

#### In This Issue:

State of the Center

**Center News** 

Faculty Profile: Tom Raffin

**People News** 

Recent Publications

**Student Publications** 

SCBE Upcoming Events

SCBE Faculty and Staff

Stanford Center for Biomedical Ethics

**Stanford University** 

1215 Welch Road Modular A Stanford, CA 94305-5417

Ph: (650) 723-5760 Fax: (650) 725-6131

http://bioethics.stanford.edu info@med.stanford.edu

# Stanford Bioethics

Volume 6, Number 1: Fall 2010

## State of the Center

Renewal of the Center on the Integration of Research On Genetics and Ethics (CIRGE)

The NHGRI has renewed CIRGE, one of several interdisciplinary Centers of Excellence in Ethical, Legal, and Social Implications (ELSI) of genetic research, for another five years. For this renewal, CIRGE will implement a new program, the Integrating Values and Ethics in Science and Technology (INVEST) Forum, based on the

concept of constructive technology assessment (CTA). The premise of CTA is that the implications of scientific research and development are not only a function of characteristics of technology, but of the interaction between



science and its social and moral context. CIRGE will serve as an intermediary between stakeholders and end-users of the research on the genomics of behavior, the scientists who conduct that research, and the ELSI research community. We will create a forum for integrating ethical and social considerations into specific areas of genomic research through 1) <del>prognostic</del> normative analyses that identify the values, principles and assumptions that are implicated by research and technology and its application 2) empirical analysis to map relevant genomic research and technology and identify stakeholders, 3) empirical analysis to assess relevant features of the ethical, legal or social context, such as how different stakeholders think genome information or technology will be used, should be used, perceived, or who it might benefit or harm, 4) -diagnostic"

normative analyses to assess whether and how genomic research and technology supports or undermines stakeholder values, and 5) feeding back normative and empirical ELSI findings into research and development priorities, design criteria or requirements. These feedback processes are intended to inform the design and application of genome research in a way that enhances benefit and utility to end-users. Current projects include:

- Attitudes towards genetic testing for mood disorders and other psychiatric conditions
- Application of and attitudes towards fetal testing of cell-free maternal serum
- Genetic research and the Navajo Nation
- Use of genetic testing for psychiatric conditions and anti-social behavior by government agencies
- Requirements for clinical application of whole genome sequencing
- Social networking and knowledge, attitudes and beliefs about personal genomics

#### **Prominent Bioethicist Joins Stanford**

The Stanford University School of Medicine has brought Laura Roberts, MD, psychiatry chair at the Medical College of Wisconsin, to lead its Department of Psychiatry and Behavioral Sciences. Widely acknowledged as a national leader in psychiatric ethics, Dr. Roberts' work is interdisciplinary and utilizes empirical, theoretical and clinical methods. She has been

(Continued on Page 2)



#### State of the Center (continued)

especially influential in her work on informed consent and research ethics, particularly with research subjects with psychiatric illness. In addition, she serves as co-Chair of the American Psychiatric Association Task force on research ethics and has a keen interest in ethics in medical education, residency training and research ethics training. At Stanford, Roberts will chair a department that includes more than 60 full-time faculty members and is highly regarded for its basic, translational and clinical research.

#### Social Networking and Personal Genomics: Emerging Issues for Health Research

NHGRI has awarded the Center for Biomedical Ethics with a three year R01 grant (R01HG05086) to examine the perspectives of customers of direct-to-consumer personal genetic information companies in order to better understand the networks which arise from the sharing of personal genetic information as well as the potential uses of consumer surveys and data bases for genome wide population studies. Rapid development of increasingly efficient high throughput genetic sequencing technologies and ubiquitous internet use by the public has encouraged the emergence of an increased number of direct-to-consumer (DTC) personal genomic information (PGI) companies. The growing industry premises its services on the following paradigm shifts. First, knowledge of a person's genetic code is empowering and will enable individuals to make better decisions about personal health, medical care and lifestyle. Second, the new era of openness facilitated by new technology challenges traditional approaches to genetic testing and therefore requires new ethical approaches towards protecting consumers. Finally, taking advantage of easy and continued access to their consumers via the internet, DTC PGI companies assert that they can take the lead in scaling up' genotypic and phenotypic population DNA data collections. Under the direction of Sandra Soo- Jin Lee, PhD (PI), this project will use the leading DTC personal genomic company, 23andMe, Inc., as a case study in order to evaluate the validity of each of these claims so as to understand the ethical and social implications of DTC personal genomics.

## Center News

## David Magnus Named Thomas A. Raffin Professor of Medicine and Biomedical Ethics

David C. Magnus, PhD, Director of the Stanford Center for Biomedical Ethics, and professor of pediatrics and by courtesy, of medicine, was appointed Thomas A. Raffin Professor of Medicine and Biomedical Ethics on December 8, 2009. The investiture ceremony was held at a celebration dinner to honor donors Colleen and Robert Haas, Thomas A. Raffin, MD, and Dr. Magnus,



on April 15, 2010. Philip A. Pizzo, MD, Dean, Stanford University School of Medicine and Carl and Elizabeth Naumann Professor, gave a welcome address and toast, followed by remarks from the honorees (see also Faculty Profile: Tom Raffin, pages 4 – 8, in this issue).



Endowed professorships, also known as endowed chairs, are the highest academic award the university can bestow upon a faculty member. It becomes an enduring tribute to the donor's belief in academic excellence and social responsibility. The honor and prestige associated with appointment to an endowed chair is shared equally by each successive chair holder, the university, and the donor.

At Stanford, the roster of endowed chair holders stands as an honor roll of the most distinguished faculty members—scholars, scientists, and teachers—in its history. Similarly, the roster of donors whose generosity makes endowed chairs possible is a celebration of Stanford's most farsighted and committed friends.

