

BIOETHICS BULLETIN

NIH CLINICAL CENTER DEPARTMENT OF BIOETHICS

INTERVIEW WITH SEEMA SHAH

A long-time NIH faculty scholar & former fellow reflects on the past, present, and future of bioethics

In Spring 2016, Seema Shah transitioned to a new position as a member of the University of Washington's Treuman Katz Center for Pediatric Bioethics, after ten years on faculty at the NIH Department of Bioethics. The Bulletin caught up with Seema to discuss her life, time in the department, and plans for the future.

Q: How did you first become interested in bioethics? What was the first issue in Bioethics that you became interested in?

As an undergraduate at Stanford, I was interested in Biology, and started taking the Human Biology Core. I found myself frustrated by the lack of discussion of the social implications of the things we were learning. A friend of a professor of mine approached me and said: "you should take my course on Bioethics". I had never heard of bioethics before that, but I took his course, and I was bitten by the bioethics bug. I was fortunate to meet the right mentors at the right times, who guided me to opportunities that were luckily open as I was ready for them. In particular, I was interested in how new technologies challenge our understanding of what's important. My thesis at Stanford was on surrogate motherhood, and I was interested in the idea that it upends our traditional understanding of how someone becomes a mother and what it means to carry a child. Agnieszka Jaworska, a former postdoc in the department and a professor at Stanford as well as a mentor, pressed me to move away from bare intuitions and think concretely about how our notions of forming relationships that can lead to possible harms.

Q: How did you come to the NIH Department of Bioethics?

Agnieszka had just started at Stanford in the philosophy department, after a postdoc in the Department of Bioethics. She took me under her wing. So I applied here. It was funny – I didn't really want to move to the East Coast – I'm a California person at heart, and my parents didn't want me to move. But Marion called me the day after my interview. She ended up calling my home number, listed on my CV, and talked to my mom about this position. What this meant is that when I called my parents to tell them I had this offer but I'm not sure about moving so far away, Marion had already convinced them that it was a great opportunity and they said I should absolutely take it. I had no idea what was in store for me but I really did find a surrogate family in the department.

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CHRISTINE'S
CORNER

Greetings and Happy 20th Birthday from the CC Department of Bioethics! The Department of Bioethics continues to thrive, produce great research and incomparable fellows as well as offer high quality services to the NIH.

Our bioethics consultation service continues to be very active, always presenting us with novel and interesting questions to address. Many of the successful departmental activities continue in a form that you may remember- e.g. Ethics Grand Rounds, Works-in-Progress, the Joint Bioethics Consortium, and, of course, afternoon tea☺. The Bioethics fellowship and the IRB internship programs are quite competitive and increasingly popular. For 2016, we have accepted 6 bioethics fellows and 4 IRB interns (from Thailand, Malawi, Uganda, and Jamaica). For Visiting Scholars, we have had Sam Kerstein from University of Maryland Department of Philosophy with us this spring,

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ETHICS AND THE ZIKA VIRUS OUTBREAK

By Pauline Osamor

A pressing issue of today is the current outbreak of the Zika virus. One ethical issue raised by the rapid spread of the virus is what women should do if they are pregnant or planning to get pregnant, given the dire consequences of Zika in fetuses, such as microcephaly.

To delve briefly into the topic, there is a conflict between on-the-ground realities and advice given by the World Health Organization (WHO). One salient WHO recommendation is that women should have the capacity to choose among the relevant reproductive options available, ranging from delaying pregnancy, using contraception, emergency contraceptive services/counseling and termination of pregnancy.

However, the reality is that most women in the hardest-hit countries do not have access to the full range of reproductive services due to legal, religious, cultural and practical barriers. For instance, some of the 46 affected countries do not offer reliable and affordable access to birth control. In other Zika-afflicted countries, women may not be able to exercise the option to terminate a pregnancy because they live in countries where abortion is not legal. Four of the six countries that do not allow abortion under any circumstances are in Latin America and are likely to face widespread infections with Zika, while other countries in the region allow abortion only in very restricted situations. In other countries, prenatal ultrasound testing, which could enable the detection of severely affected fetuses, is often not available or too expensive. These are just a few of the challenges that make it difficult for women in Zika-affected countries to have full reproductive choice in practice.

