Community Consultation:
A New Approach to Scientific Research
Mariam Negaran

When Stanford University scientists first developed the Human Genome Diversity Project (HGDP) in 1991, they could not have anticipated the shockwaves it would send all over the world. Protests rang high as indigenous people angrily reacted to the project, which facilitated the collection of diverse DNA samples.

“[People] were very outraged about the fact that scientists would come in and take their DNA…while they hadn’t been consulted about it at all,” Pilar Ossorio, assistant professor of law and bioethics at the University of Wisconsin-Madison, explained. “They thought that they were either being stigmatized or having their origin myths undermined.”

In order to alleviate the situation, scientists at the National Institutes of Health (NIH) started thinking of ways to bridge the gap between the indigenous and scientific communities in the early 1990s. One of these ways was community consultation, a concept that would allow scientists to interact and learn more about ethnic communities, leading to discussions between community members and scientists. “Those initial meetings were NIH’s attempts to reach out to certain minority groups in this country to try and begin to build partnerships so that they could do things like actual community consultations,” Ossorio explained.

(Continued, p.5)

Committee Works to Create Guidelines for Stem Cell Research
Sophia Estante

Even without funding from the national government, stem cell research will continue in the United States—and the National Academies of Science (NAS) wants to create ethical guidelines that can guide researchers’ work in this controversial new field. The guidelines will be created by a committee, the Committee on Guidelines for Human Embryonic Stem Cell Research, and one of the 11 committee members is UW Medical School Professor Norman Fost.

“The Bush administration has no authority over most stem cell research because it is not funded by the government, and neither Congress nor the United Nations can agree on how to proceed,” Fost said. Researchers and committee members, which include scientists, ethicists, a community member, lawyers and doctors, also hope to reassure the public that the research is being conducted in an ethically acceptable way.

(Continued, p.7)
**Message from the Chair**

In the early twenty-first century, most major medical schools boast at least one department that includes scholars from ethics, history and the qualitative social sciences. Here at Wisconsin, we focus on medical history and bioethics. At UCSF, medical anthropologists and historians nestle together; at Harvard, ethicists join these two groups in the Department of Social Medicine; and elsewhere one finds more sociologists, health economists, and scholars in medical humanities added to the mix. The contributions these various departments make to the medical curriculum, to the general intellectual life of their medical schools, and to the work of the university as a whole, are significant.

This edition of the newsletter concentrates on developments in our bioethics program, but it also suggests the many ways in which work in ethics intersects with the interests of medical historians and social scientists. As you can see from the feature stories and descriptions of faculty work, our bioethicists and historians collaborate with researchers across the medical school, the biosciences, engineering, and the humanities. We also actively engage in state and national debates on matters of great importance to our collective social lives. At Wisconsin, the bioethics and medical history programs are flourishing—and we hope that another senior appointment will soon be made in bioethics.

We expect also to develop further over the next few years our expertise in health social sciences, especially in relation to population health. Working together, we will be better able to satisfy the increasing interest in our work across the university, especially in the new medical curriculum and the major recent initiatives in the biosciences and population health.

~ Warwick Anderson MD, PhD

---

**Science and Religion in Upper Dairyland**

In recent months school boards around the country—from Pennsylvania and Ohio to Georgia and Kansas—have challenged the dominance of evolution in public-school curricula. Although so-called young-earth creationists remain active, much of the current agitation comes from a group of evolution critics known as intelligent-design (ID) theorists. Rather than insisting that life on earth appeared no more than 10,000 years ago, and attributing the fossil record to Noah’s flood, the ID camp focuses on the “scientific” evidence of design in the world and calls for a revolutionary change in scientific methodology: the allowance of supernatural explanations. To avoid the constitutional barriers that stopped young-earth creationism at the schoolhouse door in 1987, ID advocates avoid any reference to the Bible and package their claims as strictly scientific.

Hostility toward evolution in America remains surprisingly strong. A recent CBS News poll showed that over half of all Americans believe that God created humans in their present form—and about two-thirds of them want creation to be taught along with evolution. A similar Gallup poll that 57% of Americans embraced or “leaned toward” creationism.

For the past two decades, and especially since the publication of his book *The Creationists* (Knopf, 1992), Ron Numbers has been trying to educate the American public about the origins and aspirations of the antievolutionists. Thus in the fall when the school board in Grantsburg, a small town in northwestern Wisconsin, called for the teaching of “various models/theories” of origin, not just evolution, it was not surprising that journalists turned to Ron for help in understanding what was going on in upper Dairyland. Stung by the national criticism they received, the Grantsburg school board in early December approved the following clarification:

> The policy may not call directly for the teaching of creationism or intelligent design, but, predicts Numbers, it will surely encourage it.

Students are expected to analyze, review, and critique scientific explanations, including hypotheses and theories, as to their strengths and weaknesses using scientific evidence and information. Students shall be able to explain the scientific strengths and weaknesses of evolutionary theory. This policy does not call for the teaching of Creationism or Intelligent Design.

The policy may not call directly for the teaching of creationism or intelligent design, but, predicts Numbers, it will surely encourage it.

Editor’s note: information for this news item was provided by Ron Numbers.
Jewish Responses to Stem Cell Research

Anneli Radestad

Ever since 1998 when James Thomson at University of Wisconsin-Madison first isolated and cultured human embryonic stem cells, ethicists and legislators have struggled with the moral and legal implications of stem cell research and therapy. When President George W. Bush in 2001 passed a federal policy setting restrictions on government-funded embryonic stem cell research, Jewish groups were in the forefront of efforts to reverse the Bush administration’s policy. Judaism brings a different twist to the ethical issues of stem cell research.

