

Annual Report

Center for Biomedical Ethics

University of Virginia

July 2000 – June 2001

Overview

The Center for Biomedical Ethics enjoyed another successful year, invigorated by its first academic year in its renovated Barringer Hall office suite and the arrival of new colleagues. Again this year the center's faculty received national and international attention as leaders in a growing field, called upon by government entities, professional and research organizations, and the news media for assistance in evaluating an array of complex new ethical problems in the life sciences.

Closer to home, center faculty participated in the planning and execution of a new first year medical school curriculum that integrates content on the history of values in the medical profession with the rest of the students' basic science education. Planning for the new second year curriculum proceeded even as the first year was unfolding, with half a dozen sessions on medical ethics throughout the human life span as the theme of the series. Several of us also took part in the new "Clinical Connections" sessions for third year students, in which social, spiritual, ethical and legal issues were discussed during their day-long clinical pathology conferences. The center continued its successful series of conferences for adult learners and welcomed another group of highly qualified students into its M.A. in Bioethics program. Among many other activities, we also welcomed a wide array of important speakers and participated in the inauguration of the new, university-wide Institute for Practical Ethics.

Leslie Blackhall Joins the Center

No event can be more important to any faculty than welcoming a distinguished new member. This year Leslie Blackhall, a well-known physician ethicist whose work on ethics at the end of life is widely recognized, joined the center in her research role while practicing in the health system's expanded palliative care program. Leslie came most recently from the University of

Southern California, with a background in theology as well as medicine. After getting settled in her clinical responsibilities she began to chart several exciting research projects. Although Leslie has significantly strengthened our faculty's reputation in the area of death and dying, she brings the same intelligence and enthusiasm to all the topics encompassed by our work.

New Center Research Associate Angelique Reitsma

Another welcome addition to the center was Dutch-born and trained physician Angelique Reitsma. Angelique received her medical training at Utrecht and for a year was an instructor in medical ethics in The Netherlands. She brings experience as a laboratory investigator as well as clinician, and is completing her M.A. in bioethics while coordinating several new research projects in bioethics. The center was exceedingly fortunate to obtain the services of such a well-trained and sophisticated researcher.

Core Faculty Composition

Last year the center's Faculty Advisory Board established three criteria for "core faculty" status: teaching in center course offerings, participation in at least one center research project or outreach program, attendance at center meetings, and ability to represent the center's mission and goals to the rest of the university and the public.

Apart from the welcome addition of Leslie Blackhall, our core faculty has been stable this year. John Arras directs the nationally respected undergraduate bioethics program in the Department of Philosophy. Bob Boyle is in charge of an active Ethics Consultation Service for the hospital. Jim Childress directs the Institute for Practical Ethics and Ruth Gaare is the executive director of the Institute. Paul Lombardo directs the Program on Law and Medicine in the center. Ann Mills is associate director of outreach programs, newsletter editor and

organization ethics specialist. Walt Davis initiated our renewed course on clinical ethics and helped develop the new ethics curriculum for the medical school. Margaret Mohrmann coordinates our spirituality and ethics activities. Ed Spencer directs our outreach program and is liaison to the Virginia Healthcare Ethics Network.

Besides Angelique Reitsma, others closely associated with the center this year were Phil Neiburg, who is completing his two-year assignment to work on ethical issues in public health for the Centers for Disease Control, and Nick Minich, who continues as the center's liaison and community educator. Carrie Gumm continues as the center's administrator and Charlene Kaufman is our receptionist.

For a complete listing of all center faculty and staff 2000-2001, see Appendix I.

Faculty Advisory Board

Our Faculty Advisory Board counsels the director of the center in all policy matters, and approves of nominees to the list of Faculty Associates, colleagues from throughout the university who bring special interests and expertise that complement our focus on bioethics. The Board consists of Tom Daniel (Surgery), Doris Greiner (College of Nursing), Walter Wadlington (School of Law), and Mark Williams (Internal Medicine).

Clinical Associates

All members of the Ethics Consultation Service are given the title of "Clinical Associate" of the Center. The service reports to the University hospital ethics committee and the center provides academic support. UVa's ethics consultants are exceptionally well-trained in clinical ethics, having studied ethics and related fields at the graduate level and contributed to the literature on clinical ethics.

The service has continued to provide 24-hour/seven-day a week consultation services to the Medical System. It averages 3-4 consultations per month in addition to 8 to 10 phone call inquiries for information on issues in decision making, end-of-life care, etc. Over the past two to three years, issues related to patient capacity, surrogate decision-making, and family conflict continue to be the most common reason for consultation requests.

A new and on-going problem resulting in ethics consultation has to do with surrogate decision-making, particularly the identification of appropriate surrogates. This problem will be one of the foci for the annual Piedmont Liability Trust Continuing Education Seminars this next cycle.

Faculty Associates and Adjunct Associates

To help maintain and develop its relationships with the rest of the university and with the wider community, the center maintains a group of faculty associates who serve three-year terms. They are university faculty whose expertise complements the center's work. The first three year cycle for the current group of faculty associates has been completed this past June, and the center director in consultation with the Faculty Advisory Board will invite several colleagues to join a number of continuing faculty associates.

Last year a new category, "adjunct associates," was established. Adjunct associates are individuals who are not university faculty but members of the community with significant expertise in fields related to the center's work. Center faculty members are especially proud of John Fletcher, adjunct associate and previous Center director, who has been awarded the Lifetime Achievement Award by the American Society for Bioethics and Humanities.

Full Center Meetings and Guest Speakers

A primary venue for gatherings of faculty associates, adjunct associates, and other friends of the center are full center meetings, which take place at least once a month during the academic year. Each meeting includes a guest speaker, among whom this year were Leonard Harris (Purdue University), Mark Williams (University of Virginia), Hon. Stewart Pollack (New Jersey Supreme Court, Retired), Ellen Feder (American University), Greg Bloche (Georgetown University), Nicholas Christakis (University of Chicago), Susan Okie (Washington Post), Robert Arnold (University of Pittsburgh), Mark Kuczewski (Loyola University, Chicago), and Eric Meslin (National Bioethics Advisory Commission).