Thank you to Colleen and Robert Hass, and congratulations, Dr. Magnus!

#### **SCBE Moves to New Offices!**

The Stanford Center for Biomedical Ethics has relocated to 1215 Welch Road, Modular A. Even though the exterior of our modular unit is underwhelming, we were fortunate to move into offices that were completely renovated to meet our specific needs. The new location is very convenient to the hospital and to the Medical School Office Building. Drop in and see us!

#### Jonathan J. King Lecture:

SCBE has had an extraordinary group of speakers for our annual Jonathan J. King lecture and 2010 is no exception. Pauline W. Chen, MD, will be speaking at 5:30 pm on October 11, 2010, at Paul Berg Hall, in the new Li Ka Shing Center, Stanford University School of Medicine.

Pauline W. Chen, a liver transplant and liver cancer surgeon, is author of *Final Exam: A Surgeon's Reflections on Mortality*, a *New York Times* bestseller. Dr. Chen graduated from Harvard University and Northwestern University's Feinberg School of Medicine, completing her surgical training at Yale University, the National Cancer Institute (NIH), and UCLA, where she was most recently a faculty member in the Department of



Surgery. In 1999 she was named UCLA Outstanding Physician of the Year. She has been nominated for a National Magazine Award, has written for numerous publications, including The New York Times, and speaks regularly to medical and general audiences across the country.

#### **Bioethics in Film:**

A short film based on *The Revolutionary Optimists* was presented at TEDxChange on September 20 in New York City. The event, co-hosted by TED and the Gates Foundation, was convened by Melinda French Gates and featured some of the world's most inspired thinkers and doers. TEDxChange marks the anniversary of the Millennium Development goals. Ten years in, where does the global community stand in its work to save and improve lives around the world and what does the future hold?



The Revolutionary Optimists (directed by Nicole Newnham and Maren Grainger-Monsen) is in production, and follows Amlan Ganguly, a lawyer turned social entrepreneur who has made a significant impact in the poorest neighborhoods of Calcutta by empowering children to become leaders in improving health and sanitation. Using street theater, dance, and data as their weapons, the children have cut malaria and diarrhea rates in half, increased polio vaccination rates, and turned garbage dumps into playing fields. Now, pushing at the limits of optimism, Amlan is attempting to take his work into the brickfields outside Calcutta, where child laborers live and work in unimaginable conditions

The short film, produced by Maren Grainger-Monsen and Nicole Newnham, was streamed live and can be viewed on the Gates and Sundance websites below. It focuses on the children's successful drive to increase polio immunization rates in their community.

http://www.sundance.org/blog/entry/tedxchange-reaches-global-audiences/ http://www.tedxchange.org/ http://www.gatesfoundation.org/tedxchange/pages/revolutionary-optimists.aspx

## Faculty Profile: Tom Raffin



In 1999, a gift from *Colleen and Robert Haas* established a professorship in honor of *Thomas A. Raffin, MD*, who conceived and founded the Stanford Center for Biomedical Ethics. The professorship was renamed for Tom Raffin upon his retirement, at the request of the Haases, and on December 8, 2009, *David Magnus, PhD*, Director of the Stanford Center for Biomedical Ethics and professor of pediatrics and by courtesy, of medicine, was named the Thomas A. Raffin Professor of Medicine and Biomedical Ethics. At a celebratory dinner on April 15, 2010, to honor Colleen and Robert Haas, Tom Raffin, and David Magnus, Tom gave the following speech, which we are pleased to publish in its entirety, in place of an interview.

Thank you, everyone. It is a great honor and pleasure to be here. Happy Tax Day! Enjoy the current rates since they will not be this low for another decade. First, I would like to express my deep appreciation, love and thanks for the caring and strong support provided me by my family: Michele, my lovely and talented wife who had to live through being woken up every one to two hours all night when I was on-call for the intensive care unit, and our four wonderful children, two of whom are here-Lizzy and Ross—and Jason and Nick, who are away at school. Michele left her job as a successful Silicon Valley executive to care for me and our children. Our children have all left home, but we do not have an empty nest. Michele founded a non-profit to save birds. It's called Pandemonium Aviaries, and currently is home to 300 birds, including 80 parrots. Since we breed endangered species, we often have a lot of full nests.

Next, I want to thank Colleen and Bob Haas. They are wonderful human beings. I met Colleen while we were

both undergraduates at Stanford in the mid-1960's, and watched as she became a brilliant lawyer helping to defend the disenfranchised of our society, including members of the Black Panthers. Colleen is always there for her friends and family when they confront challenges, and over the past several decades she has helped to care for a number of close friends with severe health problems. As a care provider, Colleen's nickname has been Flo, standing for Nurse Florence Nightingale. Besides making diagnoses and recommending therapies, Dr. Haas, or Flo, also helps her friends keep their homes in order through the Colleen Haas Maid Service. Colleen has taken friends for care to Stanford so many times she parks for free. Her caring and love for her friends and family is unmatched in my experience.

Although Bob Haas and I grew up in San Francisco, we really did not get to know each other well until he met Colleen. Of interest, Bob and I came from Jewish families who originally settled in San Francisco in the mid-1800's. Unfortunately, my family thought that making blue jeans was a fershlugginer idea!

