#### Rationale

This course is intended for students with an underlying interest in the biotechnology industry and medicine. The aim of the course Bioethics II is to focus on the ethical questions concerning the beginning and end of human life and genetic diagnosis, meaning genetic screening of and genetic interventions in humans arising from the new possibilities produced by the life sciences and the biotechnological industry. The students will gain the skills needed to understand the fundamental challenge: we can do right or wrong by using new technologies, but we can also do right or wrong by not using them. They will learn a method of ethical evaluation regarding options in decisions at the beginning of life, i. e. stem cell research, reproductive technology, cloning, pre-implantation and prenatal genetic diagnosis, abortion; decisions at the end of life, i. e. euthanasia and issues in organ transplantation; and decisions concerning genetic diagnosis, and genetic screening of and interventions in humans.

This class prepares potentially high-ranking administrators to become ethically skilled managers and leaders who take into consideration not only their business or their country, but also the future of mankind. Participants will gain a better understanding of the global challenges facing companies that produce biotechnology and physicians today and an enlightened perspective of their leadership roles in influencing the future of our world.

## Program Objectives

Bioethics II offers the state-of-the-art of ethical knowledge concerning the life sciences. It improves the capacity of individuals to act responsibly in light of the new challenges in biotechnology and medicine. As a consequence, managers and leaders who act responsibly will earn, at least in the long run, the support of society. Thereby, ethical knowledge combined with responsible action strengthens the performance of their companies, the biotechnology industry and developments in medicine. The program affords participants the unique opportunity to just learn this in these central areas:

- Acquire a state-of-the-art knowledge of the most important options and ethical positions concerning biotechnological and medical possibilities or future possibilities at the beginning and end of human life.
- Acquire the capacity to evaluate different ethical approaches and positions.
- Identify ethical challenges in the life sciences, biotechnological industries and the field of medicine.
- Learn to implement ethical standards in their own field.
- · Learn to internalise the importance of responsibility.

Thereby, the class in bioethics offers many advantages:

- A curriculum that allows students to take a wide array of courses.
- A hands-on, team-based approach to learning that applies theory to real-world challenges.
- A shared student experience with peers in the program, including extracurricular and leadership opportunities.
- Access to world-class experts and facilities in bioethics.
- Together with courses in Management of Biotechnology and Law of Biotechnology, outstanding career opportunities in a wide range of functions and industries, including general management, operations and production, finance, product development, business development, marketing and strategic planning.

#### Curriculum

The program incorporates case studies, lectures and panel sessions to explore today's defining issues; and to engage participants in interactive discussions and exercises with the program faculty, guest speakers and peers. The intensive curriculum examines critical areas that have serious implications for political decision-making, thus, influencing the course of the life sciences and respective companies or clinics.

Key topics in Bioethics II include:

- Stem cell research (including therapeutic cloning)
- Reproductive technology (including reproductive cloning)
- Pre-implantation genetic diagnosis
- · Prenatal genetic diagnosis
- Abortion
- Euthanasia
- Issues in organ transplantation
- Genetic diagnosis in born humans (including genetic screening)
- · Genetic interventions in humans

## **Course Schedule**

Week 1: Different ethical approaches and the question: Who is a human being

- 1 Different Ethical Approaches
  - a principle-based approach
  - an absolute rule approach
  - · a theocentric approach

- a kantian approach
- a utilitarian approach
- a contractarian approach
- · a virtue ethics approach
- · a care approach
- a case approach

Kuhse, H./Singer, P. (ed.) 2001: A Companion to Bioethics. Blackwell: Oxford, 61-114.

Sterba, J: P. (ed.)1998: Ethics: The Big Questions. Blackwell: Oxford.

List of further readings

Beauchamp, T. L. /Childress, J. F. 2001: Principles of Biomedical Ethics. 5<sup>th</sup> ed., Oxford University Press: Oxford.

Beyleveld, D./Brownsword, R. 2001: Human Dignity in Bioethics and Biolaw. Oxford University Press: Oxford.

Engelhardt, H. T. 1996: The Foundations of Bioethics. 2<sup>nd</sup> ed., Oxford University Press: Oxford.

Gewirth, A. 1978: Reason and Morality. Chicago University Press: Chicago.

Kant, I. 1785: Grundlegung der Metaphysik der Sitten/Groundwork of the Metaphysics of Morals (various editions).

