

CHILDREN'S MERCY HOSPITAL  
CERTIFICATE PROGRAM IN PEDIATRIC BIOETHICS  
--- 2016-17 Program Syllabus ---

**Readings**

Readings are required unless noted as "Other Suggested Readings" which are optional.

**Online Discussion**

Students are required to participate in the weekly online discussion. Further details will be outlined during Opening Session in Kansas City. Students are allowed one non-participation week per semester.

**Webinars**

The Bioethics Center will host nine or more webinars and one or more program-specific mid-year webinar. Additional program-specific and Center webinars may be added throughout the year. Each student must attend (or watch the taped recording of) five of the webinars and must attend (or watch the taped recording of) **all** program-specific webinars. Students who are not able to attend the webinar will participate in an online discussion of the webinar to fulfill the requirement. The webinar schedule will be distributed via email and posted to CourseSites.

**Final Paper/Project Deadlines**

The final paper/project is an important component of the Certificate Program. You will be working with one of the four core faculty (Brian, Jeremy, Angie & John) who will assist in helping you narrow your topic as well as match you with additional faculty to work with. To help you stay on track, see timeline below.

- **Oct. 20:** Subject narrowed for final paper topic/project. A list of 1-3 possible topics due to Jeremy Garrett, who will assign you a faculty mentor and topic specialists.
- **Dec. 1:** Topic/project picked. Abstract due.
- **Jan. 19:** Outline due.
- **Mar. 2:** First draft due.
- **Mar. 13-Mar. 24:** Practice presentations.
- **Apr. 27:** Second draft due.
- **May 18-20:** Final paper/project due with presentation.

**Weeks 1-9: Foundations**

**Week #1 → Parental Authority (Sept. 14 - 20) - Brian Carter, Jessica Brunkhorst, Jill Beck**

- Verkerk MA et al. Where families and healthcare meet. *J Med Ethics*. 2015 Feb;41(2):183-5. doi: 10.1136/medethics-2013-101783. Epub 2014 Sep 10.
- Noggle R. The Moral and Political Status of Children. Chapter 6: Special Agents - Children's Autonomy and Parental Authority. David Archard & Colin McLeod (Eds.). Oxford University Press (2002): 97-117. (posted to CourseSites)
- Groll D. Four models of family interests. *Pediatrics*. 2014 Oct;134 Suppl 2:S81-6. doi: 10.1542/peds.2014-1394C.

Other suggested reading:

- Humikowski CA. Confession. *Arch Pediatr Adolesc Med*. 2012 Jul 1;166(7):593-4. doi: 10.1001/archpediatrics.2012.28.
- Clark JD. Balancing the tension: parental authority and the fear of paternalism in end-of-life care. (comment on "Confession"). *Arch Pediatr Adolesc Med*. 2012 Jul 1;166(7):594. doi: 10.1001/archpediatrics.2012.556.
- Smetana J et al. Adolescents' and parents' changing conceptions of parental authority. *New Dir Child Adolesc Dev*. 2005 Summer;(108):31-46. (posted to CourseSites)
- Mercurio MR. Parental authority, patient's best interest and refusal of resuscitation at borderline gestational age. *J Perinatol*. 2006 Aug;26(8):452-7.

**Week #2 → Parental Consent and Pediatric Assent (Sept. 21 - 27) - John Lantos, Doug Myers, DeeJo Miller, Donna McKlindon**

- Unguru Y. Pediatric decision-making: informed consent, parental permission, and child assent. *Clinical Ethics in Pediatrics A Case Based Textbook*. Cambridge: Cambridge University Press; 2011, pages 1-6. (posted to CourseSites)
- McCullough LB. Contributions of ethical theory of pediatrics-pediatricians and parents as co-fiduciaries of pediatrics patients. *Pediatric Bioethics*. Cambridge: Cambridge University Press; 2010, pages 11-21. (posted to CourseSites)
- McHaffie HE et al. Deciding for imperiled newborns: medical authority or parental autonomy? *J Med Ethics*. 2001 Apr;27(2):104-9.
- Mercurio MR et al. Unilateral pediatric "do not attempt resuscitation" orders: the pros, the cons, and a proposed approach. *Pediatrics*. 2014 Feb;133 Suppl 1:S37-43. doi: 10.1542/peds.2013-3608G.

Other suggested reading:

- Unguru Y et al. Rethinking pediatric assent: from requirement to ideal. *Pediatr Clin North Am*. 2008 Feb;55(1):211-22, xii. doi: 10.1016/j.pcl.2007.10.016.

- Plantz DM, Lantos J. Parental Authority. Bioethics, 4th Edition, edited by Bruce Jennings, et al. Detroit: Macmillan Reference USA, 2014, in press. (posted to CourseSites)

**Week #3 → Best Interest Standard (Sept. 28 – Oct. 4) - Jeremy Garrett, Jessica Brunkhorst, DeeJo Miller, Erin Thomasma**

- Kopelman LM. The best-interests standard as threshold, ideal, and standard of reasonableness. *J Med Philos.* 1997 Jun;22(3):271-89.
- Salter EK. Deciding for a child: a comprehensive analysis of the best interest standard. *Theor Med Bioeth.* 2012 Jun;33(3):179-98. doi: 10.1007/s11017-012-9219-z.