Bob Haas is an amazing, brilliant, courageous and humble person. However, he has one festering fault, which is an infatuation with Oski, the sloth. Bob was Class Valedictorian at Cal, served in the Peace Corps in the Ivory Coast, received his MBA as a Baker Scholar at Harvard, was a White House Fellow, worked for McKinsey, joined Levi Strauss in 1973, and was CEO from 1984 to 1999, during which time he enormously increased the value of Levi Strauss and took the company private. Clearly, Bob is no sloth. Bob was a unique American CEO. He balanced excellent and insightful management with a devotion to corporate social responsibility. Bob led Levi Strauss to become one of the first companies to define and support labor and safety

standards for employees in its worldwide operations. This humanistic approach to business was a model for all to see and admire. Of course, this took great courage, since compassion and caring often compete with corporate profitability and efficiency. At the same time Bob was running one of the world's great corporations, he displayed leadership and



courage in being one of the first business leaders in America to call for strong support of employees and people with HIV and AIDS during a time when there was little support and much national bias. Bob was the first recipient of the National Leadership Coalition on AIDS' Edward N. Brandt, Jr. Award for his pioneering efforts in addressing HIV and AIDS in the workplace. In 1998, President Bill Clinton honored him with the first annual Ron Brown Award for Corporate Leadership, in recognition of Levi's anti-racism initiative, Project Change." Bob became chairman of the board of Levi Strauss in 1989 and was named chairman emeritus in 2008. Across the Bay in the land of Oski, the Robert D. Haas Chancellor's Chair in Equity and Inclusion was established in 2008 in his honor as part of a campuswide initiative for equity and inclusion. In April 2009, he was honored as Cal Alumnus of the Year.

Third, I am delighted David Magnus will be the first holder of the Thomas A. Raffin Professorship in Medicine and Biomedical Ethics. I was lucky enough to help recruit David to Stanford in 2003 to become the director of the Stanford Center for Biomedical Ethics. David has done an outstanding job building the center and infusing ethical thought and leadership in the medical school, across the campus, nationally and internationally. David is truly a star.

Fourth, I wanted to use this opportunity to congratulate Phil Pizzo on the superb job he had done as dean of Stanford University Medical School. When I was a medical student, I was called the —junior dean" by the faculty and most people felt I would become a dean. However, when Norm Shumway told me that the only good dean was Gunga Dean, I decided to go in a different direction. I want to honor Phil tonight because he has been courageous, strategic, paradigm-shifting, incredibly hard working, and highly ethical. A large part of Phil's career was devoted to the care and study of children with cancer and HIV. We are lucky Phil is Stanford's dean.



## Colleen and Robert Haas Professorship Donors

Colleen and Robert Haas established a professorship in honor of Thomas A. Raffin, MD, who conceived and cofounded the Stanford Center for Biomedical Ethics in 1999. The Haases asked that the professorship be renamed for Dr. Raffin upon his retirement and that it be called the Thomas A. Raffin Professorship in Medicine and Biomedical Ethics going forward.

Colleen Gershon Haas earned two degrees from Stanford—a BA in 1968 and a JD in 1971. After law school, she practiced civil rights law with the firm Garry, Dreyfus, McTernan, and Brotsky in San Francisco.

Robert D. Haas is an alumnus of the University of California, Berkeley, and Harvard business School. Following graduation, he taught English in western Africa (Ivory Coast) as a member of the newly formed Peace Corps. Mr. Haas also served as a White House Fellow in the Johnson Administration before returning home to work as a management consultant. In 1973, he joined Levi Strauss & Co., the world's largest apparel company. He served as chief executive officer of the company from 1984 to 1999 and was chairman from 1989 to 2008. Under his leadership in the early 1980's, Levi Strauss & Co. pioneered HIV/AIDS awareness and education policies, which were widely adopted by corporations and other institutions. Mr. Haas is a Berkeley Fellow and serves on the Chancellor's Executive Advisory Council, UC Berkeley, and is Chairman of the Stanford Humanities and Sciences Council.

Over the years, Mr. and Mrs. Haas have enjoyed a close friendship with Dr. Raffin, whom they describe as —an extraordinary physician, brilliant academician, gifted and empathetic clinician, and medical visionary."

I want to share with you how I discovered that Colleen and Bob were endowing a chair for me. I was returning from the ICU to my office at Stanford in 1999 around 3:00 PM and on my table was a gift with a large bow: an enormous glass pig, four feet by three feet by two feet, filled with little pink pig candies. Let me digress. One of my two totems has been the pig, since falling in love with pigs when I was a boy helping to feed them, slop them, at a ranch in Canada. I loved the way pigs would eat anything. They would jump into their feeding troughs with great enthusiasm and roll around in their food as they devoured everything in site, making an enormous mess. Further, I discovered through my first empiric research project conducted at the ranch that pigs would eat anything. My

other totem is the donkey or burro or ass, which I fell in love with in Montana when I was working at a ranch as a teenager. Donkeys are very smart, quirky, amusing and interactive. My three miniature donkeys are all characters: Trixie, Trudy and Miss T. Back to how I learned about the endowed chair. In my office at Stanford I had a four-foot by three-foot by three-foot enormous pink paper mache pig lovingly made by Stanford medical students hanging from my office ceiling and pig paraphernalia were everywhere in my office. Thus, when I saw the large glass pig filled with pink candies standing on my office table, I simply smiled, accepted it as an amusing contribution to my nutty office, and continued working for another few hours until it was after 6:00 PM. At this point I had things under control in the ICU and I returned to look more closely at the glass pig. Inside among the candies was a note I had not seen before. I pulled out the cork snout and read the note. I blinked. I read the note a second time since I thought it said that Colleen and Bob were endowing a chair for me at Stanford. I couldn't believe it. I thought it was a joke. I phoned them and discovered they were serious and I was overwhelmed with this amazing gift. I told them I was honored and proud of their offer, but they should aim their philanthropy elsewhere and not endow a chair for me. This fell on deaf ears.



