



Stanford Bioethics

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SCBE Welcomes New Co-Director, David Magnus, PhD



The Center for Biomedical Ethics welcomes a new Co-Director, David Magnus, PhD. David joins the Center after spending six years as Graduate Studies Director at The University of Pennsylvania, School of Medicine. David replaces Ernlé Young, PhD, who retired in January, 2002.

David brings with him experience and innovative ideas for the Center. He will spend his first few months focused on the Stanford Medical School curriculum, revamping required classes as well as helping create a new

Bioethics and Humanities Scholarly Concentration. Starting this fall, new threads in the curriculum such as bioethics, health policy and community activism/advocacy will be introduced and highly integrated into the medical school curriculum with required hours and a variety of elective courses.

David will continue his legacy of creating academic programs by developing a Master's Program in Bioethics. A Master's program will not only provide continued education to individuals in the Bay Area working at biotechnology and other biological science related companies, but it will also help diversify the fiscal foundation of the Center. A Master's program as well as other academic programs will help support the efforts of the Center and its faculty.

In addition to his academic endeavors, David will concentrate on developing new ways for the Center to stand out in

the public eye. The Center, he believes, should be "a conduit for communication between the school of medicine and the public." He would like to see the Center "play more of an educational role, develop more educational programs and become more visible in the Bay Area and nationally for (its) expertise in bioethics." It is his hope that, as a whole, the Center will publish more op-ed pieces in local papers, hold focus groups and use the internet as a means of publicizing the work.

On the clinical front, David will Co-Chair the Ethics Committee of Stanford University Hospital and will serve on the Ethics Committee of Packard Children's Hospital. He looks forward to finding ways to enhance clinical education and clinical ethics activities for both hospitals. David hopes to focus specifically on increasing the Center's

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New Co-Director, David Magnus, PhD

involvement with Packard Children's Hospital.

Finally, David will spend a good deal of time working with other SCBE faculty to develop Stanford's newest initiative "The Benchside Consultation Program" which affords scientists engaged in cutting edge scientific research the opportunity to consult with the faculty at the Center about the ethical dilemmas they face in their work. The Benchside Consultation program is the only one of its kind in the country and David, along with several faculty members, will present the program at the American Society for Bioethics and Humanities meeting to be held in Montreal in October.

David earned his BA in Philosophy from the University of California at Riverside and his PhD in Philosophy from Stanford in 1989. His early interests lay in the philosophy of science, "what makes good science", history of biology, and evolutionary biology and later broadened to include technology, medical technology, genetics and ethics. He was Chair of the Technology Studies

program at Grinnell College and subsequently The Philip M. Phibbs Professor of Ethics and Science at The University of Puget Sound. It was during this time that David was asked by National Endowment for the Humanities and the National Science Foundation to run a Summer Institute for college and university faculty on "Contemporary Genetic Technology: Scientific, Social and Ethical Issues". David left his liberal arts teaching background in 1997 to accept the position of Director of Graduate Studies at The University of Pennsylvania where he developed a Master's Degree in Bioethics.

Despite his large time commitment to the SCBE, David continues to pursue his own research which is primarily focused on genetic technologies, reproductive technologies and genetic engineering of non-human organisms. For the past year he has served on the National Research Council Committee of the National Academy of Sciences working on the bioconfinement of genetically engineered organisms. David is also the Associate Editor of the

American Journal for Bioethics (bioethics.net) and sits on the Secretary of Agriculture's Advisory Committee on Biotechnology in the 21st Century.

David is a "sports junkie" and an avid wine collector. He met his wife, Julie, at Stanford and they were married on the University's campus. "Stanford is the only place I would have left Penn for," David explains. "I am very happy to be back home".



"The Benchside Consultation program is the only one of its kind in the country."



State of the Center

The last year brought many new ethical and social challenges to medical practice and research, ranging from SARS to the use of human stem cells. As the Stanford Center for Biomedical Ethics completes its 14th year, we embark on a host of new programs to meet these challenges, as part of a new strategic plan developed in spring 2003. We are deeply indebted to Dr. Barbara Koenig, former Executive Director of SCBE, for ten years of leadership and growth, establishing the Center as a national resource for ground-breaking research in biomedical ethics. We welcome Barbara back from her productive and well-deserved sabbatical leave at the Stanford Humanities Center. We also welcome Dr. David Magnus as the new Co-Director, and Dr. Mildred Cho as the new Associate Director.

