OLLI Course Syllabus Winter 2016 Term Biomedical Ethics (subject to change)

<u>NB</u>: This field has a rich and fascinating range of interdisciplinary material. If the readings are too long for you, do what you can. I thought some of you might want a wider array of citations for some or all topics. I've also pulled excerpts from many sources. Enjoy!

<u>Important General Instructions</u>: You need <u>never</u> read footnotes – cases or articles. They are often present, so you can read if you want to. Do not read "Headnotes" in case opinions (numbered sections at beginning of opinion). Don't worry about citations of administrative/procedural matters within the text. <u>Just read for substance</u>.

I. Division of Authority between Health Professionals and Patients/Families; Mistakes

Informed Consent & Exceptions: Theory and Actual Use Difficult cases: Refusal (Truman), Alternatives, COI (Kokemoor) Malpractice & Medical Mistakes (Reporting, Apology Laws) Parental Decisions (HCA v. Miller).

Readings: Remember, you may skip footnotes or citations in the text here and in all readings.

Cobbs v. Grant, 502 P.2d 1 (1973) (Focus on Part III) Avedon v. Arato, 858 P. 2d 598 (1993).

In the matter of Baby K, 16 F.3d 590 (1994).

Katherine Shaw & Alex Stein, Abortion, Informed Consent, and Regulatory Spillover, forthcoming in 91 *Indiana Law Journal* (2016), pp. 1-20.

Institute of Medicine, *To Err is Human* (1999), Executive Summary pp. 1-4 D. Hilfiker, "Facing Our Mistakes," *New England Journal of Medicine* 1984

Recommended Reading:

Troyen A. Brennan, M.P.H., M.D., J.D., Lucian L. Leape M.D., et *al*, Incidence of Adverse Events and Negligence in Hospitalized Patients: Results of the Harvard Medical Practice Study I, 370 New England Journal of Medicine 2/7/1991.

II. Decisions at the Margins of Life and Death: Definitions

A. Definitions of Death

Cardio Pulmonary v Brain Death Definitions & Terminology; Higher brain death v whole brain death; Critiques of brain death definition; Pressure from transplant potential: "Dead Donor Rule" changing?; Pregnant brain dead women.

B. Parallel to debates over abortion and contraception "Personhood" v. "Alive"; Clashes recently mostly on state level. Status of anenchephalic babies (T.A.C.P.); Different stance for abortion & non-treatment of neonate.

Readings:

- T.M Pope, "Brain Death and Total Brain Failure, 25 *J. of Clinical Ethics* 245 (2014)
- C. Jarrett, "What Is Brain Death?" *Wired*: Brain Watch Feb 10, 2014.
- J. Groopman, "Silent Minds," New Yorker, Oct 15, 2007.
- A. Billings et al, Severe Brain Injury and the Subjective Life, Hastings Center Rep't (May-June 2010) 17.
- J. Fins, Rethinking Disorders of Consciousness, *Hastings Center Rep't* (March-April 2005) 22.
- J. Fletcher, Humanhood: Essays in Bioethics, Excerpt from Chap. 1 (1979).

Recommended Readings:

P. Singer and H. Johnson, "Unspeakable Conversations," *NYT*, 2003. Check out the website for Not Dead Yet <www.notdeadyet.org>. *Gary Greenberg, As Good as Dead" *The New Yorker*, Aug 13, 2001. N.J. Declaration of Death Act §26:6A-5. In re T.A.C.P., 609 So.2d 588 (1992).

III. End of Life Care

Capacity to decide; Expansion of right to refuse treatment, but not to Demand; Physician Assisted Suicide (PAS); Hospice and palliative care; Advance Directives: (Living Will, Health Care PoA, POLST etc.); Difference between before and after - courts unwilling to overturn and/or punish docs after they have acted.(e.g., Wanglie).

Readings:

- Patrick McGreevy, After Struggling, Jerry Brown Makes Assisted Suicide Legal in California, *LA Times*, Oct 5, 2015.
- In Re Bouvia, 179 Cal.App.3d 1127 (1986).
- Copies of various Health Care Directives (POLST, CA Form for Power of Attorney for Health Care, Five Wishes, Values Form, etc.). [Flip through these per your interest].
- P. Ditto & J. Danks *et al*, "Advance Directives as Acts of Communication," (*Read only* through to Outcome Section, depending on your Interest, go further). *Arch Intern Med.* 2001;161(3):421-430.
- R.K. Sharma *et al*, "Family Understanding of Seriously III Patient Preferences for Family Involvement in Health Care Decisions," *J Gen Intern Med.* 2011 August; 26(8): 881–886 (*Read only* through the Introduction, depending on your interest).
- T.M. Pope, "Abstract: Clinicians May Not Administer Life-Sustaining Treatment Without Consent," 9 *J. of Health & Biomedical Law* 213 (2013).
- D. White and T Pope, "Viewpoint: The Courts, Futility and the Ends of Medicine" *JAMA* Jan 11, 2012.
- P. Span, "Complexities of Choosing an End Game for Dementia," NYT (1/19/2015)

Recommended Readings:

Physician Assisted Suicide WA statute §70.245.020 et seq (2008).

