

DIVISION OF MEDICAL ETHICS AND HUMANITIES REPORT JULY 2006 – JUNE 2007

EXECUTIVE SUMMARY

This year included significant advances in ethically controversial technologies such as genomics, stem cell research, and electronic medical records. The emerging and related epidemics of obesity and diabetes raised questions about personal responsibility and the public policy response. Infectious Diseases that evolve and emerge, like antibiotic-resistant bacteria and avian influenza, posed ethical challenges to professionals who must weigh the duty to treat against personal risk, and to institutions and governments who must reallocate resources and reassign priorities to actual, and even potential threats to public health. The disaster that followed Hurricane Katrina, the allegations of euthanasia, and the threat of biological weapons raised questions about the professional response to a public health emergency and possible constraints on personal freedom. Finally, long standing concerns about ethics at the end of life were reflected in the organ retrieval process called Donation after Cardiac Death and an innovative Advance Directive statute passed by the Utah Legislature.

DIVISION ACTIVITIES AND ACCOMPLISHMENTS:

Our Division provided a forum to discuss almost all of these issues in our regular Evening Ethics Discussion program (Page 17) and through special presentations to local and national audiences such as the Salt Lake City Rotary Club, American Society for Bioethics and Humanities and American Academy of Pain Management. Our discussions involve individuals from many different disciplines, health care providers, and public policy makers. We've included guests who contribute special expertise to our dialogue. Mark Rothstein, J.D., a speaker at our annual Ethics Conference, Epidemics: Ethics, Edicts and Economics spoke about Public Health Emergencies: Containment, Strategies and Law. Stephen Reynolds, PhD, an economist on the University of Utah faculty, recounted some surprising information about the economic impact and recovery from epidemics. David Sundwall, M.D., the Executive Director of the Utah State Health Department and Robert Rolfs, M.D. our State Epidemiologist also spoke at the conference. The conference this year and our visitor Mark Rothstein were featured on KSL Television News. Mark and Kathy Supiano hosted our February Evening Ethics Discussion about Utah's new Advance Directive statute on the evening of the day in which the statute passed. Charles Sorensen, M.D., Vice President of Intermountain Healthcare, hosted a discussion called the "Ethics of Business and the Business of Medicine: Which Principles Apply?" which drew leaders from the healthcare community and the business community together to discuss this intriguing topic.

Over the year, we've continued all of our regular programs: our newsletter, *Medical Ethics in Utah*, Evening Ethics Discussions, Resident Teaching Conferences, Literature and Medicine Discussion groups, Medical Student Ethics Course, Senior Medical Student Electives, and Scientific Integrity seminars. These are designed for medical students, medical residents, academic and community physicians, other health professionals, and interested members of the public. We have continued a semi-annual program of presentations and facilitated discussions about medical ethics at Ophthalmology Grand Rounds.

In addition to our distinguished visitor Mark Rothstein, who gave the keynote talk at our Annual Conference, we also hosted Chris Feudtner, M.D., PhD, M.P.H, as our David Green Memorial Lecturer. Chris gave a provocative talk entitled “Beyond Decision Making: Ethics and the Everyday of Pediatric Palliative Care” at Pediatric Grand Rounds. He also was scheduled to present a lecture to our senior medical students in the context of their 4th year ethics course. On the spur of the moment he dropped his original topic and gave a superb extemporaneous talk about communicating bad news which was perfectly matched to the theme the students were studying on that day.

Our Division members provide medical ethics consultation and serve on and collaborate with the LDS Hospital, CW/AV Hospitals, University of Utah Medical Center, and PCMC Ethics Committees.

We have continued our search for a Nurse Ethicist to join our Division. Support for that position will be shared by LDS Hospital and the University Of Utah College Of Nursing. In January we invited Pamela Grace, PhD, RNCS, ANP, Assistant Professor of Adult Health and Ethics at Boston College. She did an excellent job at sustaining and increasing interest in ethical issues for nurses at both institutions. Because another extraordinarily well qualified individual emerged as a candidate, we have elected to continue our search into the next academic year. We are hopeful that we will be able to entice this remarkable individual to join us.