Educational Initiatives: New medical school curriculum and establishment of Scholarly Concentration

Last year, SCBE faculty taught in over 30 courses across the Stanford campus. In this 2003-2004 Academic year,

SCBE initiates two major educational programs at the Stanford School of Medicine. One is the addition of a core, required ethics curriculum for medical students, as part of the newly overhauled medical school curriculum. This ethics curriculum is integrated with health policy and community health in a 3-quarter course, *Physicians in Society*. SCBE is pleased to be an integral part of the new Scholarly Concentration in Biomedical Ethics and Medical Humanities, directed by Dr. David Magnus, and Associate Directors Drs. Audrey Shafer and Linda Hogle. Two new courses are being developed for this concentration: *The Human Condition: Literary, Visual and Performing Arts* and *Inquiry Methods in Biomedical Ethics and Medical Humanities*. Participation of medical students in this scholarly concentration will allow up to a year dedicated to an independent project, mentored by faculty from Biomedical Ethics or the Medical Humanities programs.

Research Initiative: New Benchside Consultation Program

SCBE is pilot testing a new Benchside Consultation program to address in real time the ethical and social issues raised by basic and clinical biomedical research, as a service for Stanford scientists. It is analogous to the bedside consultation provided to physicians by the hospital ethics committee, but designed to consider ethical and societal implications of science as or before the research is conducted. The program will explore ways to not only identify issues for consideration, but to identify stakeholders and facilitate public engagement with scientists about the issues.

SCBE looks forward to an exciting new year!



“In this 2003-2004 Academic year, SCBE initiates two major educational programs at the Stanford School of Medicine.”

Maren Grainger-Monsen, MD: Biomedical Ethics in Film



Maren Grainger-Monsen, MD, is Director of the Biomedical Ethics in Film Program at the Stanford Center for Biomedical Ethics. Maren trained in Emergency medicine, as well as attended film school, and has used her dual interest in art and medicine to produce medical education and documentary films. She produces creative films for medical students and the public which inspire and expose viewers to the ethical dilemmas facing our society.

Maren is currently working on *Worlds Apart* a documentary film and medical education project to improve multicultural health. The project, which includes four short films for medical education, a facilitator guide, as well as a full length documentary film for broadcast, aims to explore the impact of culture on medical decision making as well as the roots of disparities in healthcare for racial and

ethnic minorities. The film follows four patients and their families faced with critical medical conditions as they navigate their way through the medical system. The film captures the patients in their homes, neighborhoods, doctors' offices, hospitals and places of worship and seeks to highlight the impact that different cultures have on medical decision making. In all four cases, there are three active cultures: the culture of the patient, the culture of the doctor and the culture of medicine.

The four patients include: Mohammad Kochi, an Afghan man who has stomach cancer and who refused chemotherapy because, as a devout Muslim, he believed it would have made it impossible to observe daily prayer. Justine Chitsena is a five-year old Laotian girl who requires surgery to repair a hole in her heart. Her mother and grandmother worry that the scar left by the surgery will stay with her into her next reincarnation, and wish to seek the advice of monks at the local Buddhist temple. Robert Philips suffers from renal failure and is on dialysis while he awaits a kidney transplant. Robert knows that since he is African-

American he is likely to wait twice as long to receive his new kidney. Alicia Mercado is a Puerto Rican woman with diabetes, hypertension and asthma, who was evicted from her apartment, causing her to become depressed and to stop taking her medication. Many of the families in these films relied on family members to translate for them in the medical setting. Maren explained that a family translator often has a huge impact on the medical situation and family dynamic. The English speaking family member is frequently a child of the patient which inverts the family hierarchy and can destabilize the family. The translator can become an active participant in the doctor/patient conversation, thus integrating his/her own opinions or withholding information from the patient at his/her discretion.

Maren also discussed how trust plays a pivotal role in the doctor/patient relationship. She repeatedly saw patients enter the doctor's office wondering if they can and should trust their doctor and waiting for the doctor to earn their trust. Only over time does a trusting relationship develop.



“The project...aims to explore the impact of culture on medical decision making as well as the roots of disparities in healthcare for racial and ethnic minorities.”

Biomedical Ethics in Film



“Worlds Apart will raise awareness about the role of sociocultural barriers in patient-provider communication...”