I would like to repeat some advice I have given to Lizzy, Ross, Jason, and Nick. I am a strong believer in working hard, doing the best job you can, always helping others (doing mitzvahs), being a good person, and being prepared for good luck and timing. The goal is to behave like a mensch. Whether or not you are highly successful will in large part be a function of luck and timing. If you are very successful, you should share your success with others. If you are not very successful, it is fine as long as you have done your best. Many wonderful people do not achieve success due to poor luck and timing. This is quite evident among businesses in the real world. What matters most is how you play the game, not whether you win or lose. One

should fight to be straightforward and follow your judgment. If you strongly believe in something, you should be tenacious in pursuing your goals.

For example, when I was nine years old my parents wanted me to attend a prestigious San Francisco private school named Town School. I did not want to leave my friends in the public school system and refused to take the Town School Admissions Test. After a great battle with my parents, including many threats, I relented and said I would take the test. Following the exam, the Principal of Town School phoned my parents and told them I was either mentally deficient or very bright, since I had answered every test question wrong. I did not attend Town School.

As a Stanford undergraduate in 1966, I spent six months studying and doing research in marine biology at Hopkins Marine Station with one of my favorite and most talented mentors, Professor David Epel, which laid a strong foundation for later basic and clinical research as a medical student, and then faculty member at Stanford. I chose a very difficult research project, dealing with RNA synthesis in Pollicipes polymerus, the goose-neck barnacle. No one at Hopkins had been doing RNA research and no one could talk me out of working on this project. I was being overly tenacious. The lesson I learned and which has stayed with me throughout my career, is to be strategic and judicious in making decisions, but don't be shy.

Another story: In the evening in 1974, as a 27 year old intern in the Emergency Room at the Brigham, I began caring for an 80 year old blind, thin Irishman, who came in throwing up blood and had a low blood pressure. He was accompanied by his wife. He needed to have an endoscopy to visualize from where in his upper GI track he was bleeding, which would dictate therapy. I phoned the professor on call for GI at home, explained the situation, and asked him to please come in immediately to perform the endoscopy. The professor asked if the tube we had placed in the man's stomach (to suck out the blood and place in iced saline to retard the bleeding) was aspirating out clear saline, or was it pink? In other words, was he still bleeding? I told him that the saline being aspirated out of the old man's stomach was almost clear, the bleeding was definitely stopping, and since the professor lived 20 minutes away, it would definitely be clear when the professor arrived at the Brigham. The professor said: call me back when it is clear. I told him he needed to come in now. The patient's life was in danger and we needed to know how to treat the patient NOW. He hung up on me. I walked into the coffee room in the Brigham ER, where I knew there would be two older Irish cops taking a break. I explained the situation of the old Irishman and asked if they could get the police operator to order a squad car to drive code three with sirens and lights

to pick up the professor in Newton. They agreed and 20 minutes later, the professor was dropped off by a police cruiser at the Brigham ER. It suffices to say that the professor was extremely pissed off at me. The endoscopy was done. The old Irish patient lived. The next day, Gene Braunwald, international leader in cardiology and feared Chairman of Medicine at the Brigham, walked up to me and asked if it were true that I had sent a police car to pick up the GI professor. I told him it was true and recounted the story. At the end of the story, Gene said, —Good job, Tom."

In 1982 I wanted to develop closer ties between Stanford, Japan, and Hong Kong. I networked and made contact with the Deans and Chairmen of Medicine at Hong Kong University and Keio University in Tokyo. Tony Felsovanyi, one of the best internists in the Palo Alto area, cared for many leading citizens in Hong Kong and was instrumental in helping me develop a plan. I flew to Asia alone and networked among the contacts I had made both in academics and business. Eventually, the group of supporting businessmen in Hong Kong turned out to include Li Ka-shing, Stanley Ho, Ho Tim, and several others. This was a result of luck and timing. After working together for a couple of years, I began to provide medical care to them and their families and friends. The endowed fellowship programs I began in Asia under the name Stanford University - Asia Medical Fund, or SAMFUND, have enabled 70 outstanding fellows from Japan and China to come to Stanford for one year of research training since 1983. The programs are ongoing today.

Since being a young boy, I was always interested in making sure that all people, no matter what race, religion, ethnic group, or socioeconomic status, were treated fairly and with equality. My formal interest in ethics began as an undergraduate at Stanford. The summer before medical school I worked in an OEO health care project for migrant farm workers in King City, California. I continued my interest in helping others at Stanford Medical School and I had great mentors like Roy Maffly, with whom I began caring for patients in my first few months as a medical student. As a fourth-year medical student on the medical ward, I joined together with a courageous medical resident and we tried to stop the hematologists from continuing to administer toxic chemotherapy to a young Hispanic woman who was dying from acute myelogenous leukemia. She was not benefitting from therapy, her quality of life was horrible, and it was time to let her die with dignity. The hematologists wanted to continue to push therapy; the

patient was involved in a clinical study. An enormous fight ensued where we had to back down, and the patient was infused with more chemotherapy. She died in misery two weeks later. I was upset by this incident for many months.



At the Brigham as an intern when I first worked in the ICU, I was shocked at the poor communication between critical care physicians on the ICU team and critically ill patients and families. In one situation I became outraged because a family had been kept in the dark while the ICU team helped their relative die. I had always tried to optimize communication with patients and families and I discovered that critical care practitioners were weak in the areas of ethical decision-making, communication, and knowing how to withhold or withdraw life support.