Office Space

Since March 2000 the center has occupied enlarged and renovated space in Barringer Hall and the Davis Wing. The space is bright and comfortable, supporting the collegiality so important to a successful academic center. The conference room in particular is a highly utilized space, generally considered to be one of the most attractive at the university. Our reception area provides the sense that visitors can be easily oriented and that they are indeed welcome.

We are pleased that the space is shared with the Program of Humanities in Medicine. This arrangement encourages both sharing of faculty and engaging in planning for activities relevant to both the center and the program. Increasingly, speakers at the popular and historic Medical Center Hour are cosponsored by the center and meet with smaller group of center faculty and students following the main presentation.

Teaching

The University of Virginia offers an unsurpassed array of opportunities to study bioethics, from the undergraduate program to graduate programs at the masters and doctoral levels in the

liberal arts, medicine, nursing, and in the law school. The center houses the M.A. Program in Bioethics, with administrative support provided by the Department of Religious Studies. The degree is offered jointly by the medical school and arts and sciences. Approximately six to eight highly qualified students begin the program each year, with strong preference given to applicants who are continuing in their current career but wish formal bioethics education or who are also enrolled in the MD, JD, or a PhD program. Our graduates who have not already been enrolled in a terminal degree program have been quite successful in gaining admission to prestigious institutions.

Center faculty members direct and teach in numerous courses in their primary schools and departments as well as in other disciplines. The required course on “Foundations of Bioethics,” for example, is directed by Jonathan Moreno, with sessions taught by John Arras, Jim Childress, faculty associate Ann Hamric, Margaret Mohrmann, and others. As well, this year center faculty taught in the schools of medicine, law, nursing, and arts and sciences.

Missing from our curriculum for several years but re-instituted this year was a course on Clinical Ethics. Walt Davis directed this course with a number of guest faculty presenters. With little advance notice the course was nonetheless well subscribed with a diverse array of students. “Clinical Ethics” will be a regular spring course.

John Arras, Jim Childress, and faculty associate Pat Werhane of the Darden School were awarded a two-year grant from the College of Arts and Sciences to pursue a research project on the theme of Global Justice and International Research Ethics. Several faculty members affiliated with the center and the Institute for Practical Ethics will be participating.

As in previous years, in January the center sponsored a research ethics course in

cooperation with the graduate studies office. The course is required for school of medicine basic science graduate students and was also taken by a number of students in other programs. It is designed to satisfy increasing federal requirements for basic education in research ethics. Sessions include human and animal research ethics, professional integrity and conduct, and local university protocols and systems for ensuring ethical research. Small group discussion sessions follow each plenary presentation.

Conferences

The Center continues to try and address both recognized and emerging needs of healthcare professionals through its Outreach Program. This year the Center sponsored or co-sponsored three program activities.

In November 2000, the Center co-sponsored with the Virginia Healthcare Ethics Network the workshop: “*Ethics in Healthcare Institutions: New Issues, Controversies and Practical Considerations.*” This annual one and one half-day workshop serves primarily to address ethical issues arising in Virginia that need the attention of Virginia’s healthcare professionals.

“*Developing Hospital Ethics Programs*” (DHEP) was offered in March 2001. This annual program attracted the largest (44) and most diverse group of participants ever. Participants came from Canada, California, Japan, Florida, and Texas, as well as the Mid-Atlantic states to attend this intensive 5-day program that is designed to facilitate or strengthen the implementation of ethics programs within healthcare organizations.

“*Spirituality in Healthcare: A Training Program for Professionals*” a one-day workshop, was offered in May 2001. This program was an experiment and occurred because of the need to translate academic concepts and ideas (offered through last year’s conference “*Belief and*

Bioethics”) into tools that can be used clinically by healthcare professionals. Its goal was to train professionals – chaplains, nurses, physicians, social workers, and others – in two broad areas: (1) to recognize and respond appropriately to the influence of specific religious beliefs in healthcare decision-making so spiritual well being is sustained or supported, and (2) to identify spiritual distress in patients and family members and find responsive and meaningful strategies to ensure appropriate resolutions. The program was co-directed by Margaret Mohrmann and Joan Murray and supported by the Warmath Family Foundation. It drew over 70 participants from Virginia and North Carolina – all of whom expressed their eagerness that the Center should continue this program offering.

Related to the spirituality outreach program, Margaret Mohrmann completed the first year of a \$100,000 grant from the Fannie E. Rippel Foundation for the spirituality and medicine curriculum. The grant was awarded under the auspices of the Program in Medical Humanities whose co-director, Marcia Childress, is a center faculty associate and works with Dr. Mohrmann on this project.

Research

All members of the center’s core faculty are actively engaged in research in bioethics. Much of this work resembles research in the humanities and social sciences. For example, the center is well known for its leadership on foundational questions in medical ethics, especially for its contributions to those theoretical frameworks commonly known as principlism and pragmatism. The center is also known for its expertise on the history of medical ethics, including for example Paul Lombardo’s ongoing research on the history of eugenic sterilization.

The center also continues to build a program of ongoing, funded research projects. Some

are based entirely in the center, in other cases center staff are invited to participate in projects that originate elsewhere in the medical school or university.

Racial Categories in Health -- This project was spurred by two conflicting trends: a spate of recent findings that indicate significant racial disparities in health status, and indications from the Human Genome Project that race is an insignificant genetic component. Ruth Gaare, Paul Lombardo and Jonathan Moreno submitted a proposal for an analysis of this issue to the Pettus Crowe Foundation, which responded with a \$10,000 grant. A research group composed of authorities from medicine, law, the humanities, and the social sciences met half a dozen times in the past two years. Guest speakers have included experts from the National Institutes of Health and the Centers for Disease Control. It is anticipated that a report will be completed this year by Carlton Haywood, former center MA student and now a research associate at the Johns Hopkins Bioethics Institute.