Stem cells can be derived from adult cells as well as from embryos. The adult cells, however, are already specialized and their potential to regenerate damaged tissue is more limited than embryonic cells. At UW, the stem cells used for research are derived from the small clump of cells that compose the fertilized egg just days following conception. “They are ‘left-over’ embryos donated by couples after attempts to in-vitro fertilization, Terry Devitt, science writer at University Communications explained.

Stem cells derived from the early embryo are capable of considerable variation in the kinds of tissues they make. If scientists learn to control cellular differentiation they might be able to create replacement cells and organs, potentially treating illnesses such as diabetes, and Parkinson’s disease.

Many Americans are concerned about embryos being destroyed for research purposes. But the argument takes a different shape in Judaism, which places central importance on efforts to save lives and improve health. This becomes a critical factor to a moral valuation of the destruction of embryos to pursue stem cell research.

Science journalism students Sophia Estante, Anneli Radestad and Mariam Negaran have contributed feature articles to this issue. Department faculty support good science journalism and hope to continue our positive relations with faculty, students and professionals in this field.

Stelarc

Visiting Artist Stelarc presented a multimedia artist lecture and demonstration on November 3rd in the Elvehjem Art Museum. Stelarc is an Australian-based performance artist whose work explores and extends the concept of the body and its relationship with technology through human-machine interfaces incorporating medical imaging, prosthetics, robotics, virtual reality systems and the internet. The interest is in alternate, intimate and involuntary experiences. Recently, he has developed strategies to augment the body’s capabilities, using prosthetics and computer technologies. He explores the question, “is the body as we know it obsolete?” through the use of interactive avatars with speech-response programming, computer-controlled bodily movements and tissue-engineered body parts that have programmed functions.

Stelarc has held a Visual Arts & Craft Board Fellowship from the Australia Council, and has held honorary professorships and artist-in-residence fellowships at Carnegie Mellon, the University of Hamburg, Monash University, Ohio State University, and Nottingham Trent University. He has presented his work extensively in Europe, Latin America, Australia, the U.S. and Japan. Stelarc’s visit to campus was co-sponsored by the Department of Medical History and Bioethics and the University of Wisconsin Visiting Artists Program.

Photos: Todd Brown
Pharmacists around the country are standing on conscience, refusing to fill prescriptions for birth control pills. Indeed, here in Wisconsin, a pharmacist not only refused, he would not refer the patient elsewhere or return the original prescription. By the time the patient had the prescription filled elsewhere, she had missed a pill.

The question of personal conscience in the face of obligations to provide patient care is not new. Physicians have been facing this dilemma for years, in the context of abortion services and requests for assistance in dying. For pharmacists, the question of conscience first arose with respect to emergency contraception (the so-called morning after pills, which can be taken for up to 72 hours after unprotected intercourse). It then moved on to situations involving requests for medications to facilitate assisted suicide, in those states where it is legal.

Pharmacists are licensed by the State of Wisconsin to provide professional services to patients seeking to fill authorized prescriptions. As a state-authorized monopoly for providing these services, pharmacists are, in many ways, akin to a public utility. In exchange for their monopoly, they take on an obligation to serve the general public in a non-discriminatory fashion. This obligation is enshrined in the Wisconsin Administrative Code Rules of the Pharmacy Examining Board, Section 10.03(9). Because oral contraceptives are taken exclusively by women and constitute basic health care for many women, refusing to dispense them has a disparate and discriminatory impact on women.

The ethical code of the American Pharmacists’ Association (“APhA”) calls for the pharmacist to “respect the autonomy and dignity of each patient.”

This pharmacist’s actions have a significant and dangerous effect on patient care. Patients exist in a world in which it is not easy to see a doctor, get a prescription, and have the prescription filled: they are busy, health care is expensive, and the process is inconvenient and sometimes confusing. Any barrier to receiving a prescription, even a transfer to a pharmacy next door, burdens the patient. Obstacles to obtaining care and filling prescriptions are magnified when the medication required is time-sensitive, as oral contraceptives are. Any barrier to time-sensitive medications seriously reduces the quality of health care patients receive, and puts their health at risk. For a woman waiting to receive birth control pills, a single day’s delay, just twenty-four to forty-eight hours, meant not just that she doesn’t get her medication, but that for a month she would not be able to engage in perfectly legal sexual activity without additional methods of contraception, inconvenience, and possibly increased risk to her health.

Pharmacists ought not be allowed to place their personal views above their duty to serve their patients. That is the essence of professionalism.
Community Consultation: A New Approach to Scientific Research

(Continued from front page)

Ossorio is currently developing the idea of community consultation in collaboration with colleagues Joan Fujimura, UW Professor of Sociology; Dan Hausman, UW professor of philosophy; and Richard Sharp, Assistant Professor of Medicine in the Center for Medical Ethics and Health Policy at Baylor College of Medicine, Houston, Texas.

Last February, Ossorio and her colleagues were awarded a three-year $1 million grant, "Community Consultation as an Ethics Method," by NIH to address the concerns of ethnic communities and develop a code of ethics for scientific research. The team specifically aims to develop the theoretical underpinnings for the practice of community consultation, conduct pilot empirical studies to determine how current consultations are done, and establish guidelines and policy recommendations to guide ethics oversight committees and NIH scientists in future endeavors. At this time, NIH scientists have a working relationship with native communities, such as the Yoruba tribe in Nigeria, which are interactions that they want to maintain. However, they have very little literature to guide them in their consultation, which is something Ossorio and her colleagues are trying to remedy. "They’re doing it because they think it will help, but they don’t necessarily have very good ideas of how to do it yet or what needs to be done to have a sufficient kind of consultation," Ossorio said.