DIVISION MEMBER UPDATES:

Division members have 18 articles, 10 book chapters, and 5 books published or in press. We made dozens of presentations at local, state, national and international meetings. Division members are frequently invited to comment on ethical issues for local radio, television and newspaper media. Peggy Battin, Leslie Francis and Jay Jacobson, in collaboration with Dr. Charles Smith and Research Associate Linda Carr-Lee, have nearly concluded work on a book about Ethics and Infectious Diseases, which is under contract with Oxford University Press.

Peggy Battin has helped plan and made personal presentations at the most important international meetings in our field. She continues to write prolifically and her focus now has expanded from ethical decisions at both ends of life to include ethical problems linked to infectious diseases. Peggy has been leading our Division-wide effort to complete a book with a more expanded and coherent practical and theoretical examination of ethics and infectious disease.

Jeff Botkin, who is our Associate Vice President for Research Integrity, has continued to lead innovative programs in that capacity. He holds positions at a national level that draw on his strengths as an ethicist, pediatrician and physician knowledgeable about genetic issues. He now serves on the Board of Directors of the American Society of Law, Medicine and Ethics. He is a member of the ad hoc Pediatrics Advisory Committee of the FDA and a member of the DHHS Secretary’s Advisory Committee on Human Research Protection. He also serves on the Center for Disease Control’s Committee on the Evaluation of Genomic Applications and Practice and Prevention. In his capacity as Chair of the Pediatric Division of Medical Ethics, he has revived a program called geneSIS, which will help move research ideas from bench to bedside and explore the ethical issues that new tests and technology always pose. Jeff has two projects currently underway that are funded by the Mountain States Genetics Network. One is laboratory-based and focused on functional characteristics of enzymes in stored blood spots, and the other one is both clinical and epidemiologic. It is a newborn screening surveillance program. Jeff also continues to be a frequent contributor to the

literature in ethics related to his domains of scholarship. His publications appear in the leading ethics journals as well as the premier journals in his medical specialties. These include: the *American Journal of Medical Genetics, Pediatrics*, and the *Journal of Clinical Ethics*. Jeff also did an excellent job this year directing our required course in Medical Ethics for senior students. This course continues to earn student ratings that are among the highest for courses at our medical school.

Armand Antommara, who for several years has been a member of the Primary Children's Medical Center Ethics Committee, now serves as its Chair. He's also on the national Ethics Committee of the American Academy of Pediatrics. He is now making good use of the training he received as a Fellow in the Medical Scholars Program at the University Of Utah School Of Medicine, and his certification in the mediation program offered by the University. Armand's publications are now finding a home in prestigious journals in our field, including: the *Kennedy Institute of Ethics Journal*, the *Journal of Law and Family Studies*, and *Teaching Ethics*. Armand was a featured panelist at the American Society of Bioethics and Humanities' annual meeting last October, where he joined other ethicists to speak about mediation as an approach to solving ethical conflicts.

Leslie Francis continues to juggle her own multi-disciplinary responsibilities as Chair of the Philosophy Department and Chair of the Programs Committee at the Law School. She is a key member of our team that is working on the Ethics and Infectious Disease book project. Leslie and two colleagues have co-authored the new Blackwell Guide to Medical Ethics, which was published this year. Leslie's double disciplines in Law and Philosophy have made her a sought-after and very effective member on federal advisory panels. She now works on a panel charged with considering ethical issues that are raised in the course of generating and sharing electronic medical records.

Jay Jacobson continues his interest in the disclosure of medical error and on the relationship between physicians and the pharmaceutical industry. He maintains a regularly updated article about disclosure of errors on The American College of Physicians PIER online resource. He was the keynote speaker at the annual meeting of The American Academy of Pain Management, where he spoke about new ethical challenges to appropriate pain management. His work with Professor Cal Boardman of the University of Utah School of Business has resulted in the development of a multi-college, campus-wide Institute for Values and Applied Ethics.

Therese Jones has collaborated with our Program Associates to offer even more electives in medical humanities for senior students. She also plans to develop a program for 3rd year clerks in Internal Medicine to reflect on and discuss their experiences in real time. She will also bring her knowledge and teaching techniques to our other courses and conferences that involve students and medical residents. Her presence will help us extend and strengthen our interdisciplinary connections to the College of Humanities. These connections are also growing with the College of Law, the College of Nursing and the School of Business.

