

BIOETHICS BULLETIN

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NIH Bids Farewell to Zeke Emanuel

In 2010, we bid farewell to former Department Chair Zeke Emanuel, who in September began his new post as Vice Provost for Global Initiatives and Levy University Professor at the Perelman School of Medicine and the Wharton School of the University of Pennsylvania.

Nearly eighty guests crowded the Department during the afternoon tea in Zeke's honor. Dr. John Gallin, director of the Clinical Center, praised Zeke for his vision and his tenacity.

In his remarks, Zeke thanked the Clinical Center leadership for its support throughout the years. He gave a brief history of his time at the Clinical Center, including dust ups with the powers that be and how he and Christine Grady



inadvertently found themselves with a fellowship program after being contacted by Neal Dickert over a decade ago. Zeke thanked that Department of Bioethics faculty and former and current bioethics fellows for enriching his experience at NIH. He praised the special collegial environment at the NIH and its remarkable generosity and cooperativeness.



Interview with Walter Sinnott-Armstrong, Visiting Scholar



Photo from Princeton Weekly Bulletin

Tell us about your work in moral philosophy.

I'm interested in ethics, and I think the best way to understand ethics is to look at the relations between ethics and other fields. For example, I look at the relations between ethics and neuroscience, both how can neuroscience illuminate the processes that lead to the ethical judgments that we hold so dear, but also what ethical issues are raised by neuroscience?

What brings you to the Department?

Zeke convinced me that it would be a place where I could learn a lot, and I wanted to learn things. I don't know that much about consent, but I got interested in whether you could use the new technology of neuroscience to ask patients in persistent vegetative states [PVS] whether they want to die (Contd. Page 7)

Meet the Fellows (2011-2012)

Justin Lowenthal is incredibly excited to join the Department of Bioethics as a new pre-doc fellow! Justin came to NIH from Yale University, where he received his B.S. in Biomedical Engineering. His research projects address the ethics surrounding emerging technologies, including prospective consent for future research on stem cells. Justin enjoys a cappella music, Baltimore sports, and television (both good and bad). He plans to apply for MD/PhD programs in regenerative medicine at the end of the fellowship.



background in combination with bioethics to improve drug access and the drug development process.

Tina Rulli is a first year postdoctoral fellow. She just finished her PhD in philosophy at Yale University. Her dissertation argues for a moral duty to adopt rather than create children based on the duty to rescue and the principle that *we ought to make needy people happy rather than make happy people*. Currently, she is exploring the duty to rescue in medical practice and research. After her NIH fellowship, she'll join the philosophy faculty at Purdue University.



John Phillips is a first year predoctoral fellow who studied philosophy at Swarthmore College. He is working on issues involving surrogate decision making, including the requirements for capacity to appoint a surrogate, as well as problems with and alternatives to the substituted judgment standard.

Chunshui Wang is a visiting fellow who is a medical doctor and also a licensed pharmacist in China. She obtained a Medical Degree and a Master's degree of Philosophy (Bioethics) in China. Currently she is a PhD Candidate at the University of Bergen in Norway. Her PhD thesis examines health sector reform in China, particularly ethical issues in priority setting.



Catie Gliwa is a first year predoctoral fellow with a BA in History of Science, History of Medicine from Yale University, where she focused on childbirth in 20th century America. In the department, she is working on a paper about whether there is an obligation to look for incidental findings in genomic research. Other interests include graphic design, television, and brunch.



Amulya Mandava received her BA in Anthropology from the University of Chicago and is now a 2nd year pre-doctoral fellow. Her research is focused on the ethics of informed consent and she is on the verge of completing two projects: an empirical paper comparing quantitative data on the quality of informed consent in developed and developing country settings, and a conceptual paper on the ethics of manipulation and its effect on participant consent to research. She is currently applying to Divinity School with the intention of furthering her understanding of how ethical dispositions are shaped by religious texts and contexts.



Doug MacKay is a first year postdoctoral fellow, having recently completed a PhD in philosophy from the University of Toronto. His doctoral work focused on questions of domestic and global distributive justice. He is now working on the standard of care debate in international research ethics as well as questions of priority setting and resource allocation in international aid.

