



# Stanford Bioethics

Volume 8, Number 1: Fall 2012

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State of the Center

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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](mailto:info@med.stanford.edu)

Welcome to the exciting start of a new academic year! We've got talented new people on board, it's the time of our Annual Jonathan J. King Lectureship, we're now in the third year of our revamped training program in clinical ethics, and our post-doctoral fellows are moving ahead with their training and beginning to take call.

We welcome new teaching fellows to the center, Jessie Bardill, Nate Olson, and Nicole Martinez, who are involved in teaching the new Thinking Matters freshman course at Stanford, and our new bioethics course. Welcome to a new set of pre-doctoral fellows, Hayden Harvey and Emily Liu, a new CIRGE program manager, Colleen Berryessa, for our P50 grant, and a new project manager, Emily Borgelt, for Sandra Lee's R01 grant. Also welcome to Marsha Michie, a new post-doctoral fellow, who is here on a K99/NHGRI grant. Joining our faculty is Steve Goodman, a long-time member of the Berman Institute for Bioethics at Johns Hopkins University and an expert on issues in research ethics and clinical trials. Also joining us is Hywote Taye, as AJOB Managing Editor and research assistant for the ethics component of Spectrum, the CTSA funded program at Stanford.

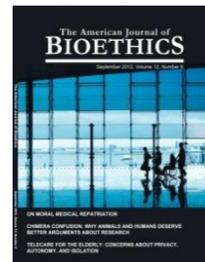
**EDUCATION:**

David Magnus will be teaching a new Thinking Matters Course, Bioethical Challenges of New Technology, to meet the new first year core requirement for Stanford undergraduates. He will be assisted by our new teaching fellows. A new grant-supported course for bioengineering majors, Ethics and Bioengineering, has been developed collaboratively by faculty at the Center for

Biomedical Ethics and the Bioengineering Department. Our BEMH Concentrators are doing excellent research and presenting their work at ASBH. It's very exciting to see the integration of medical students into the center.

**RESEARCH:**

We've had a great year for publishing, especially in high-impact factor journals. The big news is that Stanford has become the the new editorial office of the *American Journal of Bioethics*, and David Magnus is now the Editor-in-Chief of the journal. AJOB's publication record has been excellent.



Congratulations to the Program in Bioethics and Film for receiving a \$575,064 grant from the Bill & Melinda Gates Foundation.

**CLINICAL ETHICS:**

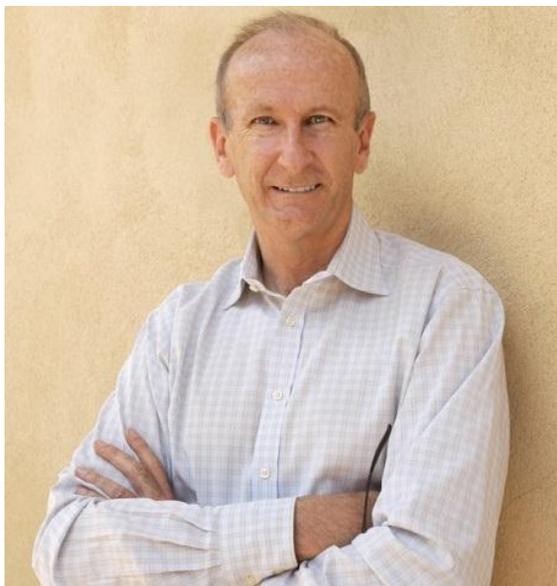
Our clinical ethics service continues to grow in the number of consults that we do. In addition, this is now the third year of our revised training program in clinical ethics for our own post-doctoral fellows, as well as clinical fellows.

**RESEARCH ETHICS:**

Our research ethics consult service is evolving and developing, as we play a leadership role nationwide, with many references to the Stanford model of research ethics consultation. Recently, we published an article in *Translational Medicine* on triggers for research ethics consultation.



# Faculty Profile: Christopher Thomas Scott



Paula Bailey interviews Chris Scott, Director of the Program on Stem Cells in Society, and faculty and senior research scholar at the Stanford Center for Biomedical Ethics. He directs multiple Stanford courses on stem cell research. His academic interests focus on the social, legal, economic, political and ethical dimensions of new biotechnologies. He is the author of over 75 publications, chapters, and peer-reviewed papers. His widely read book, *Stem Cell Now* (2007 Plume) has been translated into four languages. He is a contributing editor at *Nature Biotechnology*. Scott was the former Assistant Vice Chancellor at the University of California, San Francisco, where he led an array of units, including technology transfer, legal affairs, clinical research, and business development. While there, he founded the Program in Bioentrepreneurship. He was a co-founder of The Stem Cell Advisors, Inc., providing stem cell research oversight for research institutions. Scott was also the co-founder of Acumen Sciences, a research and consulting company based in San Francisco and the founding executive editor of the award-winning Acumen Journal of Sciences, a magazine focused on life sciences business and policy. Scott is an ethics and policy committee member for the International Society of Stem Cell Research, and a board member of the Institute for Stem Cell Biology (Zurich).

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## **Chris, how did you wind up getting into bioethics and becoming head of the Program on Stem Cells in Society?**

It's an interesting story. I was at the University of California San Francisco in 2001, at that point the Assistant Vice Chancellor of Research. I learned one of my senior faculty members was leaving the university because of presidential politics. George W. Bush was campaigning at that time, running on a platform that would restrict or stop embryonic stem cell research. This was our best stem cell researcher. He was internationally-known, he had a huge lab and dozens of people working for him. This was the first time I had ever encountered a faculty member making a substantial career decision because of what a president threatened to do, and I've been in academia most of my career. I began to think that if this would impact a senior person in the United States, what would this mean if it was written really large, and researchers all across the U.S. would be making decisions like this? I wrote an article about it and it was well-received.

A while later, I left UCSF to start a biotech company. I was focused on getting the company going, but occasionally I would write an editorial or article about the ethics of stem cell research. I was always surprised to see that those got a lot more recognition and interest than some of my other research writing. I decided that I would take a year off to write a book. For nine months I locked myself in a small office in San Francisco. I got up in the morning, walked from my house to my office, which was a couple of blocks away, and wrote a book that became *Stem Cell Now*. Of

all the books that came out during that time, it did pretty well, and still continues to do pretty well. It's used as a textbook in undergraduate classes across the country. It was an interesting and fun project for me, and I realized that there were so many issues involved with regenerative medicine, stem cell biology, and bioethics.