Other suggested reading:

- Blustein J. Doing the best for one's child: satisficing versus optimizing parentalism. *Theor Med Bioeth.* 2012 Jun;33(3):199-205. doi: 10.1007/s11017-012-9222-4.
- Brennan S. The goods of childhood and children's rights. In: Baylis and Mcleod (eds.), *Family-Making: Contemporary Ethical Challenges.* Oxford: Oxford University Press, 2014, pp. 29-45. (posted to CourseSites)
- Kopelman LM. Using the Best-Interests Standard in Treatment Decisions for Young Children. In: Miller (ed.), *Pediatric Bioethics.* Cambridge: Cambridge University Press, 2010, pp. 22-27. (posted to CourseSites)
- Griffith R. Determining what is in the best interests of a critically ill child. *Br J Nurs.* 2013 Jan 24-Feb 13;22(2):112-3.
- De Vries MC et al. What Constitutes the Best Interest of a Child? Views of Parents, Children, and Physicians in a Pediatric Oncology Setting. *AJOB Primary Research.* 2013. 4:2, 1-10, DOI: 10.1080/21507716.2012.757254. (posted to CourseSites)

**Week #4 → Harm Principle/Open Future (Oct. 5 – 11) - Jeremy Garrett, Hank Puls, Julie Cakici**

- Diekema S. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theoretical Medicine and Bioethics.* 2004;25(4):243-264. (posted to CourseSites) *Note: only pp. 243-254 are required; the rest is suggested.*
- Wilkinson D, Nair T. Harm isn't all you need: parental discretion and medical decisions for a child. *J Med Ethics.* 2016 Feb;42(2):116-8. doi: 10.1136/medethics-2015-103265. Epub 2015 Dec 18.
- Lombrozo T. NPR Commentary: "Why do we judge parents for putting kids at perceived—but unreal—risk?" August 22, 2016. Available at: <http://www.npr.org/sections/13.7/2016/08/22/490847797/why-do-we-judge-parents-for-putting-kids-at-perceived-but-unreal-risk>
- Feinberg J. The child's right to an open future. Chapter Three of *Freedom and Fulfillment: Philosophical Essays.* Princeton, NJ: Princeton University Press, 1992. (posted to CourseSites) *Note: only pp. 76-78 are required; the rest is suggested.*

- Davis DS. Genetic dilemmas and the child's right to an open future. *Hastings Cent Rep*. 1997 Mar-Apr;27(2):7-15.

Other suggested reading:

- Harrosh S. Identifying harms. *Bioethics*. 2012 Nov;26(9):493-8. doi: 10.1111/j.1467-8519.2011.01889.x. Epub 2011 Mar 25.
- Thomas AJ, Stanford PK, Sarnecka BW. No child left alone: moral judgments about parents affect estimates of risk to children. *Collabra*. 2016;2(1):10,1-4.
- Ross LF. Constrained parental autonomy. Chapter Three of *Children, Families, and Health Care Decision Making*. Oxford: Oxford University Press, 2002. (posted to CourseSites)
- Millum J. The foundation of the child's right to an open future. *J Soc Philos*. 2014 Winter;45(4):522-538.
- Bredenoord AL et al. The right to an open future concerning genetic information. *Am J Bioeth*. 2014;14(3):21-3. doi: 10.1080/15265161.2013.879952.

**Week #5 → Professional Integrity/Judgement (Oct. 12 – 18) - Brian Carter, Laura Miller-Smith, Donna McKlindon, Laura Murkin**

- Mitchell LA. Integrity and virtue: the forming of good character. *Linacre Q*. 2015 May;82(2):149-69. doi: 10.1179/2050854915Y.0000000001.
- Johnson. Nursing Professionalism: Innate, taught, or caught? *J Nurses Prof Dev*. Mar-Apr;31(2):114-5. doi: 10.1097/NND.0000000000000149.
- Thomas TA et al. A qualitative study exploring moral distress among pediatric resuscitation team clinicians: challenges to professional integrity. *Pediatr Crit Care Med*. 2016 Jul;17(7):e303-8. doi: 10.1097/PCC.0000000000000773.
- Brudney, D. "Pregnancy is not a disease": conscientious refusal and the argument from concepts. *Hastings Cent Rep*. 2014 Sep;44(5):43-9. doi: 10.1002/hast.357.

Other suggested reading:

- Crigger N, Godfrey N. From the inside out: a new approach to teaching professional identity formation and professional ethics. *J Prof Nurse*. 2014 Sep-Oct;30(5):376-82. doi: 10.1016/j.profnurs.2014.03.004. Epub 2014 Mar 28.
- Hillis DJ, Grigg MJ. Professionalism and the role of medical colleges. *Surgeon*. 2015 Oct;13(5):292-9. doi: 10.1016/j.surge.2015.04.001. Epub 2015 Apr 27.
- Salloch S. Same same but different: why we should care about the distinction between professionalism and ethics. *BMC Med Ethics*. 2016 Jul 22;17(1):44. doi: 10.1186/s12910-016-0128-y.

**Week #6 → Conscience and Moral Distress (Oct. 19 – 25) - Jeremy Garrett, Angie Knackstedt, Jill Beck, Jenni Linebarger, Laura Murkin**

- Sulmasy DP. What is conscience and why is respect for it so important? *Theor Med Bioeth.* 2008;29(3):135-49. doi: 10.1007/s11017-008-9072-2.
- McCullough LB. Review of Mark R. Wicclair, Conscientious Objection in Health Care: An Ethical Analysis. *Notre Dame Philosophical Reviews.* 2012.09.22.
- AAP Committee on Bioethics. Policy statement--Physician refusal to provide information or treatment on the basis of claims of conscience. *Pediatrics.* 2009 Dec;124(6):1689-93. doi: 10.1542/peds.2009-2222.
- Weber E. Moral distress, workplace health, and intrinsic harm. *Bioethics.* 2016 May;30(4):244-50. doi: 10.1111/bioe.12181. Epub 2015 Aug 26.
- Rushton CH et al. CE: Moral distress: a catalyst in building moral resilience. *Am J Nurs.* 2016 Jul;116(7):40-9. doi: 10.1097/01.NAJ.0000484933.40476.5b.
- Gallagher A. Moral distress and moral courage in everyday nursing practice. *Online J Issues Nurs.* 2011 Mar 21;16(2):8.

