



# STANFORD BIOETHICS

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*STANFORD UNIVERSITY*

## State of the Center

The Stanford Center for Biomedical Ethics (SCBE) continues to evolve, integrating into many facets of the Stanford community.

### **New faculty**

A new faculty member, Dr. Julie Collier, joined the SCBE this Fall. She is co-chair of the Lucile Packard Children's Hospital Ethics Committee. Her arrival at SCBE signifies the very substantial and growing involvement of SCBE in providing clinical ethics services to our local hospitals.

**see profile, page 4**

### **New Center of Excellence**

In September, SCBE established a new Center of Excellence, through a grant awarded by the National Human Genome Research Institute. Funding

the establishment of a center is a new type of grant for the National Institute of Health and provides for collaboration among over 30 faculty members in a wide range of disciplines.

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### **New film**

Dr. Maren Grainger-Monsen premiered her new film, *Hold Your Breath* at the annual American Society for Bioethics and Humanities October 5, 2004. The film continues to receive awards and acclaim, as it changes and improves medical curriculum.

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### **New Publications**

SCBE faculty lead national discussions on leading biomedical issues with their publications and research awards.

**see compilation, pages 5-6**



# STANFORD TEAM SELECTED IN NIH CENTER FOR EXCELLENCE INITIATIVE

*Dr. Mildred Cho heads the new Center for Integration of  
Research on Genetics and Ethics*

In a new grant initiative, the National Institutes of Health founded four interdisciplinary Centers for Excellence that will address the most important ethical, legal and social questions raised by recent advances in genetic and genomic research. This initiative is led by the National Human Genome Research Institute, also receiving significant support from the US Department of Energy and the National Institute of Child Health and Human Development.

Stanford was joined by Case Western Reserve, Duke, and University of Washington in being selected from a larger number of applicants to be awarded the NHGRI grants.

The Center for Excellence that was established at Stanford will be housed at the Stanford Center for Biomedical Ethics. Named the Center for Integration of Research on Genetics and Ethics (CIRGE), the center was awarded a \$3.9 million, 5-year grant to test new models of deliberative, interactive processes that integrate ethical, legal, and social considerations into the design and conduct of current and emerging genetic research.

CIRGE will be led by Dr. Mildred Cho and a team of over 30 faculty in the fields of genetics, neuroscience, law, history, medicine, radiology, psychiatry, anthropology, and philosophy.

Dr. Cho said, "CIRGE will focus on the impact of behavioral and neurogenetic research on human identity, which has begun to identify important genetic differences between individuals and groups that raises questions about individual, group, and species identity."

Researchers will work on questions raised by findings on the genetic basis of behavior that challenge beliefs about what determines individual personality, control over actions, moral agency, and what makes us human. Dr Cho continued, "These areas of genetic research are ripe for proactive inquiry about how the research may affect society's notions of identity and how ideas about identity shape genetic research."

CIRGE will achieve these goals by establishing a number of innovative programs that integrate ethical and social considerations into the earliest stages of genetic research design.

First, the Program for Integrated ELSI Research (PIER) will identify and conduct research on ethical, legal and social issues raised by behavioral and neurogenetics and the impact of the research on individual, group, and species identity.

Second, the innovative Benchside Consultation Program (BCP) is being developed as a model for similar programs. It will be a resource for genetic researchers seeking real-time ethics consultation to anticipate and develop policy guidance to address ethical, legal,

or social issues that could arise from current or future research that are not addressed by other institutional mechanisms.

Finally, a Training and Education Program will train four postdoctoral scholars in genetics research, and use the ethi-

*"These areas of genetic research are ripe for proactive inquiry about how the research may affect society's notions of identity and how ideas about identity shape genetic research."*



cal issues identified by the other programs as the basis for producing educational materials for genetic and ELSI researchers.

The work done on these programs will produce issue briefs, interactive dialogues and public forums, web-based consultation tools, documentary films, and scholarly publications. Dr. Cho said, "CIRGE will serve as a national model for incorporating ethical, legal and societal considerations into the design and conduct of cutting-edge genetic research as it unfolds."