Program associates Mark Matheson and Susan Sample have continued to refine our Medical Humanities electives for senior students. Ali Choucair has led a task force to clarify the mission of the LDS Hospital's Ethics Committee and to improve its service to the hospital. Howard Mann continues to be cited as one of the best teachers in the Masters and Clinical Investigation program, which is funded by the NIH.

LOOKING AHEAD:

Next year looks especially promising with the possible addition of a new Nurse Ethicist and a new member of the Philosophy Department, James Tabery, PhD, who has substantial interest

and expertise in medical ethics and human genetics. We expect to expand our collaboration with interdisciplinary connections to the College of Humanities, the College of Law, The College of Nursing, and the School of Business.

Our greatest challenge remains sustainability and growth of our program. Our Division members and Program Associates all have major responsibilities in addition to their Division duties. Their financial compensation for Division work is at a token level or none at all. While virtue may be its own reward, it will be difficult to sustain the amount of uncompensated effort that our current colleagues provide. Also, as varied as our disciplinary training is, it would be desirable to add Division Members with partial support, who would bring us expertise in the area of health law and possibly added strength in medicine and the medical humanities. We hope to identify junior and mid-level scholars at our university who would collaborate with us and ultimately commit part of their time to our Division. Also, as requests for our services and the scope of our expertise expands, we would like to evolve into a Center for Medical Ethics and Humanities that more broadly serves the School of Medicine and the University of Utah. We will turn to our Development Advisory Board to help us design a plan for additional support that this will require.

We've launched an effort with the development team in the Department of Internal Medicine and the College of Humanities to identify key religious and medical leaders in our state who recognize the importance of a state and regional program in Medical Ethics and who will help us generate the funds necessary to provide an endowment that will assure the sustainability and growth of our program. People in the academic and larger community who contribute to our programs and who host our Evening Ethics Discussions continue to be most generous. Their names are listed on our acknowledgements page.

Our expanded efforts this year to include literature, poetry, drama, and film in our teaching and our emphasis on self-reflection and empathy support the broadening of our name to the Division of Medical Ethics and Humanities.

DIVISION ACTIVITIES

EDUCATION:

We focus on medical students, internal medicine trainees, academic and practicing physicians, other health professionals, and members of the public interested in ethical issues. Each year we conduct a two-week required ethics course for senior medical students, three 2-4 week electives focused on reading and writing about the doctor/patient relationship in film, drama and literature, a monthly literature and medicine discussion group for students, and one that meets even monthly for academic and practicing physicians. We plan and facilitate evening ethics discussion groups on topical issues for a multi-disciplinary audience. We present monthly resident ethics teaching conferences at each of the three hospitals that constitute the University of Utah Internal Medicine training program. We conduct a seminar series on Scientific Integrity that is required by the NIH as a condition of the grants awarded to our Medical School and University. We bring distinguished speakers to Salt Lake City and to our two sponsoring institutions on a regular basis. For this we use the funds available through the Cowan Memorial Lectureship and the David Green Memorial Lectureship.

INTERNAL MEDICINE RESIDENT ETHICS CONFERENCES:

The objectives of these conferences are to raise residents' awareness of ethical problems in medicine, to develop their skills in moral reasoning, and to offer them strategies and tools to resolve common ethical problems. We use a case-based format, pre conference quizzes, and helpful handouts and articles. We invite guests to co-facilitate the conference with a Division member, which provides at least two perspectives on each topic. When possible, we include a clinician with significant experience and skill related to our discussion.

Ten to thirty five people attend each of these monthly conferences, which we conduct at LDS Hospital, the VA Medical Center, and the University of Utah Medical Center. In addition to the internal medicine residents, attendees include third year medical students, nurses, social workers, and attending physicians. The topics of the conferences are listed on page 15. When asked to comment on the usefulness of the conferences, 83% of respondents gave a good or excellent rating.

STUDENT LITERATURE AND MEDICINE GROUP:

The purpose of this group is to satisfy the appetite of first and second year medical students to understand what "real medicine" feels like. It is also to help them prepare for the moral dilemmas they will face as physicians. We meet monthly with 30 to 40 students who read and discuss short texts and poems. Therese Jones leads these discussions.