Other suggested reading/resources:

- Daniel Sulmasy, OFM, MD, PhD: The Role of Conscience in Medical Decisions. The Center for Practical Bioethics (video): <http://practicalbioethics.tv/2009/08/06/Daniel-Sulmasy/Role-of-Conscience-in-Medical-Decisions.html>.
- Wicclair MR. Is conscientious objection incompatible with a physician's professional obligations? *Theor Med Bioeth.* 2008;29(3):171-85. doi: 10.1007/s11017-008-9075-z.
- Hamric AB. Moral distress in everyday ethics. *Nurs Outlook.* 2000 Sep-Oct;48(5):199-201.
- Jameton A. Dilemmas of moral distress: moral responsibility and nursing practice. *AWHONNS Clin Issues Perinat Womens Health Nurs.* 1993;4(4):542-51.
- Billharz, J. Truth Telling Is It Ever Virtuous to Lie. AAP Section on Bioethics Newsletter, Fall 2011. (posted to CourseSites)
- Chen, P. When doctors and nurses can't do the right thing. *The New York Times.* February 6, 2009.
- McCarthy J, Deady R. Moral distress reconsidered. *Nurs Ethics.* 2008 Mar;15(2):254-62. doi: 10.1177/0969733007086023.

**Week #7 → Religious and Cultural Issues (Oct. 26 – Nov. 1) - Angie Knackstedt, Charlotte Jacobsen, Paige Johnson, DeeJo Miller, Dane Sommer, Beth Sonnevile, Erin Thomasma**

- Wein S. Spirituality--the psyche or the soul? *Palliat Support Care.* 2014 Apr;12(2):91-4. doi: 10.1017/S1478951514000303.
- Schaffer, A. How Jehovah's Witnesses are changing medicine. *The New Yorker.* August 12, 2015.
- Kipnis, K. Ethics, Morality and Pediatric Gender Dysphoria. *Am J Bioeth.* 2014;14(1):50-1. doi: 10.1080/15265161.2014.862411.

- Meadow W et al. A premature infant with necrotizing enterocolitis whose parents are Jehovah's Witnesses. *Pediatrics*. 2010 Jul;126(1):151-5. doi: 10.1542/peds.2010-0079. Epub 2010 Jun 21.
- Motl  
Brody: <http://www.npr.org/templates/story/story.php?storyId=96998483&sc=nl&cc=h-h-20081117>
- Desai et al. Latino caregiver coping with children's chronic health conditions: an integrative literature review. *J Pediatr Health Care*. 2016 Mar-Apr;30(2):108-20. doi: 10.1016/j.pedhc.2015.06.001. Epub 2015 Jul 15.

Other suggested reading:

- Puchalski CM et al. Physicians and patients' spirituality. *Virtual Mentor*. 2009 Oct 1;11(10):804-15. doi: 10.1001/virtualmentor.2009.11.10.oped1-0910.
- Bruzzone P. Religious aspects of organ transplantation. *Transplant Proc*. 2008 May;40(4):1064-7. doi: 10.1016/j.transproceed.2008.03.049.
- Culley L. Transcending transculturalism? Race, ethnicity and health-care. *Nurs Inq*. 2006 Jun;13(2):144-53.
- Sulmasy DP. Distinguishing denial from authentic faith in miracles: a clinical-pastoral approach. *South Med J*. 2007 Dec;100(12):1268-72.
- Wiener L et al. Cultural and religious considerations in pediatric palliative care. *Palliat Support Care*. 2013 Feb;11(1):47-67. doi: 10.1017/S1478951511001027. Epub 2012 May 22.

**Fall Break → Nov. 2 – 8**

**Week #8 → Justice and Allocation (Nov. 9 – 15) - Jeremy Garrett, Jill Beck, Charlotte Jacobsen, Julie Cakici, Laura Murkin**

- Nichols LM. Government intervention in health care markets is practical, necessary, and morally sound. *Journal of Law, Medicine, and Ethics*. 2012 Fall;40(3):547-57. doi: 10.1111/j.1748-720X.2012.00688.x.
- Taylor JS. Market-based reforms in health care are both practical and morally sound. *Journal of Law, Medicine, and Ethics*. 2012 Fall;40(3):537-46. doi: 10.1111/j.1748-720X.2012.00687.x.
- Eyssalenne, AP. How far do you go? Intensive care in a resource-poor setting. *New England Journal of Medicine*. 2012;367(1):8-9.
- Blinderman C. Palliative care, public health and justice: setting priorities in resource poor countries. *Developing World Bioethics*. 2009;9(3):105-110.
- Boss RD, Henderson CM, Wilfond BS. Decisions regarding resuscitation of extremely premature infants: should social context matter? *JAMA Pediatrics*. 2015;169(6):521-522.
- Beck JC, Smith LD, Gordon BG, Garrett JR. An ethical framework for responding to drug shortages in pediatric oncology. *Pediatr Blood Cancer*. 2015;62:931-934.

Other suggested reading:

- Callahan D. Health care reform: can a communitarian perspective be salvaged? *Theor Med Bioeth.* 2011 Oct;32(5):351-62. doi: 10.1007/s11017-011-9194-9.
- Menzel PT. Justice and fairness: a critical element in U.S. health care reform. *J Law Med Ethics.* 2012 Fall;40(3):582-97. doi: 10.1111/j.1748-720X.2012.00691.x.
- Trotter. No theory of justice can ground health care reform. *J Law Med Ethics.* 2012 Fall;40(3):598-605. doi: 10.1111/j.1748-720X.2012.00692.x.
- Mosely KL & Kershaw DB. African American and white disparities in pediatric kidney transplantation in the United States -- unfortunate or unjust? *Cambridge Quarterly of Healthcare Ethics.* 2012;21;353-365.
- Wightman A, Largent E, Del Beccaro M, Lantos JD. Who Should Get the Last PICU Bed? *Pediatrics.* 2014 Apr 28. [Epub ahead of print]
- Ubel PA. Why it's not time for health care rationing. *Hastings Center Report.* 2015;45(2):15-19.