Ethics and Public Health -- This project is an outgrowth of the on-grounds Public Health Ethics Forum that began in fall 1999. It was made possible by a \$15,000 grant from the Greenwall Foundation, center faculty and associates have organized a research group composed of ethicists from Johns Hopkins, Georgetown, Minnesota, and the University of Washington, as well as Virginia. An organizational meeting was held in May 2000, and it was subsequently decided to fold this project with efforts by academic public health leaders to develop a curriculum in the ethics of public health. A final report will be submitted in December 2001. The co-investigators are Jonathan Moreno and Ruth Gaare, with Richard Bonnie as moderator.

Effects of Breast Cancer Diagnosis on First Degree Relatives -- Under the auspices of the university's breast cancer genetics group, Jonathan Moreno is participating in this Arthur Vining

Davis-funded project that aims to educate professionals about the impact of a diagnosis upon those who are closely related to the patient. He was a faculty member in a project-sponsored conference on “The Cancer Family” this spring in Charlottesville.

Infected Physicians and Invasive Procedures: Development of National Policy

Recommendations -- The Rockefeller Foundation funded this project to develop guidelines for physician disclosure of infection status if they are undertaking invasive procedures. The Principle Investigator is Patti Tereskerz of the Center for International Health Care Worker Safety, and Jonathan Moreno is co-chair of the working group. The first meeting of the working group, composed of experts from various disciplines from throughout the country, will take place this fall in Charlottesville.

Innovative Surgery and Ethics – The center is developing an expertise on ethical issues in innovative surgery. This past year we conducted a survey-based study of authors of reports on innovative surgical procedures, the data from which are now being analyzed for publication. Our intent is to prepare a grant application to broaden our study on the attitudes of surgeons toward research regulation. A related project on “sham” interventions is also under way. Research associate Angelique Reitsma is taking the lead in this area.

Pediatric Research Ethics – Another pilot study, this project will begin by surveying a group of pediatric investigators and IRB members on the practical meaning of important elements of the current regulations governing research that involves children as subjects. Our goal is to produce a grant-supported report with recommendations for clarifications of the regulations. Jonathan Moreno directs this project with assistance from Angelique Reitsma.

Nurse-Physician Communication and End of Life Care – A critical issue that has emerged

from previous empirical work on end of life care is the relationship between physicians and nurses, especially concerning communications of the values and preferences of the patient. This project, now being conceptualized, will seek funding to develop empirical data on this subject (including observational studies), with the goal of improving end of life care by enhancing physician-nurse cooperation. Leslie Blackhall and faculty associate Ann Hamric are developing the project.

Center Newsletter

The center newsletter, “Bioethics Matters”, was published on its regularly quarterly schedule this year under Ann Mills’ editorship. The newsletter is distributed to over 1200 friends of the center and is posted on the center’s website. Its mix of news about recent center events, upcoming programs, staff activities, and substantive essays is a critical venue for the center to maintain contact with its extended community.

Public Affairs and Public Service

Center faculty are contacted frequently by members of the press for analysis on emerging bioethical issues. When a volunteer research subject was reported as having died in the course of a study at The Johns Hopkins University this past spring, our office was flooded with calls. Major newspaper contacts include The Washington Post, The New York Times, The Los Angeles Times, The Washington Times, and the Richmond Post-Dispatch, as well as wire services such as the Associated Press. International press interviews this year have included media outlets in the United Kingdom, France and Australia. Various internet news services have also contacted center faculty for their expertise this year. Our faculty also appeared on a number of television news, radio, and documentary programs.

Center faculty also continue to serve on important state and federal commissions and as

advisors to government entities and professional organizations. John Arras is a consultant to the Centers for Disease Control in Atlanta, Jim Childress has continued as a member of the National Bioethics Advisory Commission, and Jonathan Moreno was appointed to the new National Human Research Protections Advisory Committee. Within the profession of bioethics and medical humanities, several center faculty members served on program committees for the annual meetings of the American Society for Bioethics and Humanities.

International Relations

Previously colleagues from countries including Argentina, Germany, and Russia have visited the center. This coming year we expect to receive visitors from the Ministry of Health in Iran this year, the first tangible result of contacts made two years ago. The Ministry is responsible for the curriculum of all state medical schools in the country, and is seeking to create a bioethics program. The Iran center contacted us in spring 2001 with an interest in offering the M.A. in Bioethics in Riyadh under the auspices of the University of Virginia.

Development

Funds derived from the Bell Fellowship in Biomedical Ethics will be available for the first time in 2001-02. They will help us support worthy graduate students in biomedical ethics. Through the university-wide Institute for Practical Ethics, the center continues to benefit from the Donchian Foundation gift that provided the initial support for the institute and related ethics program on the grounds. This past year Donchian funds helped to support several MA students. Funds sufficient to endow a Wallenborn Professorship of Biomedical Ethics are either already received or committed.

Bruce J. Cohen
Julia E. Connelly
Thomas M. Daniel*
Cora Diamond
Carolyn L. Engelhard
Mimi Foster
Gertrude Frazer
R. Edward Freeman
Doris Greiner*
Carlos F. Gomez
Ann Hamric
William A. Knaus
Thomas A. Massaro
Lynn Noland
Karen J. Schwenzer
Walter J. Wadlington*
Amy Wax
Pat Werhane
Mark Williams*

**(Faculty Advisory Board)*

Adjunct Associates
Henry Bourignon
John Fletcher
Ruth Hanft
Frank Miller

Appendix II:

Selected Core Faculty Publications - July 2000 - June 2001

Arras, J., Two entries for the *Encyclopedia of Ethics*: "Slippery Slope Arguments" and "Narrative Ethics". In press, forthcoming 2001.

Arras, J., "Freestanding Pragmatism in Law and Bioethics," *Theoretical Medicine*, vol. 22, no. 2 (2001): pp. 69-85.

Arras, J., "The Internal Morality of Medicine: A Method in Search of a Purpose," forthcoming *Journal of Medicine and Philosophy*.