O'Neill, O. 2000: Bounds of Justice. Cambridge University Press: Cambridge.

- 2 Biological data at the beginning of human life
  - the process of fertilization
  - the process of differentiation
  - the process of implantation
  - the process of organogenesis
  - the process up to birth

#### Readings:

a book on embryology (there a various introductions into embryology)

- 3 Discussion of the arguments of five different positions
  - position 1: a human being (morally spoken) begins with fertilization
  - position 2: a human being (morally spoken) begins with implantation
  - position 3: a human being (morally spoken) begins at some later stage before birth

- position 4: a human being (morally spoken) begins with birth
- position 5: a human being (morally spoken) begins at some later stage after birth

- Kuhse, H./Singer P. (eds) 1999: Bioethics. An Anthology. Part I: Before Birth, Blackwell: Oxford, 9-81.
- Knoepffler, N. 2004: Stem Cell Research: An Ethical Evaluation of Policy Options, in: Kennedy Institute of Ethics Journal 14/1, 55-74.
- Warren, M. A. 2005: Moral Status. In: Frey, R. G./Wellmann, C. H. (eds): A Companion to Applied Ethics. Blackwell: Oxford, 439-450.

List of further readings

Board of Social Responsibility (ed.) 1996: Personal Origins, 2. Aufl., London.

Hare, R. M. 1990: Essays on Bioethics. Clarendon: Oxford.

- Harris, J. 1990: Embryos and hedgehogs: on the moral status of the embryo, in: Dyson/Harris (ed.): Experiments on Embryos, London, 65-81.
- Heaney, S. J. 1992: Aquinas and the Presence of the Human Rational Soul in the Early Embryo, in: The Thomist 56, 19-48.
- Pasnau, R. 2002: Thomas Aquinas on Human Nature: A Philosophical Study of Summa Theologiae 1a, 75-89, Cambridge (Cambridge University Press).
- Warren, M. A. 1997: Moral Status. Obligations to Persons and Other Living Things. Oxford University Press. Oxford.
- Williams, B. 1995a: A philosopher's point of view, in: Nature 376, 10.
- 1995b: Which slopes are slippery?, in: ders. 1995c, Making sense of humanity and other philosophical papers. 1982-1993, Cambridge (Cambridge University Press), 213-223.
- 4 Biological data at the end of human life
  - the dying process of consciousness
  - the dying process of the whole brain
  - the dying process of the whole organism

## Readings:

a medical book on the terminal phase (there a various introductions into the topic)

- 5 Discussion of the arguments of three positions
  - position 1: a human being is dead after the death of the whole organism

- position 2: a human being is dead after the death of the whole brain
- position 3: a human being is dead after the death of parts of the brain who are essential for consciousness

- McMahan, J. 2001: Brain death, cortical death and persistent vegetative state. In: Kuhse, H./Singer, P. (eds) 2001: A Companion to Bioethics. Blackwell: Oxford, 250-260.
- Kuhse, H./Singer, P. (eds) 1999: Bioethics. An Anthology: Brain death. Blackwell: Oxford, 287-301.

## List of further readings

- Bernat, J. L. u. a. 1981: On the definition and criterion of death. In: Annals International Medicine 94, 389-394.
- Mollaret, P./Goulon, M. 1959: Le coma dépassé (Mémoire préliminaire). In: Revue Neurologique 101, 3-15.
- Shann, F. 1991: The Cortically Dead Infant Who Breathes. In: Sanders, K./Moore, B. (Hg.) 1991: Anencephalics, Infants and Brain Death Treatment Options and the Issue of Organ Donation, Melbourne (Law Reform Commission).
- Veatch, R. M. 1988: Whole-brain, neocortical, and higher brain related concepts. In R. M. Zaner (ed.): Death: Beyond whole-brain criteria. Kluwer: Dordrecht, 171-186.