Remy Brim is a first year postdoctoral fellow. She completed her PhD in Pharmacology at the University of Michigan. Her thesis work was focused on the pre-clinical development of a pharmacotherapy for cocaine toxicity including protein stabilization, rodent toxicity studies as well as pharmacokinetics and pharmacodynamics. She is currently working on issues surrounding drug approval and regulation. She hopes to use her pharmacology



Ruqayyah Abdul-Karim is a second year predoctoral fellow who earned her BA in Anthropology from Columbia University. Her work in the department includes research on disclosure of pediatric incidental genomic findings, the obligation to return of research samples, and guidelines on the ways in which physicians can address poverty in their patient populations. She is currently applying to medical school and is hoping to hear some good news by the time this newsletter goes out.



NIH Bioethics at ASBH

Current NIH fellows and faculty attended the American Society for Bioethics and Humanities (ASBH) Conference in Minneapolis this past October. They were joined by several NIH alumni, including Benjamin Wilfond, Nir Eyal, Maria Merritt, Sarah Gollust, Donna Chen and Samia Hurst. As always, the conference offered talks and panels on topics spanning the bioethics discipline.

Fellows, faculty and alumni gathered at Sarah Gollust's house in Minneapolis for delicious food and great company. Thank you, Sarah!

The fellows concluded that Minneapolis is a great city with fantastic food, drink and art; bioethics is a vast and fascinating field with many disciplinary perspectives; and the value of alumni reunions is a good reason to host a get together at next year's ASBH in Washington D.C.

Meet the Fellows (contd.)



Roseanna Sommers is a second year predoctoral fellow with a BA in psychology from Swarthmore College. Her work explores several topics: the obligation to debrief research subjects who have been deceived, patient attitudes toward discussing medical costs with physicians, and responsible transition out of research. Up next is graduate school in either law or psychology, or (gulp) both.

Robert Hughes is a second year postdoctoral fellow with a Ph.D. in philosophy from UCLA. His dissertation argued that neither coercive enforcement nor the entitlement to coerce is central to law or to political authority. His work at the NIH concerns the ethics of international clinical research. When research sponsors from high-income countries recruit subjects in low- and middle-income countries, do they have an obligation to ensure that the research benefits members of the host community other than the subjects? Robert is currently on the academic job market.



Elizabeth Pike is a second year postdoctoral fellow with a law degree and masters of law in global health from Georgetown University Law Center.

She has spent her time in the department focused on compensation for research-related injuries, and is turning her attention to whether law has a place in regulating false scientific speech. Next up is (ideally) a health-related legal position at a government agency (here's looking at you HHS, USAID, State Department, etc.) or NGO (hello Gates Foundation!), or (perhaps less ideally) a law firm in a health law practice group.

Jennifer Schwartz is a second year postdoctoral fellow with a background in surgery from the University of Virginia. Her current projects examine how medical and surgical societies approach cost in their clinical guidance documents; the utilization of ethics consultation services by surgeons; and the ethical



issues surrounding the use of surgical innovations in pediatric patients. In addition to her work in the Department, and her new role as mother of Michael (below), Jenn is concurrently pursuing a Masters in Clinical Research from Duke University.

New Arrivals

Congratulations to Fellows Deena Levine, Jennifer Schwartz and Doug MacKay on their newest additions and welcome to the Bioethics family!



Maytal Levine



Michael Paul Schwartz



A surprise double baby shower for Jenn and her husband Pete and Doug and his wife Allie.



August Glynn Lee MacKay and George Frederick Lee MacKay

Updates from Department Members

Ben Berkman and **Sara Hull** continue to work at the intersection of ethics and genetics. This past year, they won an NIH Director's Award for "significant achievements in helping intramural researchers and IRBs navigate the complex ethical terrain associated with next generation sequencing research."

Becky Chen has had a busy year. This past summer she had two weddings to attend: that of her daughter Rachel and her youngest son, Jason. She was also honored with a Clinical Center Director's Award for Customer Service in December.