**Week #9 → Intersection of Ethics, Society and Health Care Policy (Nov. 16 – 22) - Angie Knackstedt, Denise Dowd, Charlotte Jacobsen, Paige Johnson, Hank Puls, Vanessa Watkins, Susie Wootton**

- Burns J, Mitchell C. Resource allocation and triage in disasters and pandemics *Clinical Ethics in Pediatrics A Case Based Textbook.* Cambridge: Cambridge University Press; 2011, pages 199-204. (posted to CourseSites)
- AAP Policy Statement. Community Pediatrics: Navigating the Intersection of Medicine, Public Health, and Social Determinants of Children's Health. DOI: 10.1542/peds.2012-3933 *Pediatrics* 2013;131;623; originally published online February 25, 2013.
- Thornton, RL et al. Evaluating Strategies for reducing health disparities by addressing the social determinants of health. *Health Aff (Millwood).* 2016 Aug 1;35(8):1416-23. doi: 10.1377/hlthaff.2015.1357.
- TedMed Talk. Nadine Burke Harris: How childhood trauma affects health across a lifetime:  
[https://www.ted.com/talks/nadine\\_burke\\_harris\\_how\\_childhood\\_trauma\\_affects\\_health\\_across\\_a\\_lifetime?language=en](https://www.ted.com/talks/nadine_burke_harris_how_childhood_trauma_affects_health_across_a_lifetime?language=en)

Other suggested reading:

- Aasim I. Padela , Huda Adam, Maha Ahmad, Zahra Hosseinian, Farr Curlin. Religious identity and workplace discrimination: A national survey of American Muslim physicians. *AJOB Empirical Bioethics.* (posted to CourseSites)
- Frieden TR. Shattuck Lecture: The Future of Public Health. *N Engl J Med.* 2015 Oct 29;373(18):1748-54. doi: 10.1056/NEJMsa1511248.

**Thanksgiving Break → Nov. 23–29**

## **Weeks 10-15: Critical Care & End of Life**

### **Week #10 → Futility (Nov. 30 – Dec. 6) - Brian Carter, John Lantos, Mo Gessouroun, Jenni Linebarger, Laura Miller-Smith, Dane Sommer, Matt Mayer, Drew Lasky**

- Frader J, Kodish E, Lantos JD. Ethics rounds. Symbolic resuscitation, medical futility, and parental rights. *Pediatrics*. 2010 Oct;126(4):769-72. doi: 10.1542/peds.2010-1379. Epub 2010 Sep 13.
- Fine RL. Point: the Texas Advance Directive. *Chest*. 2009;136(4):963-967. doi:10.1378/chest.09-1267.
- Truog RD. Counterpoint: the Texas Advance Directive Act Is Ethically Flawed. *Chest*. 2009;136(4):968-971. doi:10.1378/chest.09-1269.
- Jox RJ et al. Medical futility at the end of life: the perspectives of intensive care and palliative care clinicians. *J Med Ethics*. 2012 Sep;38(9):540-5. doi: 10.1136/medethics-2011-100479. Epub 2012 May 5.
- Courtwright A. Who is "Too Sick to Benefit"? *Hastings Cent Rep*. 2012 Jul-Aug;42(4):41-7. doi: 10.1002/hast.51.

#### Other suggested reading:

- Schneiderman LJ. Defining Medical Futility and Improving Medical Care. *J Bioeth Inq*. 2011 Jun;8(2):123-131. Epub 2011 Mar 20.
- Lantos JD. Not practicing what we preach. *JAMA Pediatr*. 2013 Oct;167(10):899-900. doi: 10.1001/jamapediatrics.2013.2495.
- White DB, Pope TM. The courts, futility, and the ends of medicine. *JAMA*. 2012 Jan 11;307(2):151-2. doi: 10.1001/jama.2011.1990.
- Mendola, Bock. Faith & Futility in the ICU. *Hastings Center Report*. Jan-Feb 2015.
- Dunphy K. Futilitarianism: Knowing how much is enough in end-of-life health care. *Palliat Med*. 2000 Jul;14(4):313-22.

### **Week #11 → Brain Death, Minimal Consciousness, and Vegetative States (Dec. 7 – 13) - Brian Carter, John Lantos, Mo Gessouroun, Jenni Linebarger, Laura Miller-Smith, Dane Sommer, Matt Mayer**

- Shah SK, Truog RD, Miller FG. Death and legal fictions. *J Med Ethics*. 2011 Dec;37(12):719-22. doi: 10.1136/jme.2011.045385. Epub 2011 Aug 2.
- Gardiner D, Shemie S, Manara A, Opdam H. International perspective on the diagnosis of death. *Br J Anaesth*. 2012 Jan;108 Suppl 1:i14-28. doi: 10.1093/bja/aer397.
- Du Toit J, Miller F. The ethics of continued life-sustaining treatment for those diagnosed as brain-dead. *Bioethics*. 2015 Jul 16. doi: 10.1111/bioe.12178. [Epub ahead of print].

Other suggested reading:

- Verheijde JL et al. Brain death, states of impaired consciousness, and physician-assisted death from end-of-life organ donation and transplantation. *Med Health Care Philos.* 2009 Nov;12(4):409-21. doi: 10.1007/s11019-009-9204-0. Epub 2009 May 13.
- Bernat JL. A defense of the whole brain concept of brain death. *Hastings Cent Rep.* 1998 Mar-Apr;28(2):14-23.
- Bernat JL. The whole-brain concept of death remains optimum public policy. *J Law Med Ethics.* 2006 Spring;34(1):35-43, 3.

**Winter Break → Dec. 14–Jan. 3**

**Second Semester/SPRING  
(Jan. 4 – May 20, 2017)**

**Week #12 → A Personal Matter (Jan. 4 - 10) - Brian Carter, Jeremy Garrett, Angie Knackstedt, John Lantos, Martha Montello, Diane Plantz**

- Kenzaburo Oe, *A Personal Matter*. Chapters 1-13.