## Week 2 Beginning of Life Decisions I

- 6 Stem cell research: different options and the ethical reasoning behind
  - option 1: no stem cell research at all
  - option 2: stem cell research only with stem cells harvested from existing stem cell lines
  - option 3: research with stem cells harvested from surplus embryos
  - option 4: research with stem cells harvested from embryos produced through fusion of egg and sperm in vitro for the purpose of research
  - option 5: research with stem cells harvested from embryos produced by SCNT
  - option 6: research with stem cells harvested from embryos produced through fusion of egg and sperm in vitro or produced by SCNT and then genetically modified
  - option 7: research with stem cells harvested from embryos produced by SCNT into nonhuman oocytes
  - option 8: research with stem cells harvested from embryos produced by SCNT into oocytes created from stem cells and then enucleated

- Knoepffler, N. 2004: Stem Cell Research: An Ethical Evaluation of Policy Options. In: Kennedy Institute of Ethics Journal 14/1, 55-74.
- Walters, L. 2004: Human Embryonic Stem Cell Research: An Intercultural Perspective. In: Kennedy Institute of Ethics Journal 14/1, 3-38.

## List of further readings:

- EGE European Group on Ethics in Science and New Technologies to the European Commission 2000: Ethical Aspects of Human Stem Cell Research and Use. No. 15, 14.11.2000.
- Hübner, K. u. a. 2003: Derivation of Oocytes from Mouse Embryonic Stem Cells. Science, Vol. 300, Issue 5623, 1251-1256, May 23.
- Kennedy Institute of Ethics Journal 14/1 2004: Special Issue: Human Embryonic Stem Cell Research: International and U.S. Public Policy. John Hopkins University Press: Baltimore (here more further readings up to 2004).
- Steinhoff, G. et al., Stem Cells in Tissue Regeneration, Pabst: Lengerich.
- Ying, Q. L. u. a. 2002: Changing potency by spontaneous cell fusion, in: Nature 416, 545-548.
- 7 Reproductive technology: options and the ethical reasoning behind them
  - option 1: homologue insemination
  - option 2: heterologue insemination
  - option 3: surrogate mothering
  - option 4: reproductive cloning

#### Introductory readings:

- Arras, J. D. 2005: Reproductive Technology. In: Frey, R. G./Wellmann, C. H. (eds): A Companion to Applied Ethics. Blackwell: Oxford, 342-355.
- Harris, J. 2005: Cloning. In: Frey, R. G./Wellmann, C. H. (eds): A Companion to Applied Ethics. Blackwell: Oxford, 382-395.
- Kuhse, H./Singer, P. (eds) 1999: Bioethics. An Anthology. Part II: Issues in Reproduction. Assisted Reproduction. Blackwell: Oxford, 83-119.

#### List of further readings:

Different Reports from various political and religious bodies (since 1997), e. g. National Bioethics Advisory Commission 1997: Cloning Human Beings: Report and Recommendations. Rockville.

- Purdy, L. 2001: Assisted Reproduction. In: Kuhse, H./Singer, P. (eds). A Companion to Bioethics. Blackwell: Oxford, 163-172.
- Tong, R. 2005: Surrogate Mothering. In: Frey, R. G./Wellmann, C. H. (eds): A Companion to Applied Ethics. Blackwell: Oxford, 369-381.
- Wilmut, I. et al. 1997: Viable offspring derived from fetal and adult mammalian cells. In: Nature 385, 810-813.

# Week 3 Beginning of Life Decisions II

- 8 Pre-implantation genetic diagnosis: different purposes, different options, different lines of ethical reasoning
  - different purposes (to get a child without a certain disposition for a disease, to get a child with a certain trait, to get a child which can save his sick brother or sister)
  - different options (similar to criteria for passive euthanasia, similar to the different criteria for prenatal diagnosis)
  - different lines of ethical reasoning (status of the embryo, consequences for the society, comparison with abortion and prenatal diagnosis)

# Introductory readings:

Knoepffler, N. 2004: Menschenwürde in der Bioethik. Springer: Berlin, 110-128.

Peterson, J. C. 2001: Genetic Turning Points. The Ethics of Human Genetic Intervention. Eerdmans: Grand Rapids, 192-199.

## List of further readings:

- Buchanan, A. u. a. 2000: From Chance to Choice: Genetics and Justice, Cambridge University Press: Cambridge.
- 9 Prenatal genetic diagnosis: different purposes, different options, different lines of ethical reasoning
  - different purposes (to get a child without a certain disposition for a disease, to get a child with a certain trait, to get a child which can save his sick brother or sister)
  - different options (diseases which will lead to immediate death after birth, serious diseases, serious dispositions for diseases, other reasons, sex-selection)
  - different lines of ethical reasoning (status of the embryo, consequences for the society, comparison with abortion and pre-implantation genetic diagnosis)

# Introductory readings:

Knoepffler, N. 2004: Menschenwürde in der Bioethik. Springer: Berlin, 110-128.