In the face of these practical barriers, the WHO recommendation begins to sound more aspirational than practically achievable. It is likely that many women will be unable to exercise their rights to autonomy and self-determination in pregnancy given realities of sexual & reproductive health services in

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thinking currently in the Department of Bioethics on ethical issues related to the Zika outbreak. Fellows Dana Howard and Katie Byron wrote a recent paper in Journal of Medical Ethics on the ethics of advising by institutions such as CDC and WHO, and Pauline Osamor has a paper in PLOS Neglected Tropical Diseases on the role of men in helping to stem the tide of the Zika virus. As always, the Department loves visits from and welcomes collaboration with past members, and alumni can keep up with the department's progress in this area on our website and in future newsletters

A PROFILE OF BECKY CHEN

Becky Chen is retiring at the end of the year, after being in the Department since June 21, 1999. The Bioethics Bulletin caught up with her for an interview and profile for the newsletter.

There were 12 people in the Department when Becky started, between fellows and faculty. The original faculty were Zeke, Christine, Marion, Dave Wendler, Sara Hull, Frank Miller had started a few weeks earlier, and Ben Wilfond was here. It was the transition at the end of an academic year, so there were still a few fellows here.

Becky has consistently maintained that the most enjoyable part about the Department is the people. She likes the fact that she can come here and figure out how to make things run smoothly, but the people make it all worthwhile. They are, in her words, "easy to work with, funny, smart, and kind, and for a place that's as high powered and productive as this department is, they treat each other with great respect."

Becky also claims that she is not the only one in the Department with a love of politics. Politics is a game, according to Becky, and she and her parents used to talk about politics all the time, but in Washington it's pervasive, so it's always a topic for discussion. And some political times are more interesting than other political times.

It's also clear that the Department has become like family to Becky over time, and that Becky has been the glue that holds the Department together. We all gather around tea, poke fun at each other, and hear about each other's successes; even though fellows and faculty leave, we still collaborate with them, and, for Becky, it isn't just that she knows the fellows and faculty but also that she goes to their weddings, sees their kids born, and knows their spouses. As many of you know, we put together a book where past fellows and Department members wrote in to tell us about their memories of Becky, and we presented her with this book at her retirement party. It was clear from so many of the responses just how much Becky has touched the lives of everyone who has passed through here. It's a unique department, and people are members of a family when they come here for any time at all – and Becky has been a key part in making that happen.

As far as retirement goes, there is no shortage of things Becky has planned. She's going to play with her grandkids. She plans to reconnect with friends who she never gets to see anymore, plans to travel, including up to New York to see plays more often. She plans to read a lot. Becky also says that she's done crosswords all her life – she picked it up from her mother – and has no intention of stopping: "you guys may miss me but I'll still be doing the crossword every day."

And we can certainly hope to see Becky again soon. She plans to come back to visit the Department. She'll float through, hop in at the potlucks and say hi to people. People can come visit her too for that matter! And now she'll be able to keep up with people (alums) better too. Becky says she will miss the cheerful atmosphere of the Department and the group of very smart, but very big-hearted and generous, kind people, and that it will be strange for her to not come here every day.

Becky has been the glue that holds the Department together and makes the Department run. She says she will miss the people tremendously. "It's just the nicest group of people to work with, always has been, always will be."

Interview with Seema Shah, contd.

Q: Of the various topics you've addressed over the course of your career, what have you found most enjoyable, or most challenging to work on?

Concepts in international research ethics. That is because I have had the great benefit of working with people like Alan Wertheimer – he read every single paper I wrote, always provided comments quickly, and challenged me to think whether exploitation was the animating concern for some of the protections perceived to be important in research ethics, or whether other concerns could be operating in that space. It is also because I have had the opportunity to present at workshops and interact with people from all different countries. We have had many conversations that make me think hard about the role of culture relative to the individual. Why do we place the individual in this exalted position over the interests of the community? On the other hand, I remember one conversation, a woman in the audience said that 'community consent' sometimes means getting consent just from people at the top of the hierarchy. So she thought it was important to have protections for people who might have a hard time saying no.

Q: How have you seen the Department evolve over time?

I learned how the department changes over time based on cohorts of different fellows. At first it was hard to say goodbye to people, but over time I really valued the way in which the department could change and respond based on the people who were in it. Of course the department maintains core traditions – collaborative scholarship, a strong tradition of different activities - the people who have been there for so long keep the department ethos constant across time.