Four trigger tapes and a facilitator guide will accompany the documentary film for *Worlds Apart* and will be used to teach medical students and health care professionals about cross-cultural communication and cultural sensitivity. National broadcast of the documentary will “raise awareness about the role of sociocultural barriers in patient-provider communication and health outcomes for culturally and ethically diverse patients in the United States”. *Worlds Apart* has just been released and is available through Fanlight Productions (800) 937-4113 (www.fanlight.com). Maren plans to present *Worlds Apart* at the National Association of American Medical Colleges meeting to be held in Washington DC in November.



“The Vanishing Line has won several prestigious awards and recognitions including an Emmy Award nomination.”

Prior to her work on *Worlds Apart*, Maren produced *The Vanishing Line*, which depicts her journey toward understanding the “art and issues of dying”. After completing her residency in Emergency Medicine and learning first hand how to complete procedures to save and prolong life, Maren began to question the ethical implications of these

techniques. Although possible, would patients really want to undergo these life saving heroics?

Maren teamed up with Jim Brigham, a hospice social worker, and followed him during his rounds to visit terminally ill clients. The film “takes viewers on a lyrical and heartfelt quest to discover the ‘art of dying’ in a world that teaches physicians how to prolong life, but offers few prescriptions for coping with death”. In all of her work and in *The Vanishing Line* especially, Maren seeks to enhance the artistic aspects of medical education films. She puts tremendous energy into creating imagery that evokes emotion; for example, in order to illustrate the anxiety of waiting for a medical result, Maren uses the image of a buzzing bee. She uses the image of drops of water hitting a pond and slowly fading into silence to accompany a scene in which a patient is dying and the heart monitor slowly becomes a straight line. Maren strives to use her artistic talent to bring documentary medical filmmaking to a new level.

Maren received her BA in Art History from Stanford University in 1984, and her MD from the

University of Washington in 1991.

During medical school, she received a Rotary Fellowship to attend the London International Film School. Maren’s first film which she produced during medical school entitled *Where the Highway Ends: Rural Healthcare in Crisis*, won a regional Emmy Award. In 1996, while working at San Francisco General Hospital, Maren produced *Grave Words*. *Grave Words*, which was awarded first place in the American Medical Association Film Festival, is a film that uses comedy to teach physicians how to talk about death. *The Vanishing Line* was broadcast on national PBS as part of the coveted POV Program of Independent Film, and has won several prestigious awards and recognitions including an Emmy Award nomination, First Place at the Nashville Independent Film Festival, The National Hospice Organization Program of the Year Award, and a PBS sponsored Internet website and interactive chat room. In addition to awards won by her films, Maren was honored to be named a Distinguished Alumnae of Lakeside High School in Seattle, Washington.

Stanford Center for Biomedical Ethics Upcoming Events

Bioethics Grand Rounds:

September 4, 2003, 12:00pm:

David Magnus, PhD, SCBE
"The Future of Bioethics"

October 2, 2003, 4:00pm:

Art Caplan, PhD,
Univ. of Pennsylvania
"What is Wrong with Improving
Our Brains?"

November 6, 2003, 12:00pm:

Noel Schwerin, Backbone Media
"Bloodlines: Technology Hits
Home"

December 4, 2003, 12:00pm

Margaret Eaton, JD,
PharmD, SCBE
"Physicians Working in Biotech
Companies – Should They Take
Their Professional Ethics With
Them?"

Faculty and Academic Staff:

David Magnus, PhD: Co-Director

Mildred Cho, PhD: Associate Director

Thomas A. Raffin: Co-Founder & Co-Director

Henry Greely, JD: Chair of Steering Committee

LaVera Crawley, MD

Margaret Eaton, JD, PharmD.

Linda F. Hogle, PhD, MBA

Judy Illes, PhD

Barbara Koenig, PhD

Maren Grainger-Monsen, MD

Sara L. Tobin, PhD, MSW

Sandra Soo-Jin Lee, PhD

Ernlé WD Young, PhD: Emeritus Co-Director &
Co-Founder

Administrative and Research Staff:

Anne Footer: Assistant Director

Katrina Karkazis, PhD, MPH, Research Assoc.