When I finished my fellowship in pulmonary medicine at Stanford in 1978, I became the first full-time faculty member in the Department of Medicine to lead the ICU team and care for 15 to 20 critically ill patients at a time, most on extraordinary life support. I would go and speak with patients on breathing machines (a very uncommon practice among ICU physicians), and I would meet with the families. Often times the families had been told that the prognosis was favorable, even though after a thoughtful review many of these patients had essentially no chance to regain a reasonable quality of life. Thus, I would counsel the patients and families, when appropriate, about withholding and withdrawing life support. The main question was to decide whether or not the critically ill patient was salvageable and care should be continued, or to help the dying patient have a peaceful and dignified death. Within several days of beginning a month as the leader of the ICU team and after meeting with all of the patients and their families, approximately 20% of the patients and families would have made the decision to withdraw life support, and we would move ahead to make this happen. The nurses were extremely supportive of this more open and honest communication. They had not seen it very often in the past, and they had been frustrated with the physicians. However, some of my attending ICU faculty colleagues who did not spend time

communicating with patients and their families, and felt personally uncomfortable dealing with emotional and demanding discussions surrounding the withholding or withdrawing of life support, began to refer to me as —the black death." This lasted for one to two years until the culture of the Stanford ICU changed.

Biomedical ethics was in its infancy in the late 1970's and early 1980's and as it advanced, pressure was placed nationally on critical care physicians to focus more on communicating with patients and families, and supporting appropriate end-of-life decisions. Luck and timing played a major role in my helping to move this trend forward in the young field of biomedical ethics.

In the mid-1980's, I convinced Dean David Korn to form a policy-oriented Stanford University Center Committee on Biomedical Ethics with members from throughout the medical center, Stanford campus, and community. Very few universities had established Ethics Committees or Centers. The Stanford Committee on Biomedical Ethics wrote three *New England Journal of Medicine* articles on withholding and withdrawing life support, the use of fetal tissue in research, and the use of animals in research. Shortly thereafter, the hospital agreed to form the Stanford University Hospital Ethics Committee and Packard Hospital followed this trend.

In 1988, we were able to raise a large sum of money from a donor in the community and I told Dean Korn that the money would not be brought into Stanford unless we created a Stanford Center for Biomedical Ethics. The Stanford University campus administration wanted buy-in for the establishment of a Stanford Center for Biomedical Ethics in the medical school from the foundational campus departments, which felt the field of ethics was predominantly in their province, so we went and met with the leaders of the Departments of Philosophy, Economics, Religious Studies and History. The campus departments decided to support our effort, and thus in 1989, the Stanford Center for Biomedical Ethics was founded in the Stanford Medical School. Following the founding of the Center, we expanded our focus from end-of-life issues to ethical issues in genomics, health care delivery, biotechnology, basic and clinical research, neuroethics, and we developed an innovative film program to increase understanding about ethical issues.

I am incredibly grateful to Stanford for a wonderful career and many great opportunities. The quality of the faculty, students, residents, and fellows is superb; the resources and facilities are top notch; and the intellectual and scholarly environment is remarkable. Since graduating from high school, I have spent my entire professional career at Stanford, except for two years at the Brigham. I have had great luck and timing in caring for patients, teaching students and trainees, performing research, and contributing to the development of pulmonary and critical care medicine and biomedical ethics.

One decade ago I decided to try my hand at working in the real world of business. It was critical to me that the colleagues with whom I co-founded Telegraph Hill Partners, a private equity firm in San Francisco, were of high integrity and wanted to operate an ethical healthcare investment firm. I believe our entire team is known for being honest, having integrity, and trying to find ways for the different business investors and operators to all do well. The good news is that thus far, my business partners do not describe me in my role working with healthcare companies as —the black death!"

## Thomas A. Raffin, MD Colleen and Robert Haas Professor of Medicine and Biomedical Ethics, Emeritus

Thomas A. Raffin, MD, received his undergraduate degree magna cum laude from Stanford University in 1968, as well as his medical degree in 1973 from the School of Medicine. After a medical residency at the Peter Bent Brigham Hospital in Boston, Dr. Raffin returned to Stanford as a fellow in pulmonary and critical care medicine.

A devoted physician and teacher, Dr. Raffin cared for patients throughout the world. In the early 1980's, he founded the Stanford University – Asia Medical Fund, providing research training to more than 65 fellows from Asia. He received the Bloomfield Award for Excellence in the Teaching of Clinical Medicine and, on four occasions, the Henry J. Kaiser Foundation Award for Excellence in Teaching.

Dr. Raffin has more than 300 publications to his name and wrote the book, *Intensive Care: Facing the Critical Choices*. As Chief of Pulmonary and Critical Care Medicine, he recruited more than 20 faculty members to the division. Dr. Raffin founded the Stanford University Center for Biomedical Ethics in 1989, the Program in Genomics, Ethics and Society in 1995, and the Hutchison Program in Translational Medicine in 1998.

In 1999, he became the first holder of the Colleen and Robert Haas Professorship in Medicine and Biomedical Ethics in the School of Medicine. Per the wishes of the Haas family, this professorship was renamed in Dr. Raffin's honor upon his retirement in 2009.

## People News

#### Megan Allyse - Post-Doctoral Fellow

Megan will receive her PhD in Sociology and Social Policy from the University of Nottingham, where she has studied ethics and science policy related to oocyte donation in California, the UK, and China. Her research interests include normativity in public and social policy, intercultural ethical comparisons, and public health ethics and policy. She joins CIRGE as one of three new post-doctoral fellows.

#### Jessica Erickson - Post-Baccalaureate Fellow

Jessica graduated cum laude from Harvard as a Psychology major with a citation in Spanish. She worked as a research assistant for two years and a primary investigator for one year in Harvard's Health and Psychophysiology Lab, which primarily researches physiological reactions to stress. She joined CIRGE in September as one of two fellows in CIRGE's new post-baccalaureate fellowship program.

#### Nanibaa' Garrison- Post-Doctoral Fellow

Nanibaa' earned her PhD in Genetics at Stanford University and her undergraduate degree at the University of Arizona in Molecular and Cellular Biology, with minors in American Indian Studies and Psychology. Her PhD dissertation was on the genetic architecture of human hair and skin pigmentation. Her research is on the attitudes towards genetic research among Navajos.