I think a lot of thought has been put into the fellowship program to make sure that people get

out of it what they need to be successful later in their careers. When I was a fellow, the question of whether people could actually do bioethics when they left – it wasn't always clear. The hope was that people would succeed in their fields and also do bioethics if they could. What's nice is that the field has changed, with more opportunities in bioethics, so more and more we're producing people who are going to go and continue to focus on bioethics in a big way.

I think the loss of Alan Wertheimer was a really significant loss to the Department, and a really hard loss on all of us – he was not only an exceptional scholar and incredible mentor, but also had a lot of wisdom to share with the Department, and made everyone's scholarship better. I think all of us try to remember the kinds of comments Alan used to make, and make sure we're doing justice to his very large role in the Department for so long.

Q: What did you enjoy most about being in the Department, and what do you miss?

I think it's the people. I miss the wonderful colleagues, easily accessible, to help with all kinds of questions I had, to make my scholarship better, to make my ethics consultation more respectful and responsible, to help me to be a better mentor, and to participate in wide-ranging discussions about politics and everything else. I always heard people say that the department is this really unique place where people are actually in the office and lots of interaction goes on, and contributes so much to the intellectual life of the department, and there's no place like it, and I think that's true.

Continued....

Q: What are you enjoying about your new job, what's it like, and what are you looking forward to about it in the coming years?

It's really interesting to be in a center where everyone is doing pediatric ethics, there are special questions I've always been interested in in how we make decisions on behalf of children that are appropriate- being in a place where everyone focuses on that is really unique and interesting. Also, starting a new position, it's an opportunity to wrap up certain obligations and think of how I want to focus my scholarship in a few areas, which projects I wanted to pursue but didn't get a chance to.

Seattle is also an entrepreneurial place, with lots of collaborations here that are really interesting. I was on a grant application recently with an economist and a clinician, trying to understand the impact of various financial incentives on adolescents to get them to engage in various health behaviors. I also really enjoy Seattle, it's a great city that has a combination of an urban environment surrounded by natural

beauty. It's great to explore. We tried to do a 'toddler hike' with our kids, and found that what is described as a toddler hike in the Pacific Northwest is very different than that kind of hike in DC!

Q: How is your family?

It's been a series of big transitions for all of us, but all is well. Selilah is in a bilingual school and has lots of friends. Shivani only knows Seattle – I've been told that babies who are born in the Pacific Northwest will always want to come back to it, so even if we don't live here she might want to come back! And Mehesh has had a great series of interesting and good opportunities. Also, drivers in Seattle are incredibly courteous – they let you merge! There are lots of little funny things about the West coast culture and the Seattle culture that we are getting used to. If anyone wants to come out to Seattle, we have a guest room and we love to have visitors, so we would welcome anyone who wants to come out to Seattle to visit!

Introducing New Department Members

Carl Runge is a research associate in the department. He graduated from Yale with a BA in History of Science and Medicine, and is interested in the interdisciplinary nature of bioethics. He assists and collaborates on a broad range of faculty projects and helps out with various administrative responsibilities.

Renee Goodman comes to the Department with several years of experience and knowledge in the area of Federal Administration. She joined the NIH community in 2006 as a Lab Secretary, transitioned into the role of Operations Coordinator in 2008, and joined the Department of Bioethics May 2016. She is taking over the role of Senior Program Support Specialist from Becky, and will support and manage all areas of administrative and operational function for the Department of Bioethics.

CHRISTINE'S CORNER, CONTINUED

...and Alex Voorhoeve from the London School of Economics joined us in the fall. We have also had a number of wonderful short term visitors here during the year. Internally, we have had some significant changes:

- Seema Shah moved to Seattle. She is now working for Ben Wilfond at the Treuman Katz Center at Seattle Children's Research Institute. (And she and Mahesh had another beautiful little girl!).
- Reidar Lie will be here working with us part time on international research ethics and capacity building.
- Becky Chen is retiring after 17 years in the Department. (YIKES!)
- Renee Goodman has been hired for Becky's position

Please send me the names of any good bioethicists who you think might thrive here, especially if their work focuses on global health and research or neuroethics, and/or if they have experience with clinical consultation.

Many things are happening at the NIH that might be of interest.