Luana Colloca continues her research on the placebo and nocebo effects as an affiliate of the National Center for Complementary and Alternative Medicine (NCCAM) and the Clinical Center Department of Bioethics. This year she authored scientific articles in several journals, including [The Journal of Neuroscience](#), [Philosophical Transaction of the Royal Society B](#), and aspects of her work recently appeared in the December 12, 2011 issue of [The New Yorker](#).

Marion Danis also celebrated two family weddings this past year: one of her daughters and her son each got married this summer.

Christine Grady has served on President Obama's Commission for the Study of Bioethical Issues since July, 2010. Christine writes, "The



Commission has focused on 2 topics thus far: Synthetic Biology and Human Subjects Research (spurred by the discovery of U.S. conducted STD studies in Guatemala in the 1940s). Reports are available at www.bioethics.gov. At our next meeting, we will begin a discussion about genetics. I have found participating as a member of the Commission a very interesting process of public deliberation and intense study of an issue with the goal of making useful recommendations and increasing public awareness."

Joe Millum has traveled the world this past year, making stops in Norway, South Africa, and the UK. He also managed to travel through Southeast Asia by bike, train, bus, boat, and crane.

Steve Pearson continues to direct the Institute for Clinical and Economic Review ([ICER](#)), whose work promotes the incorporation of technology assessments, including measures of cost effectiveness, into decision-making. Steve works on evidence policy issues and is involved in commenting on the new Patient-Center Outcomes Research Institute ([PCORI](#)) created as part of health care reform. On the personal side, this year he traveled to Russia, where his 17-year-old daughter dances classical ballet, and to Australia where he went canyoneering. And, he's still playing tennis.

Seema Shah helped put on research ethics workshops in China and Japan this summer, and traveled to Geneva with Christine for a meeting on post-trial access, where she spent time with Samia Hurst, Annette Rid, Maria Merritt, and Jennie Hawkins.

Mertis Stallings got engaged to her boyfriend, Edward Johnson last year. The couple recently acquired a new Chihuahua puppy, Buttercup.



Tanya Vaughn welcomed her first grandchild, Meadow Marie Eckloff to the world on September 20, 2011. Baby, Mom, Grandma, and Great-Grandma (Tanya's mother) all live within a twelve mile radius and get together frequently. 2011 also marked the twentieth year that Tanya has worked at the NIH.



David Wendler has several personal and professional updates. He got married three years ago and bought a house last year. At work, thinking about vulnerable subjects has gotten him interested in research on animals.

Alan Wertheimer writes from Vermont to remind us that his latest [book](#), *Rethinking the Ethics of Clinical Research: Widening the Lens*, will be the topic of a workshop at Duke University in late February. See <http://www.dukeresearchethicsworkshop.org/> for more details.

Reidar Lie Leaves the Department

After over ten years at the NIH and traveling the world, Reidar Lie has accepted a position as the Chair of the Philosophy Department at the University of Bergen. Although we miss having him here on campus, the Department continues to collaborate with him on international workshops and projects, and to jointly train doctoral students through the combined Bergen PhD/NIH Bioethics Fellowship Program.



Interview with Karen Rothenberg, Visiting Scholar

What brings you to the Department?



I started working with the NIH in the early 1980s on a number of policy and research projects and I have used sabbaticals and leaves to keep my interest and my relationships going ever since.

Sara Hull invited me to meet Ben Berkman after she attended a talk I gave last year at NGHRI, and Ben and I discussed the possibility of creating a [unique workshop](#) at the law school at the University of Maryland on the regulation of genomic research. From that first meeting I knew it would be a lot of fun and very stimulating to work together. What evolved was the possibility that I would spend the year as a special advisor to the Director of NHGRI and split my time as a visiting scholar here so I could work with the legal fellows and with Ben and Sara on our scholarship.

We are working on a number of projects (together with some of the Maryland law graduates) that evolved from the legal workshop last spring that are all framed within genomic research and the return of incidental findings: the right not to know, whether there is an ethical foundation to return results and the resource excuse, liability and legal obligations (Lizzy Pike is working with us on this), CLIA [Clinical Laboratory Improvement Amendments], and group harms and benefits. Ben and I wrote a piece that is coming out in JLME about the Maryland workshop. I have also coauthored two short plays exploring informed consent for whole genome sequencing and the return of incidental findings.

