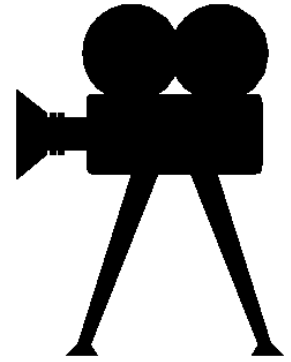


*The Bioethics Research Library invites participants of the Intensive Bioethics Course to . . .*

## **BIOETHICS MOVIE MATINEE**

Wednesday, June 3, 2009, 3:30 pm to 5:30 pm  
Healy 104



*You may come to any portion of the program; however, if you are seeking credit for the session, please plan to stay. Video selections highlight resources that might be used to enrich course syllabi, to promote community or group discussion, and/or to inform ethics committees. These titles are only samples of the vast array of documentary and commercial films available. Handouts will focus on resources useful for identifying and acquiring bioethics-related videos and the effective use of videos. In the interests of maximizing the number of programs viewed, discussion of the ethical issues depicted in these films will occur at the end of the program or informally during the remainder of the IBC. Video clips have been chosen to cover a range of bioethics topics and issues and to support the 2008 IBC theme of “Bioethics: Beyond the Sound Bite.”*

*The program this year begins with an early history of bioethics (eugenics, Nazi medicine); then three historical clips that highlight some of the major foci of American bioethics (reproductive technologies, gene therapy, and the right to refuse treatment); then three clips that point to ethical issues more dominant in global bioethics (AIDS/HIV infection and infectious disease, issues of access to basic human needs such as clean and safe drinking water, and the effects of a growing international market in human organs and transplant tourism demands from the West). The remainder of the program is topical: the information needs of children born using sperm from anonymous donors (a genuinely funny bioethics documentary); basics of informed consent; patient information about clinical trials; confounding and unethical influences in clinical trials (Jesse Gelsinger’s story); genetic testing; helping terminally ill adolescents (part of a larger pediatric palliative care resource); and end-of-life decision making and advance directives. As always, we recognize and honor the families and individuals who generously share their stories so that we might learn from, reflect on, and teach others about their experiences with the hope of improving ethical practice and living.*

### **PREVIEW/PRESHOW PERFORMANCE**

#### **GENERAL HISTORICAL ORIGINS BIOETHICS / RESEARCH ETHICS**

**3:25 p.m. to 3:30 p.m.** — *In the Shadow of the Reich: Nazi Medicine*, 1997, 54 minutes (segment will be shown), color and black and white, First Run Features, 153 Waverly Place, New York, NY 10014; tel. 800-229-8575; <http://www.firstrunfeatures.com>; \$22.46 (now packaged with *The Cross and the Star*); DVD. A documentary overview of the way in which medical professionals became involved in Nazi experimentation and euthanasia programs. The Nuremberg Trials and resulting Nuremberg Code governing research ethics provide the historical background for much of bioethics. This program also points to the role that early American eugenic efforts played in influencing the programs of the Third Reich.

#### **PROGRAM**

**3:30 p.m. to 3:35 p.m.** — **Introduction**

A brief introduction to the program and a description of The National Reference Center for Bioethics Literature’s video collection.

#### **HISTORY OF AMERICAN BIOETHICS**

**3:36 p.m. to 3:46 p.m.** — **Donahue [The Phil Donahue Show: Segment on Test Tube Babies]**, 1978, approx 50 minutes (segment will be shown), color, [transferred from U-Matic to DVD, historical recording, not generally available]. In this segment host Phil Donahue interviews Dr. André Hellegers, M.D., first director of the Kennedy Institute of Ethics, and Father William Smith, professor of Moral Theology at St. Joseph’s Seminary in New York, about their views on in vitro fertilization or “test tube

babies.” The segment of the show was filmed shortly after the birth of Louise Joy Brown took place in England on July 25, 1978. Ms. Brown was the world’s first in-vitro conceived baby. Both Dr. Hellegers and Fr. Smith express concerns about in-vitro. Dr. Hellegers speaks particularly about “false hopes” often generated by media presentations about new scientific or medical advances that are years away from effective development or use in human beings. Most of the concerns Smith and Hellegers express continue to have some resonance today in discussions about assisted reproduction although Hellegers’ expectation that not very many children would be born using IVF within 10 years was proven wrong.