Blackhall, L., "Common Sense" Innovations in End of Life Care (www.edc.org/lastacts/) collected in Innovations in End of Life Care: Practical Strategies and International Perspectives Solomon, M., Romer A., Heller K., ED. Marry Ann Liebert, Inc., 9/2000.

Blackhall, L., Frank G., Murphy S., Michel V., "Bioethics in a Different Tongue: The Case of Truth Telling," J Urban Health, 2001; 78(1):59-71.

Reigle J. and **Boyle R.**, Hamric A.B., Spross J.A. and Hanson C.M. "Ethical Decision-Making Skills In Advanced Practice Nursing: An Integrative Approach." Philadelphia: WB Saunders Co, 2000.

Boyle, R.J., "Ethics in the Neonatal Intensive Care Unit and Beyond." Infants and Young Children 2001;13(3):36-46.

Finnerty J.J., Thomas T., Howards S., **Boyle R.J.**, Karns L. "Gamete Retrieval From the Dead or Dying: Technical and Ethical Considerations," *Am J Obstet Gynecol* (in press)

Boyle R.J., McIntosh N., "Ethical Considerations in Neonatal Resuscitation: Clinical and Research Issues." Seminars in Neonatology (in press)

Childress, J.F., Principles of Biomedical Ethics, 5th ed., co-author: Tom L. Beauchamp, March, 2001. Both German and Japanese translations are now being prepared of this fifth edition - there is already a Japanese translation of two previous editions.

Childress, J.F., "Euthanasia and Assisted Suicide," for Contemporary American Religion (forthcoming from MacMillan Reference)

Childress, J.F., "Nuremberg's Legacy: Some Ethical Reflections," *Perspectives in Biology and Medicine* 43, No. 3 (Spring 2000): 347-361.

Childress J.F., Managed Care: Some Basic Ethical Issues," Frontiers in Bioethics: Essays Dedicated to John C. Fletcher, ed., Franklin G. Miller (Hagerstown, MD: University Publishing Group, 2000), pp. 149-169.

Childress, J.F., "The Failure to Give: Reducing Barriers to Organ Donation," Kennedy Institute of Ethics Journal, forthcoming in March, 2001.

Childress, J.F., "Bioethics on the Brink of the New Millennium: An Overview," in Medical Ethics and the Future of Healthcare, eds., Kenneth Kearon and Fergus O'Ferrall (Dublin: The Columbia Press, 2000), pp. 15-33.

Childress, J.F., "Case Narratives and Moral Perspectives: An Appreciative Response to Chambers," American Journal of Bioethics, forthcoming in first issue.

Childress, J.F., Numerous unsigned articles in BioLaw, a monthly update service.

Davis, W.S. "Disability and Bioethics: Removing Barriers to Understanding And Setting the Agenda for a New Conversation."(Invited Peer Commentary) American Journal of Bioethics. Summer 2001, Vol. 1, No. 3.

Kahler, D.M., **Davis, W.S.** "Ethics in Practice: Inability to Obtain Formal Informed Consent in the Face of a Standard Surgical Indication." Journal Of Bone and Joint Surgery. 83-A(1):143-144, Jan 2001.

Davis, W.S. "A Bioethicist's Perspectives on Catastrophic Injury," in Catastrophic Injury Handbook. Edited by KA Anchor. Nashville: American Board of Disability Analysts, 2001.

Davis, W.S. "Dantrolene," in Clinical Evaluation and Management of Spasticity. Edited by DA Gelber and DR Jeffery. Totowa, NJ: Humana Press Inc., 2001.

Davis, W.S. "Mother Knows Best," in Developing Organization Ethics in Health Care: A Case-Based Approach to Policy, Practice, and Compliance, edited by AE Mills, EM Spencer, and PM Werhane. Hagerstown, Maryland: University Publishing Group, 2001.

Davis, W.S. "Home Again, Home Again," in Developing Organization Ethics in Health Care: A Case-Based Approach to Policy, Practice, and Compliance, edited by AE Mills, EM Spencer, and PM Werhane. Hagerstown, Maryland: University Publishing Group, 2001.

Lombardo, P.A., "Substance Abuse Treatment Records: A Special Corner of Medical Privacy" 26 Virginia Bar Association News Journal 6-8 (October, 2000); Reprinted in Bioethics Matters 3-5 (Winter, 2001).

Lombardo, P.A., "Medicine, Eugenics and the Supreme Court: From Coercive Sterilization to Reproductive Freedom" in Frontiers in Bioethics, Franklin G. Miller, ed. (Hagerstown, Maryland: University Publishing Group, 2000).

Lombardo, P.A., "Offenders with Mental Retardation in Virginia: Challenges and Opportunities" Final Project Report to the Virginia Bar Foundation, December, 2000.

Mills A., Spencer E., Werhane P. (editors) Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice, and Compliance. (2001) University Publishing Group

Mills, Spencer, Werhane, "Introduction," in Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice and Compliance. p. 1-9.

Mills, A.E. "A Good Neighbor" in Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice and Compliance. p. 19-23.

Mills, A.E. "Introduction to Organization Issues in Research Ethics," in Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice and Compliance. p. 107-114.

Mills, A.E. "A Strategic Alliance," in Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice and Compliance. p. 123-124.

Mills, A.E. "The Olivieri/Apotex Affair," in Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice and Compliance. p. 129-138.

E. M. Spencer, **A. E. Mills**, "An Overview of Organization Ethics" in Frontiers in Bioethics, edited by Franklin G. Miller, University Publishing Press: MD 2000. p. 171-186.

Mohrmann, M.E., Healey, D.E., Childress, M.D., "Suffering's Witness: The Problem of Evil in Medical Practice," Second Opinion (Sept. 2000), 55-70.

Mohrmann, M.E., "It's What Pediatricians Are Supposed to Do," in Caring Well: Religion, Narrative, and Healthcare Ethics, ed. David Smith (Louisville, KY: Westminster/John Knox Press, 2000), 89-116.