Judith Greenberg, director of genetics and developmental biology at the National Institute of General Medical Sciences (NIGMS), a branch of NIH, has attended some community consultation meetings. The NIGMS has a collection of cell lines from many ethnic groups, a fact that concerns bioethicists, since scientists could use the cells in any way they please. "We started to hear from some people that we should really discuss these collections with communities because when you study a population, what you might learn can be extrapolated —either rightly or wrongly—to other members of that population," Greenberg said. "This is why it’s important to bring the communities in, explain what we’re doing and hear their concerns." Ossorio agrees, since there is a danger that the information gathered from willing participants of a certain ethnicity can be extended to the entire group.

Scientists used to believe that people whose ancestors are predominantly from one continent would be genetically similar. We now know that nearly all human genetic variation is found within any group of people. Individuals may be more similar to someone of a different race than their own. If a group under study is geographically concentrated, such as a particular tribe in which most members live on a small reservation, claims about genetic traits could be attributed to any member of the tribe, even persons who were not part of the research. This could create false assumptions with consequences for employment and social stigma. For example, if scientists were to research alcoholism in a particular Native American group and find that they have a propensity towards the disease, the conclusion could have negative impacts on the reputation of Native Americans throughout the U.S., regardless of their genotype. This could also lead to economic problems because potential employers may then refuse to hire Native Americans.

Because of such harmful possible outcomes, members of a group have a shared interest in the conduct and outcomes of a research project. Native Americans are a special case where community consultation is concerned because of their tribal sovereignty. By law, scientists must engage in consultations regarding anything in the tribal jurisdiction. Failure to properly consult with communities in the past has alienated some Native American communities, who continue to distrust the scientific community. As a result, even when Native American leaders come to a consensus on scientific research, it may be difficult to convince all tribal members to participate.

Donald Warne, a Lakota Indian and clinical professor at the University of Arizona at Tempe, believes that community consultation may help ease this lack of trust. He thinks that it is a good idea for the government to include Native Americans in decision-making. However, Warne says that federal agencies do not reach out to the communities very often when they make decisions, which can alienate the very group that scientists would like to test. "Federal agencies need to think of the Native American communities as important in order to include them and they need to adhere to their considerations, which is something that doesn’t always happen," Warne said.

Here is where the new wave of community consultation can be applied. Ossorio and her colleagues
Nanotechnology, the manipulation and control of matter at the atomic and molecular levels, is currently one of the hottest fields of scientific research and industrial development worldwide. Nanotechnologies enable the development of novel materials with applications in a wide variety of areas, including pharmaceuticals, biotechnology, disease detection, tissue engineering, cosmetics, electronics, information technologies, energy development, military technologies, and space exploration. Analysts predict that by 2015, the annual global market for nano-related products and services will exceed $1 trillion.

In September 2004, the University of Wisconsin received a five-year, $13.4 million Nanoscale Science and Engineering Center (NSEC) grant from the National Science Foundation (NSF) for research and development of materials for computers and electronics, antibiotics, biosensors, and other applications. The NSEC grant includes a $1.25 million “Initiative on Nanotechnology and Society,” which will explore the social, ethical, economic, environmental and political dimensions of nanotechnologies. The nanotechnology and society initiative also includes partners in the Program in Science, Technology, & Society at Harvard University and in the James Martin Institute for Science and Civilization at Oxford University. At UW, scholars in the Department of Medical History and Bioethics join sociologists, policy scholars, and engineers to study an array of social dimensions, including economic effects, patenting and property law, security, organization and the “knowledge economy,” and governance issues. Clark Miller (Lafollette School of Public Policy) is the co-principal investigator of the Initiative with projects led by faculty in five university departments.

One of the interdisciplinary projects funded by the Initiative on Nanotechnology and Society, led by Linda Hogle, Gregg Mitman and Maria Powell, will explore how scientists, industry, policymakers, media, and the public frame the potential health risks related to nanotechnologies. This team of scholars brings a unique combination of backgrounds and perspectives to the project. Linda Hogle brings expertise in the study of cultural, social, and legal-regulatory issues in emerging biomedical engineering technologies, as well as an understanding of interdisciplinary collaborations among researchers in complex, large fields of inquiry. Gregg Mitman’s expertise in cultural, medical and environmental history will provide important laypersons from diverse socioeconomic and cultural backgrounds construct and communicate their knowledge, emotions and uncertainties about environmental risks.

Hogle, Mitman, and Powell plan to explore several questions related to the potential health and environmental risks of nanomaterials. Although nanotechnologies promise many benefits, some scientists, regulators, and non-governmental organizations are concerned about the potential health and environmental consequences of their widespread production and use. Recent scientific studies suggest that the same properties that make nanomaterials so desirable for many applications may make them more toxic than existing materials. Many nanomaterials include metals and other potentially toxic materials, and researchers suspect that their small size will allow them to stay airborne longer and to more readily pass through human bodies and through air, water, and soil.

The group will pursue several questions, including what kinds of risk models and regulatory approaches are scientists, industries and regulatory agencies developing to assess the safety of nanomaterials, given these uncertainties and unknowns? Do risk assessments and regulations use compartmentalized, short-term models or broader ecological, long-term models—that is, models that consider whether and how nanomaterials might cross biological, social geographical, temporal and regulatory boundaries? How do the disciplinary backgrounds and the political, cultural and economic contexts of scientists, regulators, industry, media and public shape their risk models and understandings of uncertainty? How do interactions among different kinds of scientists, regulators, media, and the public influence the nature of the risk assessment models and the kinds of uncertainties and unknowns they consider? Finally, what can the histories of the development and use of other synthetic materials (i.e., PCBs, DDT, asbestos, pharmaceuticals, GMOs) tell us about how scientists, regulators and others develop risk models and regulations and about cross-disciplinary communications among scientists, regulators, media, and public? Findings from the UW Initiative will benefit government agencies and health risk researchers as they begin to consider how to regulate these materials.
Departmental Teaching