**3:47 p.m. to 3:53 p.m. — David Vetter, Video Clips**, 1971-1984, 6 minutes, color, online streaming video. PBS American Experience (online). [http://www.pbs.org/wgbh/amex/bubble/sfeature/sf\\_video.html](http://www.pbs.org/wgbh/amex/bubble/sfeature/sf_video.html); free; first scenes have not audio. This online footage is part of an extensive companion website (<http://www.pbs.org/wgbh/amex/bubble/>) to the PBS American Experience program “The Boy in the Bubble” which aired April 10, 2006. David Vetter was born in September 1971 with Severe Combined Immunodeficiency (SCID) a genetic condition that left him essentially without an immune system. His older brother died at 7 months of age from SCID and when doctors discovered via an amnio before David’s birth that he too had SCID, they prepared for his delivery and life in a germ-free environment. David lived all of his 12 years of life except the last few weeks inside a germ-free plastic isolator. David died from lymphoma in 1984 that developed from a latent Epstein Barr virus in bone marrow transplanted from his sister in hopes of creating some immunity for him. Was the plastic isolator simply an experiment or a desperate effort to save the life of a young boy with the belief that science might offer a treatment for his condition, or both? “Using blood samples taken from David and other patients, scientists isolated the gene that carries SCID. David’s greatest legacy is in medicine. By altering this gene in the stem cells of babies born with SCID, doctors are able to cure the disease (although some of the treated patients develop leukemia as a side effect of their cure).” (quote from program website) Treatment of SCID is one partially successful outcome from gene therapy research - an area of research that has yet to show as much promise as had been hoped.

**3:54 p.m. to 4:04 p.m. — Man of Endurance: The Amazing Story of Dax Cowart**, 1999 March 22, 18 min. (segment will be shown), color, VHS. ABC News, 20/20 (Segment 2), 1-800-CALL-ABC; [www.abcnewsstore.com](http://www.abcnewsstore.com) In combination with two earlier films, *Please Let Me Die* (1974) and *Dax’s Case* (1984), as well as several articles and books, this recent program about, and an interview with, Dax Cowart provides a rare 29-year overview of one case involving a patient’s right to refuse treatment. Now a practicing attorney, Mr. Cowart remains firm in the belief that he should have been allowed to die after suffering second and third-degree burns over sixty-eight percent of his body in a 1973 explosion due to a gas line leak. He gave permission for the original film to be made specifically because he wanted medical students to know his story and his beliefs that patients have the right not to be treated.

## GLOBAL BIOETHICS CONCERNS

**4:05 p.m. to 4:11 p.m. — A Closer Walk: A Film about AIDS in the World**, 12/2002, <http://www.acloserwalk.org/>; (segment will be shown) DVD and VHS; \$95.00. A compelling program about AIDS in the world outside of the US that raises questions about the inadequacy of the world’s response to this disease that is a tragedy for the whole human race. We’ve passed the 25<sup>th</sup> Anniversary of the first US AIDS cases, This program reminds us of the destruction of families and societies that has occurred outside of the US. As of the end of 2007 an estimated 33 million people (30.8 million adults and 2 million plus children) are living with HIV around the world; 64.4% in Africa (with a 5% adult infection rate in Sub-Saharan Africa). More than 25 million AIDS deaths have occurred since the epidemic began (UNAIDS seems to be no longer updating this number - same quoted in 2008) New persons are infected every day. (By comparison, US HIV or AIDS cases since 1981-2004 number 1,147,697(CDC, 2006); US AIDS deaths since 1981 number 583,298 - (CDC, 2007)). The spirit of Olivia Nantongo speaks to us years after her death from AIDS. She probably contracted the virus when she cared for her mother as a young child or as a result of being sexually assaulted. Her story is that of many families and children in Africa and elsewhere affected by this virus. There are 11.6 million AIDS orphans (UNAIDS/WHO). Washington, DC has a rate of HIV infection (3%, 2009) that rivals that in the most severely affected countries.