Mohrmann, M.E., review of R.B. Baker, et al., "The American Medical Ethics Revolution: How the AMA's Code of Ethics Has Transformed Physicians' Relationships to Patients, Professionals, and Society," (Baltimore, MD: The Johns Hopkins University Press, 1999), in Perspectives in Biology and Medicine 44:148-52, 2001.

Moreno, J.D. Undue Risk: Secret State Experiments on Humans. New York: Routledge Publishers, 2001 (paperback Edition)

Moreno, J.D., "Protectionism in Research Involving Human Subjects," Ethical and Policy Issues in Research Involving Human Participants, Volume II: Papers Commissioned by the National Bioethics Advisory Commission, National Bioethics Advisory Commission, Washington, DC, 2001.

Moreno, J.D. and London, A.J. "Consensus, Ethics, and Politics in Human Embryo Research," In: Cloning and the Future of Human Embryo Research, P. Lauritzen, ed., Oxford University Press, 2001.

A.M. Reitsma, "Interview with Heleen Dupuis, Dutch ethicist." Bioethics Matters. May 2001

A.M. Reitsma, T.C. Schuler, M.W. Hasz, K.A. Poelstra: "Surgical Treatment of Symptomatic Bertolotti's Syndrome in Post-Fusion Patients" (Accepted for publication to Orthopedics)

A.M. Reitsma, associate editor: "Otolaryngology, Head and Neck Surgery." In: Surgical Recall, 3rd Ed. L.H. Blackbourne, Ed. 2000 Lippincott Williams & Wilkins, Baltimore, MD.

Spencer E., Mills A., Werhane P. (editors) Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice and Compliance (2001 University Publishing Group).

Spencer E., Mills A., Werhane P., "Introduction," in Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice, and Compliance. p. 1-9.

Spencer E., "Compassionate but Costly Care", in Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice, and Compliance. p. 27.

Spencer E., "What Kind of Furnace?" in Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice, and Compliance. p. 45-46.

Spencer E., "Introduction to Organization Issues in Professional Ethics." In Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice, and

Compliance. p. 81-84.

Spencer E., "A Researcher's Dilemma," in Developing Organization Ethics in Healthcare: A Case-Based Approach to Policy, Practice, and Compliance. p. 121-122.

Spencer E., Mills A., "An Overview of Organization Ethics," in Frontiers in Bioethics, edited by Franklin G. Miller, University Publishing Press: MD 2000. p. 171-186.

Appendix III:

Selected Core Faculty Professional Activities

John D. Arras**Extramural Teaching:**

Helped design course on research ethics and delivered 4 lectures at the National Institutes of Health (NIH), Winter/Spring/Fall 2000. Audience consisted of two groups of 150 research fellows from NIH and Duke School of Medicine.

Lectures:

Commentator, symposium on “*From Chance to Choice*,” Brown University, February 7, 2001. (Panelist with Dan Brock, Allen Buchanan, and Norman Daniels)

"Pragmatism in Bioethics: Been There, Done That" at an invitation-only conference on Bioethics sponsored by the Institute for Social Philosophy and Policy, Bowling Green State University, Ohio. April 20, 2001. Article forthcoming in *Journal of Social Philosophy and Policy* (Cambridge University Press).

Research:

Continued collaboration with several co-editors from UVa and the NIH on a book project in research ethics. We are now in the final stages of editing our introductions and the selected articles. The book proposal has been accepted for publication at the Johns Hopkins University Press.

“Global Justice and the Ethics of International Research,” (co-principal investigator with Jim Childress and Pat Werhane), two year research project funded by College of Arts and Sciences

National Academic and Public Services:

Fellow, Chair of Fellows’ Council, and ex officio Board Member, The Hastings Center, Briarcliff Manor, New York

Continuing member, Board of Directors of American Society of Bioethics and Humanities.

Member, Data Safety and Monitoring Board, Autoimmunity Centers of Excellence, Immune Tolerance Network, National Institutes of Health, 2000--

Consultant, Project on “Medicine Online: Ethical, Legal and Policy Challenges,” Greater New York Hospital Association, Spring-Fall, 2000.

Advisory Board, *Yale Journal of Health Policy, Law, and Ethics* (2000--)

Editorial Board, *Bioethics* (Blackwell Publishers, 2000--)

Consultant, The Greenwall Foundation

Leslie Blackhall

Presentations:

"Asian Spiritual Practices and Care at the End of Life" at Asian Therapies in Cancer, NYC, NY, February, 2001.

"Cultural Diversity in End-of-Life Care at Eliminating Racial and Ethnic Health Disparities, April, 2001, The Center for Improving Minority Health, University of Virginia.

"Spirituality, Purpose, and Care at the End of Life." Keynote address at Spirituality and Healthcare: A Training Program for Professionals, May, 2001, The Center for Biomedical Ethics, University of Virginia.

James F. Childress

Dissertation Committees:

Mitchell Hammond (History)

Robert Urofsky (Education)

Administrative Appointments and Activities:

Director, Institute of Practical Ethics

Committees:

Member, Hospital Ethics Committee

Faculty Fellow, Brown College

Departmental Graduate Committee (1995-)

Chair, Advisory Committee for MA in Bioethics (term ended in 2000)

Member of Search Committee for new Chair of Technology, Communication, and Culture (TCC) in the School of Engineering (1999-2000)

Member of Search Committee for Ethics Professor in TCC in the School of Engineering (2000-)

Thomas Jefferson Award Selection Committee, 1999-, Chair, 2000

Algernon Sydney Sullivan Award, 2000-, Chair, 2000

Member, Search Committee for Provost, 2000-2001

Public Service:

Member, National Bioethics Advisory Commission, Appointed by President Clinton in 1996 for a three year term, which was subsequently renewed

Member, Data and Safety Monitoring Board for Cooperative Clinical Trials in Organ Transplantation (NIH)

Member, Ethics Committee, United Network for Organ Sharing

Member, Scientific and Ethics Advisory Committee for Roche Genetics

Editorial Activities:

Editorship: Co-Editor BioLaw

Membership on Editorial Boards or Advisory Boards for Journals

Journal of Religious Ethics

Kennedy Institute of Ethics Journal

AIDS and Public Policy Journal

Human Gene Therapy Journal

Journal of Medicine and Philosophy

American Journal of Bioethics (AJOB)

Editorial Advisory Board - University Press of Virginia

Editorial Advisory Board - Cambridge Dictionary of Bioethics

Reader of manuscripts for several of the above journals and others as well as for various publishers

Honors or Awards:

Visiting Scholar, Department of Clinical Bioethics, National Institutes of Health, July, 1999 - May, 2000.