I had been involved in the bioethics program at Stanford when I was here in the late nineties. I was one of the first members of the Program in Genetics, Ethics, and Society, called PGES. Since I had been involved in bioethics issues in my first career at Stanford, I thought why not unify those interests with a new program on stem cells and society in 2007. I approached David Magnus, Hank Greely, and others, and we all thought it would be a great idea to start an interdisciplinary program that would weave together law, ethics, policy and economics. I came back in 2007, after eight years away, and started the program.

## **What do you hope to accomplish with the program?**

Our little group publishes and researches more on these topics than any other group. It's great because we've been able to migrate from strict policy and ethics type papers to more empirical research. That's been a tremendous amount of fun! Co-authors and collaborators who work with me here, in the U.K., Canada, and the EU focus on several issues. One of them is intellectual property—how stem cells are encumbered by the patent process. We focus a lot on quantitative approaches to qualitative research, so we do projects that involve content coding and

## ***Faculty Profile (continued)***

then statistical analysis of those projects. That research has appeared in good journals—*Cell*, *Nature*, *Nature Biotechnology*, *AJOB*, and *AJOB Primary Research*. I like that work because when you are involved with policy-making you can point to data, rather than just pointing to an argument. It's nice to be able to look someone in the eye and ask, "Can you prove it?", and provide the data that suggests we are right (for now, until someone else comes along and knocks us off)! In scientific circles, that gives us clout.

Plus, you don't find a lot of ethics-related research in science journals. You find science in science journals. One of the things I decided to do very early on was to lobby the big journals—*Nature*, *Science*, *Cell*, and others—to start running these articles in their pages right along with their science articles.

### ***Was there resistance to that?***

Yes, there was. The resistance is that, oh, you don't really do science. Ethics isn't science, it's something else. Or policy research is soft science, it's fuzzy. I think coming at this with a strong quantitative focus has helped alleviate those concerns, and these are also peer-reviewed. If there is anything that journal editors understand, it's a peer review. We go through the same process that a scientific paper would, more or less, and that gives them some comfort that when they put that on pages, it's going to be a real thing. For example, we had a paper in *Cell* last year. That's the number one journal in the world. It was a big, thick, data-rich article, and it got in front of millions of researchers. And after all, we are writing about them. So it just makes sense that researchers would read what we think about the job they are doing.

### ***Do you get a lot of feedback from them?***

I do. It's interesting. The most fun example is another research project where we interviewed forty or fifty of the top stem cell scientists. This particular interview was with a guy in the Midwest. We went in and introduced ourselves very briefly. We didn't say much more than that we were doing a research project and were there to ask some questions. In the middle of the interview, the researcher said (excitedly), "Yeah, you know I read this article by these guys at Stanford and it was really interesting because it told about how scientists like me are actually using these lines, but I just can't remember their names!" It was gratifying. It made the conversation really fun from that point. The second thing about getting in front of eyeballs, is when you publish in journals that are read by a lot of people, you also get the attention of policymakers and journalists. We've gotten a lot of good press, and action from think tanks and

policymakers in Washington. Some of our articles have been quoted or referenced in policy documents, which means that when people make laws or guidelines or give testimony, our work is hopefully in that mix.

### ***There has been a lot of debate over the moral status of embryos. What are the other major issues?***

I think we've moved beyond this one. This question preoccupied us for six years, and we've agreed to disagree. We, meaning those supporters of embryonic stem cell research that see no real issues with using donated embryos to make cell lines, and those individuals and conservatives, sometimes right-to-life folks, who feel like it's immoral to use them. That argument probably will never be satisfied, or settled satisfactorily, for either side.

The thing that has changed dramatically, first off, is the field is on a tear. I'll give you a couple of figures. In 1998 to 2004, we did a census of how many embryonic stem cell publications (not the other kinds of stem cells, because there are tons of other kinds of stem cells) internationally, there were. It was about one hundred, and only about sixty of them were published by U.S. authors. It was right in the middle of the Bush administration's restrictions. We could say, "OK, at least now we know, with this policy we get this output." Fast forward to 2010. We just published a paper that appeared last month, doing the same analysis now under Obama, and this time we looked at the number of publications just for the year 2010—five hundred by U.S. authors. An order of magnitude difference! You can argue a lot of things are responsible for that—the field is maturing, people are getting more comfortable with the technology, a new field often goes off a curve and matures quickly. That's part of it, too. You can also argue that the effect is due to the way American policy has shifted from the moral status of the embryo to more pragmatic concerns about how are we going to treat disease, how are we going to cure diabetes, how are we going to understand human development, how on earth can we understand infertility, if we don't look at the cells, eggs, and sperm and how they develop?

Those essential questions are part of the language of the articles that are coming out now. Not so much whether we can use a line or not, but what the lines are useful for. With that new focus comes the reality that it's time to put them in humans. That's a signal for ethics, an important one, because the last time something this big happened was gene therapy, and we all know the story behind gene therapy. Many policymakers and ethicists hearken back to the Gelsinger case as a word of warning to what we might be facing with new stem cell therapies, same sort of hyped

## ***Faculty Profile (continued)***

technology, lots of promise, lots of controversy. Will we make the same mistakes? I'm an optimist by nature, and I don't think we will, because I think we did learn from the gene therapy experience, but from practical points of view, there are some real concerns about this move into the clinic. I think they center on two or three big issues.

One of them is the question of when do we find enough comfort with saying, "OK, we're ready for transplants?" In other words, when do we see the science as being mature enough to say it is a fairly safe way to go for a first-in-human clinical trial. These questions are enormous and asking them for certain patient populations causes a lot of conversation. The recent trial for spinal cord injuries is just one example of a completely vulnerable set of patients who've recently been injured, facing lifetime paralysis, and all of a sudden you waltz in with a stem cell protocol and say, "Hey, you wanna join?" It's not an easy decision.