**Week #13 → Critical Analysis: Ethics Consultation (Jan. 11 – 17) - Brian Carter, Jeremy Garrett, Angie Knackstedt, John Lantos**

**Week #14 → Palliative Care (Jan. 18 – 24) - Brian Carter, Jenni Linebarger, Erin Thomasma, Laura Murkin**

- Feudtner C et al. Parental hopeful patterns of thinking, emotions, and pediatric palliative care decision making. *Arch Pediatr Adolesc Med.* 2010 Sep;164(9):831-9. doi: 10.1001/archpediatrics.2010.146.
- Rushton CH. Ethics and Palliative Care in Pediatrics. *Am J Nurs.* 2004 Apr;104(4):54-63; quiz 63-4.
- Humikowski CA. Confession. *Arch Pediatr Adolesc Med.* 2012 Jul 1;166(7):593-4. doi: 10.1001/archpediatrics.2012.28.
- Gillis J. "We Want Everything Done". *Arch Dis Child.* 2008 Mar;93(3):192-3. doi: 10.1136/adc.2007.120568.

Other suggested reading:

- Feudtner et al. Pediatric Palliative Care Patients: a Prospective Multicenter Cohort Study. *Pediatrics.* 2011 Jun;127(6):1094-101. doi: 10.1542/peds.2010-3225. Epub 2011 May 9.
- Feudtner. The Breadth of Hopes. *N Engl J Med.* 2009 Dec 10;361(24):2306-7. doi: 10.1056/NEJMp0906516.
- Bluebond-Langer M et al. "I want to live, until I don't want to live anymore": Involving Children with Life-Threatening and Life-Shortening Illnesses in

Decision Making About Care and Treatment. *Nurs Clin North Am*. 2010 Sep;45(3):329-43. doi: 10.1016/j.cnur.2010.03.004.

- Diekema DS, Botkin JR. AAP Committee on Bioethics. Policy statement: Forgoing medically provided nutrition and hydration in children. *Pediatrics*. Vol. 124 No. 2 August 1, 2009 pp. 813 -822 (doi: 10.1542/peds.2009-1299).
- Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations. *Pediatrics*. 2013;132;966; originally published online October 28, 2013; DOI: 10.1542/peds.2013-2731.

### **Week #15 → Pediatric Organ Donations and Transplants (Jan. 25 – 31) -**

***John Lantos, Jessica Brunkhorst, Laura Miller-Smith, Doug Myers, Dane Sommer, Michael Deem***

- AAP Policy Statement: Pediatric Organ Donation and Transplantation. *Pediatrics* 2010;125;822; originally published online March 29, 2010. DOI: 10.1542/peds.2010-0081.
- AAP Clinical Report: Minors as Living Solid-Organ Donors. *Pediatrics* 2008;122;454 DOI: 10.1542/peds.2008-1525.
- Workman JK, Myrick CW, Meyers RL, Bratton SL, Nakagawa TA. Pediatric organ donation and transplantation. *Pediatrics*. 2013 Jun;131(6):e1723-30. doi: 10.1542/peds.2012-3992. Epub 2013 May 20.
- Bernat JL. Life or Death for the Dead-Donor Rule? *N Engl J Med*. 2013 Oct 3;369(14):1289-1291.
- Truog RD, Miller FG, Halpern SD. The Dead-Donor Rule and the Future of Organ Donation. *N Engl J Med*. 2013 Oct 3;369(14):1287-1289.

#### Other suggested reading:

- Ross LF. An ethical and policy analysis of elective transplantation for metabolic conditions diagnosed by newborn screening. *J Pediatr*. 2010 Jan;156(1):139-44. doi: 10.1016/j.jpeds.2009.06.067.
- Hippen BE, Thistlethwaite JR Jr, Ross LF. Risk, prognosis, and unintended consequences in kidney allocation. *N Engl J Med*. 2011 Apr 7;364(14):1285-7. doi: 10.1056/NEJMp1102583. Epub 2011 Mar 16.
- Bendorf A, et al. Intimacy or utility? Organ donation and the choice between palliation and ventilation. *Critical Care*. 2013, 17:316.
- Ziegler A. Donation After Circulatory Death Determination (DCDD): Social Work Code of Ethics Promotes Social Work Involvement. 2013.

## **Weeks 16-19: Special Issues in Pediatrics**

### **Weeks #16 → Adolescent Medicine (Feb. 1 – 7) - Angie Knackstedt, DeeJo Miller, Christine Moser, Beth Sonnevile**

- Cherry MJ. Ignoring the data and endangering children: Why the mature minor standard for medical decision making must be abandoned. *Journal of Medicine and Philosophy.* 2013;38:315-331.
- Piker A. Balancing liberation and protection: A moderate approach to adolescent health care decision-making. *Bioethics.* 2011;25(4):202-208.
- Davies J, Willsher M. Professional boundaries when working with adolescents. *Br J Nurs.* 2012 Sep 27-Oct 10;21(17):S23-4, S27-8, S30.
- Michaud PA et al. Assessing an Adolescent's Capacity for Autonomous Decision-Making in Clinical Care. *J Adolesc Health.* 2015 Oct;57(4):361-6. doi: 10.1016/j.jadohealth.2015.06.012. Epub 2015 Aug 15.
- Ted Talk:  
[http://www.ted.com/talks/sarah\\_jayne\\_blakemore\\_the\\_mysterious\\_workings\\_of\\_the\\_adolescent\\_brain](http://www.ted.com/talks/sarah_jayne_blakemore_the_mysterious_workings_of_the_adolescent_brain).