Courses in the Department continue to be popular among undergraduate, graduate and medical students. Departmental course evaluations reliably receive rave reviews from students. Across the board our instructors consistently receive a 4.4 or better out of 5 on nearly all the questions asked. A class on ethical problems raised by biomedical technology (taught by Alan Weisbard this spring), is consistently oversubscribed, and classes on such topics as abortion, women’s health, international health continually draw large numbers of students. New courses include “Science, Medicine, and Race: A History” to be taught by Richard Keller and Judy Houck, “Colonialism and Psychoanalysis” by Warwick Anderson and Richard Keller, and Linda Hogle’s “Ethics of Transplantation and Cellular Therapies” for medical students. Called the “hottest new class on campus” by the Wisconsin State Journal (“Class Focuses On Ethics Of Body Modification,” October 19, 2004, p.B1), Linda Hogle’s course on Bodily Modifications: Biology, Culture and Technology combined ethics, humanities and anthropology to discuss emerging trends in alterations and enhancementsto the body. Internationally-renowned, Australian artist Stelarc participated in the class, demonstrating his work on the intimate connections between humans and technologies in contemporary life (see related article, p.3).

Community Consultation

(Continued from p.5)

want to establish a way to tailor consultations to ethnic groups while understanding the differences between them. Ossorio hopes that working on community consultation will help alleviate some of the strain between the ethnic and scientific communities. However, consultation alone is not enough to ensure ethical scientific research. “The flip side is that just doing a consultation won’t ensure that the research is ethical,” Ossorio said. “If anything, consultation should be seen as one step in a process of ethical assessments of the research protocol, and we have such a process.”

Currently, there are few laws mandating community consultation. NIGMS director Greenberg also looks forward to a day when community consultation will be accepted. “It’s an idea that I hope is catching on. The scientific community was initially pretty resistant to the idea...but, I think they’ve realized that it is in fact a good thing, so, they’ve bought into it,” Greenberg said. “Whether it ever reaches the level of regulation, I don’t know, but I do know that many, many people are taking it very seriously.”

Guidelines for Stem Cell Research

(Continued from front page)

The NAS, a non-governmental, non-profit organization that develops policy, reports and books, often at the request of the government, created the committee in July 2004 in an effort to develop voluntary guidelines for stem cell research in the United States. The committee hopes to have a set of guidelines in place by February 2005 but realizes the process might take more time, Fost said.

Given the history of stem cell research, it makes sense that NAS would want a UW-Madison representative like Fost on the committee. In 1998, UW-Madison biologist James Thomson first isolated stem cells, which are cells that have not yet differentiated into specialized cells such as nerve and blood cells. The scientific community immediately saw the possibility of using these undifferentiated cells to treat a number of diseases, including Alzheimer’s and paralysis, by growing healthy new tissue from them.

Although regulations guiding stem cell research are relatively new, the committee has a lot of information to work with. Other countries, including Canada, the United Kingdom and Australia, have written guidelines—as have many institutions and private industries doing work with stem cells.

The committee also gathered information on the guidelines ethicists and scientists developed for DNA research when that field of study was new in the 1970s. (Continued, p.8)
Committee Works to Create Guidelines for Stem Cell Research

Sophia Estante

At the time, researchers and the public worried, for example, that DNA from pesticide-resistant crops would mix with DNA from weeds through crossbreeding, resulting in hardy weeds that farmers wouldn’t be able to kill, Fost said.

“The NAS committee was set up in the spirit of the 1970s Asilomar conference, which brought together recombinant DNA researchers to set voluntary guidelines to ensure the safe pursuit of what was then a new technology,” said Alta Charo, professor in the Department of Medical History and Bioethics and an ethics advisor to the NAS committee. “This committee, too, is set up to develop voluntary guidelines for the pursuit of embryonic stem cell research, as the absence of significant federal funding has left the federal government in a weak position to set ethical guidelines on a national level.”

But the research contains possibilities beyond curing life-threatening diseases. Referring to scenarios as seemingly far-flung as growing a human brain in a pig’s body, Fost said, “We’re reviewing all the existing information, but we’re also thinking of other scenarios—things that have not been addressed.” Charo agreed that one of the main challenges the committee faces is thinking through all the ‘what-ifs.’ “This research is evolving very quickly, and it is difficult to envision all the forms that the research might take, thus making it difficult to set guidelines now to cover all situations,” Charo said. “For that reason, there is a need for basic guidelines as well as a mechanism for revisiting those basic guidelines on a periodic basis.”

Fost said the committee is addressing issues ranging from how scientists acquire stem cells to anticipating what might happen if researchers transplant stem cells into patients. The issue of how scientists obtain stem cells is particularly controversial. Although the cells may be acquired from existing stem cells, aborted fetuses and adult humans, the idea of growing human embryos for the purpose of harvesting cells has also been raised, Fost said.

Although the public and policy makers have an interest in how researchers acquire stem cells, in particular because of the strong views people have on the issue of abortion, scientists working with stem cells want guidelines more than anyone, according to Fost.

“Lack of uniformity in guidelines, or the complete absence, is actually a barrier to doing research,” he said. “For example, WiCell leases stem cell lines developed by James Thomson to investigators all over the world, and requires those investigators to agree to guidelines established at the University of Wisconsin. If an investigator receiving those cells works at a university with different guidelines, he or she may not be allowed to use them.”

Charo said, “The guidelines must be flexible enough to be useable by many kinds of institutions where research takes place—universities, private companies, consortia involving researchers in other countries.” Ideally, all groups working with stem cells would adopt the NAS committee’s guidelines. If not, said Fost, “their effectiveness in facilitating research and reassuring the public would be limited.”