Invited Lecturers, Addresses, Papers, Etc:

Lecture on "Ethical Issues on New Frontiers of Transplantation," International Conference on Transplantation, Zuers, Austria, January 6-8.

Lecture on Religion, Morality and Public Policy, for Association for Practical & Professional Ethics, Crystal City, VA, February 27.

Lecture, Bioethics and Belief Conference, University of Virginia, March 15-16.

Lecture on "Religion, Morality, and Public Policy," Shenandoah University, March 29.

Three presentations at the National Undergraduate Bioethics Conference, University of Virginia, March 31- April 2.

Keynote Address, Conference on Bioethics, University of Tennessee, Knoxville, TN, April 7-8.

Lecture on "Religion, Bioethics, and Public Policy," Pendle Hill (Quaker Retreat Center), April 17-18.

Seminar on NBAC's Report on Research Involving Persons with Mental Disorders that May Affect their Decision Making, NIH, April 25

Panelist on "Paying Research Subjects," Grand Rounds, NIH April 26.

Lecture on methods in bioethics, Developing Hospital Ethics Programs, University of Virginia, April 27

Three lectures and discussion leader, Institute Intensive Bioethics Course, Kennedy Institute of Ethics, June 6-11

Presentation on ethical issues, Surgeon General's Conference on Children's Oral Health, Washington, DC June 13

Keynote Address on "Restoring the Person to Medicine," School of Medicine, Trinity College, Dublin, June 23.

Seminar with judges on bioethics, Judges Program, UVA Law School, June 28

Keynote Address, "Religion, Bioethics, and Public Policy," Annual Meeting of Association of Politics and the Life Sciences, Washington, DC. August 29.

Lecture on Ethical Issues in Research Involving Human Subjects, Carillion Health Systems, Roanoke, VA September 28.

Paper on "Gifts and Commodities in Tissue Transplantation," Case Western Reserve University School of Medicine, October 5-6.

Panelist at two sessions, annual meeting, American Society of Bioethics and Humanities, Salt Lake City, October 26-27

In addition, I conducted Grand Rounds at the University of Virginia Health System for Pediatrics (2/3) and for Psychiatry (10/17), as well as participating in the Medical Center Hour (3/29), lecturing to the Jefferson Scholars (2/13), and providing an overview of ethical issues in stem cell research at an UVA conference (10/7).

Walter S. Davis

Abstracts:

"Adding Insult to Injury?: Disability and Ethics in the Care of the Elderly Trauma Patient." (Accepted for presentation at A-Not-So-Kind-Or-Gentle-World: Ethical Issues in Disability and Aging, June 29-30, 2001, Neiswanger Institute for Bioethics and Health Policy, Loyola University Chicago.

Hamric A.B., Davis W.S., Jameton A., Fuerst D.M., Fuerst C.W., Moazam F.

"Interdisciplinary Perspectives on Moral Distress: What It Is and What You Can Do About It." (Workshop presentation accepted for the 2001 American Society of Bioethics and Humanities Annual Meeting in Nashville, Tenn., October, 2001.)

Committees:

Admissions Committee – I have been appointed to the medical school admissions committee, with my term to begin September, 2001.

Practice of Medicine-I Planning Committee

Practice of Medicine-II Planning Committee

Presentations and Invited Lectures:

"Issues in Clinical Ethics: Rehabilitation Medicine," for Developing Healthcare Ethics Programs 3/5/01-3/9/01, Charlottesville, VA

"Comfort/Conflict/Compromise: The Spirituality of the Caregiver," with Ann Hamric and Richard Haines, for Spirituality in Healthcare: A Training Program for Professionals, 5/11, Charlottesville

"Functional Issues in Amputation," for Physical Medicine and Rehabilitation Grand

Rounds, 3/15/01

“Ethics of Biomedical Research,” for American College of Cardiology - Virginia Chapter, 12th Annual Meeting, Charlottesville, VA, 4/27/01

Awards:

“You Make a Difference,” Award, University of Virginia Health System, 2/19/01

Paul A. Lombardo

Classes, Lectures, Intramural Presentations:

School of Medicine

August 28, 2000, Practice of Medicine “History of Medicine at UVa”

August 31, 2001, Foundations of Bioethics “Introduction to Bioethics”

January 25, 2001, Clinical Ethics “Confidentiality and Privacy”

January 26, 2001, Pediatric ICU Residents “Issues in Ethics and Law: Treatment Refusal”

February 8, 2001, Clinical Ethics “Capacity, Competence, and Consent”

April 2, 2001, Medical Class, 3rd Year, “Refusal and Withdrawal of Care—Legal Issues”

March 30, 2001, Symposium: The Cancer Family: at the Intersection of Science and Society “Legal Aspects of Genetic Testing for Cancer Risk” & Roundtable Moderator, “Legal Issues and Legislation”

Center for Biomedical Ethics/School of Law

(Fall, 2000) Great Cases in Bioethics

(Spring, 2001) Genetics and the Law

March 5, Conference: Developing Hospital Ethics Committees “Law & Ethics; an Unsettled Relationship” and “Privacy & Confidentiality in Medical Communication”

March 6, Conference: Developing Hospital Ethics Committees “How Lawyers Relate to Ethics Committees”

February 20, Mental Health Law “Confidentiality, Privacy, Privilege”

Regular participation in monthly Ethics Rounds in the Department of Psychiatry

College of Arts and Sciences

February 1 & 6, 2001 Research Ethics “The Tuskegee Study”

Extramural Presentations:

July 5, 2000 “Advance Directives and Patient Consent” Grand Rounds, Western State Hospital, Staunton, Va.