I have two other major research projects. One is the culmination of two years of bioethical and historical research with a colleague from Columbia University on

how innovations in medicine and the drive to control fate are reflected in theater. It is our belief that these plays enhance dialogue among folks from different disciplines and perspectives to discuss the societal implications and complex ethical dilemmas raised by emerging technologies.

I have another piece of legal scholarship on prenatal genetic testing and abortion that builds on work that I first examined twenty years ago. Coauthored with Professor Rachel Rebouche, the draft article is called "Mixed Messages: Prenatal Genetic Testing and Abortion." It analyzes how on the one hand, we are expanding prenatal testing and on the other, significantly contracting abortion access as medical care, as illustrated by recent health care reform and related legislation.

What are you doing as special advisor at NGHRI?

I was asked by the Director to evaluate twenty years of the ELSI [Ethical, Legal, and Social Implications] research program and work with colleagues on a vision for the future for genomics and society. As part of this process, I have been able to better understand the richness of the research portfolio and the impact that ELSI research has had on the development of public policy.

Sounds like quite a busy year.

It's a joy being here. The level of collegiality and support for one another is really nice. It's like being a faculty member without having to teach class every week and grade papers. Because you're all so smart and interested in learning. This office is really a gem.

Karen Rothenberg is the Marjorie Cook Professor of Law at the University of Maryland Francis King Carey School of Law.

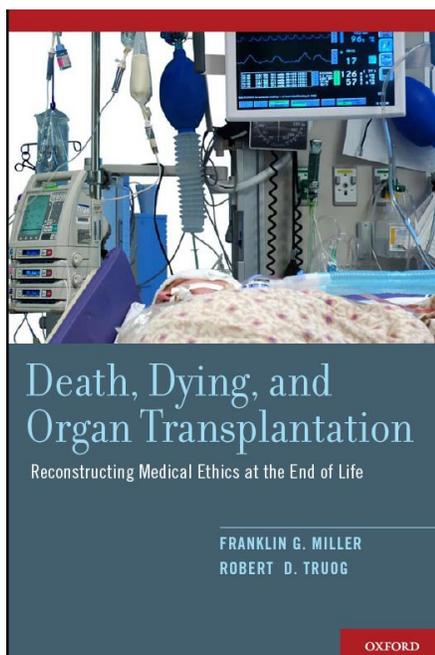
Frank Miller's New Book

Tell us about your new book, "Death, Dying, and Organ Transplantation," which you wrote with Bob Truog.

The central focus is on the definition of death and what we've come to learn about people who are diagnosed as brain dead, and the implications of these developments for the ethics of so-called "vital organ donation." We look at the whole spectrum of end-of-life decisions including withdrawing life-sustaining treatment and active euthanasia. That sets the stage for our view: that people who are diagnosed as brain dead are still alive.

When you take a look at the functioning that is still preserved in people who are diagnosed with brain death and maintained on a ventilator, you find circulation, respiration, digestion, elimination of waste, wound healing, fighting infection. There have been case reports of pregnant women with traumatic brain injury who have been able to gestate a fetus for up to three months. All of that looks pretty unlikely to be going on in a dead body.

This creates quite an ethical conundrum because we have the "dead donor rule," which is the norm that you must not take vital organs from individuals – from bodies – unless they are dead. How do you justify vital organ donation without the dead donor rule? [Our justification is] tied to the understanding of withdrawing life-sustaining treatment as causing death. If it's acceptable to cause death of patients via withdrawing of life-sustaining treatment – and both the law and medical ethics have established that this is acceptable – then if you link up vital organ donation to a prior decision to withdraw life-sustaining treatment, then no one is going to be dead by virtue of organ donation who wouldn't otherwise be dead by stopping treatment. So that's the strategy we developed.