Just to illustrate to students in one of my classes how tough a decision it is, I asked a young woman who participated in an embryonic stem cell trial to come in and talk about her decision. Her story was riveting. The class was freshman and sophomore students, but it was standing room only, with faculty and researchers who had heard about it. We probably had 50 people in a 15 person seminar room. Her parents and her sister and brother came. She rolled up in her wheelchair, she's paralyzed from upper waist down, and she talked about being in the hospital seven days past her injury, being on drugs, being out of her mind with worry, and having to decide whether or not she was going to have a life-altering clinical trial. She described her interactions with the doctors, what she thought of the informed consent, how she argued with her parents. Her parents heard about the trial before she did, and brought it to her attention. Her parents then had a change of heart and said, "We've thought about this and we don't want you to do it. We just want you to go through the physical therapy and try to get better, like everybody else." She said, "No, I am my own person. I can make my own decisions about my future. It's my future, it's my injury." So she said yes to it and got the transplant here at Stanford, actually Santa Clara Medical Center, but Stanford surgeons were in on the procedure.

It raises a whole host of issues about informed consent, about risk and benefit in first-in-human clinical trials, and in this particular case, about the obligations of the company and the scientists who performed the surgery. Here, the company stopped the trial three days before she got the stem cells. So imagine yourself struggling with this decision and then learning that the rug is to be pulled out

from under you. She not only chose to go ahead, but she consented to this procedure twice, which is an amazing thing. She said yes, based on a certain set of facts, and then heard in a casual conversation that the company had pulled out, and then had to make a second informed decision based on the knowledge that that company was not going to be there for her. It turns out that the company did the right thing, at least on the care issue, and said that they would follow the patients for up to fifteen years and dedicated money to do that. I think her experience is not uncommon for a lot of Americans who have this trust in the medical system, and in biomedical innovations, that it's always going to be there for them. She said, "When I said yes the second time, I thought that this is going to be OK, the company will sell to another company or someone else will pick it up, and the field will move forward and people like me will benefit. The fact of the matter is that here we are ten months later, and nothing like that has happened."

### ***I'm confused. So she didn't have the procedure?***

She did have the procedure. She was the last person and she was retroactively enrolled after the group said no, so Stanford and the company and the surgeons and hospitals came together and said we've got to do the right thing. She's only one of six patients, so you can't make any solid clinical decision about her improvement or the effects. That will only be evident, if it ever is evident, over a long period of time. However, she says, at least anecdotally, that her improvement, among the six, has been the most remarkable. She has gained more function than the doctors thought she would. Whether that's due to her young age, and the fact that her injury is the way that it is, or stem cells, is an open question.

### ***Individual stories are so powerful.***

They are, and that leads to the second issue we're studying, something that's been part of ethics for a long time, and that's medical tourism. For stem cells, now that we're talking about patients, there has been an explosion in folks that are traveling to get unproven treatments or injections in other countries. It's all over the news. There's also been a push by patient advocacy groups, among others, to start treating patients with stem cells, when we really don't understand what the mechanism is. For example, the FDA just approved a trial using stem cells for autism. Parents are desperate for their kids to be treated. They're not only considering and wishing for trials here, they go and empty their bank accounts and travel to India to get treatments we know nothing about, to get injections where there is no published data, to be enrolled in clinics where there is no clue whether those clinics are following good clinical practice or good manufacturing

## Faculty Profile (continued)

practice. It's a real worry that something terrible will happen, for me and for others who are looking at this as a phenomenon. I think we've been lucky so far. There is this movement among some conservative Americans that government regulation is bad, but we need good regulations. We have to be careful not to over regulate and to do it in a way that's not so conservative that we don't bring treatments to patients, but we can't abandon it. That's a huge issue for us.

***It's too bad people are desperate and don't think that clearly.***

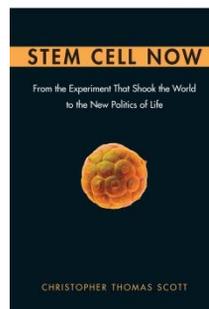
Actually, it's amazing how clearly patients and their families do think about this. I don't think that they're operating out of pure desperation. They do their homework. Their homework isn't always informed in the best way, but they talk to doctors, they talk to their own doctors, they talk to other patients, they talk to clinics, they surf the web, they read the literature. A good example is one of the students in my class. He suffers from a rare hereditary ataxia. When I asked everyone to introduce themselves, he told the group that he had just come back from China, where he got a stem cell transplant. He was trained as an engineer. Not a person whom you would think would be uninformed, ignorant or not appreciative of the scientific method or clinical research. He understood all of it. He knows about clinical trials, he knows about randomization and double blind studies. He understands how important a hypothesis is. He explained all of that. He basically said, "It's my choice to be in a scientific experiment, and if I choose not to be altruistic, and selfish because I have a child and I want that child to see me live a long time, I'm going to do whatever I can."

***Related to that are people with chronic diseases. You hope that something will happen at some point that will be useful, before you reach a point where you really need it.***  
Right, and I hear that a lot.

***Because personally, you think about it differently.***

Exactly, when family is involved or when your own life is there in the balance, you think about these things pretty deeply. There are cases in the press—I read a good one yesterday—where a woman was having a bake sale in her church parking lot because she had melanoma and wanted a stem cell transplant. The connection between melanoma and stem cells is just non-existent, but she'd heard about a clinic in some other country and was raising money to go. A guy pulled up in a car who was lost and needed directions. She gave him directions and told him she was raising money for a stem cell transplant. He wrote a \$50 check and drove off, got a ways down the road and then turned around, came back and wrote her a \$20,000 check. It happens that the guy was the

founder of the Beanie Babies empire and he's a multi-millionaire. It's these heart-tugging individual stories that provide an example of what has become a problem. The rich person unwittingly caused a problem by enabling the sick



person to go to a place where maybe she could get hurt, or be completely disappointed. On the other hand, do you want to send out the ethics police to every street corner, bake sale, and to every desperate parent with a sick child, to say no, you shouldn't do that? You should give up hope and just wait. We'll get there. I don't know—it's a complicated issue.