**4:11 p.m. to 4:19 p.m. — Rx for Survival - A Global Health Challenge**, <http://wgbh.org>, 336 minutes (segment will be shown), color, DVD and VHS. WGBH tel. 888-255-9231 or <http://www.wgbh.org/>; \$39.95-\$59.95 (with book as set). Documenting public health efforts to make healthcare resources accessible to all people of the world, this program explores a variety of global health issues, including: access to vaccines; the rise of drug-resistant disease; and the influence of geography, politics, finances on access to health care and basic needs for sufficient nutrition and safe water/sanitation. In the segment we view, Ugandan Kiwe Subunya, a UNICEF engineer, struggles to bring safe drinking water to his fellow Ugandans (80% of child deaths world-wide result from malnutrition or poor sanitation). Safe water, is basic to life and to health, and something that most of us take too much for granted. More developed countries are also at risk from poor sanitation; Mexico experienced an outbreak of cholera in the early 1990s after 100 years without the disease. We will not view Jaime Spulveda from the Mexican National Institute of Health speaking about public health efforts to stop the disease outbreak. Supported by the Bill and Melinda Gates Foundation and the Merck Pharmaceuticals, this program offers a teacher’s guide, activities, a companion website, and expert commentary and profiles.

**4:19 p.m. to 4:29 p.m. — Organs for Sale**, 2004, 58 minutes, color, VHS, Danish and other languages with English subtitles. Filmmakers Library, NY, NY, USA; tel. 212-808-4980; fax. 212-808-4983; email: [info@filmmakers.com](mailto:info@filmmakers.com); Web: <http://filmmakers.com/>; \$295. One of over 500 Danes waiting for a kidney transplant, Jim Jarlman - married and the father of two

pre-teen children - decides to travel to Pakistan to buy the kidney of a stranger. The going rate for a kidney of \$1500 to \$3000 represents several years wages for poor Pakistanis. Jim's body has already rejected a kidney donated by his mother and one from a cadaver, so he has few options. Donors usually are not warned of health risks from donation. Many suffer chronic pain and other health problems due to almost non-existent health care and the need to return to strenuous work just days after surgery. Some lives are extended, hospitals and middle-men make money from the surgeries; the poor donors do too, but at what cost to their futures? See also: **The Transplant Trade**, 2004, 78 minutes, color, VHS. True Vision, Ltd. Productions, London in association with Channel 4; <http://truevisiontv.com/>; email: [tash@truevisiontv.com](mailto:tash@truevisiontv.com), companion website at [http://www.channel4.com/health/microsites/T/transplant\\_trade/index.html](http://www.channel4.com/health/microsites/T/transplant_trade/index.html); fax 44-20-8742-7853; £75 UK. Despite condemnation of organ marketing, shortages of transplantable human organs in Westernized countries and desperate financial need in developing countries, have led an increasing number of Westerners to purchase life-sustaining organs from strangers in other countries willing to sell their body parts (their most valuable asset). The program covers the truly international nature of the trade and commerce in organs with filming in England, India, Israel, the United States, South Africa, and Brazil. Donors, recipients, those waiting for transplants, organ brokers, transplant physicians, and Nancy Schepper Hughes, an American medical anthropologist trying to outlaw the trade are interviewed.

## TOPICAL ISSUES

**4:29 p.m. to 4:39 p.m. — Offspring**, 2001, 55 minutes (segment will be shown), color, VHS. This film may be acquired from the producer Barry Stevens; email: [barrystevens@canada.com](mailto:barrystevens@canada.com). This film documents producer Barry Stevens' very personal search for the identity of his anonymous sperm donor father. Barry and his sister Janice were born to his parents with the assistance of a clinic in London in the early 1950s. The desire for more information about their genetic donors often is quite strong among children born by donor insemination. The information available to donor children varies from sperm bank to sperm bank; records for children born decades ago either do not exist, were destroyed, or are quite limited.