#### Other suggested reading/resources:

- Steinberg L. Does recent research on adolescent brain development inform the mature minor doctrine. *Journal of Medicine and Philosophy.* 2013;38:256-67.
- Ruhe KM et al. Decision-making capacity of children and adolescents – suggestions for advancing the concept's implementation in pediatric healthcare. *Eur J Pediatr.* 2015 Jun; 174(6):775 -782. doi: 101007/s00431-014-2462-8. Epub 2014 Nov.27.
- Hill BJ. Medical decision making by and on behalf of adolescents: Reconsidering First Principles. *Journal of Health Care Law & Policy*, Vol. 15, 2012; Case Legal Studies Research Paper No. 2012-10.
- Barina R, Bishop JP. Maturing the minor, marginalizing the family: On the social construction of the mature minor. *Journal of Medicine and Philosophy.* 2013;38:300-314.
- Morgan Gleason (pediatric patient perspective):  
<https://www.youtube.com/watch?v=iVt3eHAsdK4>

### **Week #17 → Reproductive and Fetal Medicine (Feb. 8 – 14) - Brian Carter, Jessica Brunkhorst, Meghan Strenk, Michael Deem**

- de Melo-Martin I, Rosenwaks Z. Searching for the perfect child. *Fertil Steril.* 2015 Feb;103(2):342-3. doi: 10.1016/j.fertnstert.2014.12.097.
- Brown SD, Donelan K, Martins Y, et al. Differing attitudes toward fetal care by pediatric and maternal-fetal medicine specialists. *Pediatrics.* 2012 Dec;130(6):e1534-40. doi: 10.1542/peds.2012-1352. Epub 2012 Nov 5.
- Lyerly AD, Mitchell LM, Armstrong EM, Harris LH, Kukla R, Kuppermann M, Little MO. Risk and the pregnant body. *Hastings Cent Rep.* 2009 Nov-Dec;39(6):34-42.
- Jankowski J, Burcher P. Home birth of infants with congenital anomalies: a case study of ethical analysis of careproviders' obligations. *J Clin Ethics.* 2015 Spring;26(1):27-35.

- Cheney M. Of missing voices and the obstetric imaginary: commentary on Jankowski and Burcher. *J Clin Ethics*. 2015 Spring;26(1):36-9.

Other suggested reading:

- Chervenak FA, McCullough LB, Skupski D, Chasen ST: Ethical issues in the management of pregnancies complicated by fetal anomalies. *Obstet Gynecol Surv*. 2003 Jul;58(7):473-83.
- Black BP. Truth telling and severe fetal diagnosis: a virtue ethics perspective. *J Perinat Neonatal Nurs*. 2011 Jan-Mar;25(1):13-20. doi: 10.1097/JPN.0b013e318201edff.
- Tan ML. Fetal discourses and the politics of the womb. *Reprod Health Matters*. 2004 Nov;12(24 Suppl):157-66.
- Hartmann KE, McPheeters ML, Chescheir NC, et al. Evidence to inform decisions about maternal–fetal surgery: technical brief. *Obstet Gynecol*. 2011 May;117(5):1191-204. doi: 10.1097/AOG.0b013e318216151d.
- McMann CL, Carter BS, Lantos JD. Ethical issues in fetal diagnosis and treatment. *Am J Perinatol*. 2014 Aug;31(7):637-44. doi: 10.1055/s-0033-1364190. Epub 2014 Feb 10. Review.
- Rick Lewis, PhD. Healthy Infant Born After ‘Three-Parent’ Mitochondrial Intervention. Sept. 28, 2016. Retrieved from [www.medscape.com](http://www.medscape.com) in October, 2016. (posted to CourseSites)
- Nuffield Bioethics. Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review: <http://nuffieldbioethics.org/project/mitochondrial-dna-disorders/>. June 2012.
- Mitalipov S, Wolf DP. Clinical and ethical implications of mitochondrial gene transfer. *Trends Endocrinol Metab*. 2014 Jan;25(1):5-7. doi: 10.1016/j.tem.2013.09.001.
- Moraes CT et al. Manipulating mitochondrial genomes in the clinic: playing by different rules. *Trends Cell Biol*. 2014 Apr;24(4):209-11. doi: 10.1016/j.tcb.2014.02.002.

**Week #18 → Child Abuse and Neglect (Feb. 15 – 21) - John Lantos, Hank Puls, Erin Thomasma, Amy Terreros, Andrea Vandeven**

- Webb E, Moynihan S. An ethical approach to resolving value conflicts in child protection. *Arch Dis Child*. 2010 Jan;95(1):55-8. doi: 10.1136/adc.2009.158667. Epub 2009 Jun 15.
- Diekema DS. Parental refusals of medical treatment: the harm principle as threshold for state. *Theor Med Bioeth*. 2004;25(4):243-64.
- Bergman AB. Child protective services has outlived its usefulness. *Arch Pediatr Adolesc Med*. 2010 Oct;164(10):978-9. doi: 10.1001/archpediatrics.2010.175.
- Eicher, M. The new child abuse panic. *The New York Times*. July 11, 2015.

Other suggested reading:

- Black MM et al. Failure to thrive as distinct from child neglect. *Pediatrics*. 2006 Apr;117(4):1456-8; author reply 1458-9.
- Ellingson CC, Livingston JS, Fanaroff JM. End-of-life decisions in abusive head trauma. *Pediatrics*. 2012 Mar;129(3):541-7. doi: 10.1542/peds.2011-1988. Epub 2012 Feb 6.
- Protecting our Infants Fact Sheet, March of Dimes. 2015. (posted to CourseSites)
- Calhoun, Ada. The Criminalization of Bad Mothers. *New York Times*. April 25, 2012.
- Roberts SC, Nuru-Jeter A. Universal alcohol/drug screening in prenatal care: a strategy for reducing racial disparities? Questioning the assumptions. *Matern Child Health J*. 2011 Nov;15(8):1127-34. doi: 10.1007/s10995-010-0720-6.

**Week #19 → Complex Pediatric Care (Feb. 22 – 28) - Brian Carter, Angie Knackstedt, Amber Hoffman, Ingrid Larson, Jenni Linebarger, DeeJo Miller, Hank Puls**

- Elias ER, Murphy NA; Council on Children with Disabilities. Home care of children and youth with complex health care needs and technology. *Pediatrics*. 2012 May;129(5):996-1005. doi: 10.1542/peds.2012-0606. Epub 2012 Apr 30.
- Wilfond BS. Tracheostomies and assisted ventilation in children with profound disabilities: navigating family professional values. *Pediatrics*. 2014 Feb;133 Suppl 1:S44-9. doi: 10.1542/peds.2013-3608H.
- Heaton J et al. Families' experiences of caring for technology-dependent children: a temporal perspective. *Health Soc Care Community*. 2005 Sep;13(5):441-50.
- Gillis J, Tobin B. How certain are you, doctor. *Pediatr Crit Care Med*. 2011. Jan;12(1):71-2. doi: 10.1097/PCC.0b013e3181e2a4cd.
- Thomson J et al. Financial and Social Hardships in Families of Children with Medical Complexity. *J Pediatr*. 2016 May;172:187-193.e1. doi: 10.1016/j.jpeds.2016.01.049. Epub 2016 Feb 17.