Jewish Responses to Stem Cell Research

Anneli Radestad

“[In Judaism] the very notion of life is different,” Professor Alan Weisbard of the Department of Medical History and Bioethics at University of Wisconsin-Madison said. “When life starts depends on how you ask the question and that is where I think the different religions come to different conclusions,” he said. “While many Catholics and Protestants assume that life starts at conception and that the pre-natal phase is equal to life following birth, Jewish law states that the fetus does not attain full human status until birth.”
A Moving Opportunity
Micaela Sullivan-Fowler

The Rare Books and Special Collections in the Middleton Health Science Library at the University of Wisconsin at Madison, moved in June of 2004. The Collections are now housed in the Ebling Library within the new Health Sciences Learning Center (HSLC). The HSLC was designed with collaboration in mind. The Ebling, covering two floors, coexists with the Medical School on the other two floors. Across the street from the HSLC is the School of Pharmacy, and through a corridor from the HSLC are the School of Nursing and the UW Hospital. This interdisciplinary layout encourages health science students of all “stripes” to interact in ways that will eventually impact professional collaboration as well as encourage empathetic attitudes towards their common as well as specialized roles in patient care and research.

Central to this environment is the presence of the Historical Services Unit. Our space on the third floor is visible from many vantage points in the HSLC because of its atrium and balcony layout. The Historical Reading Room with four large exhibit cases, wireless access, comfy coaches, large study tables and comfortable lighting has already become a favorite of health science students, weary practitioners, and the occasional history student (we are now geographically removed from central campus, which is one of the shortcomings of such a move). We look forward to imparting a historical sensibility to previously untapped patron groups. Through our collections and exhibits, we hope to visually and programmatically impact their education and practices.

In addition to the move we were able to hire a Historical Services Librarian. His name is Greg Prickman, and he is responsible for the increased images and content we have on our web pages. He is also responsible for much of our exhibit design, for providing back up reference service, for eventually processing our in-house archives and artifacts, and for reorganizing our Vault (another of the shortcomings of the move, we didn’t get our collection arranged perfectly in its new environmentally controlled space).

We are confident that we can continue to serve undergraduates, graduate students, faculty and visiting scholars in our usual fashion in our wonderful new “digs.” Here’s our new contact information:

Micaela Sullivan-Fowler ~
Curator of Rare Books and Special Collections
Greg Prickman ~
Historical Service Librarian

University of Wisconsin-Madison
Historical Services Unit
750 Highland Ave.
Madison, WI 53705
msullivan@library.wisc.edu
gprickman@library.wisc.edu
Micaela (608) 262-2402
Greg (608) 262-4421

Jewish Responses to Stem Cell Research

To explain the Jewish response, Weisbard recalled a passage from the Talmud. It states that traditional mourning rituals do not apply to a miscarriage that happens during the first 40 days of the pregnancy. “The first 40 days the fetus is seen as ‘merely water’… although there are varying interpretations of the status of the early embryo,” Weisbard said.

According to a report on Israeli stem cell research written by the Bioethics Advisory Committee of the Israel Academy of Sciences and Humanities, The Jewish Law distinguishes between six stages of human maturation from the first phase of the pre-implantation embryo which begins with the fusion of the sexes, until the “dislodged” fetus at the start of thesecond stage of labor. Only when the newborn’s head is fully visible does it acquire full human status.

“There is a question of how to characterize the developing embryo and fetus before the time of birth. Abortion during the course of the pregnancy is not without moral concern. But the fetus is not an entity on its own with the same kind of moral value as an adult,” Weisbard said.

So does Judaism have an issue with embryos that are specially made for stem cell research? “Well, there is no consensus on that question yet. Nevertheless, many rabbis oppose the deliberate creation of embryos for the purpose of their destruction, as this would cheapen the value of human life,” Eisenberg said.

(Continued from p.8)
News from Current Faculty

With Professor Adele Clarke (UCSF) ***Warwick Anderson*** has been offered a one-month residency at the Rockefeller Center in Bellagio, Italy on Lake Como, to work on a project on the gloabalization of biomedicine in June-July 2005. His book, *The Cultivation of Whiteness* was awarded the W.K. Hancock prize in 2004, the major book award of the Australian Historical Association. A second Australian edition will be issued by Melbourne University Press early in 2005. Duke University Press will publish *Colonial Pathologies: American Tropical Medicine and Racial Hygiene in the Philippines* early in 2006, along with a US paperback edition of *Cultivation of Whiteness*. In February 2004 Anderson delivered the John Fulton Lecture at the Beaumont Medical Club of Yale University, and in December he gave a series of lectures at Academia Sinica in Taiwan.

***Tom Broman*** served as Local Arrangements Committee Chair for the American Association for the History of Medicine meeting last April. Broman has been awarded the National Endowment for the Humanities Fellowship to finish his book on the press and the emergence of the public sphere in 18th-century Germany. It is tentatively titled "Journalism and the Ideology of the Public in Enlightenment Germany."

***Alta Charo*** continues to be a leader in national service in bioethics and medical law. In November she was the Swarsensky Scholar in Residence at Temple Beth El, speaking on comparative religious views on the acceptability of altering "natural" processes in human reproduction. Charo serves on the Institute of Medicine Committee to Examine the HIVNET Maternal-Child Transmission Prevention research in Uganda and on the National Academy of Sciences Institute of Medicine committee to develop voluntary guidelines for embryonic stem cell research, and the Institute of Medicine committee overseeing the implementation of the smallpox vaccine program in the US, and was recently named to the Planned Parenthood Federation of America’s National Medical Committee. She was a keynote speaker for the Wisconsin Academy of Arts, Sciences & Letters public lecture series at the new Overture Center in Madison, and a plenary speaker at the annual meeting of the United Resource Network (a national transplant group).