**4:39 p.m. to 4:49 p.m. — Medical Ethics: The Catholic Perspective: Informed Consent**, 2007, 250 minutes, color, DVD. Office of Pastoral Communications, Roman Catholic Diocese of Brooklyn, New York; order online <http://www.pastcomm.org/medicaethics/> or by tel. 718-499-9705; \$200 (discount for multiple sets). A series of ten 25-minute programs introduced by Daniel Sulmasy, O.F.M., M.D., Ph.D. Chair, John J. Conley Department of Ethics, St. Vincent Catholic Medical Centers, NY and designed to provide the Catholic Church's position on important medical ethics issues. Msgr. Robert Thelen presents the Church's position on ten issues with supporting comments from five nationally recognized ethicists. Each topic concludes with a small, multi-profession roundtable discussion including physicians, medical residents, medical students, nurses and pastoral care directors. Intended to spur discussion, the series covers 1) informed consent; 2) beginning of life care; 3) end of life care; 4) persistent vegetative state [PVS]; 5) clinical research.; 6) organ donation & transplantation; 7) abuse issues; 8) impact of pregnancy on medical situations; 9) patient wishes vs. medical judgement; and 10) prioritizing care & balancing the healthcare budget. Faculty members are Rev. Msgr. Robert Thelen, STL; Sidney Callahan, Ph.D.; Kevin Fitzgerald, S.J., Ph.D.; John Collins Harvey, M.D., Ph.D.; Kevin O'Rourke, O.P., J.C.D., S.T.M.; Edmund Pellegrino, M.D. These basic introductions are also helpful for non-Catholic audiences.

**4:49 p.m. to 4:59 p.m. — Entering a Clinical Trial: Is It Right for You?**, 2004, 20 minutes (segment will be shown), color, free DVD and online with educational booklets <http://www.dana-farber.org/res/clinical/trials-info/default.html>; Dana-Farber Cancer Institute; Boston, MA; tel. 617-632-3029; [oprs@dfci.harvard.edu](mailto:oprs@dfci.harvard.edu); (in Spanish and English), low cost for multiple copies. The Dana-Farber Cancer Institute (in collaboration with other hospitals) created a basic introduction to clinical trials that is appropriate for persons and their family members who are considering entering a trial as an option. The booklet provides suggested questions to ask oneself and medical staff before deciding to participate in an study.

**4:59 p.m. to 5:09 p.m. — Why Did Jesse Have to Die?**, 2002, 44 minutes (segment will be shown), color, DVD (needs conversion from PAL to NTSC format). Gruppe 5 Filmproduktion GmbH, Kartausserwall 19-21, Germany; tel. 49-(0)-221-946-707-11; fax. 49-(0)-221-946-707-20; <http://www.gruppe5film.de>; [Susanne.Scheben@gruppe5film.de](mailto:Susanne.Scheben@gruppe5film.de) (assistant to Mr. Uwe Kersken ); Thomas Weidenbach [weidenbach@laengengrad.de](mailto:weidenbach@laengengrad.de). This German documentary focuses on the story of Jesse Gelsinger, an 18-year-old American teen, who took place in an early-stage gene therapy clinical trial at the University of Pennsylvania. The trial used an injection of genetically modified adenoviruses in an effort to develop new treatment methods for an X-linked disease in which the liver cannot metabolize ammonia (a by product when proteins are broken down). Jesse died as a result of an overwhelming infection. Numerous questions were raised about financial conflicts of interest especially for Dr. James Wilson, the lead investigator; about how well safety guidelines intended to protect research volunteers were followed; about failure to report animal deaths in an earlier stage of the trial. Paul Gelsinger's (Jesse's father) determination that his son's death and clinical research practices be investigated led to a major review of research ethics and guidelines for research participation throughout the US and world. Gelsinger observes, "It wasn't until much later that I discovered all the influences involved in this work [clinical research trials] and it had affected their [the researchers] perspective and they had lost sight of what was really important. That's the tragedy here....because they lost sight, I lost my son."

**5:09 p.m. to 5:20 p.m. — In the Family**, 2008, 83 minutes (segment will be shown), color, DVD, Kartemquin Films. Available from First Run Features <http://www.firstrunfeatures.com>; The Film Center Building, 630 Ninth Avenue, Suite 1213, New York, NY 10036; tel. (212) 243-0600; fax. (212) 989-7649; [info@firstrunfeatures.com](mailto:info@firstrunfeatures.com); \$18.71. At age 31, filmmaker Joanna Rudnick is facing the decision of whether to remove her breasts and ovaries because she is positive for BRCA gene that makes lifetime risk of ovarian and breast cancer much higher than in the general population. This program follows Joanna and other women making decisions about their bodies and their lives based on predictive genetic tests. See online resources at <http://inthefamily.kartemquin.com/film>.