Other suggested reading:

- Reeves E, Timmons S, Dampier S. Parents experiences of negotiating care for their technology-dependent child. *J Child Health Care*. 2006 Sep;10(3):228-39.
- Mack JW, Joffe S. Communicating about prognosis: ethical responsibilities of pediatricians and parents. *Pediatrics*. 2014 Feb;133 Suppl 1:S24-30. doi: 10.1542/peds.2013-3608E.
- Hofmann B. Is there a technological imperative in health care? *Int J Technol Assess Health Care*. 2002 Summer;18(3):675-89.
- McCann D, Bull R, Winzenberg T. The Daily patterns of time use for parents of children with complex needs: A systematic review. *J Child Health Care*. 2012 Mar;16(1):26-52. doi: 10.1177/1367493511420186. Epub 2012 Feb 3.

## **Weeks 20-22 Research Ethics**

### **Week #20 → Research Ethics (Mar. 1 – 7) - Jeremy Garrett, DeeJo Miller, Ryan McDowell, Dane Sommer**

- Williams G. Children as means and ends in large-scale medical research. *Bioethics*. 2012 Oct;26(8):422-30. doi: 10.1111/j.1467-8519.2010.01873.x. Epub 2011 Feb 14.
- Binik A. On the minimal risk threshold in children. *AJOB*. 2014 Sep;14(9):3-12.
- Ross LF. Children in medical research. Chapter 6, Phase I Research and the Meaning of 'Prospect of Direct Benefit'. (posted to CourseSites)
- NPR Audio. Medical Studies Involving Children Often Go Unpublished. <http://www.npr.org/sections/health-shots/2016/08/04/488708038/medical-studies-involving-children-often-go-unpublished>.

#### Other suggested reading:

- Greenhalgh T et al. Research impact: a narrative review. *BMC Med*. 2016 May 23;14:78. doi: 10.1186/s12916-016-0620-8.
- Ioannidis JPA (2016). Why Most Clinical Research Is Not Useful. *PLoS Med* 13(6): e1002049. doi:10.1371/journal.pmed.1002049
- Pica N, Bourgeois F. Discontinuation and Nonpublication of Randomized Clinical Trials Conducted in Children. *Pediatrics*. 2016 Sep;138(3). pii: e20160223. doi: 10.1542/peds.2016-0223. Epub 2016 Aug 4.
- Chwang E. Against harmful research on non-agreeing children. *Bioethics*. 2014. 1-9. doi:10.1111/bioe.12117.
- Shaddy RE. Ethics and clinical trials in congenital heart disease. *World J Pediatr Congenit Heart Surg*. 2013 Jan 1;4(1):50-2. doi: 10.1177/2150135112454551.
- Gutmann A. Safeguarding Children—Pediatric Research on Medical Countermeasures. *N Engl J Med*. 2013 Mar 28;368(13):1171-3. doi: 10.1056/NEJMp1302093. Epub 2013 Mar 19.

### **Week #21 → Pediatric Genetics and Personalized Medicine: Research and Clinical Care (Mar. 8 – 14) - Jeremy Garrett, Julie Cakici, Meghan Strenk, Michael Deem**

- Andermann A. et al. Revisiting Wilson and Jungner in the genomic age: a review of screening criteria over the past 40 years. *Bull World Health Organ*. 2008 April;86(4):317-319.
- Bailey D, Gehtland L. Newborn Screening: Evolving Challenges in an Era of Rapid Discovery. *JAMA*. 2015;313(5):1511-1512.
- Kemper AR et al. Weighing the evidence for newborn screening for early-infantile Krabbe disease. *Genetics in Medicine*. 2010;12(9):539-542.
- Hewlett J, Waisbren SE. A review of the psychosocial effects of false-positive results on parents and current communication practices in newborn screening. *J Inherit Metab Dis*. 2006;29:677–682.
- AAP. Ethical and policy issues with genetic testing and screening of children. *Pediatrics*. 2013.
- Ulm E et al. Genetic professionals' opinions of whole-genome sequencing in the newborn period. *Journal of Genetic Counseling*. 2015;24(3):452-463.

**Spring Break → Mar. 15 – 21**

**Final Project Practice Presentations (Mar. 13 – 28) Each student will present their draft paper/presentation for feedback with faculty advisor(s)**

**Week #22 → Critical Analysis: Research (Mar. 29 – Apr. 4) - Brian Carter, Jeremy Garrett, Angie Knackstedt, John Lantos**

**Weeks 23-26: More Special Issues in Pediatrics**

**Week #23 → Immunizations (Apr. 5 – 11) - Angie Knackstedt, Vanessa Watkins, Susie Wootton, Paige Johnson, Laura Murkin**

- Lantos JD et al. Controversies in vaccine mandates. *Curr Probl Pediatr Adolesc Health Care*. 2010 Mar;40(3):38-58. doi: 10.1016/j.cppeds.2010.01.003.
- Frader J, Flanagan-Klygis E. Ethics and Immunizations. In: Miller (ed.), *Pediatric Bioethics* (pp. 219-230). (posted to CourseSites)
- Ethical quandary about vaccinations sparked by tension between parental rights and protecting public health. NYU Langone Medical Center / New York University School of Medicine.