Another leader in bioethics service is ***Norm Fost***, who served as a member of FDA Pediatric Drug Advisory Committee, which recently reviewed relationship between SSRI’s and suicidal behavior in adolescents, leading to a "black box" warning on the label. He also served as a Member of the National Academy of Sciences – Institute of Medicine Committee on Guidelines for Stem Cell Research (see related story on p. ) Fost chaired a panel discussion at October meeting of ASBH on "Evolving Dilemmas in Newborn Screening." Fost continues his work on the use of human growth hormone and the regulation of research and innovative therapy, including restrictions on performance enhancing drugs. Pediatric endocrinologists and ethicists were once unanimous that use of human growth hormone and the regulation of research and innovative therapy, including restrictions on performance enhancing drugs.

---

MHB Faculty in the news

---

***Charo, A.*** Appeared on local radio and television multiple times, as well as twice on the Al Franken show.

***Numbers, R.*** "A Big Bang For Creationism,”

***Fost, N.*** "Voice of Dissent in Drug Wars; Taking the contrarian's view, Dr. Norman Fost says risks of steroid use have been exaggerated and athletes should be allowed to take them,”
Cited in: Los Angeles Times, Calif.: May 9, 2004. pg. D.1

***Fost, N.***, "Revelations Only Confirm Suspicions About Drugs,”

***Fost, N.***, "Ethics Guru: Steroids No Big Deal”

***Hogle, L.*** "Class Focuses On Ethics Of Body Modification,”

***Houck, J.*** , "Crabby? Bloated? Some Are Skeptical, But New Studies Point To A Male Counterpart To Menopause: Irritable Male Syndrome” Cited in:

***Houck, J.*** Study Casts Doubt on Limits to Fertility”

***Streiffer, R.*** "Of Mice, Men and In-Between”

***Weisbard, A.*** “Real Bodies Make For Real Learning”
News from Current Faculty

Fost has been working on ways of achieving a more rational approach to regulatory structures, which have resulted in increasing regulatory burden, impacting returns on innovators’ investments. In particular, the potentially dangerous arena of innovative therapy continues to grow with little oversight, abetted by ethically and legally problematic marketing techniques by the major pharmaceutical companies.

To monitor the health of populations and to evaluate the benefits of different policies, economists and health analysts would like to be able to measure health. But since health states differ so much from one another, health analysts have concluded that the most they can do is to evaluate health states. As a philosopher who is interested in conceptual and ethical issues and who has done a good deal work with forms of economic evaluation, Dan Hausman has become very interested in the difficult problems that the attempt to value health states raises. In particular, he questions whether health states should be valued by the extent to which they satisfy preferences. Hausman does not believe that anyone has come to terms with the conceptual difficulties involved in the task of valuing health states. Dan participated in a two-day workshop on the regulation of stem cell research sponsored by the National Academies of Science on October 12 and 13 and in an Institute of Medicine Workshop to evaluate measures of health benefits for environmental, health, and safety regulation on November 30. He also made a presentation at the National Institute of Health on December 7th on philosophical issues concerning the measurement of health.

Linda Hogle’s current work explores ways to rethink ideas about what counts as evidence with emerging technologies, and how this may inform new designs for technically and ethically appropriate trials. What is the nature of evidence when evaluating novel biological or combination therapeutics with unknown effects in humans? Decades-old approaches based on drug testing models (animal trials followed by large-scale, randomized human trials) have been the accepted “gold standards” for evaluation of new products and therapies. However, with many of the emerging cellular and hybrid therapies (such as cell-based microchips, engineered tissue or nanoscale drug delivery systems) there are few existing models with which to evaluate functionality, efficacy or safety. Computational methods are increasingly relied upon to create multiscale models and predictive simulations, but these techniques do not fit easily into a century-old regulatory scheme, such as we have in the U.S. In addition to research sponsored by the National Science Foundation and Greenwall Foundation on regenerative medicine, she has served as an advisor on the Canadian Regeneration Research Network Expert Panel, the European Science Foundation Advisory Council on regulatory affairs and tissue engineering, and an NSF-sponsored project to analyze risk and risk models in the use of xenogeneic materials. She is a member of Innovia, a network of European, Asian and American scholars working on social and ethical issues in emerging technologies and their assessment.

Judy Houck’s book, Hot and Bothered: Women, Medicine and Menopause in America 1900-2000 will be forthcoming in 2005. Menopause has frequently been cited as an example of the medical take-over of a natural process. This book examines this process of medicalization and challenges some of the widely held assumptions about how menopause came to be understood as a deficiency disease that required medical intervention. By examining the history of menopause over the course of the twentieth century, this book shows how the experience and representation of menopause has been profoundly influenced by biomedical developments and cultural shifts in the valuation of women.

An excerpt from Richard Keller’s book manuscript on psychiatry and colonialism will appear in the Bulletin of the History of Medicine. He has also been working on related articles, including one on the links between colonial medicine and the globalization of public health, and another on the place of everyday suffering and violence in Algerian literature. This winter Keller begins a new project, with the support of the UW’s Center for Interdisciplinary French Studies. This will be a social history of the deadly heat wave that gripped France in the summer of 2003. Keller and Warwick Anderson will be co-directing a graduate seminar, “Imagining the Global Unconscious: Histories and Literatures of Colonial Psychoanalysis.” The course is being taught in preparation for an international meeting on “Unconscious Dominions: Comparing Histories of Psychoanalysis, Empire, and Citizenship,” which will be hosted at UW in October 2005 thanks to the generous sponsorship of the UW’s International Institute in (see http://www.intl-institute.wisc.edu/ResearchCircles/Unconscious.htm for more information).

Following in the footsteps of Judy Houck, who visited Taiwan in May, Judy Leavitt traveled to Taiwan in November, 2004. She gave talks at Tsing Hua University and at the Kaohsiung Medical University in Kaohsiung, in the southern part of the country. Hsiu-yun Wang, UW PhD, 2002, hosted the visit and did on-the-spot translations. The students and faculty Leavitt met were lively, well read, eager, and charming, as you can see in the photo of Leavitt and Wang with faculty and staff from the Graduate Institute of Gender Studies at KMU. Leavitt talked about her new (Continued, p.12)
News from Current Faculty

project on fathers and childbirth, the history of childbirth in general, Typhoid Mary, and participated in a panel discussion about some current public health implications of Mary Mallon’s story.