# 'HOLD YOUR BREATH' DEBUTS AT ASBH ANNUAL MEETING

*New film premier, receives standing ovation*

A standing ovation at its ASBH premier, a scheduled PBS broadcast, increasing matriculation into medical curriculum—what is the best measure of Dr. Maren Grainger-Monsen's new film's success? The purposeful message of the recently premiered *Hold Your Breath* delivers not only to its intended medical audience, but achieved its purpose with those immediately involved; Grainger-Monsen was satisfied that through watching the film, even the family of the patient began to see misunderstanding where they used to see mistake.

"Hold Your Breath" expands the story of Mr. Kochi, first introduced in Grainger-Monsen's earlier film, *World's Apart*, on his journey as a devout Muslim being treated for cancer in the western medical system.

The film uses verite style to convey the human face of both the immigrant family and the well intentioned practitioners. Having access to the family in their home and also at the clinics and hospitals meant the chance to tell this as the story of real people, which evoked a level of empathy not typical of scripted case films in medical education.

*Hold Your Breath* raises the level of documentary film. Grainger-Monsen was very clear in her purpose—she said, "I wanted to make tremendously beautiful, emotional character driven story lines involving medical ethics."

To accomplish this, she followed a deceptively simple plan. First, she found an issue—in this case, understanding the impact of using a family member to interpret on the outcome of health care.

Next was the challenge of finding a story that exemplifies this issue with the nuances that a thoughtful examination of the issue would indicate. With the experiences of the Kochi family, Grainger-Monsen said she was able to choose an exquisitely nuanced situation, because in navigating the system, no one, nei-



ther Kochi nor his daughter who was acting as a translator, nor Kochi's doctor, had done anything wrong. It was a perfect example of how the system did not facilitate cross-cultural dialogue.

After finding the right story, Grainger-Monsen captured months of Kochi's life on film, following the story as it unfolded. Next, she focused on the arduous task of culling a very complex story down to its essentials. The edited story line was then transformed into Grainger-Monsen's vision of what her documentary could be by developing beautiful images of the patient's spiritual traditions and shooting them on 16mm film, which were then woven into the verite footage.

Grainger-Monsen said "This style allowed [the audience] to re-

flect; it gave them "breathing space."

The title of the film cites a scene in the hospital where Kochi is in an MRI machine with a mechanized voice chanting the instructions to "hold your breath." The theme of the film is captured in the subtext of the scene: a concerned technician asks, "Is that even in the right language?"

In choosing this title, Grainger-Monsen emphasizes this scene with its juxtaposition of the personal pathos felt towards Kochi against the mechanized, computerized face into which the health care system has evolved. The title also recalls the moment of diagnosis where any patient instinctively holds his breath as his doctor announces his fate.

In creating a beautiful film, Grainger-Monsen also had in mind solutions for the issues she was documenting.

She said, "We need to educate providers to see that disparities happen not because of racism, but because of a lack of understanding of how cultural or social background combine to make it difficult for the patient to adhere to the treatment. They are often not adhering for reasons not visible to the health care provider." Using education to improve the system is not only for providers. She would also like to see education for the patients so that they are empowered by understanding their rights and responsibilities.

Even outside of the patient/provider relationship, this film encourages improvement. Grainger-Monsen hopes it will encourage public dialogue that will increase the use of interpreters and also increase the number of ethnic and racial healthcare providers.



# DR. JULIE COLLIER JOINS SCBE FACULTY

Dr. Julie Collier's appointment to the faculty of the Center for Biomedical Ethics tries to capture in one position the work of a woman who has chaired the Lucile Packard Children's Hospital ethics committee since 1999 and runs her own private clinical practice. It also indicates the growing clinical role of SCBE in the surrounding hospitals as Collier joins the ranks of Jose Maldonado, Clarence Braddock, Margaret Eaton, and David Magnus, who staff the ethics committee at Stanford Hospital.