***Would you talk a little bit about the significance of the recent Supreme Court ruling affirming last year's ruling that federal funding of human embryonic stem cell research is legal?***

The ruling in *Sherley v. Sebelius* was a huge victory for stem cell research because it confirms the NIH's interpretation of a long-standing legal statute called Dickey Wicker, which says you cannot use federal funds to destroy embryos for embryonic stem cell research or for research, generally. The interpretation is that it's fine for the federal government to fund embryonic stem cell research, but not destroy embryos, so that's a balance. That was the decision and it did a couple of things. It removed a niggling doubt on the part of everybody who supports stem cell research—that it could be stopped—because the lawsuit would have banned it. That would have been horrible for the field.

The second thing it did was, for the time being, underscore Obama's dedication to his 2009 policy in an executive order, where he said he wanted this research to go ahead, he wanted us to fund it, and to start with new lines. So far, all three of those things have happened. The Republicans are challenging Obama to run on his record. His record on stem cell research so far has been pretty good.

***Did you think this day would ever come?***

Yeah. Maybe if you'd asked me halfway through Bush 1 or Bush 2, I may not have been so optimistic. And early on, Obama had other things on his mind. I think other researchers would say the same thing, that we wish Congress had passed a bill that would fund the research explicitly, but that didn't happen. This is the second best thing. I think this is a critical issue for science in general, not just stem cell research. If science is going to maintain its position in American policy, we have to make sure we have a president who understands how important it is. Mitt Romney, though he supported embryonic stem cell research in 2002, reversed.

## ***Faculty Profile (continued)***

his position in 2008, and though he supported abortion, he then reversed his position. Now he wants to grant personhood to a one or two-celled embryo. We know where Paul Ryan, an avowed Catholic, is on the issue—strict right-to-life. The combination of those facts and the fact that they have appointed no scientific advisors yet to their team is a real fear. I'm hoping that in the three upcoming debates, the question about science policy is going to get raised. ✦

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### ***22<sup>nd</sup> Annual Jonathan J. King Lectureship***

**Ira Byock, MD**

**The Ethics and Practice of Loving Care**

**Tuesday, October 2, 2012, 5:30 pm**

**Auditorium, 1<sup>st</sup> Floor**

**Lucile Packard Children's Hospital**



Ira Byock, MD, is Chair, Palliative Medicine, at the Geisel School of Medicine at Dartmouth, Director of Palliative Medicine, Dartmouth-Hitchcock Medical Center, and Professor, the Geisel School of Medicine at Dartmouth in the Departments of Medicine, Anesthesiology, and Community and Family Medicine. Involved in hospice and palliative care since 1978, Dr. Byock has authored numerous articles and several books on the ethics and practice of hospice, palliative and end-of-life care. *The Best Care Possible* is his most recent book. As a consistent advocate for the rights of dying patients and their families, he has received many awards, and has been featured on numerous national television and radio programs.

The 2011 Jonathan J. King Lecture is free and open to the public. No reservations are necessary. LPCH Hospital is located at 725 Welch Road, Palo Alto. A map and parking information can be found at <http://bioethics.stanford.edu>.

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## ***People News***

### **Jessica Bardill – Teaching Fellow**

Jessi earned her PhD in English from Duke University and her undergraduate degree at Emory University in English, with High Honors, and Biology. Last year, she was a Chancellor's Postdoctoral Fellow in American Indian Studies at the University of Illinois, Urbana-Champaign. Her research focuses on genetics/genomics and indigenous peoples, particularly the uses of genetic testing for tribal membership. Jessi is a new Teaching Fellow, and will be supporting the course, Bioethical Challenges of New Technology, in the Thinking Matters Program, taught by David Magnus.

### **Colleen Berryessa - CIRGE Program Manager**

Colleen graduated from Harvard University in 2011 with a degree in Government with secondary study in Mind, Brain and Behavior. Colleen's main academic and research focus is on the legal, social, bioethical, and policy-oriented effects of advances in neuroscience, behavioral genetics, and other sciences and technology on criminology, criminal justice, law, punishment, the legal system, and public policy. Accordingly, her Harvard senior thesis explored how new scientific understandings of the origins of sexually deviant and pedophilic behavior could change and affect current American criminal justice policy and legislation, as well as the societal, cultural, ethical, and legal reactions to these changes and future policies. Colleen joined us at CIRGE's new Program Manager in the Summer of 2012.

## People News (continued)

### Emily Borgelt – Project Manager

Emily Borgelt is the current Project Manager of Sandra Soo-Jin Lee's grant titled "Social Networking and Personal Genomics: Emerging Issues for Health Research." She also works with Chris Scott on projects related to stem cell ethics and education. Emily holds a B.S. in Neuroscience and Behavioral Biology from Emory University and a M.A. in Bioethics from Case Western Reserve University. Prior to joining SCBE, she worked as a Research Coordinator at the National Core for Neuroethics, University of British Columbia, and as a manager of the group's Clinical Neuroethics program.



Colleen Berryessa, Hayden Harvey, Emily Liu, Marsha Michie, Emily Borgelt, Hywote Taye

**Jessica Erickson**, former CIRGE Post-Baccalaureate Fellow, has begun the Post-Baccalaureate Premedical Program at Bryn Mawr College.

### Hayden Harvey – Post-Baccalaureate Fellow

Hayden Harvey graduated magna cum laude from Seattle University as a Philosophy major concentrating in Ethics and Political Philosophy as well as Philosophy of Mind. His honors thesis entitled "A Neurocomputational Approach to Moral Particularism" examined moral rule formation through the lens of various models of mental architecture. He spent six months at the Mayo Clinic Bioethics Department as an intern investigating genetic understandings of addiction. He will be one of two fellows in CIRGE's new post-baccalaureate fellowship program.

**Molly Havard**, former CTSA and Stem Cell Research Assistant, is beginning a Master in Physiology program at Georgetown University.

### Emily Liu – Post-Baccalaureate Fellow

Emily graduated magna cum laude from Harvard as a History and Science major. As an undergraduate, she conducted original thesis research on the experience of mental disability in China, using autism as a case study. Prior to coming to CIRGE, Emily worked as a residential instructor at the New England Center for Children, a special school for autism in Southborough, Massachusetts, and interned at the Children's Neurodevelopment Center at Rhode Island Hospital. She is currently one of two fellows in CIRGE's post-baccalaureate fellowship program.