#### Molly Havard - CTSA and Stem Cell Research Assistant

Molly graduated from Stanford as a HumBio major. She conducted research in the Emergency Department on patient satisfaction and familiarity with attending physicians. She was a founding member of the Stanford Student Society for Stem Cell Research and designed a student-initiated course, —Introduction to Stem Cells: An Interdisciplinary Approach."

**Jenn Ladd** left her role as CIRGE Program Manager to attend Stanford Medical School. We are happy to have her so close by!

**Haerin Lee** left her role at SCBE as CTSA and Stem Cell Research Assistant to attend medical school at Vanderbilt University. She is still helping us by editing our website.

#### **Lauren Milner - Post-Doctoral Fellow**

Lauren will receive her PhD in Behavioral Neuroscience from Oregon Health and Science University, where she studied the role individual genes play in alcohol, physical dependence and withdrawal. She has published and



Lauren Sayres, Nanibaa' Garrison, Lauren Milner, Simone Vernez, Maya Wolpert, Molly Havard, Megan Allyse and Jessica Erickson, with SCBE's new home, Modular A, in the background.

presented her research in national and international journals and venues, and is active in educational outreach activities related to psychology and neuroscience. She joined CIRGE in September as one of three new post-doctoral fellows.

#### Lauren Sayres - Post-Baccalaureate Fellow

Lauren graduated from Stanford as a HumBio major, with a minor in Ethics in Society. She conducted research in the Department of Orthopedic Surgery and presented her findings at several meetings. She led the student organization, Organ Donor Education, which educates the community about organ donation. She is one of two fellows in CIRGE's new post-baccalaureate fellowship program.

#### Maya Wolpert - CIRGE Program Manager

Maya graduated from Stanford as a HumBio major, with a concentration in Bioethics, and has worked at SCBE for four years. She has spent her summers conducting AIDS research in South Africa, interning at the NIH Bioethics Center, and at Cleveland Clinic studying conflicts of interest in biomedical research. Her work was most recently published in the AAMC's June 2010 Report.

#### Simone Vernez - Project Manager

Simone is the new project manager for Sandra Lee's R01 grant project, —Social Networking and Personal Genomics: Emerging Issues for Health Research." She is a Stanford graduate in International Relations, with extensive background in the biological sciences. She comes with experience in project management in the Departments of Psychiatry and Radiology. Most recently, she provided research support for a project that focused on imaging and pediatric and teen bipolar disorder.

### Recent Publications

#### Paula Bailev

Bailey P. The Legend of the Tiger: Stories from Shaolin. Kung Fu Tai Chi 2010:68-72.

#### **Mildred Cho**

Cho M. Patently unpatentable: Implications of the BRCA court decision on genetic diagnostics. Trends in Biotechnology 2010.

Meslin EM, Cho MK. Research Ethics Challenges in the Era of Personalized Medicine: Updating Science's Contract with Society. Public Health Genomics 2010;13:378-84.

Cho MK, Relman D. Synthetic "life", ethics, national security and public discourse. Science 2010;329:38-9.

Ladd JM, Lappe MD, McCormick JB, Boyce AM, Cho MK. The "How" and "Whys" of Research: Life Scientists' Views of Accountability. Journal of Medical Ethics 2009;35:762-7.

Tobin SL, Lee SSJ, Greely HT, Ormond KE, Cho MK, Not a loophole: Commercial exploitation of an IRB error, PLoS Genetics 2010;6.

#### LaVera Crawley

Scott CT, DeRouen MC, Crawley LaVera M. The language of hope: Therapeutic intent in stem cell trials. AJOB Primary Research 2010;1:4-11.

Crawley LM. Having a say: Agency and end-of-life decision-maing in The Chaneysville Incident. Journal of General Internal Medicine 2010;25:995-6.

McLaughlin RM, Clarke Dur T, Crawley LM, Glaser S. Are cancer registries unconstitutional? Social Science & Medicine 2010;70:1295-300.

Crawley LM, Hisaw LD, Illes J. Direct-to-consumer advertising in black and white: Racial differences in placement patterns of print advertisements for health products and messages. Health Marketing Quarterly 2009;26:279-92.

#### Joanna Fanos

Fanos JH, Little GA, Edwards WH. Candles in the Snow: Ritual and Memory for Siblings of Infants who Died in the Intensive Care Nursery. J Pediatr 2009;154:849-5.

Fanos J, Wiener L, Brennan T. Potential Impact of Genetic Information on Childhood Sibling Relationships. In: Tercyak KP, ed. Handbook of Genomics and the Family. Issues in Clinical Child Psychology: Springer Publishing; 2010:141-61.

#### **Hank Greely**

Greely HT. Enhancing Brains: What Are We Worried About? Cerebrum 2010.

Greely HT, Hernandez MM. Technology Law: What Is It? - And What Should It Be (Foreword). Journal of Technology Law and Policy 2010;15:1-8.

Rissman J, Greely HT, Wagner D. Detecting Individual Memories Through the Neural Decoding of Memory States and Past Experience. Proc National Academy of Science 2010;107:9849-54.

Ormond KE, Wheeler MT, Hudgins L, Klein TE, Butte AJ, Altman RB, Ashley EA, Greely HT. Challenges in the Clinical Application of Whole-Genome Sequencing. The Lancet 2010;375:1749-51.

