State of the Center

The 2005-2006 academic year has been one of continued expansion of the major research, teaching and service activities at the Stanford Center for Biomedical Ethics. The new Program on Stem Cells in Society (PSCS) held its first public symposium, “Beyond the Embryo”, featuring many key players in national and state stem cell policy who are in the Bay Area. Don Kennedy delivered the keynote address, giving the editor-in-chief’s perspective on the Hwang scandal and lessons learned. PSCS members David Magnus, Mildred Cho, Judy Illes and Executive Director Chris Scott each talked about various aspects of stem cell research. Tim Caulfield of the University of Alberta presented an analysis of the political debates over stem cell policies in Canada, followed by Alta Charo, providing a contrast with the nature and history of feminist responses in the U.S. Alta is a visiting scholar at U.C. Berkeley this year, and we hope she will be making many more visits to SCBE throughout the year. PSCS member Ken Taymor described how intellectual property claims on stem cell research can affect science, while Jennifer McCormick presented her research comparing the widening gap in US stem cell research compared to other countries. PSCS Director Hank Greely closed with a discussion of ethical issues in stem cells and chimeras.

Three new courses have been developed by SCBE faculty this year, including Foundations in Bioethics, by David Magnus, The Stem Cell: Science, Ethics and Politics by Chris Scott, and a new section of the Responsible Conduct of Research course focusing on stem cell research, by David Magnus and Hank Greely. In addition, two new seminar series were initiated this quarter, with the intention of developing them into full-fledged courses for medical students in the Biomedical Ethics and Medical Humanities scholarly concentration and graduate or advanced undergraduate students. These include the Classic Papers in Bioethics series, and the CIRGE and BEMH Research Methods seminar on methods in bioethics.

CIRGE launches new Benchside Ethics Service

The Center for Integration of Research on Genetics and Ethics is launching its new Benchside Ethics Consultation Service (BECS) for Stanford bioscience researchers. The service is analogous to hospital ethics committees consulting at the bedside, but instead providing real-time advice to researchers and a forum for discussion of ethical and social issues raised by their specific studies. We will bring you an update on this program in a future issue of the newsletter, but so far the pilot phase of the service has been very successful and already incorporated into other facets of the institution such as the IRB.
Taiwanese Delegation Visits SCBE

The Center for Biomedical Ethics hosted the visit of a task force of Taiwanese scholars, led by Dr. Terence Tai, on February 10, 2006. Dr. Tai coordinates the Ethical, Legal, and Social Implications program affiliated with the National Research Program on Genomic Medicine funded by the Taiwanese National Science Council. The role of this task force is to monitor the development of a national biobank of genomic samples in Taiwan, and the purpose of the trip was to confer with scholars at Harvard, Yale, and Stanford about the ethical issues associated with creation of the biobank. In addition to Dr. Tai, the task force included scholars Drs. Huei-Chih Niu, Wenmay Rei, and Hong-Nerng Ho, ably assisted by Yu-Yen Lan. Many issues of mutual interest, including concerns about indigenous ethnic groups, use of film to highlight issues, offering results of genetic assessments to participants, and crafting of appropriate educational programs, were discussed by David Magnus, Sandra Lee, Maren Monsen, Hank Greely, Jen McCormick, Holly Tabor, and Sally Tobin. Members of the task force were highly knowledgeable and keenly interested in these subjects, and the interactions were enjoyable and productive for all concerned.

SCBE Education Update

Classic Papers in Bioethics

SCBE has started a new monthly discussion series for SCBE members and medical students in the Biomedical Ethics and Medical Humanities scholarly concentration, called “Classic Papers in Bioethics”. SCBE faculty introduce and lead discussions on classic writings and cases in clinical and biomedical research ethics. Hank Greely led our first discussion on Moore v. Regents of the University of California, adding interesting background on “what actually happened” that is not reflected in the court documents. Sally Tobin will discuss Tarasoff v. Regents of the University of California, followed in subsequent months by two sessions on clinical end of life care by LaVera Crawley, and visiting scholar John Paris, respectively. Mildred Cho will revisit the Ramsay/McCormick debates on research in children, and Judy Illes will consider the impact of Beecher’s 1966 article on clinical research ethics. The series could evolve into a course for medical, graduate, and undergraduate students in the future.