**5:20 p.m. to 5:27 p.m. — Difficult Conversations in Pediatric Palliative Care: Supporting an Adolescent Facing Death** (part three), 2003, 2007, 23 minutes (segment will be shown), color, DVD. The Initiative for Pediatric Palliative Care (IPPC), Center for Applied Ethics and Professional Practice (CAEPP), Education Development Center, 55 Chapel Street, Newton, MA 02458-1060; tel. 617-618-2454; fax. 617-969-1569; email: Jean Doherty, Coordinator, [jdoherthy@edc.org](mailto:jdoherthy@edc.org); <http://www.ippeweb.org/curriculum.asp>; print materials free online, DVD cost \$109-\$229. This curriculum contains mainly small group seminars to stimulate discussion with videotapes, case studies, problem scenarios, other activities, and short lectures. It consists of five curriculum modules: engaging with children and families, relieving pain and other symptoms, analyzing ethical challenges in pediatric end-of-life decision making, responding to suffering and bereavement, and improving communication and strengthening relationships. Topics include the importance to trust, respect and caring in relationships between families with terminally ill children and health care providers; family coping; including the thoughts and feelings of ill children into care; understanding opioid analgesics; the need for health care workers to be able to make sense of their roles as caregivers to dying children; and modeling conversations about end of life.

**5:27 p.m. to 5:35 p.m. — Peter Wegner Is Alive and Well and Living in Providence** (segment will be shown), 20 minutes (segment will be shown), color, VHS. Filmmakers Library, 124 E. 40th Street, NY, NY 10016; <http://www.filmakers.com>; tel. 212-808-4980; fax. 212-808-4983; email: [info@filmakers.com](mailto:info@filmakers.com); \$195. The film profiles Brown University Computer Science Professor Emeritus Peter Wegner and his recovery from a near fatal brain injury. Hit by a bus while on a holiday in London, Dr. Wegner suffered contusions on both temporal lobes and his right frontal lobe. Doctors told the family that there was only a 5% chance of survival, within that group another 5% chance to have brain function and a further 5% chance of meaningful brain activity. Wegner certainly beat the odds, but this program raises interesting questions about life after brain injury or the development of dementia for people who define themselves through the capacities of their minds and cannot see themselves as having a worthwhile life otherwise. One of Wegner's colleagues states that he would not want to live with diminished mental capabilities Peter now has, despite the fact that Dr. Wegner functions at a level higher than many people could ever aspire to achieve. Mrs. Wenger finds her relationship with her husband more enjoyable because he is more emotionally expressive than before his brain injury.

— **Funny Clip** - approx 5 minute

*\*\*NRCBL's audiovisual collection contains many other programs. We would be interested in other appropriate commercial or educational films you might suggest. If you have questions or comments about any of the audiovisual material shown or about other bioethics-related AVs, please contact Laura Bishop or other staff at the Bioethics Research Library – tel. 888-BIO-ETHX and email [bioethics@georgetown.edu](mailto:bioethics@georgetown.edu).*

*Search for audiovisuals in our online databases, “ETHXWeb” and “GenETHX” by selecting the advanced search screen, and then choosing the audiovisual publication type from the drop down menu on the basic search screen. In the boolean search box, enter keywords or classification numbers and add **and av[pt]**, e.g., 20.5.\$ and av[pt] would search for audiovisuals on prolongation of life and euthanasia (see the classification scheme online at <http://bioethics.georgetown.edu/databases/classscheme/>). The command av[pt] requests retrieval of records items bearing the “audiovisual” publication type designation. Each record provides a program description, acquisition information, and other details. The Bioethics Research Library is located in the Healy Building, Room 102 on the Georgetown University main campus. Audiovisuals do not circulate but may be viewed in the library. Increasing numbers of programs are available online as streaming video resources.*