Ashley EA, Butte AJ, Wheeler MT, Chen R, Klein TE, Dewey FE, Dudley JT, Ormond KE, Pavlovic A, Morgan AA, Pushkarev D, Neff NF, Hudgins L, Gong L, Hodges LM, Berlin DS, Thorn CF, Sangkuhl K, Hebert JM, Woon M, Sagreiva H, Whaley R, Knowles JW, Chou MF, Thakuria JV, Rosenbaum AM, Zaranek AW, Church GM, Greely HT, Quake SR, Altman RB. Clinical Assessment Incorporating a Personal Genome. The Lancet 2010;375:1525-35.

Greely HT. Collecting Biomeasures in the PSID: Ethical and Legal Concerns. Biodemography and Social Biology 2009;55:270-88.

Greely HT. Law and the Revolution in Neuroscience: An Early Look at the Field. Akron L Rev 2009;42:687-715.

Greely HT. Panel on Collecting, Storing, Accessing, and Protecting Biological Specimens and Biodata in Social Surveys. Washington DC: National Academies Press; 2010.

Greely HT. From Nuremberg to the Human Genome: The Rights of Human Research Participants. In: Rubenfeld S, ed. Medicine After the Holocaust: From the Master Race to the Human Genome and Beyond. New York: Palgrave; 2010.

Greely HT. To the Barricades! American Journal of Bioethics 2010;10:1-2.

Tobin SL, Lee SSJ, Greely HT, Ormond KE, Cho MK. Not a loophole: Commercial exploitation of an IRB error. PLoS Genetics 2010;6.

Greely HT. Where Do We Go From Here? AJOB: Neuroscience 2010;1:1-2.

## Recent Publications (continued)

#### **Henry T. Greely (continued):**

Greely HT, King JS. The Coming Revolution in Prenatal Genetic Testing. Professional Ethics Report 2010;23:1-3.

Greely HT. How Should We Deal with the Arrival of Very Common Prenatal Testing for a Broad Set of Genetic Characteristics? Genomics Law Report 2009.

Greely HT. How Will We Handle the Rapidly Approaching Flood of Genomic Information on Individual Patients and Consumers? Genomics Law Report 2009.

#### Katrina Karkazis

Karkazis K, Tamar-Mattis A, Kon A. Surgery for Disorders of Sex Development: Implementing a Model for Shared Decision-Making. Journal of Pediatric Endocrinology & Metabolism 2010;8:789-806.

#### Sandra Lee

Lee SSJ, Social Networking in the Age of Personal Genomics, Saint Louis University Journal of Health Policy and Law 2010;3:41-60.

Lee SSJ. The Social and Ethical Implications of Pharmacogenomics in Asia. In: Sleeboom-Faulkner M, ed. Frameworks of Choice: Predictive Genetic Testing in Asia: University of Amsterdam; 2010.

Lee SSJ. The Ethics of "Statistical Race" and its Implications for Health Disparities in a Genomic Age. Current Pharmacogenomics and Personalized Medicine 2009:7:238-42.

Lee SSJ. The Ethics of Pharmacogenomics. California Pharmacist 2009;56:24-7.

#### **David Magnus**

Braddock CH 3<sup>rd</sup>, Magnus D. Empirical methods in bioethics: a cautionary tale. Ann Intern Med 2010;152:358-65.

Pretz IL, Magnus D, Spain DA. Emergency innovation: implications for the trauma surgeon. J Trauma 2009;67:1443-7.

Magnus D. Translating stem cell research: challenges at the research frontier. J Law Med Ethics 2010;38:267-76.

Magnus D. Bioethics and President Obama. American Journal of Bioethics 2010;10:1-2.

#### **Mary Rorty**

Rorty M, Mills C, Mills I. Viewing Trading Zones Developed to Advance Health as Complex Adaptive Systems. In: M. G, ed. Trading Zones and Ethics: MIT Press; 2010:267-81.

Rorty M. Rules for the Human Zoo: Sloterdjik's Elmauer Rede. Environment and Planning D: Society and Space 2009;27:12-28.

Rorty M, Frankel LR. The Paradoxical Placebo. American Journal of Bioethics 2009;9:4-12.

Rorty M. The Third Face of Medicine. In: Arnold D, ed. Business, Ethics and Biomedicine: Oxford University Press; 2009

#### **Chris Scott**

Scott CT, Murdoch CE. Response to open peer commentaries on "Stem cell tourism and the power of hope. Am J Bioeth 2010;10:W1-3.

Caulfield T, Scott C, Hyun I, Lovell-Badge R, Kato K, Zarzeczny A. Stem cell research policy and iPS cells. Nat Methods 2010;7:28-33.

Murdoch CE, Scott CT. Stem cell tourism and the power of hope. Am J Bioeth 2010;10:16-23.

Scott CT, DeRouen MC, Crawley LC. The Language of Hope: Therapeutic Intent in Stem Cell Clnical Trials. American Journal of Bioethics Primary Research 2010;1:4-11.

Simon BM, Murdoch CE, Scott CT. Pluripotent patents make prime time: an analysis of the emerging landscape. Nat Biotechnol 2010;28:557-9.

Scott CT Owen-Smith J, McCormick J. We must reverse the Bush legacy of stem-cell problems. Nature 2009;460:33.

Skene L, Testa G, Hyun I, Jung KW, McNab A, Robertson J, Scott CT, McCormick JB, Owen-Smith J. Ethics report on interspecies somatic cell nuclear transfer research. Cell Stem Cell 2009;5:27-30.

Scott CT, McCormick JB, Owen-Smith J. And then there were two: use of hESC lines. Nat Biotechnol 2009;27:696-7.

Taymor K, Scott CT. The practical consequences of a national human embryonic stem cell registry. Stem Cell Rev 2009;5:315-18.