### Nicole Martinez – Teaching Fellow

Nicole Martinez received her BA from Princeton University in Anthropology and Latin American Studies. She then completed a law degree at Harvard Law School and worked in public interest law and international project finance. Nicole studies Comparative Human Development at University of Chicago, where she received a Master's, with a particular interest in mental health policy. She was a Greenwall Fellow in Bioethics at Johns Hopkins University.

### Marsha Michie – Post-Doctoral Fellow

Marsha received her Ph.D. in Anthropology from the University of North Carolina at Chapel Hill. Her research interests include moral and social dimensions of translational pathways for genetic technologies, and the experiences and self-perceptions of genetic patients and research participants. Marsha's current research, supported by a K99/R00 grant from NHGRI, examines the social and ethical implications of noninvasive prenatal genetic testing.

### Nate Olson – Teaching Fellow

Nate Olson comes to Stanford from Georgetown University where he received his PhD in philosophy. His dissertation, written under the direction of Henry S. Richardson, explores why relationships like those with our friends and family members are the source of moral obligations. More generally, he works on topics in ethics, including bioethics, related to the question of how our personal commitments affect what we ought to do. He is a lecturer in Stanford's Thinking Matters program and will be collaborating with David Magnus on his course "Bioethical Challenges of New Technology" in the winter quarter.



Teaching Fellows Jessica Bardill, Nate Olson, and Nicole Martinez

**Lauren Sayres**, former Post-Baccalaureate Fellow, is entering Duke University School of Medicine, Class of 2016.

**Simone Vernez**, former Project Manager, is entering the School of Medicine, Class of 2016, at University of California, Irvine.

**Hywote Taye – AJOB Managing Editor and CTSA Research Assistant**

Hywote graduated in 2012 from Stanford University with an MA in Philosophy. She concentrated in Ethical Theory as well as Philosophy of Language. In 2011, she also received her BA from Stanford, where she majored in Human Biology with a concentration in Bioethics and a minor in French. During the summer of 2010, she interned at the Stanford Center for Biomedical Ethics under the direction of Dr. Sandra Lee and assisted her in investigating the relation between social media and direct to consumer genetic testing. She returned to the Center in July of 2012 and will serve as managing editor for the American Journal of Bioethics as well as coordinator for the Center's Benchside Ethics Consultation Service.

**Maya Wolpert**, former CIRGE Program Manager, is entering the School of Medicine, class of 2016, at the University of California, Davis.

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**Recent Publications**

**Megan Allyse**

- Allyse, M., K. Karkazis, et al. (2012). "Informational risk, institutional review, and autonomy in the proposed changes to the common rule." *IRB* 34(3): 17-19
- Allyse, M., L. Milner, et al. (2012). "The G.I. Genome: Ethical implications of genome sequencing in the military." *Nature Reviews Genetics* 12(9): 589.
- Allyse, M., L. C. Sayres, et al. (2012). "Cell-free fetal DNA testing for fetal aneuploidy and beyond: clinical integration challenges in the US context." *Hum Reprod*.
- Goodspeed, T. A., L. C. Sayres, et al. (2012). "Translating cell-free fetal DNA technology: Structural lessons from non-invasive RhD blood typing. ." *Trends in Biotechnology*.
- Sayres, L. C., M. Allyse, et al. (2012). "Integrating stakeholder perspectives into the translation of cell-free fetal DNA testing for aneuploidy." *Genome Med* 4(6): 49.
- Sayres, L. C., M. Allyse, et al. (2012). "In the public interest? The consequences of broad patenting, restrictive licensing, and a monopolized market for cell-free fetal DNA testing." *Sci Transl Med* 4(144): 144fs123.
- Sayres, L. C., M. K. Cho, et al. (2011). "Cell-free fetal DNA testing: a pilot study of obstetric healthcare provider attitudes toward clinical implementation." *Prenatal Diagnosis*.
- Tobin, S. L., M. K. Cho, et al. (2012). "Customers or research participants?: Guidance for research practices in commercialization of personal genomics." *Genet Med*.

**Emily Borgelt**

- Borgelt, E., D. Buchman, et al. (2012). *Informed Consent and Mental Health Care: Practitioner Perspective and Future Directions*. For I know what you're thinking: Brain and mental privacy. I Know What You're Thinking: Brain and Mental Privacy. S. R. S.J.L. Edwards, G. Rees, Oxford University Press.
- Borgelt, E. L., D. Z. Buchman, et al. (2012). "In Search of "Anything That Would Help": Parent Perspectives on Emerging Neurotechnologies." *J Atten Disord*.
- Buchman, D. Z., E. L. Borgelt, et al. (2012). "Neurobiological narratives: experiences of mood disorder through the lens of neuroimaging." *Social Health Illn*.
- Caulfield, T., E. Borgelt, et al. (2012). "Personal medicine-the new banking crisis." *Nature Biotechnology* 30(2): 7p.