Robinson, P. 2001: Prenatal screening, sex selection and cloning. In: Kuhse, H./Singer, P. (eds): A Companion to Bioethics. Blackwell: Oxford, 173-188.

## List of further readings:

- Buchanan, A. u. a. 2000: From Chance to Choice: Genetics and Justice, Cambridge University Press: Cambridge.
- Kaplan, D. 1999: Prenatal Screening and its Impact on Persons with Disabilities. In: Kuhse, H./Singer, P. (eds): Bioethics. An Anthology. Blackwell: Oxford, 130-136.
- 10 Abortion: ethical evaluation of different reasons
  - fundamental observations
  - abortion because of the risk to the mother's life
  - abortion because of rape
  - · abortion because of other reasons regarding woman involved
  - abortion because of reasons named by society

## Introductory readings:

- Little, M. O. 2005: Abortion. In: Frey, R. G./Wellmann, C. H. (eds): A Companion to Applied Ethics. Blackwell: Oxford, 313-325.
- Dworkin, R. 1994: Life's Dominion. An Argument about Abortion, Euthanasia, and individual Freedom. Vintage: New York, 30-68.

#### List of further readings:

- Harris, J. (ed.) 2001: Bioethics. Part 1: Beginnings of Life. Oxford University Press: Oxford, 25-89.
- John Paul II. 1995: Encyclica "Evangelium Vitae" (various english editions).
- Kuhse, H./Singer, P. (eds) 1999: Bioethics. An Anthology. Part I: Before Birth. Blackwell: Oxford, 9-81.

#### Week 4 End of Life Decisions

- 11 The fundamental difference: action of the physician or will of the patient
  - the physician: passive, indirect, active (and assisted suicide)
  - the patient: voluntary, supposed voluntary, non-voluntary, involuntary
  - fundamental decision I: balancing the value of life and the wish of dying persons

- fundamental decision II: balancing the value of life and the suffering of persons not able to consent
- fundamental decision III: balancing the value of life and the shortage of resources

- Dworkin, R. 1994: Life's Dominion. An Argument about Abortion, Euthanasia, and individual Freedom. Vintage: New York, 179-241.
- Hope, T. 2004: Medical Ethics. A Very Short Introduction, Oxford University Press: Oxford.

#### List of further readings:

- Beauchamp, T. L. /Childress, J. F. 2001: Principles of Biomedical Ethics, 5. Aufl., Oxford University Press: Oxford.
- Harris, J. (ed.) 2001: Bioethics. Part 1: Beginnings of Life. Oxford University Press: Oxford, 25-89.
- Kuhse, H./Singer, P. (eds) 1999: Bioethics. An Anthology. Part IV: Life and Death Issues. Blackwell: Oxford, 189-348.
- Knoepffler, N. 2004: Menschenwürde in der Bioethik. Berlin: Springer, 139-164.
- Tooley, M. 2005: Euthanasia and Assisted Suicide. In: Frey, R. G./Wellmann, C. H. (eds): A Companion to Applied Ethics. Blackwell: Oxford, 326-341.
- 12 Different positions concerning euthanasia a cross-cultural perspective (Leo Castro)
  - · ancient perspectives
  - · Buddhist perspectives
  - Christian perspectives
  - Jewish perspectives
  - Muslim perspectives
  - "humanistic" perspectives
  - · WHO perspectives

## Introductory readings:

Gbadegesin, S. 2001: Bioethics and cultural diversity. In: Kuhse, H./Singer, P. (eds). A Companion to Bioethics. Blackwell: Oxford, 24-31.

#### List of further readings:

- Engelhardt, H. T. 2000: The Foundations of Christian Bioethics. Swets & Zeitlinger: Lisse, 309-336.
- John Paul II. 1995: Encyclica "Evangelium Vitae" (various english editions).

- 13 Ethical issues in organ transplantation
  - organ donation after brain death: obligations and balancing of wishes
  - organ donation and the anencephalus
  - organ donation of healthy persons
  - · organ transplantation: paradigm of the problem of resource allocation in health care?

Rhodes, R. 2001: Organ transplantation. In: Kuhse, H./Singer, P. (eds). A Companion to Bioethics. Blackwell: Oxford, 329-340.

Engelhardt, H. T./Smith Iltis, A. 2005: Allocation of Medical Resources. In: Frey, R. G./Wellmann, C. H. (eds): A Companion to Applied Ethics. Blackwell: Oxford, 396-409.