Zarzeczny A, Scott C, Hyun I, Bennett J, Chandler J, Charge S, Heine H, Isasi R, Kato K, Lovell-Badge R, McNagny K, Pei D, Rossant J, Surani A, Taylor PL, Ogbogy U, Caulfield T. iPS cells: mapping the policy issues. Cell Stem Cell 2009;139:1032-37.

Stanford Bioethics Vol. 6 No. 1: Fall 2010 11

## **Recent Publications** (continued)

#### **Audrey Shafer**

Gardner C, Golestaneh L, Dhillon B, Shafer A. People say there are no accidents: Poetry and Commentary. Journal of Medical Humanities 2010;31:257-63.

Shafer A. Charles Dickens: A Tale of Two Cities. In: LaCombe M & Elpern DJ, ed. Osler's Bedside Library: Great Writers Who Inspired a Great Physician: American College of Physicians Press; 2010:169-77.

#### Larry Zaroff

Zaroff L. What's the Problem. Learning Through The Arts 2009;5.

Zaroff L. To Mount a Camel. Hektoen International: A Journal of Medical Humanities 2009;5.

Zaroff L. Drowning in Science ... saved by Shakespeare: teaching literature to premedical students. Pharos 2010;73:13-5.

Zaroff L. Always a Plague: Camus' Dr. Rieux and the AIDS Pandemic. Family Medicine 2010;42: 479-80.

Zaroff L, Chan T. Emily Dickinson's mystifying in-sight. Hektoen International: A Journal of Medical Humanities 2010;2.

Zaroff L. The Right Time. In: Cell 2 Soul; 2010.

Zaroff L. A Death in the Operating Room. Hektoen International: A Journal of Medical Humanities 2010;2.

Zaroff L. Tsunami Time. In: Cell 2 Soul; 2010.

#### Student Publications: Biomedical Ethics and Medical Humanities Scholarly Concentration

#### **Blake Charlton**

Charlton B, Verghese A. Caring for Ivan Ilyich. J Gen Intern Med 2010;25:93-5.

Charlton B. Spellwright: Tor Books; 2010.

#### Jennifer Pretz

Pretz IL, Magnus D, Spain DA. Emergency innovation: implications for the trauma surgeon. J Trauma 2009;67:1443-7.



## SCBE Upcoming Events

#### October 5, November 2, November 30, 2010 7:00 - 9:30 pm

Tuesday Evening Writing Group Series SCBE Conference Room (62) 1215 Welch Road, Modular A

#### October 13, 2010, 11:00 am - 12:00 pm

CIRGE Journal Club Evaluating Genomic Tests for Translation to Clinical Practice: EGAPP and the Example of Warfarin, facilitated by Mildred Cho, PhD CCSR 4205

#### November 20, 2010, 8:45 – 4:30

November One-Day Writing Workshop Facilitated by Sharon Bray Home of Audrey Shafer

#### February 23, 2011, 10:00 -11:00 am

CIRGE Writing Seminar SCBE Conference Room (62) 1215 Welch Road, Modular A

#### October 6, 2010, 1:00 – 2:30 pm

Ethics Methods Seminar with LaVera Crawley, MD, MPH SCBE Conference Room (62) 1215 Welch Road, Modular A

#### October 27, 2010, 10:00 – 11:00 am

CIRGE Writing Seminar The -age of personalized medicine" – are we there yet?, facilitated by Maya Wolpert SCBE Conference Room (62) 1215 Welch Road, Modular A

#### December 1, 2010, 10:00 – 11:00 am

CIRGE Writing Seminar SCBE Conference Room (62) 1215 Welch Road, Modular A

#### March 23, 2011, 10:00 –11:00 am

CIRGE Writing Seminar SCBE Conference Room (62) 1215 Welch Road, Modular A

#### October 11, 2010, 5:30 pm – 6:30 pm

20th Annual Jonathan J. King Lecture Pauline W. Chen, MD Li Ka Shing Center: Paul Berg Hall Stanford School of Medicine

#### November 10 and December 8, 2010

11:00 am-12:00 pm CIRGE Journal Club CCSR 4205

#### January 26, 2011, 10:00 -11:00 am

CIRGE Writing Seminar SCBE Conference Room (62) 1215 Welch Road, Modular A

#### April 12, 2011, 5:00 – 7:00 pm

Medicine and the Muse Richard Kogan, MD Li Ka Shing Center: Paul Berg Hall

Stanford School of Medicine

#### **Stanford Center for Biomedical Ethics**

1215 Welch Road, Modular A Stanford, CA 94305-5417

http://bioethics.stanford.edu

Steering Committee Chair: Henry Greely, JD **Director:** David Magnus, PhD

Administrative and Research Staff: **Associate Director:** Mildred Cho, PhD

Assistant Director: Anne Crowe, MBA **Director Emeritus:** Thomas Raffin, MD

#### **Faculty:**

Clarence Braddock, MD, MPH Julie Collier, PhD LaVera Crawley, MD, MPH Maren Grainger-Monsen, MD Henry Greely, JD Katrina Karkazis, PhD, MPH Sandra Soo-Jin Lee. PhD Jose Maldonado, MD, FAPM, FACFE Kelly Ormond, MS, CGC Laura Roberts, MD Christopher T. Scott, MLA Audrey Shafer, MD Sara Tobin, PhD, MSW Abraham Verghese, MD, MACP

Lawrence Zaroff, MD, PhD

Administrative Assistant: Rachelle Roxas, MBA

**Education Coordinator:** Paula Bailey, MA

#### **Research Staff:**

Megan Alyse, PhD Jessica Erickson, BA Nanibaa' Garrison, PhD Molly Havard, BA Lauren Milner, PhD Lauren Savres, BA Simone Vernez, BA Maya Wolpert, BA

Editor-in-Chief: Katrina Karkazis, PhD, MPH

Managing Editor: Paula Bailey, MA