**Mildred Cho**

- Allyse, M., K. Karkazis, et al. (2012). "Informational risk, institutional review, and autonomy in the proposed changes to the common rule." *IRB* 34(3): 17-19.
- Allyse, M., L. Milner, et al. (2012). "The G.I. Genome: Ethical implications of genome sequencing in the military." *Nature Reviews Genetics* 12(9): 589.
- Allyse, M., L. C. Sayres, et al. (2012). "Cell-free fetal DNA testing for fetal aneuploidy and beyond: clinical integration challenges in the US context." *Hum Reprod*.
- Cho, M. K., S. A. Tishkoff, et al. (2012). "Human evolutionary genomics: ethical and interpretive issues." *Trends in Genetics* 28(3): 9p.
- Cho, M. K. and M. N. Wolpert (2010). "Not Yet in Sequence: Clinical, Technical, Ethical Questions Linger Over Personal Genomics." *Modern Healthcare*: 24.
- Erickson, J. A. and M. K. Cho (2011). "Ethical Considerations and Risks in Psychiatric Genetics: Preliminary Findings of a Study on Psychiatric Genetic Researchers." *AJOB Primary Research* 2(4): 52-60.
- Erickson, J. A. and M. K. Cho "Interest, Rationale, and Potential Clinical Applications of Genetic Testing for Mood Disorders: A Survey of Stakeholders." *Journal of Affective Disorders*.
- Farrelly, E., M. K. Cho, et al. (2012). "Genetic Counseling for Prenatal Testing: Where is the Discussion About Disability?" *Journal of Genetic Counseling*.
- Goodspeed, T. A., L. C. Sayres, et al. (2012). "Translating cell-free fetal DNA technology: Structural lessons from non-invasive RhD blood typing. ." *Trends in Biotechnology*.
- Havard, M., M. K. Cho, et al. (2012). "Triggers for research ethics consultation." *Sci Transl Med* 4(118): 118cm111.
- McCormick, J. B., A. M. Boyce, et al. (2012). "Barriers to Considering Ethical and Societal Implications of Research: Perceptions of Biomedical Scientists." *AJOB Primary Research* 3(40-50).
- Ormond, K. E., L. Hudgins, et al. (2011). "Medical and graduate students' attitudes towards personal genomics." *Genetics in Medicine* 13: 400-408.
- Richardson, H. S. and M. K. Cho (2012). "Secondary researchers' duties to return incidental findings and individual research results: a partial-entrustment account." *Genet Med* 14(4): 467-472.
- Sayres, L. C. and M. K. Cho (2011). "Cell-free fetal nucleic acid testing: A review of the technology and its applications." *Obstetrical & Gynecological Survey* 66: 431-442.
- Sayres, L. C., M. Allyse, et al. (2012). "Integrating stakeholder perspectives into the translation of cell-free fetal DNA testing for aneuploidy." *Genome Med* 4(6): 49.

**Mildred Cho (continued)**

- Sayres, L. C., M. Allyse, et al. (2012). "In the public interest? The consequences of broad patenting, restrictive licensing, and a monopolized market for cell-free fetal DNA testing." *Sci Transl Med* 4(144): 144fs123.
- Tobin, S. L., M. K. Cho, et al. (2012). "Customers or research participants?: Guidance for research practices in commercialization of personal genomics." *Genet Med*.
- Wolf, S. M., B. N. Crock, et al. (2012). "Managing incidental findings and research results in genomic research involving biobanks and archived data sets." *Genet Med* 14(4): 361-384.

**LaVera Crawley**

- Crawley, L. M. (2007). "The paradox of race in the Bidil© debate." *J Natl Med Assoc* 99(7): 821-822.
- Crawley, L. M., D. K. Ahn, et al. (2008). "Perceived medical discrimination and cancer screening behaviors of racial and ethnic minority adults." *Cancer Epidemiol Biomarkers Prev* 17(8): 1937-1944.

**Jessica Erickson**

- Erickson, J. A. and M. K. Cho "Interest, Rationale, and Potential Clinical Applications of Genetic Testing for Mood Disorders: A Survey of Stakeholders." *Journal of Affective Disorders*.
- Erickson, J. A. and M. K. Cho (2011). "Ethical Considerations and Risks in Psychiatric Genetics: Preliminary Findings of a Study on Psychiatric Genetic Researchers." *AJOB Primary Research* 2(4): 52-60.

**Nanibaa' Garrison**

- Garrison, N. (2012). "Cases of How Tribes are Relating to Genetics Research." *American Indian & Alaska Native Genetics Resource Center*.

**Henry T. Greely**

- Allyse, M., K. Karkazis, et al. (2012). "Informational risk, institutional review, and autonomy in the proposed changes to the common rule." *IRB* 34(3): 17-19.
- Greely, H. T. (2011). *The equality of allocation by lot. Lotteries in Public Life: A Reader*. Exeter, UK, Imprint Academic.
- Greely, H. T. (2011). *Human/Nonhuman Chimeras: Assessing the Issues*. Oxford Handbook of Animal Ethics. T. B. a. R. G. Frey. Oxford, Oxford University Press.
- Greely, H. T. (2011). *Of Nails and Hammers: Human Biological Enhancement and American Policy Tools*. Human Capacities. J. S. Reuud ter Meulen, Guy Kahane, Wiley Blackwell.
- Greely, H. T. (2012). "Designer Eggs and Stem Cell Sausage." *GeneWatch* 25(1-2).
- Greely, H. T. (2012). "Direct brain interventions to "treat" disfavored human behaviors: ethical and social issues." *Clin Pharmacol Ther* 91(2): 163-165.
- Greely, H. T. (2012). Foreword. *Neuroimaging in Forensic Psychiatry: From the Clinic to the Courtroom*. W.-B. Joseph R. Simpson.
- Greely, H. T. (2011). "Get ready for the flood of fetal gene screening." *Nature Biotechnology* 469: 289-291.
- Greely, H. T. (2012). *Mindreading, Neuroscience and the Law*  
A Primer on Law and Neurosciences. A. R. S. Morse, Oxford University Press.
- Greely, H. T. (2011). "Readings Minds with Neuroscience - Possibilities for Law." *Cortex* 27(10): 1254-1255.
- Greely, H. T. (2012) Remembering the Sheep that Changed the World. *Al Jazeera English Opinion*
- Greely, H. T. (2012). "What If? The Farther Shores of Neuroethics : Commentary on "Neuroscience May Supersede Ethics and Law"." *Sci Eng Ethics*.
- Greely, H. T. and J. S. King (2010). "The coming revolution in prenatal genetic testing." *AAAS Professional Ethics Report* 22: 1.
- Ormond, K. E., L. Hudgins, et al. (2011). "Medical and graduate students' attitudes towards personal genomics." *Genetics in Medicine* 13: 400-408.
- Rissman, J., H. T. Greely, et al. (2010). "Detecting Individual Memories Through the Neural Decoding of Memory States and Past Experience." *Proc. Nat'l Acad Sci*.
- Tischler, R., L. Hudgins, et al. (2011). "Noninvasive prenatal diagnosis: pregnant women's interest and expected uptake." *Prenat Diagn* 31(13): 1292-1299.

**Molly Havard**

- Havard, M., M. K. Cho, et al. (2012). "Triggers for research ethics consultation." *Sci Transl Med* 4(118): 118cm111.