The CIRGE and BEMH Research Methods Seminar, introduced by LaVera Crawley, is a new weekly, ongoing seminar, to provide critical skills for formulating research questions in biomedical ethics and medical humanities and for identifying strategies to investigate ethical and social issues in medicine and science. There are two implicit goals: for the seminar participant to (1) become aware of evaluative assumptions that can implicitly drive research (an important element in ethics research); and (2) to use the seminar to move current projects forward. We use a problem-based learning approach, using the participant’s own research as the basis for discussion. The seminar meets on Wednesdays from 1:00-2:30 PM and is open to all CIRGE and SCBE post-docs and BEMH Scholarly Concentrators at any stage of their research process. To join the seminar or for further information, contact LaVera Crawley, MD, MPH at 725-7585 or email: lcrawley@stanford.edu.
SCBE Education Update (continued)

**HUMBIO 157: Chris Scott** offered a new course in Winter Quarter 2006 attended by sixty undergraduates, graduate students and medical students—The Stem Cell: Science, Ethics and Politics. The class focuses on the science behind the stem cell revolution, from the landmark discovery of human embryonic stem cells to the latest research. Course directors are Christopher Scott, Roel Nusse and Irving Weissman. Guest lecturers include Paul Berg, Robert Blelloch, Hank Greely, Zack Hall, Judy Shizuru and Mylene Yao.

**INDE 136: David Magnus** introduced a new course in Winter Quarter 2006, the Foundations of Bioethics. The course provides a survey of many of the central topics in the field of bioethics. Readings and lectures introduce students to many of the classical articles, legal cases, and concepts that serve as the foundation of the field. It begins with an overview of the field and the theoretical approaches to bioethics that have been derived from philosophy. The majority of the course addresses particular topics, starting with a range of essential aspects of the ethics of medicine and moving through the fundamentals of the ethics of research on human subjects, assisted reproductive technologies, genetics, cloning and stem cell research. The course ends by returning to the clinical setting to explore ethical issues at the end of life. Many of the topics are torn from the headlines. This course makes it possible for students to develop a critical understanding of the key issues on most of the major topics within bioethics. Holly Tabor and Jen McCormick are assisting with instruction of the course.

**MED 255:** The Responsible Conduct of Research course (RCR), also known as MED 255, deals with topical issues, such as authorship, scientific integrity, advocacy, conflicts of interest, regulatory aspects of research with animals and human subjects, and appropriate uses of human tissue samples, and is now required by many Stanford departments and programs. The course was revised into a discussion format for Winter Quarter 2005 by Mildred Cho, and received outstanding student ratings. This successful discussion model will be continued, but with several changes. First, due to popular demand, RCR sections are now being offered Fall, Winter, and Spring quarters, and we are currently considering a Summer 2006 section. Three sections were offered Fall quarter 2005, taught by Tobin, Illes, and Racine. All three sections received ratings between 6.0 and 7.0 in all categories, with 7.0 the highest rating possible. Currently, in Winter quarter, five sections are being offered, taught by Lee, Magnus and Greely (specializing in stem cell issues), Sohl, and Tobin. An additional four sections will be offered Spring quarter, taught by Cho and Tobin. Participants with clinical responsibilities find it difficult to attend a class at the same time each week, so an experimental section in an intensive (1.5 day) format will be offered in Spring quarter 2006. Questions about the course should be directed to Sally Tobin (tobinsl@stanford.edu), the course coordinator.

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**Faculty Profile: Judy Illes**

Paula Bailey interviews Judy Illes, Ph.D., Senior Research Scholar and Director of the Program in Neuroethics, with a joint appointment in the Department of Radiology.

“What is the focus of your research in the Program in Neuroethics?”

“Focus’ is somewhat of an oxymoron for our Program. We define the term neuroethics broadly as ethical, social and legal challenges that arise in neuroscience, and our research has aspects that touch on all of these challenges. However, when my group and our collaborators think about advances in neuroscience, we do think about specific sub-areas, like neuroimaging and other neurotechnologies for monitoring and modulating brain function, neurogenetics, and regenerative medicine. That gives us the internal focus to forge ahead.”

“Which one of those is the hottest topic?”

“I’d like to think that they are all hot. So let me just say that much of the work we’ve done to date has been in the area of neuroimaging and there are a number of reasons for that. One is because professionally, that is the domain of neuroscience that I was originally trained in. So I understand a lot about imaging and I bring some personal perspective to questions that have to do with where neuroimaging is today compared to where it was when I was in training two decades ago.”