# List of further readings:

Kuhse, H./Singer, P. (eds) 1999: Bioethics. An Anthology. Part VI: Organ Donation. Blackwell: Oxford, 381-417.

Gutmann, A. et al. (Eds.), Ethical, Legal, and Social Issues in Organ Transplantation, Pabst: Lengerich.

# Week 5 Decisions concerning genetic diagnosis, genetic screening and genetic interventions

14 Biological framework (s. Le)

#### 15 Ethical framework

- the question of whether human nature is fixed
- risks and benefits of a change in human nature
- the difference between somatic changes in individuals and changes of the germ line

#### Introductory readings:

Brock, D. W. 2005: Genetic Engineering. In: Frey, R. G./Wellmann, C. H. (eds): A Companion to Applied Ethics. Blackwell: Oxford, 356-368.

#### List of further readings:

- Buchanan, A. u. a. 2000: From Chance to Choice: Genetics and Justice, Cambridge University Press: Cambridge.
- Nordgren, A. (Hg.) 1999: Gene Therapy and Ethics, Uppsala (Uppsala University Library).
- Peterson, J. C. 2001: Genetic Turning Points. The Ethics of Human Genetic Intervention. Eerdmans: Grand Rapids, 1-89.
- 16 Ethical issues in genetic diagnosis and genetic screening (apart from pre-implantation and prenatal genetic diagnosis)
  - · different forms of genetic diagnosis
  - different purposes of genetic diagnosis
  - genetic diagnosis and genetic screening
  - · different purposes of genetic screening
  - genetic testing and pharmacogenics

Peterson, J. C. 2001: Genetic Turning Points. The Ethics of Human Genetic Intervention.

Part II: Genetic Testing. Eerdmans: Grand Rapids, 149-228.

# List of further readings:

- Burke, W. 2004: Genetic Testing. In: Guttmacher, A. E. et al. (eds): Genomic Medicine. John Hopkins University Press: Baltimore, 14-27.
- Clarke, A. 2001: Genetic Screening and counselling. In: Kuhse, H./Singer, P. (eds) 2001: A Companion to Bioethics. Blackwell: Oxford, 215-228.
- Khoury, M. J. 2004: Population Screening in the Age of Genomic Medicine. In: Gutt-macher, A. E. et al. (eds): Genomic Medicine. John Hopkins University Press: Baltimore, 28-40.
- Murphy, T. F. 2001: Mapping the Human Genome. In:
- Weinshilboum, R. 2004: Inheritance and Drug Response. In: Guttmacher, A. E. et al. (eds): Genomic Medicine. John Hopkins University Press: Baltimore, 41-53.

#### 17 Ethical issues in genetic interventions

- substitution therapy with genetically designed proteins
- somatic gene therapy for the treatment of hereditary diseases
- · somatic gene therapy of a gene defect in unborn human life
- germ line gene therapy of disease causing gene defects
- germ line intervention with the insertion of "new" genes for the prevention of disseases

- germ line intervention as preventive measure against risk factors or norm digressions
- germ line interventions for the alteration of the human species

- Peterson, J. C. 2001: Genetic Turning Points. The Ethics of Human Genetic Intervention.

  Part III-IV: Genetic Drugs: Adding Gene Products to the Body Genetic Surgery:

  Changing Genes in the Human Body. Eerdmans: Grand Rapids, 231-343.
- Winnacker, E.-L. u. a. 2002: Gentechnik. Eingriffe am Menschen. Ein Eskalationsmodell zur ethischen Bewertung/Gene Technology. Interventions in Humans. An Escalation Model for the Ethical Evaluation. 4. Aufl., Utz: München.

## List of further readings:

- Buchanan, A. u. a. 2000: From Chance to Choice: Genetics and Justice, Cambridge University Press: Cambridge.
- Chadwick, R. 2001: Gene Therapy. In: Kuhse, H./Singer, P. (eds) 2001: A Companion to Bioethics. Blackwell: Oxford, 189-197.
- Kuhse, H./Singer, P. (eds) 1999: Bioethics. An Anthology. Part III: The New Genetics. Blackwell: Oxford, 153-187.
- Peterson, J. C. 2001: Genetic Turning Points. The Ethics of Human Genetic Intervention. Eerdmans: Grand Rapids.