- The NIH Coordinating Committee on Bioethics Research and Training is busy coordinating bioethics activities across the NIH and identifying opportunities for research.
- A neuroethics working group was established as part of the BRAIN initiative Multi council Working Group. A recently published RFA RFA-MH-17-260: BRAIN Initiative: Research on the Ethical Implications of Advancements in Neurotechnology and Brain Science (R01) <http://grants.nih.gov/grants/guide/rfa-files/RFA-MH-17-260.html> is looking for high quality proposals for neuroethics research, The overall aim is to integrate ethical insight into progress under the BRAIN Initiative, and proactively consider ethical implications of the research.
- The Precision Medicine Initiative is moving full steam ahead. For those interested, more info available at <https://www.nih.gov/precision-medicine-initiative-cohort-program>
- Major changes at the Clinical Center. In response to an incident in the CC pharmacy, a Red Team was assembled to investigate safety. Despite what some of us perceive as a flawed process, their report and recommendations have significant implications for the future organization and management of the Clinical Center. A new CEO was appointed who will start in January. And of course, in January we will also likely have a new NIH director.

I hope that all of you are busy, healthy, and happy. We love to hear from you about your many adventures and accomplishments. And please remember that you are always welcome to join us for tea, give a talk, or collaborate with us on a project! Happiest Holidays to you and yours.

Christine

2015-2017 FELLOW BIOGRAPHIES

Katie Byron is a pre-doctoral fellow in the Department. She graduated from Brown University in 2015 with a double major in Computational Biology and Gender and Sexuality Studies. Both inside and outside the classroom, she focused on the science and politics of reproductive health. Her research explores the intersections between gender, sexuality, and health. Her current projects include an analysis of the ethics of advising during Zika, empirical and conceptual work on parental permission for adolescent participation in HIV prevention research, defining an ethical, legal, and social implications research agenda for sexual and gender minority populations, and an exploration of ethical issues that arise in perinatal hospice and palliative care.

Sam Doernberg is a pre-doctoral fellow in the Department of Bioethics. He graduated from Cornell University in 2015 with majors in Philosophy and Neurobiology, and a minor in Law and Society. His undergraduate research focused on the intersection of free will, neuroscience, and criminal justice. He also conducted research on carcinoma metastasis. While at the NIH, Sam has conducted research on ethical issues that come up in caring for patients who have neurological and psychiatric illnesses, and questions that arise in enrolling these patients in research clinical trials. He also works on other issues in research ethics, such as sharing clinical trials data. After his fellowship, Sam intends to pursue a career in medicine.

Derek Braverman is a pre-doctoral fellow in the Department of Bioethics. He graduated from Yale University with a Bachelor of Arts in 2015 as a double major in molecular, cellular, and developmental biology and in philosophy. Derek worked as a research assistant in several laboratories, investigating topics such as diagnostic techniques for epilepsy and the bioactivity of Amazonian fungi, before completing his research thesis on the composition of the mood-regulatory circuitry of the amygdala. In philosophy, he concentrated on both ethics and experimental philosophy; dovetailing these foci, Derek's philosophy thesis employed recent studies in experimental philosophy to challenge the notion of a substantive divide between how people conceive of moral norms as opposed to conventional norms. His interest in bioethics lies in clinical ethics, and in particular the relationship between patients and health care providers. Derek looks forward to beginning medical school next year.

2015-2017 FELLOW BIOGRAPHIES

Dr. Akilah Jefferson is a postdoctoral fellow in the Department of Bioethics. She majored in Biomedical Ethics at Brown University, where her honors thesis, "Morals in Action: Responsibilities in the AIDs Pandemic," argued for the moral responsibilities and duties that more developed nations, and individuals living in those nations, have to nations and individuals in less developed areas, with a focus on HIV/AIDs. Before medical school, she completed a Master of Science in Biomedical Science Policy and Advocacy from Georgetown. After graduating with an MD from Tulane in New Orleans, her hometown, she moved to Washington, DC, for residency training at GWU Hospital. Following residency, Dr. Jefferson entered a clinical fellowship at the National Institute of Allergy and Infectious Disease (NIAID), where she is currently a second-year clinical fellow in Allergy and Immunology. Her research interests include health policy and the ethics of health policy, with a focus on cost considerations in medicine and research, comparative effectiveness research, quality, and distribution of health care resources. She is also very interested in health disparities.