**Katrina Karkazis**

- Jordan-Young, R. and K. Karkazis (2012). *The IOC's superwoman complex: how flawed sex-testing discriminates*. The Guardian.
- Jordan-Young, R. and K. Karkazis (2012). *Sex Verification: You Say You're a Woman? That Should Be Enough*. New York Times.
- Karkazis, K. and R. Jordan-Young (2012). "Rip up new Olympic sex test rules." *New Scientists*: 26-27.
- Karkazis, K., R. Jordan-Young, et al. (2012). "Out of bounds? A critique of the new policies on hyperandrogenism in elite female athletes." *Am J Bioeth* 12(7): 3-16.
- Karkazis, K., S. L. Tobin, et al. (2012). "Informational Risk, Institutional Review, and Autonomy in the Proposed Changes to the Common Rule." *IRB: Ethics & Human Research* 34(3): 3p.
- Miller, K. and K. Karkazis (2012). "Health and Healing in Polygamist Communities in Southern Utah." *Journal of Religion and Health*.
- Moran, M. E. and K. Karkazis (2012). "Developing a multidisciplinary team for disorders of sex development: planning, implementation, and operation tools for care providers." *Adv Urol* 2012: 604135.

**Sandra Soo-Jin Lee**

- Fullerton, S. M. and S. S. Lee (2011). "Secondary uses and the governance of de-identified data: lessons from the human genome diversity panel." *BMC Med Ethics* 12: 16.
- Karkazis, K., S. L. Tobin, et al. (2012). "Informational Risk, Institutional Review, and Autonomy in the Proposed Changes to the Common Rule." *IRB: Ethics & Human Research* 34(3): 3p.
- Lee, S. S.-J. (2012). *Ethical Considerations for Pharmacogenomics: Privacy and Confidentiality*. Principle of Pharmacogenetics and Pharmacogenomics. D. F. Russ Altman, David Goldstein. Cambridge, Cambridge University Press.
- Lee, S. S.-J. (2012). "The Nature of Race: How Scientists Think and Teach About Human Difference." *Ethnic & Racial Studies* 35(8): 2p.

## ***Recent Publications (continued)***

### **Sandra Soo-Jin Lee (continued)**

- Lee, S. S.-J. (2012). "Race, Risk and Recreation in Personal Genetics: The Limits of Play." *Medical Anthropology Quarterly*.
- Lee, S. S.-J. (2012). *Waiting on the Promise of Prescribing Precision: Race in the Era of Pharmacogenomics. Genetics and the Unsettled PAst: The Collision between DNA, Race, and History.* A. N. Keith Wailoo, Catherine Lee, Mia Bay. New Brunswick, Rutgers University Press.
- Soo-Jin Lee, S. (2011). "Making Sense of the Genomic Revolution." *American Scientist* 99(3): 2p.
- Tobin, S. L., M. K. Cho, et al. (2012). "Customers or research participants?: Guidance for research practices in commercialization of personal genomics." *Genet Med*.
- Vernez, S. (2012). "Assessing the Pedagogical Goals of Self-Testing in Evaluating the Consultation Needs of Different Student Populations." *American Journal of Bioethics* 12(4): 3p.

### **David Magnus**

- Allyse, M., K. Karkazis, et al. (2012). "Informational risk, institutional review, and autonomy in the proposed changes to the common rule." *IRB* 34(3): 17-19.
- Havard, M., M. K. Cho, et al. (2012). "Triggers for research ethics consultation." *Sci Transl Med* 4(118): 118cm111.
- Magnus, D. (2011). "Beyond the IRB: Local Service Versus Global Oversight." *American Journal of Bioethics* 11(5): 2p.
- Magnus, D. (2012). "Duty-Free: The Non-Obligatory Nature of Preimplantation Genetic Diagnosis." *American Journal of Bioethics* 12(4): 2p.
- Ormond, K. E., L. Hudgins, et al. (2011). "Medical and graduate students' attitudes towards personal genomics." *Genetics in Medicine* 13: 400-408.
- Tobin, S. L., M. K. Cho, et al. (2012). "Customers or research participants?: Guidance for research practices in commercialization of personal genomics." *Genet Med*.
- Vernez, S. and D. Magnus (2011). "Can the Dead Donor Rule be Resuscitated?" *AM J Bioeth* 12(4): 1-2.

### **Lauren Milner**

- Allyse, M., L. Milner, et al. (2012). "The G.I. Genome: Ethical implications of genome sequencing in the military." *Nature Reviews Genetics* 12(9): 589.

### **Kelly E. Ormond**

- Barragan, D. I., K. E. Ormond, et al. (2011). "Concurrent use of cultural health practices and Western medicine during pregnancy: exploring the Mexican experience in the United States." *Journal of Genetic Counseling* 20(6): 609-624.
- Farrelly, A., M. K. Cho, et al. (2012). "Discussions about Disability in Prenatal Genetic Counseling: Are we providing informed consent prior to genetic testing?" *J Genetic Counseling*.
- Farrelly, E., M. K. Cho, et al. (2012). "Genetic Counseling for Prenatal Testing: Where is the Discussion About Disability?" *Journal of Genetic Counseling*.
- Ormond, K. E., L. Hudgins, et al. (2011). "Medical and graduate students' attitudes towards personal genomics." *Genetics in Medicine* 13: 400-408.
- Tischler, R., L. Hudgins, et al. (2011). "Noninvasive prenatal diagnosis: pregnant women's interest and expected uptake." *Prenat Diagn* 31(13): 1292-1299.
- Tobin, S. L., M. K. Cho, et al. (2012). "Customers or research participants?: Guidance for research practices in commercialization of personal genomics." *Genet Med*.

### **Mary Rorty**

- Rorty, M. (2012). "ASBH Core Competencies for Healthcare Ethics Consultation."
- Rorty, M. (2012). *Ethics In and For the Organization. Guidance for Healthcare Ethics Committees.* T. S. D.M. Hester, Cambridge University Press.
- Rorty, M. and A. Silvers (2012). *Alt in Amerika: zuer bioethischen Debatte in den USA. Pro-Age oder Anti-Aging?* M. S. S. Schick Tanz, Campus Verlag.