Judith Leavitt and Hsiu-yun Wang with students and faculty at KMU Graduate Institute of Gender Studies, November 2004.

Gregg Mitman is spending the 2004-2005 academic year as the Glaxo-Smith-Kline Senior Fellow at the National Humanities Center in Research Triangle Park, North Carolina, with the additional support of the American Council of Learned Societies. He is hoping to complete writing the major portion of his book, Breathing Space: An Ecological History of Allergy in America (Yale University Press), while in residence. This fall, while at the National Humanities Center, he also wrote a major historiographic article, “In Search of Health: Landscape and Disease in American Environmental History,” that will appear as the lead essay in the April issue of Environmental History. In 2004, Landscapes of Exposure: Knowledge and Illness in Modern Environments, which he co-edited with Michelle Murphy and Christopher Sellers, was published by the University of Chicago Press. He also had articles appear this year in the Journal of Allergy and Clinical Immunology and History and Philosophy of the Life Sciences.

Ron Numbers is on leave from teaching this year while finishing Science and the Americans: A History, which will eventually be published by Basic Books. He continues to co-edit (with David Lindberg) the eight-volume Cambridge History of Science, three volumes of which have now appeared (edited with David Livingstone) on Modern Science in National and International Context. On January 20th Ron gave a special 2-hour seminar on creationism for the Evolution Discussion Group. Also participating were Michale Zimmerman (Dean, College of Letters and Science, UW-Oshkosh), and Don Waller (Department of Botany, Gaylord Nelson Institute of Environmental Study). As a sought-after commentator on issues of religion and science, Ron has been interviewed by several newspapers regarding recent controversies over the teaching of intelligent design (see article p.2).

Over the past decade researchers, institutions and research sponsors have engaged in various forms of discourse with minority and indigenous populations in the US and abroad. These “community consultations” are an increasingly common adjunct to genetics research, particularly for projects aiming to create a repository of tissues and information for use by multiple researchers. Although numerous community consultations are underway, there is no agreement on which ethics and policy goals consultation can address, and which methods of consultation are best for addressing particular goals. Pilar Ossorio is leading a 3 year, $1 million project to study the theoretical grounding of consent and concerns about oversight. Funded by the National Institutes of Health, a working group of 20 scholars from diverse disciplines are collaborating on this timely topic (see related cover story).

Rob Streiffer’s recent work focuses on the creation of chimeras through the xenotransplantation of human embryonic stem cells into prenatal animals. This topic has been a subject of recent controversy, even within groups that are in general supportive of embryo research and human embryonic stem cell research. The emerging bioethics literature on this topic has focused on numerous ethical concerns arising from the societal perspective, but the existing literature does not yet examine this research from the perspective of the animal. Streiffer argues that on two plausible accounts of moral status, such research opens up the theoretical possibility of enhancing the moral status of the animal. Since most moral evaluation of research presupposes a given moral status of the subject, this possibility raises novel ethical issues that have yet to be addressed in the literature. Streiffer is constructing a taxonomy of moral principles for evaluating the enhancement of moral status and exploring their implications. On at least some of them, research that substantially enhances an animal’s moral status is, in all likelihood, an egregious wrong.

Streiffer also continues to work on genetically engineered food, and is currently analyzing ethical objections that the Ojibwa have raised to genomics work on wild rice taking place at the University of Minnesota.

Alan Weisbard continues his work on Jewish bioethics and serves on a committee for the AAAS related to this topic. In particular, he currently has an interest in how stem cell research is viewed among Jewish communities, including in Israel (see related story, p.3).
Recent Publications


**Fost N.** “Conception for donation,” JAMA 291(17):2129-2126, 2004 (May 5)

**Fost N.** “Conception for donation,” (Reply to letters) JAMA (in press, 2004).


**Mitman, G.** “In Search of Health: Landscape and Disease in American Environmental History,” will appear as the lead essay in the April 2005 issue of Environmental History.


**Streiffer, R.** Forthcoming. “Academic freedom and industry-imposed restrictions on academic biotechnology research.” The Kennedy Institute of Ethics Journal.


**Streiffer, R., and Alan Rubel.** "Respecting the Autonomy of European and American Consumers: Defending Positive Labels on GM Foods: The Journal of Agricultural and Environmental Ethics.


New Project Assistants & Postdoctoral Fellows

Fred Harrington: Fred is currently serving as the Project Assistant for the "Community Consultation as an Ethics Method" project that is under the guidance of Pilar Ossorio as the Principle Investigator and Dan Hausman, Joan Fujimura, and Richard Sharp (Baylor School of Medicine) as Co-Investigators. He is a third-year doctoral student in the Department of Philosophy with a focus in both bioethics and ethical theory.

Maria Powell is a postdoctoral researcher working with the Health, Environment and Risk group on the Initiative on Nanotechnology and Society. She holds a B.A. in biology, an M.S. in environmental studies at the Gaylord Nelson Institute, and a joint Ph.D. from the University of Wisconsin, Madison in environmental studies and journalism and mass communication. For her dissertation, she examined public uncertainties about the health risks from eating contaminated Great Lakes fish.

Using both qualitative and quantitative methods, she found that laypersons’ risk uncertainties primarily reflect social, political, communication and ethical questions—such as why no one prevented Great Lakes contamination in the first place, who will clean it up, and why media don’t say more about the health risks or the causes of this problem. These findings imply that scientists, policymakers, and risk communicators should openly address peoples’ uncertainties and moreover, should find ways to engage lay citizens in discussions about these issues early on in the process of technology development.
News from current and former affiliates


Charlotte Borst is the winner of the History of Education Society’s biennial prize for the best article in the history of education for the article “Choosing the Student Body” which appeared in the History of Education Quarterly. She was invited to present her work and receive her award at the annual meeting in November 2004 in Kansas City.