“Neuroimaging is also a really good model because it touches upon four core areas of neuroethics described in 2002: brain and the self, that is, how do we view ourselves, our consciousness, our moral agency, our sense of responsibility? The
second pillar is brain and social policy, that is, how do we move new kinds of technology from the bench into the real world, and create policies around them and potentially regulations and legislation, if we need those? How do we ensure that everyone has equal access to new kinds of technology, or that results are utilized responsibly and fairly? The third pillar is the use of neurotechnology in clinical practice, clinical medicine. We have a long way to go, as we always have had, in managing new kinds of information compared to results from other techniques that form the ‘gold standard’ of diagnosis or care, but advances today are rapid and the change significant. The fourth is really one that has to do with expanding both people capacity — the next generation (maybe the real ‘first’ generation because those of us neuroethics pioneers really have roots in other disciplines, so it’s really the first generation of neuroethicists), as well as communicating better with the public. So neuroimaging, or imaging neurosciences as another way to think about it, really touches upon all those four pillars.

“So what have you found? Does your book (Neuroscience: Defining the Issues in Theory, Practice and Policy) deal with that or is it more about the four pillars?”

“We’re one of the few laboratories doing empirical work on the discovery of clinical abnormalities in research subjects expected to be normal. I think we’ve made a really big impact especially in that domain even while a lot of work remains to be done in understanding the phenomenon and developing a good ethical approach to responding to it. The stakes both for the research enterprise and individual subjects are huge. In fact, our paper that came out in Science on February 10 addresses some of the major issues. It is a consensus paper that describes what neuroscientists need to think about as they plan their experiments (in terms of incidental findings), and what IRBs need to think about in terms of ensuring pathways for dealing with findings, clarity in consent forms, and so forth. Chapters in the book deal with these issues, but overall, the book tries to cover far more terrain than this. My goal is that it would be one of the first launching pads not only for neuroethics in neuroimaging, but for all aspects of neuroethics.”

“Let’s go back to the pillars. The last one has to do with mentoring. Tell me more about that as it is addressed by the book.”

“The fourth pillar is about disseminating information and growing capacity. So by virtue of the fact that this is one of the first books in neuroethics, we have achieved at least part of the goal. (Good reviews and sales across a wide sector of the academic community and public will determine if the other part is achieved!). Naturally, the other three pillars are also addressed by the content. The book has a section on theory, personhood and consciousness. Another section has to do with the practice of neuroscience. And a third section has to do with social implications of neuroscience. I suppose, then, it really does stay true to the original four pillars. I am also hoping that it is a very reader-friendly volume so that everyone from physicians and healthcare providers and bioethicists to the educated lay public will enjoy it. If not all of it, parts of it. It’s a first of its kind and we’re really excited about it. The contributors were just marvelous and so engaged. They are truly pioneers.”

“I would like to read the section on consciousness, as I have an interest in that.”

“Let’s talk about consciousness. One of our new initiatives is to actually try to couple questions about identity and imaging with questions about consciousness. There were some recent studies that looked at functional imaging in patients in minimally conscious states. We have to really ask questions on a number of levels
when it comes to transferring new technology to this kind of highly charged area. For example, even if we could free the technology of all its limitations in terms of how complicated it is to design and run an experiment, in terms of how complicated it is to interpret the data, what do the results in this context really mean? What would it really mean for a patient and his or her family even if we could possibly have a 100% accurate image about what is going on in the brain in response to certain discrete stimuli? Would it really change

the individual person’s outcome? How would it affect the decision-making of the patient’s healthcare provider, or their family? How do interpretation and decision making intersect with people’s values and cultures and sense of death and dying? I would agree with J.J. Fins, that before we start applying this kind of really complicated expensive technology, I think we have to ask those questions first.

“When you say discrete stimuli, what do you mean? What is an example?”
“There are simple stimuli, like tones to the ears, or black and white checkerboard patterns to the eyes, to determine if there is any brain response. Or there might be more complicated stimuli like the voices of loved ones compared to the sounds of automobile traffic.”

“So if someone did not respond to the voices of loved ones, perhaps, the family might not want that information?”
“Well, that’s definitely a question. That could be potentially devastating. What we have to be even more cautious about is how will we manage the possibility that we might have false positive answers or false negative answers? These technologies are remarkable, but in being remarkable, I believe we have to really align the ethical consequences and challenges that surround them up front in the design of experiments so that they are dealt with responsibly downstream. I think we’ve made great headway since modern neuroethics became an accepted domain of study spanning both bioethics and neuroscience.”