PHYSICIANS LITERATURE AND MEDICINE DISCUSSION GROUP:

The purpose of this group is to assist physicians with reflection about and insight into the professional and personal aspects of medicine through reading and discussion of fiction, drama, and poetry. We are fortunate to have many distinguished facilitators who lead these discussions on a regular or occasional basis. They include Rachel Borup, Brooke Hopkins, Therese Jones, Mark Matheson, Aden Ross, and Susan Sample. Between 6 and 20 physicians and health professionals attended each of our 11 evening programs. The readings are listed on page 16.

EVENING ETHICS DISCUSSION GROUP:

The purpose of this group is to raise awareness of and explore new and controversial ethical issues. We read articles that appear in the lay press or medical journals. Participants come from a variety of disciplines and bring their professional and personal perspectives to the discussion. The discussions are held in the homes of division members or participants. They serve not only as a forum for the exchange of ideas, but have also led to the formation of task forces and public policy initiatives. Between 10 and 30 people attend these monthly discussions. When asked to rate the information gained from the discussions last year, 93% of respondents gave them a 4 or 5 on a 5- point scale. The topics are listed on page 17.

MEDICAL ETHICS IN UTAH NEWSLETTER:

The purpose of our monthly newsletter is to announce programs and activities related to medical ethics. We include excerpts from topical articles drawn from the national media. Linda Carr-Lee has provided background for and summaries of our Evening Ethics Discussions. We also use the newsletter to keep readers abreast of our Division members' activities. This free newsletter goes to over 600 readers throughout the state and region. An example of our newsletter is on page 21.

17TH ANNUAL INTERMOUNTAIN MEDICAL ETHICS CONFERENCE

Our conference this year, “Epidemics: Ethics, Edicts and Economy” on May 8th, featured distinguished speakers from the state and federal level as well as faculty from our own Colleges of Law, Humanities, and Social and Behavioral Science. It also gave Division Members an opportunity to share ideas and work from our collaborative book project on Ethics and Infection Diseases. More information about the conference and our speakers is on pages 18 and 19.

DAVID GREEN MEMORIAL LECTURES

Once again we were privileged to hear from one of our country’s most insightful and compassionate pediatrician ethicists. Chris Feudtner, MD, PhD, epitomized many of the qualities that made David Green such a remarkable role model. Dr. Feudtner engaged Evening Ethics participants in a discussion of his work. He delivered a thought provoking Grand Rounds lecture. To make it more relevant to the day’s theme, he made a last minutes decision to change his presentation to senior medical students to “Telling Bad News.” This memorable talk was surely a highlight of our course. The program for his visit is found on page 20.

MEDICAL ETHICS COURSE FOR SENIOR STUDENTS:

All 100 of our senior medical students take this two week required course. The curriculum and schedule is shown on, page 9. Every day includes lectures and small group discussions that are co-facilitated by a clinician and non-clinician. More than 20 faculty from medicine, nursing, and philosophy participate in this program. All Students write papers for the course about a medical ethics issue important to them. We award a cash prize for the best paper and record the authors name on a plaque. This Year we gave two awards for the two equally outstanding papers. We also published them in our newsletter. The awards were co-sponsored by the Campus Institute for Human Values and Applied Ethics based at the Eccles School of Business. Our course outline is listed on page 9.

Student Comments:

“It is a great opportunity to think about some major issues, and learn about the views of other people. I think this is a highly educational course in a lot of ways—appreciating diversity of thought, appreciating ethics in practice, figuring out how I feel about some issues

I normally don't consider very often. I also appreciate the exposure to the great faculty who put so much time into the discussions."

"It is a great course with very stimulating discussions. The content of the course is well thought out and put together."

"Very good at confronting ethical issues, and very practical to clinical medicine. Also, I thought the discussion groups were great giving us an opportunity to think about and voice how we might act in a certain situation."

"The topics and discussions helped me become more open-minded."

SCIENTIFIC INTEGRITY:

Over 200 graduate students and fellows participate in this series of seminars. Bryan Benham coordinates this course. Seminar topics are listed in the Appendices, page 11.