September 28, 2000 “Vulnerable Populations in Research: Cases and Regulations” Carilion Roanoke Memorial Hospital, Roanoke, Va.

October 1, 2000, “Bioethics 2000, Panel Discussions at Virginia Science Museum, Richmond, Va. “Stem Cell and Fetal Tissue Research” and October 15 “Mapping the Human Genome” (Greenwall Foundation)

October 2, 2000 Federal Executive Institute, Charlottesville, Va. “Bioethical Issues and the New Genetics”

October 4-5, 2000. Virginia Healthcare Ethics Network, Conference, Charlottesville, Va.

Ethics in Healthcare Institutions: New Issues, Controversies and Practical Considerations, "New Federal Confidentiality Rules" and Panel Discussion "Virginia Legislative Update" November 16, 2000, National Alliance for the Mentally Ill, Charlottesville Chapter "Medical Information Confidentiality: Legal and Ethical Issues" January 23, 2001, Medical/Surgical Staff, Wayne Memorial Hospital (Goldsboro, NC) "What's New in Bioethics." March 9, 2001, Conference: Third Party Rights and Risks: A Forum on Informed Consent by Persons Affected by the Study of Human Subjects Richmond, Va. "Pedigrees, Propaganda, Paranoia: Family Studies in Historical Context" May 6-8, 2001, Symposium: "American Eugenics and the New Biology: Perspectives and Parallels" The Banbury Center, Cold Spring Harbor Laboratory (NY) "Legal Impact of the Eugenics Movement" May 11, 2001, Conference: Genome Sequencing and Biology Cold Spring Harbor Laboratory" (NY) Session on Ethical, Legal and Social Issues of Genomic Research: "Manifestly Unfit? Buck v. Bell & American Eugenics." May 17, Carilion Memorial Hospital, "Making Research Ethical" Roanoke, Va. June 1, American Society of Law, Medicine and Ethics, Health Law Teachers Conference "Tuskegee and Eugenics" Boston, Ma.

Service:

School of Medicine

Human Investigation Committee (Alternate Member)

Gene Therapy Task Force

Medical Center Hour Advisory Committee

MA in Bioethics Admissions Committee

Professional and Community

Virginia State Bar Section on Health Care Law, Board of Governors

Virginia Bar Association Committee on Special Issues of National and State Importance, Chair, Subcommittee on Issues of Public Health and Bioethics

Mid-Atlantic Twin Study Advisory Committee, Medical College of Virginia, Virginia Commonwealth University (W.M. Keck Foundation Grant)

Digital Archive of Eugenics Advisory Committee, Cold Spring Harbor Laboratory, (Grant from the Ethical, Legal and Social Implications Research Program of the National Human Genome Research Institute, NIH)

Peer Review Activities:

Reviewer: Journal of Health Policy, Politics and Law Journal of Clinical Ethics

Annual Meeting Proposal Reviewer, American Society for Bioethics and Humanities:

Highlights For the Year:

A series of highly visible (page 1) feature articles beginning on November 26, 2000, in the Richmond Times Dispatch relied on my publications in the history of eugenics over the past 20 years, as well as recent research by my former student Gregory Dorr. The news

coverage moved legislators to introduce a resolution denouncing Virginia's role as a leading state in the "racial integrity" and "eugenical sterilization" movements that flourished during the first third of the 20th Century. When the Virginia General Assembly passed the resolution the same week that prominent journals in the sciences announced the completion of the sequencing of the human genome, additional media attention followed, as detailed below.

Electronic Media Interviews:

February 5, 2001 Virginia National Public Radio: With Good Reason

"Forced Sterilization in Virginia"

April 22, 2001 WBRA/WMSY/WSBN (PBS-Southwest Virginia) Blue Ridge Nightline

"Eugenic Sterilization"

May 10-11, 2001 WJLA (ABC TV News, Washington, DC)

"Forced Sterilizations"

(upcoming) June , 2001, WVTF (Virginia NPR)— "Eugenics Apology"

Print Interviews and Quotes:

November-May: Interviewed and quoted by the Washington Post, Baltimore Sun, Richmond Times Dispatch, Raleigh News Observer, Charlottesville Daily Progress, Associated Press, Legal Times, and Slate.com; additional articles published in the Akron (Ohio) Beacon Journal, Albany (NY) Times Union, Memphis, (TN) Commercial Appeal, and Norfolk Virginian Pilot, among others.

Selected to make a featured presentation on Ethical, Legal and Social Issues of Genetic Research at the annual Cold Spring Harbor Laboratory Human Genome Sequencing meeting, May 2001

Ann E. Mills

Presentations:

October, 2000, Virginia Healthcare Ethics Network, Conference, Charlottesville, Va.

Ethics in Healthcare Institutions: New Issues, Controversies and Practical Considerations

"The Future of the Healthcare System."

March 7, 2001, Conference: Developing Healthcare Ethics Programs, "Economic Aspects of Healthcare Ethics" with Edward Spencer

March 8, 2001, Conference: Developing Healthcare Ethics Programs, "Practical Issues in Developing an Organization Ethics Program."

March 9, 2001, Conference: Developing Healthcare Ethics Programs, "Cases in Organization Ethics"

March 9, 2001, Conference: Developing Healthcare Ethics Programs, "Compliance, Risk Management and Quality Assurance."

Peer Review Activities:

Articles:

“Managed Rural Healthcare and the Moral Market,” Business Ethics Quarterly. 2000
 “Organization Ethics in Health Care: The Physician’s Voice in Context,” Business Ethics Quarterly. 2000
 “Ethics, Law and Policy Needs Assessment in Three Health Care Organizations,” Journal of Clinical Ethics. 2001.

Book Reviews:

"Responsibility and Health Care – Who Cares?" Kluwer Academic Publishers 2000.