“What are some of your other projects?”
“Other things we are looking at, for example, with Joachim Hallmayer and Jen Singh under the CIRGE grant, are identity and neurogenetics. We are mapping in great detail how autism research has been funded over the last 20 years, what the trends in publications have been, as well as trends in media coverage. We are having some very interesting findings and it’s all really moved us to understand how research shapes the identity of disease and vice versa: how disease, as it’s represented back to the scientific community, shapes the science. And for much of that thanks are due to patient advocacy and input from stakeholders. There is a great deal to learn and juxtapose with neuroethics. The notion of shaping identity in disease also crops up in a study that LaVera Crawley and I have just begun thanks to funding from The Greenwall Foundation. We are examining direct-to-consumer marketing of health products—drugs, genetic tests and imaging studies. Our hypothesis is that marketing strategies, and ultimately, impact are different across products, minority patients targeted, and providers.”

“You asked about hot areas, and I think another one is in the area of regenerative medicine where research with stem cells and neural engraftment may one day lead to the treatment of diseases of the central nervous system, like Parkinson’s and Alzheimer’s Disease. There are major issues with stem cells having to do with source, availability, mixed species experimentation prior to human use, and to whom this kind of therapy will be allocated. Moreover, when it comes to treating diseases of the central nervous system, especially the brain as opposed to the spinal cord, will stem cells change the personality of the recipient? How is a transplant of brain cells different than a transplant of a liver? The potential to change cognition, memory, thought, personality may really exist and it is both exciting and crucial that we think about those issues.”

“Do you guide Eric Racine’s research?”
“Eric is a post-doc here in our program. He needs very little guidance. He is a warm, outstanding scholar, who I think will go on to become one of the world’s first and best neuroethicists. For me, I look forward to having him as a lifelong professional partner.”

“Matt Kirschen was our investigator in the field in December and January looking, for the first time ever, at neuroethics challenges in developing countries. He joined Dr. Gladys Maestre at the University of Zulia in Maracaibo, Venezuela, to tackle a number of issues that intersect with neuroethics and international culture. We are now analyzing the data on management of incidental findings there, treatment of the chronically ill and the values that go into decision making for the chronically ill, as well as questions about the treatment and prognosis for individuals who have suffered traumatic head injuries and face significant altered personality and consciousness. He’s just back, with data from over 400 subjects in tow.”

“We also have a study under Eric’s leadership, looking at how the press covered the Schiavo case. We want to characterize the print media coverage and understand the impact it had on public understanding of consciousness and head injury.”

“All of these projects are made possible by the wonderful undergraduate students who come and train with us.”
Helpful Assistant
Faculty/Staff News (continued)

*Eric Racine* and Judy Illes are starting a study of print media coverage of the Terri Schiavo case to gain further insight into public understanding of neurological conditions such as persistent vegetative state and the impact of public understanding on end-of-life decisions.

*Maren Grainger-Monsen* is working on a film installation project, “Visualizing Emotion,” with Judy Illes for the Cantor Art Museum, scheduled to open Summer/Fall 2007. It will bring together images and questions inherent in the new imaging technology that attempts to measure the biology of emotion.

Maren reports that Hospital Corporation of America is using *Worlds Apart* in all their 200 hospitals across the country. They are also using the film for their annual CEO conference.

*Hold Your Breath* invited speaker/screenings include: NHLBI, UCSF, SFCH, Dartmouth, Cedar-Sinai Hospital in Los Angeles, Colorado Trust in Denver (a screening for 250 people and a forum using the film to develop programs in improving health care for minorities), University of Minnesota (keynote event for medical humanities lecture series), Blue Cross Minnesota (a screening and a forum using the film to develop programs in improving health care for minorities), and Grand Rounds at Kaiser in Santa Clara, San Francisco, and Richmond.

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**On the Move:**
Hellos and Goodbyes

*Christopher Thomas Scott* joins SCBE as Executive Director of the Program on Stem Cells and Society. He is also a life sciences author, journalist, and entrepreneur. His most recent book, *The Stem Cell Now: From the experiment that shook the world to the new politics of life*, clearly explains the science, ethics and politics of stem cells for the lay reader.