MEDICAL HUMANITIES ELECTIVES:

We offered a variety of 4th year electives under the title: Perspectives on Medicine: The Doctor-Patient Relationship in Literature and Film (page 12). The overall objectives are: 1) to gain insight into the doctor-patient relationship through the analysis and discussion of literature and film. 2) To learn more about the historical, social, and cultural contexts of medical practice. 3) To encourage discussion of relevant topics for which students' other course work and clinical practice allow little time. 4) To develop the skills of observation and interpretation, which are essential for clinical competence and professional development. 5) To consider diverse perspectives on medicine and to help students reflect upon and articulate their own roles in the medical profession. Therese Jones developed a new elective Reel Psychiatry: Cinematic Representations of Mental Illness. Susan Sample led a reflective writing elective. Mark Matheson, Therese Jones and Jay Jacobson led an elective focused on readings from different historical and personal perspectives.

We offered the course in a two-week and a four-week block. The students met for three hours daily, read and discussed a variety of texts and genres, viewed several films, and wrote reflective essays about their own developing Doctor-Patient relationships. The student responses to the course were powerful and positive:

I loved the course. Mark is an amazing professor, facilitator and humanist. He worked well with our crazy schedules and even brought us over to his home. He was always very prepared, and knowledgeable about the literature and author. At the same time was very inquisitive about who we were and always went further in relating the text to our point of view of medicine and to our own lives. He made us feel at ease to discuss the pieces and often astounded us with his point of view. It was simply a joy to attend the course.

I absolutely loved the course. Everything about the month, for me, was perfect. It was such a great break, and breath of fresh air, from my medical education up to that point, yet incredibly relevant, personally and professionally. The literature and film covered was compelling, interesting and thought provoking. The discussions and required writing was even more so. It was wonderful to have the opportunity to discuss, contemplate, explore and synthesize experiences as a student, doctor and patient, as well as relationships among them, as well as my relationship with self.

This year we introduced a new version of this elective focused on reflective writing about the doctor/patient relationship taught by Susan Sample (page 16). She used fine writing, much of

it by doctors as prompts to get students to begin writing in the genre of poetry, personal essay and memoir about their experiences. They responded with insightful and often very creative written work that expressed powerful emotions, both positive and negative, that attended their evolution from undergraduate to medical student to doctor. One piece was so moving it was read at graduation.

“Writing is a powerful way to take the experience one has had and make them more meaningful.

This course made me want to write more. It made me want to remember the details of my patient interactions. I am also more aware of how words are used and some of the deficiencies of the way I say things. Thank you for such a wonderful opportunity!

I feel my self-awareness has increased. Not so much through imaginations and creativity, but through prompts for introspections and time to just write and think.”

MASTERS IN CLINICAL INVESTIGATION PROGRAM:

A small group of physicians and fellows participate in this NIH supported program. It is designed to prepare them for careers in clinical investigation. Howard Mann teaches classes focused on Research Ethics, Clinical Trials, and the Institutional Review Board. Jeff Botkin emphasizes ethical issues in genetic research.

CLINICAL CONSULTATION:

Division members have been involved in numerous bedside consultations with patients, family and clinicians. We also participate with and assist the ethics committees in Salt Lake City Hospitals with clinical consultation. Division Members fielded phone calls from residents, nurses, physicians, and patients and families requesting advice and information. We make our extensive collection of articles and books available to these callers as well.

DIVISION WEBSITE:

The Division activities are updated regularly with the monthly calendar of events: *Medical Ethics in Utah* newsletter, Literature and Medicine Discussion Group readings; current and archived Internal Medicine Case Conferences, and Evening Ethics Discussion Group topics along with summaries of the discussions. Howard Mann's ongoing research ethics course for clinical investigators, Responsible Conduct of Research: Human Subjects Research, has the course outline and links to readings.

Our links to various resources are plentiful. Areas of special interest are state resources that include Utah's Personal Choice and Living Will Act with printable forms for the Living Will and Special Power of Attorney for Health Care. We have a timeline of key cases and events in Medical Ethics and many links to resources on death and dying, including The Partnership to Improve End-of-Life Care in Utah and *Finding our Way*, a newspaper series on end-of-life care in the U.S. We also supply links to sites about stem cell research and other timely issues. In a section called, Medical Ethics in the News, we provide an ongoing list of current ethics related articles from selected journals.

Information about Division Members is also available on our website. Our website link is <http://www.utahmedicalethics.org>