (Week of February 4) – (Rosemary Hubble, Diane Plantz, Dane Sommer)

- Sayeed et al. Ethics rounds: An Arabic family in the PICU. *Pediatrics*, 2011.
- Sulmasy. [Distinguishing denial from authentic faith in miracles: a clinical-pastoral approach](#). *South Med J*, 2007.

Week #16 → Growth Hormone – Therapy vs. Enhancement (Week of February 11) – (Angie Knackstedt and John Lantos)

- Lantos et al. [Ethical issues in growth hormone therapy](#). *JAMA*, 1989.
- Allen & Fost. [Growth hormone therapy for short stature: panacea or Pandora's box?](#) *J Pediatr*, 1990.

Week #17 → Medical Error (Week of February 18) – (Mary Kay Kisthardt, Diane Plantz, Wayne Vaught)

- Selections from Bosk, [Forgive and Remember: Managing Medical Failure](#)
- Selections from Paget, [The Unity of Mistakes: A Phenomenological Interpretation of Medical Work](#)

Week #18 → Pediatric Organ Donations and Transplants (Week of February 25) – (Doug Myers and Diane Plantz)

- [AAP statement on organ donation](#)

Week #19 → Pediatric Assent and Parental Consent (Week of March 4) – (Rebecca Ballard, Doug Myers, Diane Plantz, Wayne Vaught)

- Bartholome. [A new understanding of consent in pediatric practice: consent, parental permission, and child assent](#). *Pediatr Ann*, 1989.
- Unguru. [The experiences of children enrolled in pediatric oncology research: implications for assent](#). *Pediatrics*, 2010.
- Joffe. [Harmonization of ethics policies in pediatric research](#). *J Law Med Ethics*, 2011.

Week #20 → Issues in Adolescent Medicine (Week of March 11) – (Lynne Covitz, Jenni Linebarger, Diane Plantz, Wayne Vaught)

- Larcher et al. [This house believes that we have gone too far in granting young people the responsibility for making decisions about their own healthcare: record of a debate held in the Ethics and Law session of the RCPCH Annual Meeting, York 2009](#). *Arch Dis Child*, 2011.
- Mercurio. [Adolescent parents of critically ill newborns: rights and obligations](#). *J Peds*, 2010.
- Holder. [From chattel to consentor: adolescents and informed consent: 2009 Grover Powers Lecture](#). *Yale J Bio Med*, 2009.

Week #21 → Child Abuse and Neglect (Week of March 18) – (Diane Plantz)

- Webb. [An ethical approach to resolving value conflicts in child protection](#). *Arch Dis Childhood*, 2010.
- Solnit. [The bioethics of children's rights](#). *Isr J Psychiatry Relat Sci*, 2004.

Week #22 → Immunizations (Week of March 25) – (Angie Knackstedt and John Lantos)

- Lantos et al. [Controversies in vaccine mandates](#). *Curr Prob Peds*, 2010.
- Frader & Flanagan-Klygis. Ethics and immunization. In: Miller (ed.), *Pediatric Bioethics* (pp. 219-230).

Weeks 23-27: Great Books

Week #23 → The Private Worlds of Dying Children (Week of April 1) – (Lynne Covitz and Rosemary Hubble)

- Myra Bluebond-Langner, *The Private Worlds of Dying Children*, Chapters 1-3

Week #24 → The Private Worlds of Dying Children (Week of April 8) – (Lynne Covitz and Rosemary Hubble)

- Myra Bluebond-Langner, *The Private Worlds of Dying Children*, Chapters 4-7

Week #25 → A Personal Matter (Week of April 15) – (John Lantos and Clancy Martin)

- Kenzaburo Oe, *A Personal Matter*, All Chapters

Week #26 → The Spirit Catches You and You Fall Down (Week of April 22) – (Diane Plantz)

- Anne Fadimon, *The Spirit Catches You and You Fall Down*, Chapters 1-10

Week #27 → The Spirit Catches You and You Fall Down (Week of April 29) – (Diane Plantz)

- Anne Fadimon, *The Spirit Catches You and You Fall Down*, Chapters 11-19

**CONCLUDING ON-SITE TRAINING CONFERENCE
(Dates TBD)**

- **Schedule TBD**
- **Readings (“Great Articles”)**
 - Feudtner. [The breadth of hopes](#). *NEJM*, 2009.
 - Truog. [Is it always wrong to perform futile CPR?](#) *NEJM*, 2010.
 - Srivastava. [Denial](#). *NEJM*, 2009.
 - Janvier. [Pepperoni pizza and sex](#). *Curr Probl Pediatr Adolesc Health Care*, 2011.
- **Assignments**
 - Present Final Paper or Case Report