Scott was the scientific founder of Acumen Sciences, a life sciences research company based in San Francisco and the executive editor of the award-winning *Acumen Journal of Sciences*, a magazine focused on the business, economics and policy of life sciences. He was the Assistant Vice Chancellor at the University of California, San Francisco. At UCSF he led an array of business and research units, including technology transfer, legal affairs, clinical research, and business development. For nearly a decade Scott was a senior administrator at Stanford University. As Associate Director of the Center for Molecular Medicine, he worked with Nobel Laureate Paul Berg to develop one of the nation’s first translational medicine programs. He was the co-founder of ACCESS, a research unit devoted to clinical trials, and was Director of Research Development for the Medical Center.

Scott is a committee member for the International Society of Stem Cell Research and is a past member of the Stanford Program in Genomics, Ethics and Society, the California Health Care Initiative, and the Bay Area Bioscience Center. He has been featured in national and local media coverage of these and other issues, including *Time, U.S. News and World Report, NPR’s Fresh Air, Talk of the Nation, and TechNation, KQED radio, UPI and Fox News.*
John J. Paris, S.J., who has joined the Center as a Visiting Professor for the Winter/Spring terms, is the Walsh Professor of Bioethics at Boston College. His working clinical ethics is primarily at the intersection of law, medicine and ethics. He has published extensively in the area of treatment decisions for very low birthweight early gestational age infants.

Fr. Paris served as a consultant to the President's Commission on Ethical Decisions in Medicine, the United States Senate's Committee on Aging and the U.S. Congress Office of Technology Assessment. He has also served as a consultant or expert witness in such landmark legal cases as Quinlan, Barber, Brophy, Jobes, Messenger and Gilgunn.


Raina Glazener has moved to Portland, Oregon, where her husband accepted a new job opportunity. While we certainly wish her well, we will miss her professional and cheerful assistance.

Karen Rentschler joins us to take Raina Glazener’s place as Program Coordinator in the Biomedical Ethics in Film Program. Karen worked at the center seven years ago, following that, the School of Engineering, and she currently owns a clothing design company in San Francisco called La Bouche Rouge. Karen attended the University of Washington, completed the De Anza College Film Production Series, and currently attends San Francisco Soko Gakuen for Japanese language studies.

Recent Publications


Merz, JF and Cho, MK What are gene patents and why are people worried about them? Community Genetics 2005 8:203-208.


Recent Publications (continued)


Racine, Eric and Kevin Hayes. Surveying needs and goals for a clinical ethics service in a community healthcare service center, *Journal of Medical Ethics* (in press).


Racine, Eric. Where are we going with direct-to-consumer advertising of healthcare products? *Canadian Psychiatry Aujourd’hui*, 2006, 1(1).

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**SCBE Upcoming Events**

**March 7, 12 p.m. - 1 p.m.**  
Biomedical Ethics Grand Rounds  
Medicine and the Movies: The Power of Film in Medical Education  
Maren Monsen, M.D.  
Room M-106, School of Medicine

**March 7, 1:30 – 2:30 p.m.**  
Classic Papers in Bioethics  
Tarssoff v. Regents of the University of California  
Sally Tobin, Ph.D.  
SCBE Conference Room

**March 15, 2006, 11:30 – 12:30 p.m.**  
PSCS Guest Lecture Series  
May We Make the World? Basic Science as a Moral Gesture  
Laurie Zoloth, Ph.D.  
Munzer Auditorium, Beckman Center for Molecular Medicine

**April 4, 12 p.m. – 1 p.m.**  
Biomedical Ethics Grand Rounds  
Pilar Ossorio, Ph.D./J.D.  
Room M-104, School of Medicine

**April 4, 1:30 – 2:30 p.m.**  
Classic Papers in Bioethics  
Clinical Futility  
LaVera Crawley  
SCBE Conference Room

**April 20, 5:00 p.m.**  
Medicine and the Muse  
Bridging the Gap: Communicating Medical Knowledge  
Erica Goode  
Cantor Arts Center Auditorium

**May 2, 12 p.m. – 1 p.m.**  
Biomedical Ethics Grand Rounds  
Emotions and Decision-Making  
Jodi Halpern, Ph.D.

**May 2, 1:30 – 2:30 p.m.**  
Classic Papers in Bioethics  
John Paris  
Baby L  
SCBE Conference Room

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