**Other suggested reading/resources:**

- Livingston R. Justification of a Mandatory Influenza Vaccination. Abstract. 2013. (posted to CourseSites)
- Lantos JD, Jackson MA, Harrison CJ. Why we should eliminate personal belief exemptions to vaccine mandates. *J Health Polit Policy Law*. 2012 Feb;37(1):131-40. doi: 10.1215/03616878-1496038. Epub 2011 Oct 14.
- Mello MM, Studdert DM, Parmet WE. Shifting Vaccination Politics - The End of Personal-Belief Exemptions in California. *N Engl J Med*. 2015 Jul 22. [Epub ahead of print]
- Schwartz JL, Caplan AL. Vaccine refusal: ethics, individual rights and the common good. *Prim Care*. 2011 Dec;38(4):717-28, ix. doi: 10.1016/j.pop.2011.07.009. Epub 2011 Sep 17.
- Opel D, Diekema, D. “Youth Boxing, Parental Refusal of Vaccination and Standing on Principle”, Seattle Children’s Pediatric Bioethics Conference July 27-28, 2012, accessed from <http://www.seattlechildrens.org/pdf/douglas-diekema-presentation.pdf> and YouTube (<https://www.youtube.com/watch?v=bK5E927wF1Q>).
- Healy, C. M. and Pickering, L. K. How to Communicate With Vaccine-Hesitant Parents. *Pediatrics* 2011; 127:Supplement 1 S127-S133; published ahead of print April 18, 2011, doi:10.1542/peds.2010-1722S.
- Mueller, B. Judge Upholds Policy Barring Unvaccinated Students During Illnesses. *The New York Times*. June 22, 2014.
- Dubov A, Phung C. Nudges or mandates? The ethics of mandatory flu vaccination. *Vaccine*. 2015 May 21;33(22):2530-5. doi: 10.1016/j.vaccine.2015.03.048. Epub 2015 Apr 11.

- Texas Children's Hospital Vaccine Videos: <http://www.texaschildrens.org/vaccine/>
- Invisible Threat (film): <http://www.chstvfilms.org/> - click to watch the trailer (produced by U.S. high school students)

**Week #24 → Social Media (Apr. 12 – 18) - Angie Knackstedt, Jill Beck, Charlotte Jacobsen, Jenni Linebarger, DeeJo Miller, Donna McKlindon, Meghan Strenk, Vanessa Watkins, Matt Mayer**

- McKlindon D et al. Ethics Rounds: In the Eye of a Social Media Storm. *Pediatrics*. 2016;138(3). pii: e20161398. doi: 10.1542/peds.2016-1398. Epub 2016 Aug 5.
- Swartz MK. Professional Conduct and Social Media. *J Pediatr Health Care*. 2016 May-Jun;30(3):185-6. doi: 10.1016/j.pedhc.2016.03.002.
- Parsi K, Elster N. Why Can't We Be Friends? A Case-Based Analysis of Ethical Issues with Social Media in Health Care. *AMA J Ethics*. 2015 Nov 1;17(11):1009-18. doi: 10.1001/journalofethics.2015.17.11.peer1-1511.
- Brown J et al. How doctors view and use social media: a national survey. *J Med Internet Res*. 2014 Dec 2;16(12):e267. doi: 10.2196/jmir.3589.
- Kostick KM et al. Content Analysis of Social Media Related to Left Ventricular Assist Devices. *Circ Cardiovasc Qual Outcomes*. 2015 Sep;8(5):517-23. doi: 10.1161/CIRCOUTCOMES.115.002032. Epub 2015 Jul 28.

**Week #25 → International Medicine: Clinical and Research Realities (Apr. 19 – 25) - John Lantos – Siri Berg, Stefan Kutzsche, Jihad Zahraa, Susie Wootton**

- Berkowitz AL. A Piece of My Mind: All for One. *JAMA*. 2015 Oct 6;314(13):1341-2. doi: 10.1001/jama.2015.4888.
- Farmer, P. From "Marvelous Momentum" to Health Care for All. *Foreign Affairs*. Mar/Apr 2007, Vol 86 Issue 2. P 155-159. 5 p. (posted to CourseSites)
- Bradley S et al. Too few staff, too many patients: a qualitative study of the impact on obstetric care providers and on quality of care in Malawi. *BMC Pregnancy Childbirth*. 2015 Mar 21;15:65. doi: 10.1186/s12884-015-0492-5.

Other suggested reading:

- Blinderman C. Palliative care, public health and justice: setting priorities in resource poor countries. *Dev World Bioeth*. 2009 Dec;9(3):105-10. doi: 10.1111/j.1471-8847.2009.00264.x. Epub 2009 Oct 7.
- Carnevale FA, Manjavidze I. Examining the complementarity of 'children's rights' and 'bioethics' moral frameworks in pediatric health care. *J Child Health Care*. 2015 Dec 10. pii: 1367493515605173. [Epub ahead of print]
- Almazeedi, H. Pulse Voices, Friday, April 8, 2016: What Money Can Buy: <http://pulsevoices.org/index.php/archive/stories/710-what-money-can-buy>.

**Weeks #26→ *The Spirit Catches You and You Fall Down* (Apr. 26 – May 9) - Brian Carter, Jeremy Garrett, Angie Knackstedt, John Lantos, Martha Montello, Denise Dowd, Laura Miller-Smith, Andrea Vandeven, Briana Woods-Jaeger**  
***(note: this is a longer discussion week)***

- Anne Fadimon, *The Spirit Catches You and You Fall Down*, Chapters 1-19
- Miller-Smith L, Plantz DM. A good night. *Hastings Cent Rep*. 2014 Mar-Apr;44(2):6-7. doi: 10.1002/hast.277.
- Culley L. Transcending transculturalism? Race, ethnicity and health-care. *Nurs Inq*. 2006 Jun;13(2):144-53.
- Xiong S et al. Engaging in Culturally Informed Nursing Care with Hmong Children and Their Families. *J Pediatr Nurs*. 2016 Jan-Feb;31(1):102-6. doi: 10.1016/j.pedn.2015.08.008. Epub 2015 Sep 26.

**Closing Session May 18 - 20, 2017**