This is the first time for a reporting relationship between SCBE and the LPCH ethics committee. Collier has been a member of the ethics committee for 8 years, her involvement stemming naturally from her work as a post-doctoral fellow at Stanford, then as a staff psychologist at LPCH where she worked with the pediatric consultation-liason service and the pediatric pain program.

Collier credited this foundational experience as leading her to the work as Clinical Director of Pediatric Ethics. She said, "Working with families and with healthcare providers, I got a first hand view of the human side of healthcare."

After four years on the committee, Collier was approached by her now co-chair, Christy Sandborg MD, to officially lead the committee. Sandborg said, "Julie has been pivotal to enhancing the committee's approach to consulta-

tions and education. Through refining a consensus building methodology and identifying systemic issues and opportunities, the committee has developed high levels of decision-making and is widely respected within the institution."

Collier's current focus is clinical unit work. She wants to create unit based rounding and multidisciplinary rounds. This program will start with the pediatric ICU where the ethics committee will see a greatly expanded role.

She recognizes the continuing role that the ethics committee will play in providing consultation in difficult situations, but she sees an increased role for the committee in addressing organizational ethics. One facet of this work is advising hospital administration of difficult ethical dilemmas that arise, in part, from problematic policies or lack of clear guidelines about management of certain types of situations. One project currently underway that grew out of this focus is the creation of a task-force to address the ethical issues arising from pediatric transplantation.

In more general terms, Collier feels strongly that the committee has a vital role to play in helping the hospital make

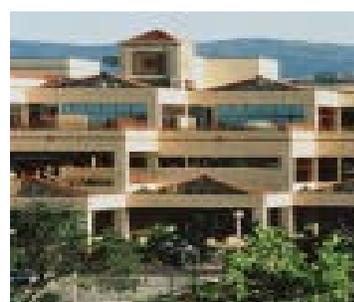
its decision processes clear and relatively transparent to staff, as well as patients and families. Organizational ethical issues affect all hospitals, but Collier stated that the application of organizational ethics would vary from institution to institution because each faces different forces and pressures.

She said, "Packard has been very successful and has undergone substantial growth. But this has created new problems that the institution has not had to struggle with at these levels before. Issues related to allocation of scarce resources are at the forefront. One of the most troubling scarce resources is a lack of beds, so having clear guidelines about how to proceed when there are more patients than beds becomes vital."

Collier's interest in biomedical ethics began early. Collier recalls a course in medical ethics taken as an undergraduate that stood out as helping concentrate her interest in working with health related issues.

She brings to the center not only her training and experience, but also her intent to be involved as a liason between staff researchers and the children's hospital, as she is able to facilitate cooperative work with a pediatric focus.

In her personal life, Collier stays busy as the mother of three children, Josh, 11, Sam, 9, and Madeleine, 4. She finds one of the most difficult, but satisfying challenges in her life balancing the demands of professional and family life.



## Selected Faculty Publications

Bhuvanewar C, **Shafer A.** Survivor of that time, that place: Clinical uses of violence survivors' narratives. *Journal of Medical Humanities* 25:109-27, 2004

Farah, M.,\* **Illes, J.**,\* Cook-Deegan, R., Gardner, H., Kandel, E., King, P., Parens, E., Wolpe, P.R., Sahakian, B. Neurocognitive enhancement: what can we do? What should we do? *Nature Reviews Neuroscience*, 2004, 5:421-425 (\*Lead authors).