Barbara Clow is currently Executive Director of the Atlantic Centre of Excellence for Women’s Health, and Associate Professor Research, Faculty of Health Professions at Dalhousie University in Halifax, Nova Scotia.

Richard Davidson and his colleagues formed a group called Driving Votes that helped people plan trips to battleground swing states to register Democratic voters. The group was endorsed by Michael Moore. His band, Radio Nationals (www.radionationals.com), was also on the campaign trail. Davidson was interviewed by ABC news and the Seattle Post-Intelligencer: http://seattlepi.nwsource.com/local/171684_voted03.html?searchpagefrom=1&sear.

Diane Edwards is editing reports for the Montana State University Water Center and other groups on campus. She continues to write and edit for the American Society for Microbiology.

W. Bruce Fye is Professor of Medicine and the History of Medicine at the Mayo Clinic College of Medicine and a cardiologist at Mayo Clinic. He is co-editor of Profiles in Cardiology: A collection of profiles featuring individuals who have made significant contributions to the study of cardiovascular disease, edited by J. Willus Hurst, C. Richard Conti and W. Bruce Fye. Mahwah NJ: Foundation for Advances in Medicine and Science, 2003, 514pp. He is currently researching and writing a history of cardiology at Mayo Clinic. His main areas of historical interest are 19th and 20th American and European medicine and physiology, professionalization and specialization, and the history of cardiology.

Ralph Gordon is at Western Michigan University and will be teaching “Race, Medicine and Health” and History of American Medicine” with Dr. Luis Toledo. His historical research continues to involve the history of medical education, the United States Christian Commission, and some Civil War topics. He recently completed a study of the Andersonville Prison Camp in Georgia and has found the politics of Lincoln and Stanton almost unbelievable in regard to that horrible debacle.

Patricia Harris is a faculty geriatrician at the Washington Hospital Center, making house calls to frail African American elderly in Washington DC. She is an assistant professor in the School of Medicine at Georgetown University. She was selected by the Department of Health and Human Services to be a Health Policy Fellow in Primary Care for 2004 (one of 30 fellows in the country this year). She also does research on caregiver burden and health outcomes in a house call program. She is always looking for collaborators to work on other social policy/social medicine/population health and its history.

Dianna Kalandros is now the Program Coordinator for a partial hospitalization program for seriously mentally ill adults at Friendship Community Mental Health Center.

Robert Oliver has recently relocated to Air Combat Command at Langley Air Force Base, VA. His duties focus on conducting research in classified areas concerning the USAF combat mission, including acquisitions and development of new weapon systems. He has been contracted by Praeger Press to produce a book on the cultural history of the veteran’s return from war in America since 1900.

In addition to establishing the Society of Philippine Health History as reported in the previous newsletter, Willie and Anna Ong have set up a medical museum with a collection of over a thousand rare photographs and old documents, write a monthly column on medical history in Health and Lifestyle Magazine, have given the first lecture on medical history to students of the University of the Philippines College of Medicine, and have contributed a chapter on Philippine cholera epidemics in the upcoming book by Dr. Milton Lewis for Routledge press. Their plans for 2005 include finishing a Coffee Table Book on Philippine Medical History and producing a 1-hour documentary on Philippine medical history to be shown to health care students and college students.

Susan Smith’s book *Japanese American Midwives: Culture, Community, and Health Politics, 1880-1950* is forthcoming from the University of Illinois Press. She received a University of Alberta Faculty of Arts Research Excellence Award (Associate Professor) and the Department of History and Classics first annual Teaching Award.

Since fall 2003, Hsiu-yun Wang has been an assistant professor in the Graduate Institute of Gender Studies, Kaohsiung Medical University (KMU), Kaohsiung, Taiwan. In the summer of 2004, she helped train interested citizens of Kaohsiung City to conduct women’s oral history in a short-term program during which the participants interviewed a dozen women who live in old military housing, including many who escaped China to Taiwan after 1949. These oral histories reveal many extraordinary details about Taiwanese women’s lives, including their childbirth experiences, experiences of hardship in the post-World War II era, and the unfolding of gendered dynamics between women from different ethnic groups in Taiwan. Hsiu-yun hopes to establish a women’s archives in Kaohsiung in the future. Most importantly, she was very fortunate to have Judith A. Houck, in June of 2004, and Judith Walzer Leavitt, in November, as guests at KMU to give talks on their research. Both were very well-received in Taiwan.


Daniel Wikler is a member of the core faculty group in the new Harvard Program in Ethics and Health. He is Honorary Professor in the bioethics faculty of the Peking Union Medical College and gave a plenary presentation at the 2004 World Congress of the International Association of Bioethics.

The Robert Wood Johnson Health Scholars Program has funded a working group to explore innovative social science and ethics perspectives on population health. The group will address problems of evidence in the formulation of population health research and the difficulties of translating data into policy. In a public health crisis, how much evidence is really needed, and how good must it be? While evidence-based models have become a priority for decision-making in health policy and practice, simply having more data may not lead to meaningful action. New forms of evidence emerging with novel technologies, data gathered ethnographically, and health problems mired in complex political or environmental situations don’t necessarily mesh well with existing models of certainty or hundred year-old regulatory schemes. The group will work in collaboration with faculty and students from a variety of disciplines to study these concerns and find ways to design data collection and interpretation so meaningful, ethically-sensitive policies can be formed. Led by Linda Hogle, participants from MHB are Warwick Anderson, Pilar Ossorio and Gregg Mitman. Jonathan Patz (Environmental Studies and Population Health), Maria Lepowsky (anthropologist) and Gail Currie (Rural Sociology) are also in the lead working group.