We also have a chapter, written in conjunction with our colleague Seema Shah, on a legal fictions approach to organ transplantation. We argue that brain death is essentially an unacknowledged legal fiction which means that the brain dead are not really dead, but they are considered dead in the eyes of the law. If we treat them as legally dead, then we can preserve what we're already doing without having to radically change the law. We see it as a kind of halfway house to the more desirable approach: to face up both in medical ethics and the law to what's going on, which means abandoning the dead donor rule. But it's going to be not so easy to get there.

Why did you decide to write a book?

It's always been something of an unfulfilled ambition to have written at least one book, with my name on it. But also, having written several articles with my colleague Bob Truog, and a couple of them joined by Dan Brock, both Bob and I felt we had the material that would lend itself to bringing this all together in a more systematic way. And it also was a way for me to get back to some of the first work I ever did in bioethics which was on assisted suicide and active euthanasia.

What has been the reception?

It's really too early to tell. To my knowledge, no book reviews have been written yet. There's a famous story of David Hume when he wrote his Treatise of Human Nature, he was very disappointed that nobody paid any attention, so he wrote an anonymous book review. I should say I've been tempted to write a review of my book for Amazon, but I would never do that [laughs].

Do you think you'll write any other books?

I don't know. I'm open to it. The experience has been a really good one for me, in the sense of making the effort to try to be more systematic than I tend to be as I segue from one topic to another. But I really feel that essentially, the essay is my form.

Interview with Walter Sinnott-Armstrong (Contd.)

I also knew [the Department] was a group of very smart people working on interesting things. How could you not want to be here?

What *have* you learned?

I've learned a lot about international research ethics. I had some exposure through Maria Merritt and discussions with her. I found it very interesting to just listen to people's discussions about adequate compensation for experimental subjects in deprived areas, for example. What is and what is not fair? Those are issues that I'd never really had thought about before, and I find them interesting.

I think it's been very stimulating to work with the fellows, not only because they're very smart and their own projects are interesting and because they've been very helpful to me, but *also* because it's really fun to go out and have Vietnamese food [laughs]. And we are undefeated at trivia!

What are you working while you're here?

My main research project in the Department is the working group on consciousness. So far, Frank [Miller] and I have produced one paper that has been sent off to the publisher. If I want to be controversial, I'll say we're arguing that it's not wrong to kill. But if I want to be more precise, I would say that death by itself is not bad; it's only bad when it involves the loss of abilities. So if some organism is still alive but has no abilities to control what they do, or what they think about, or what they feel, then life ceases to have value. And then killing is not wrong. So killing *is* wrong when, but only when, it causes loss of abilities.

This has important implications for the availability of organs for transplant.

Your work is very interdisciplinary. What role do you think philosophers should play in other fields?

Some people think that what philosophers should be doing is taking information from neuroscience and using it to answer philosophical questions – and more often than not, to undermine ethics by showing that our beliefs have no basis, whereas I think a more positive role for philosophers in neuroscience is to propose experiments.

Traditionally, neuroscientists and psychologists will study things like economic decision making, because it's easy to give different amounts of money for different acts. Morality is a whole new level of complexity because it's not clear how it fits into some kind of economic calculus. It's not just an emotion like fear – it involves very complex emotions, like guilt or shame. Neuroscientists have shied away from those more complex emotions – for good reason – but philosophers have gotten them interested in them because of the importance of those emotions.

Neuroscience never gives definitive answers. People think that neuroscience gives definitive answers and philosophy doesn't, but really, neither gives definite answers [laughs].

Walter Sinnott-Armstrong is the Chauncey Stillman Professor of Practical Ethics in the Department of Philosophy and the Kenan Institute for Ethics at Duke University.

Announcements

- We would like to hear from you! We hope to include updates from alumni in the next issue of the Bioethics Bulletin. Updates might include any of the following: personal life happenings, publications, new professional involvements or activities, or anything you'd like to share with the current and former department members. Please email Becky Chen at bchen@cc.nih.gov with your news to share.
- We recently launched a bioethics listserv as a way for alumni to share relevant news articles, job opportunities, and conference announcements. To post to the listserv, send an email to bioethics-alumni@googlegroups.com and it will go out to the 100+ network members on the list. To join the listserv, contact Becky at bchen@cc.nih.gov.