**Greely, Henry T.**, Disabilities, Enhancements, and the Meanings of Sport, 15 *STANFORD LAW AND POLICY REVIEW* 15:99-132 (2004)

**Greely, Henry T.**, Genetic Modification, review of *DESIGNING OUR DESCENDANTS: THE PROMISES AND PERILS OF GENETIC MODIFICATIONS*, Audry R. Chapman, Mark S. Frankel, ed., *J. AM. MED. ASS'N* 292:1374-75 (Sept. 15, 2004)

**Greely, Henry T.**, Genetics and the Impulse To Perfect, *Cerebrum*, Vol. 6, no. 4 (forthcoming, fall 2004)

**Greely, Henry T.**, Human Genetic Enhancement : A Lawyer's View, Review of *Wundergenes: Genetic Enhancement and the Future of Society* by Maxwell J. Mehlman, *Medical Humanities Review* (forthcoming, fall 2004)

**Greely, Henry T.**, Prediction, Litigation, Privacy, and Property: Some Possible Legal and Social Implications of Advances in Neuroscience, In: *NEUROSCIENCE AND THE LAW: BRAIN, MIND, AND THE SCALES OF JUSTICE* (Brent Garland, ed., The Dana Press 2004)

Henry MR, **Cho MK**, Weaver MA, Merz JF. (2003) A pilot survey on the licensing of DNA inventions. *Journal of Law, Medicine & Ethics*. 31(3):442-9.

**Illes, J.**, Kann, D., Karetsky, K., Letourneau, P., **Raffin, T.A.**, Schraedley-Desmond, P., **Koenig, B.A.**, Atlas, S.W. Advertising, patient decision-making, and self-referral to CT and MR imaging. *Archives of Internal Medicine*, In press

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**Lee, Sandra Soo-Jin.** *Paradoxes of Difference* PLoS, Biology Sept 2:9 1263-64

**Magnus, David.** "Thinking about caring about animals" a review of *Animal Rights*, in *Science*, 1 Oct. 2004, vo. 306

**Magnus, David.** "Stem cell research should be more than a promise", *Hastings Center Report*, 34, no.5, 2004

**Magnus, David.** "The Ethics of Preimplantation Genetic Diagnosis" in *Fertility Today*, v.1, no.1, 2004

**Magnus, David.** "A new era for AJOB", editorial, with Paul Wolpe, Kelly Carroll, Glenn McGee, in v.4, no. 3 of *AJOB*

Mills A.E., **Rorty M.V.** and Werhane, P.H. (2004) Organization ethics and the Rashomon Effect, *HEC Forum*. 2004.

## Selected Publications (con't)

### Director

David Magnus, PhD

### Associate Director

Mildred Cho, PhD

### Steering Committee Chair

Henry Greely, JD

### Faculty

Clarence Braddock, MD

Julie Collier, PhD

LaVera Crawley, MD

Margaret Eaton, JD, PharmD

Judy Illes, PhD

Barbara Koenig, PhD

Maren Grainger-Monsen, MD

Jose Maldonado, MD

Audrey Shafer, MD

Sara L. Tobin, PhD, MSW

Sandra Soo-Jin Lee, PhD

### Visiting Scholar

Azumi Tsuge, PhD

### Emeritus

Thomas Raffin, MD, Emeritus Director

Ernie Young, PhD, Emeritus Co-Founder

### ADMINISTRATIVE AND RESEARCH STAFF

### Assistant Director

Anne Footer

### Administrative Assistant

Joyce Prasad

### Education Coordinator

Melissa Payan

### Grants Manager

Shoba Kumar

### Research Staff

Katrina Karkazis

Raina Glazener

Eric Racine, PhD

Marisa Galo

Gina Capodanno

### SCBE NEWSLETTER

### Editor in Chief

Mildred Cho

### Managing Editor

Melissa Payan

Mills A.E., **Rorty M.V.** and Werhane, P. H. (2004) Organization ethics as a vehicle for organizational change. *Organizational Ethics* (2):252-266 (special issue, *Looking Ahead in Bioethics* edited by Jeffrey Kahn & Anna Mastroianni)

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**Tsuge, A.**, "Inner Conflict over Curing: Thinking about alternatives of advanced Biomedicine," in Kondo, H. and Ukigaya, S. eds., *An Ethnographic Approach to Contemporary medicine*, Akashishoten, Tokyo, pp.123-164. (Japanese).