Dana Howard is a philosopher interested in ethics, political philosophy, and bioethics. At the NIH, she is working on ethical issues that surround medical decision-making. In particular, she is thinking about the nature of having the authority to make decisions on behalf of another as well as the ethics of advising. She finished her Ph.D. in 2013 at Brown University, and after that was postdoctoral fellow at Ohio State University.

Pauline Osamor is a post-doctoral fellow in the department of Bioethics. She finished her PhD in 2012 at the University of Ibadan, Nigeria, in Medical Sociology. Prior to the NIH, she was a Research Fellow at the Institute of Child Health, College of Medicine, University of Ibadan, Nigeria. Her research combines her experience in medical sociology, bioethics, and health education, and at the NIH she plans to work on several issues. In particular, she is interested in issues related to women's decision-making autonomy in their own health care, factors that may influence the informed consent process, and attitudes and practices regarding assent from children in developing countries. After the fellowship, Pauline intends to use the skills and training from the NIH to pursue an academic career in bioethics in a developing country.

ALUMNI UPDATES

Emily Abdoler finished up residency in Internal Medicine at the University of California, San Francisco this June and has stayed on at UCSF as a fellow in Infectious Diseases since July. She and Dan welcomed a daughter, Esther Patricia Abdoler-Deckard (below) at the end of April, and just narrowly missed having the amazing Dr. Colleen Denny as OB Chief on duty!



Greer Donley is still working in healthcare law at Latham & Watkins. Her practice focuses on white collar defense in the context of healthcare fraud and abuse investigations. In May, she married Zeke Rediker at the Decatur House in Washington DC – they met in law school. They moved to New York City in the fall of 2017 for clerkships, and she will be clerking for Judge Sack on the Second Circuit. Greer was just offered a position at Pitt Law.

Collin O'Neil is currently (and since Fall 2014) an Assistant Professor in the Department of Philosophy at Lehman College, City University of New York.

Last fall, **Rob Hughes** started a tenure-track job in the Legal Studies and Business Ethics Department at the Wharton School of the University of Pennsylvania. He is teaching two courses, both for undergraduates, one entitled "Corporate Responsibility and Ethics" and one entitled "Markets, Morality, and Capitalism." The paper on health care justice that he began in his last few months at the NIH was the piece he used as his job talk.

From **Remy Brim**: Hi everyone! In the three years since I left the Department, I have been serving as Senior Health Policy Advisor for Senator Elizabeth Warren. In June, I began a new role as Senior FDA Policy Advisor for the Senate Health Education Labor and Pensions Committee. My temporary stint in DC is looking more long term by the day!

Stella Imot is still working as the IRB Administrator for the Makerere University School of Health Sciences IRB. She completed a Post-Graduate Diploma in Health Research Ethics from Stellenbosch University, Cape Town, South Africa, funded by Fogarty International Center at

the NIH. Earlier this year, she also graduated with a Master of Arts Degree in Public Administration and Management from Makerere University.

Danielle Bromwich was promoted to Associate Professor of Philosophy with tenure at the University of Massachusetts, Boston. She'll be taking a full year sabbatical and hopes to get in a couple of visits to NIH.

Roseanna Sommers just moved to Cambridge, MA and will be there for a year as a research fellow at the Behavioral Insights Group at Harvard.

Tina Rulli, in her second year as faculty in UC Davis's Philosophy Department, received a seed grant from the UCD Division of Social Sciences to work on Race, Genomics, and Informed Consent. She and her husband Stephen bought a house this past year in Sacramento and are loving the west coast.

Sarah Gollust (predoc, 2001-2003) and her husband Ezra Golberstein both earned tenure and were promoted on May 17, 2016. They are now Associate Professors of Health Policy and Management at the University of Minnesota School of Public Health.

Emily Largent successfully defended her dissertation and graduated from Harvard with a PhD in Health Policy (Ethics) and a JD at the end of May. She is staying in Boston for the time being and has been clerking for Chief Judge Howard of the 1st Circuit Court of Appeals since August. Picture of her, her husband Matt, and their daughter, Meara, at Emily's dissertation defense:



Jennifer DeSante and Mike got married in Pennsylvania this September. She still loves her job at Cincinnati Children's in the Pediatric Ethics Center and Division of Hospital Medicine.