Lois Shepherd, "The End of End-of-Life Care," 92 North Carolina Law
Review 1693, pp. 1694-1710 plus Proposed "8 Principles" (2014)

ABA Commission on Aging, "Myths and Facts about Advanced Health
Care Directives."

IV. Body as Property?

Is (and should) sale of Body Parts/Tissues Be Allowed? Why/not? Moral, legal, equitable, economic issues? How should such transactions be characterized? Property? Contract? Division of value as between researcher and source: What regulation or restriction should be imposed? Moore v. Regents of U.C.: Iceland data bank agreement; Bio-Trust?

Readings:

Moore v. Regents of U.C., 51 Cal. 3d. 120 (1990). (Read Wikipedia

Summary).

- M. Radin, Market Inalienability,100 *Harvard Law Review* 1849, (1987). Read pp. 1849-63, 1877-85.
- M. Shultz, Book Review of Radin's <u>Contested Commodities</u> 85 *Cal.L.Rev.* 1841, 1855-60. (1997)
- M. Finkel, "Complications," NYT, May 27, 2001
- M. Friedlaender, "Viewpoint," The Lancet 971-973 (2001).
- M. Katches, W. Heisel, & Ronald Campbell, "The Body Brokers, Part I-Assembly Line," *The Orange County Register*, April 16, 2000.
- O. Hlodan, "For Sale: Iceland's Genetic History," http://www.actionbioscience.org/genomic/hlodan.html (visited 1/27/2011)
- D. Winickoff & Larissa B.Neuman, "Towards a Social Contract for Genomics": 1 Genomics, Society and Policy, Read pp.8–11(2005).
 Greenberg v. Matalon, 264 F. Supp 2d. 1064 (2003).

Recommended Reading:

Diamond v. Chakrabarty 447 U.S. 303 (1980).

Moore v. Regents of U.C., 271 Cal. Rptr 146 (1990).

Del Zio v. Columbia Presbyterian Medical Center, 74 Civ. 3588 (U.S. Dist. Ct., S.D.N.Y.) Ap. 12,1978

R. Skloot, The Immortal Life of Henrietta Lacks (2010).

V. Assisted Reproduction (ART)

Methods (AI, AID, IVF, surrogacy, ICSI, PGD, gamete & embryo donation and transfer, uterine transplant, ectogenesis); effects of ARTs on parenthood and family structure; problems of decisional authority; Brain dead pregnant women.

Readings:

- Excerpts from "Practices and Controversies Surrounding Assisted Reproductive Techology (ART), www.wikigender.org (visited Nov 10, 2015).
- M. Shultz, "Reproductive Technology and Intent-Based Parenthood," 1990 *Wisconsin L.Rev.* 297. Read pp. 298-316, 372-95.
- M. Goodwin, "Assisted Reproductive Technology and the Double Bind: The Illusory Choice of Motherhood," 9 J. of Gender, Race and Justice, 1, 15-31 (2005).

Johnson v. Calvert, 5 Cal.4th 84 (1993). Read majority opinion pp. 84-101. Uniform Parentage Act (2002) Introductory Comments to Articles 7 & 8.

Recommended Readings:

Johnson v. Calvert, 5 Cal.4th 84 (1993). Read J. Kennard Dissent. *In Re* AC, *573 A.2d 1235* (D.C. Court of Appeals,1990). Robert B. v. Susan B., 135 Cal. Rptr. 2d 785 (2003).

VI. Issues in Medical and Pharmaceutical Research

Regulation of Research on Human Subjects; Consent; Conflicts of Interest DCA Ads; Compassionate Use (Abigail Alliance); Cost v Value of Drugs. Pricing.

Readings:

- M. Gladwell, "High Prices" New Yorker, Oct 25, 2004.
- C. Elliott, "The Drug Pushers," The Atlantic Monthly, April 1, 2006.
- A .Pollack, "Harvoni, a Hepatitis C Drug from Gilead, Wins F.D.A. Approval," *NYT*, Oct 10, 2014.
- A.Harmon, "Indian Tribe Wins Fight to Limit Research of Its DNA," *NYT*, April 21, 2010.
- A. Mastroianni & J. Kahn, "Risk and Responsibility: Ethics, Grimes v. Kennedy Krieger, and Public Health Research Involving Children," *Am J. of Public Health*. 2002 July; 92(7): 1073–1076. PMCID: PMC1447191.
- L. F. Ross, "In Defense of the Hopkins Lead-Abatement Studies," 30 *J. Law, Med. & Ethics* 50 (2002).
- A Pollack, "Court Rejects Right to Use Drugs Being Tested," *NYT* Aug 8, 2007 and L. Greenhouse, "Supreme Court Won't Hear Appeal on Drugs," *NYT*, Jan 15, 2008.
- Patricia Zettler, "Compassionate Use of Experimental Therapies: Who Should Decide?" *EMBO Molecular Medicine* Aug. 2015, p. 1-2

Recommended Readings:

- D. McNeil Jr., "Panel Hears Grim Details of Venereal Disease Tests," *NYT*, August 30, 2011.
- J. Kleinke, "Access v. Excess: Value-Based Cost Sharing for Prescription Drugs," 23 *Health Affairs 34*, Jan/Feb 2004.