Margaret E. Mohrmann

Chaired the University's Program Review Committee for the School of Nursing.

Appointed to the School of Nursing Academic Advisory Council.

Completed first year of a \$100,000 grant from the Fannie E. Rippel Foundation for the spirituality and medicine curriculum.

Served on the Program Committee, as chair of the Religion Subcommittee, for the ASBH 2001 Annual Meeting (and will be presenting on 2 panels at that meeting).

Teaching Activities:

Fall 2000: History of Christian Ethics -- undergraduate lecture course
 Bioethics Internship Seminar -- undergraduate course
 Practice of Medicine mentor -- first-year med student course
 Spring 2001: Suffering, Medicine, and Faith -- graduate seminar
 Bioethics Internship Seminar
 Practice of Medicine mentor
 Spirituality and Medicine -- 4th-year med student elective

Served on 3 doctoral dissertation committees.

Reviewer for journal Ambulatory Pediatrics.

Presentations:

"Let Evening Come: Using Poetry to Teach About Spirituality at Life's Ending" (workshop, with Marcia Day Childress). 2000 Spirituality, Culture, and End-of-Life conference, AAMC, Dallas, TX, September 2000.

"Access to What? Love and Justice in Medical Care." Fall Lecture Series, Westminster Presbyterian Church, Knoxville, TN, October, 2000.

"To Choose Not to Be: Meanings of Suicide." Department of Pediatrics Ground Rounds, University of Virginia, February 2001.

"Paying Attention: Stories and Suffering" and " 'Why Me, Doctor?' Recognizing and Responding to Spiritual Distress." Seminars for Consortium Ethics Program, University of

Pittsburgh, Pittsburgh, PA, June, 2001.

"Spiritual Questions/Spiritual Responses," Caring for Caregivers: Long Day's Journey Into Night. Center for Literature, Medicine, and the Health Care Professions 9th Annual Summer Seminar, Hiram College, Hiram, OH, June 2001.

Jonathan D. Moreno

New Appointments and Professional Activities:

Office of the Secretary, U.S. Department of Health and Human Services, National Human Research Protections Advisory Committee

The Hastings Center, Fellow

Howard Hughes Medical Institute, Bioethics Advisory Board

Radiation Effects Review Board, National Research Council, Committee to Review the Dose Reconstruction Program of the Defense Threat Reduction Agency

National Heart, Lung, and Blood Institute, Data Safety Monitoring Boards

Institute of Medicine, External Reviewer, Report on Human Research Protection Program Accreditation

Melissa A Warfield Visiting Professor, Children's Hospital of the King's Daughters, Norfolk, VA

Grant Award:

Standards of Risk Disclosure by Surgeons, Rockefeller Foundation, \$178,000. Co-Chair, 2001-2003

Editorial Boards:

American Journal of Bioethics

Accountability in Research Bioethics

Journal of Clinical Ethics

Presentations (selected):

"Secret State Experiments on Humans," Institute of the History of Medicine, Goettingen University, Goettingen, Germany. June 29, 2001

"Ethical Issues in Research Involving Persons at Risk for Suicide," National Institutes of Mental Health Workshop, Washington, DC. June 7 -8, 2001.

"Fiduciary Knowledge and Moral Consensus in Bioethics," Annual Conference on the Human Sciences, George Washington University, Washington, DC. April 20, 2001.

"Secret State Experiments on Humans," Institution for Social Policy Studies, Yale University, New Haven, CT. April 18, 2001.

"Bioethics and Moral Consensus," Department of Philosophy, Carnegie-Mellon University, Pittsburgh, PA. March, 15, 2001.

"Ethical Issues and the Minimal Genome" (panel), American Association for the Advancement of Science, San Francisco, CA. February 19, 2001.

"How Much Progress Have We Made in Human Experimentation Ethics," Division of

Cardiology Grand Rounds, University of Virginia. January 23, 2001.
 "Protectionism in Human Subjects Research," Maryland Psychiatric Research Center.
 January 8, 2001.
 "More Ethical Issues in Clinical Trials," Janssen Pharmaceuticals, Princeton, NJ.
 September 6, 2000.
 "The NBAC Report on Research Involving Persons with Mental Disorders," Baylor
 College of Medicine Department of Psychiatry, Houston, TX. October 6, 2000.

Angelique M. Reitsma

Presentations:

A.M. Reitsma, G.T. Rodeheaver: "A New Antimicrobial Gauze Dressing", Presented at
 the 28th Annual Educational Conference and International Meeting of the Association of
 Professionals in Infection Control and Epidemiology (APIC), Seattle, Washington. June
 11-12, 2001.

Grant Applications:

The Greenwall Foundation, New York, New York. A.M. Reitsma, J. D. Moreno:
 "Ethical Regulations for Innovative Surgery: Development of Recommendations for
 National Policy and an Education Program." (June 2001)

Edward M. Spencer

Presentations:

"The Past, Present, and Future Possibilities of the Healthcare System, with Ann Mills and
 "The American Dental Association-Building a Consensus-Is This a Model For
 Organization Ethics in the Healthcare System?" Conference: *Ethics in Healthcare
 Institutions: New Issues, Controversies, and Practical Considerations*, sponsored by the
 Virginia Healthcare Ethics Network, Charlottesville, VA October 4-5, 2000.

With Horacio Zaglol, M.D., and Kathryn Weise, M.D., Developing slide presentation,
 "Ethics in Critical Care Medicine," for committee on Resident's Education, Society of
 Critical Care Medicine.

Selected Activities:

Consultant, Wayne Memorial Hospital, on Development of Clinical and Organization
 Ethics Programs. Goldsboro, NC, September, 2000.

Program Director: Conference: *Ethics in Healthcare Institutions: New Issues,
 Controversies, and Practical Considerations*, sponsored by the Virginia Healthcare Ethics
 Network, Charlottesville, VA October 4-5, 2000.

Program Director: Conference: *Developing Healthcare Ethics Programs*, sponsored by

the Center for Biomedical Ethics, Charlottesville, VA March 4-9, 2001.