Raina Glazener, Research Staff

Shoba Kumar, Grants Manager

Joyce Prasad, Administrative Assistant

Editor-in-Chief: Mildred Cho, PhD

Managing Editor: Kim Karetsky

Recent Publications:

- Vaszar, LT, **Cho, MK** and **Raffin, TA** (2003) Privacy issues in personalized medicine. *Pharmacogenomics* 4: 107-112.
- **Cho, MK**, Illangasekare, S, Weaver, MA, Leonard, DGB and Merz, JF (2003) Effects of gene patents and licenses on the provision of clinical genetic testing services. *J. Mol. Diagnosis* 5: 3-8.
- **Cho, MK, Grainger-Monsen, M** (2003) Dilemmas of a divisive concept. *Science* Vol 300; No. 5618: 434.
- Boyd, EA, **Cho, MK**, Bero, LA (2003) Financial conflict of interest policies in clinical research: issues for clinical investigators. *Academic Medicine* 78: 769-774.
- Sankar, P and **Cho, MK** (2002) Toward a new vocabulary of human genetic variation. *Science* 298: 1337-8.
- **Hogle, LF** (2003) Life/time warranty: rechargeable cells and extendable lives. In Lock, M. and S. Franklin (eds.) *Animation and cessation: Changing definitions of life and death in the context of biomedicine*. Santa Fe: School of American Research.
- **Hogle, LF** (2003) The anthropology of bioengineering. *Anthropology Newsletter* 44(4).
- **Hogle, LF** (2003) Review of Lock, M. Twice dead: Organ transplantation in North America and Japan. *Technology and Culture* 44: 433-435.
- **Illes, J**, Kirschen, M, Gabrieli, JDE (2003) From neuroimaging to neuroethics. *Nature Neuroscience* 6(3): 250.
- **Illes, J**, Fan, E, **Koenig, B, Raffin, TA**, Atlas, SW (2003) Self-referred, whole body radiologic screening: current status and implications for health care consumers. *Radiology* 228: 346-351.
- **Illes, J** (Oct, 2003) Neuroethics in a new era of neuroimaging. Invited editorial. *American Journal of Neuroradiology*.
- **Illes, J**, Kirschen, MP (Nov, 2003) New prospects and ethical challenges for neuroimaging within and outside the health care system. *American Journal of Neuroradiology*.
- **Illes J, Raffin TA** (2002) Neuroethics: An emerging new discipline in the study of brain and cognition. *Brain and Cognition* 50(3): 341-344.
- **Illes J, Desmond JE, Huang LF, Raffin TA, Atlas SW** (2002) Ethical and practical considerations in managing incidental findings in functional magnetic resonance imaging. *Brain and Cognition* 50(3): 358-365.
- **Koenig BA, Davies E** (2003) Cultural Dimensions of end-of-life care for children. Commissioned by the Institute of Medicine for the report: *End of Life Care for Children*. Washington, DC: National Academy of Sciences.
- **Koenig BA, Back AL, Crawley LM** (2003) Qualitative methods in end of life research: Recommendations to enhance the protection of human subjects. *Journal of Pain and Symptom Management*. 25(4): S43 -S52.
- **Koenig BA** (2003) Dead donors and the "shortage" of human organs: Are we missing the point? (Commentary) *American Journal of Bioethics* 3(1): 28-29.
- **Lee, SS** (2003) "Aged bodies as sites of remembrance: Colonial memories in diaspora." Jill Bennett and Rosanne Kennedy, Eds. *World Memory: Personal Trajectories in Global Time*. Houndsmill, UK: Palgrave Macmillan.
- Starbinski J, Walker HK, Baker LC, Kobaladze A, Kirtava Z, Baker LC, **Raffin TA** (2002) The Burden of out-of-pocket payments for health care in Tbilisi, the Republic of Georgia. *JAMA* 287: 1043-1049.
- Vaszar LT, Rosen GD, **Raffin TA** (2002) Pharmacogenomics and the challenge to privacy. *The Pharmacogenomics Journal* 2(3): 144-147.

New Grants:

- **Cho, MK** United States Department of Energy. "Assessing Societal Impacts of Scientific Research."
- **Crawley, L** National Institutes of Health. "Differential Trust in Cancer Care Within Black Subgroups." # K01-CA098326-01.
- **Illes, J** The National Science Foundation and the New York Academy of Sciences. "Neuroethical Challenges in the Enhancement of Cognition and Learning." NSF #BCS 0335275.
- **Koenig, B** National Institutes of Health/National Institutes of Drug Addiction. "Genetics of Nicotine Addiction. Examining Ethics and Policy." # R01DA14577.
- **Lee, SS** National Institutes of Health Scientist Development Award in Research Ethics. "Distributive Justice and Human Genetic Variation Research." PAR-01-144. # K01 HL72465.