### **Lauren Sayres**

- Goodspeed, T. A., L. C. Sayres, et al. (2012). "Translating cell-free fetal DNA technology: Structural lessons from non-invasive RhD blood typing. ." *Trends in Biotechnology*.
- Magnus, D. (2012). "Duty-Free: The Non-Obligatory Nature of Preimplantation Genetic Diagnosis." *American Journal of Bioethics* 12(4): 2p.
- Sayres, L. C., M. Allyse, et al. (2012). "Integrating stakeholder perspectives into the translation of cell-free fetal DNA testing for aneuploidy." *Genome Med* 4(6): 49.
- Sayres, L. C., M. Allyse, et al. (2012). "In the public interest? The consequences of broad patenting, restrictive licensing, and a monopolized market for cell-free fetal DNA testing." *Sci Transl Med* 4(144): 144fs123.
- Sayres, L. C. and M. K. Cho (2011). "Cell-free fetal nucleic acid testing: A review of the technology and its applications." *Obstetrical & Gynecological Survey* 66: 431-442.
- Sayres, L. C., M. K. Cho, et al. (2011). "Cell-free fetal DNA testing: a pilot study of obstetric healthcare provider attitudes toward clinical implementation." *Prenatal Diagnosis*.

### **Christopher Scott**

- Caulfield, T., E. Borgelt, et al. (2012). "Personal medicine-the new banking crisis." *Nature Biotechnology* 30(2): 7p.
- Derouen, M. C., J. B. McCormick, et al. (2012). "The Race Is On: Human Embryonic Stem Cell Research Goes Global." *Stem Cell Rev*.
- Huggett, B. (2012). "Geron's quixotic fate." *Nature Biotechnology* 30(6): 1p.
- Owen-Smith, J., C. T. Scott, et al. (2012). "Democracy is working." *J Policy Anal Manage* 31(3): 726-728.
- Owen-Smith, J., C. T. Scott, et al. (2012). "Expand and regularize federal funding for human pluripotent stem cell research." *J Policy Anal Manage* 31(3): 714-722.
- Scott, C. T. and V. Bethencourt (2012). "Going Viral: Affymetrix Case Study." *Nature Biotechnology* 29: 975.

### **Audrey Shafer**

- Seiden, S. C. and A. Shafer (2011). *Anesthesia and Analgesia Clinical ethics in anesthesiology: A case-based textbook.* S. J. Gail A. Van Norman, S.H. Rosenbaum, S.K. Palmer. 113: 1286-1287.
- Shafer, A. (2012). "Anesthesia Checklist." *Anesthesiology* 116(2): 477-478.
- Shafer, A. (2012). *In the Emergency Room with My Mother, Again. Mission at Tenth: The Double Helix Issue,* California Institute of Integral Studies. 3: 38.
- Shafer, R. and A. Shafer (2011). "Deborah Butterfield's Horses: Commentary." *Academic Medicine (Medicine and the Arts)* 86: 1129.

## Recent Publications (continued)

### Sally Tobin

Allyse, M., K. Karkazis, et al. (2012). "Informational risk, institutional review, and autonomy in the proposed changes to the common rule." *IRB* 34(3): 17-19.  
Tobin, S. L., M. K. Cho, et al. (2012). "Customers or research participants?: Guidance for research practices in commercialization of personal genomics." *Genet Med*.

### Simone Vernez

Vernez, S. (2012). "Assessing the Pedagogical Goals of Self-Testing in Evaluating the Consultation Needs of Different Student Populations." *American Journal of Bioethics* 12(4): 3p.

### Maya Wolpert

Cho, M. K. and M. N. Wolpert (2010). "Not Yet in Sequence: Clinical, Technical, Ethical Questions Linger Over Personal Genomics." *Modern Healthcare*: 24.

### Larry Zaroff

Zaroff, L. (2012). "No Bag Lady." *Hektoen International: A Journal of Medical Humanities* 4(1).

## SCBE Upcoming Events



### September 26, 2012, 12:00 – 1:00 pm

Returning Genomic Results to Social and Biological Kin of Deceased Biobank Participants: Using Empirical Findings to Inform Policy  
Speaker: Professor Barbara Koenig  
SCBE Conference Room (62)  
1215 Welch Road, Modular A

### September 28, 2012, 4:00 – 5:00 pm

“Careening Toward Ubiquitous DNA Sequencing: Many Uses, Complex Problems”  
Speaker: Professor Robert Cook-Deegan  
SCBE Conference Room (62)  
1215 Welch Road, Modular A

### October 2, 2012 5:30 – 6:30 pm

22<sup>nd</sup> Annual Jonathan J. King Lecture  
Ira Byock, MD  
“The Ethics and Practice of Loving Care”  
Auditorium, 1<sup>st</sup> Floor  
Lucile Packard Children’s Hospital

### October 2, November 6, December 4, 2012

#### 7:00 – 9:30 pm

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

### October 10, 2012, 11:00 am – 12:00 pm

Classic Readings in Bioethics:  
Vulnerable Subjects  
Li Ka Shing Center, Room 209

### October 31, 2012, 11:00 am – 12:00 pm

Classic Readings in Bioethics:  
Emergency Research  
Li Ka Shing Center, Room 304/305

### November 10, 2012, 8:45 am – 4:30 pm

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

### November 28, 2012, 11:00 am – 12:00 pm

Classic Readings in Bioethics:  
Conflicts of Interest  
Li Ka Shing Center, Room 209

### January 17, 2013, 5:30 – 6:30 pm

Stanford Med Writers Forum  
Auditorium  
Cantor Arts Center

### April 17, 2013, 5:00 – 7:00 pm

Medicine and the Muse  
Sandeep Jauhar, MD  
Li Ka Shing Center: Berg Hall  
Stanford School of Medicine

### May 8, 2013 (time TBA)

“A Heaping Dose of Creativity : Medicine and the Arts.” Conference followed by evening concert and lecture by Richard Kogan, MD  
Cantor Arts Center Auditorium  
Bing Concert Hall

### October 8, 2013, 5:30 – 6:30 pm

23<sup>rd</sup> Annual Jonathan J. King Lecture  
Anthony Back, MD  
Auditorium, 1<sup>st</sup> Floor  
Lucile Packard Children’s Hospital

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1215 Welch Road, Modular A

Stanford, CA 94305-5417

<http://bioethics.stanford.edu>

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