

Center for Genetics and Society
Talking Biopolitics with Alondra Nelson and Jenny Reardon
Tuesday, January 23rd, 2018
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This transcript was provided by Communication Access Realtime Translation (CART) Captioning, and has been edited by the Center for Genetics and Society for clarity.

Katie Hasson

Welcome to today's Talking Biopolitics conversation. I'm Katie Hasson, Program Director on Genetic Justice at the Center for Genetics and Society. *Talking Biopolitics* is CGS' series of conversations about the social meanings of human biotechnologies, with cutting-edge thinkers, writers, and filmmakers. Today, we're honored and fortunate to have with us Alondra Nelson and Jenny Reardon.

Before I introduce them, I want to let you know that we have live captioning during the event – you can find it in the box bottom of your screen – and I'll also be describing the images that we display for those on the phone and anyone with a vision impairment.

On this first slide, on the top left, is a picture of Alondra Nelson. Alondra is the author of one of the books at the center of today's conversation: *The Social Life of DNA: Race, Reparations, and Reconciliation after the Genome*. Its cover, pictured to the left of Alondra's image, shows a DNA strand and a faint shadow in the shape of chains. There's a review quote at the bottom by Isabel Wilkerson that says, "Eye-opening, provocative and deeply humane".

A photograph of Jenny Reardon, our second speaker, is on the top right, next to an image of Jenny's book that came out just last month: The title, *The Postgenomic Condition: Ethics, Justice and Knowledge After the Genome*, is shown on a background of varied purple dots used to visualize genomic data.

Also on this slide, is the title of today's event: *Talking Biopolitics* with Alondra Nelson and Jenny Reardon; today's date, January 23rd; and, found next to the twitter logo, the hashtag for live-tweeting during the event: #TalkingBiopolitics. That's all one word: T-A-L-K-I-N-G-B-I-O-P-O-L-I-T-I-C-S.

Below that on the slide there is information about getting technical assistance with our webinar platform. If you need help with Adobe Connect, please contact Leah Lowthorp - either by phone, at 510-665-7760 (extension 308), or by email at llothrop@geneticsandsociety.org

Alondra and Jenny, who I'll introduce in a few moments, will talk for about 25-30 minutes. Then CGS' Executive Director Marcy Darnovksy will share a few comments during a very short interlude before we bring in your questions and comments, which we invite you to send in at any point during the webinar.

Now I'll take a moment to describe the other features of the webinar platform. To the right of the image area are two boxes, one labeled "Q&A" and the other labeled "Chat." You can type

your questions and comments, at any time throughout the hour, in either place. If you submit them in the Q&A box, they'll go just to Alondra, Jenny and me, and the behind the scenes CGS staff who are helping out. If you submit them in the Chat box, they'll be visible to all participants. If you have technical issues with the platform, you can type those into the chat box.

Below the image area is the live captioning box. Let me take this opportunity to thank our captioner, Christine.

This event is being recorded. It will be available in the near future with a transcript, on CGS' website, and on our YouTube Channel.

Now let me introduce our speakers and describe our next slide.

Alondra Nelson is pictured on the left side of the slide, and her name also links to her website. She is President of the Social Science Research Council and Professor of Sociology at Columbia University, where she served as the inaugural Dean of Social Science. Alondra has published numerous books and articles exploring the junction of science, medicine, and social inequality. Three hyperlinked titles are listed on the slide: *The Social Life of DNA*; *Body and Soul: The Black Panther Party and the Fight against Medical Discrimination*; and *Genetics and the Unsettled Past: The Collision of DNA, Race, and History*.

Jenny Reardon is pictured on the right side of the slide, and her name also links to her website. She is a Professor of Sociology and the Founding Director of the Science and Justice Research Center at the University of California - Santa Cruz. Her research draws into focus questions about identity, justice and democracy that are often silently embedded in modern genomic research. Her training spans molecular biology, the history of biology, science studies, feminist and critical race studies, and the sociology of science, technology and medicine. The slide also includes links to her books *The Postgenomic Condition*, which we'll be discussing today, and *Race to the Finish: Identity and Governance in an Age of Genomics*.

So now, Alondra and Jenny, would you start sharing your webcams and unmute your mics, please?

Each of our video feeds should now be on the screen, and in the upper right-hand corner, there is a small slide of the CGS logo: the name of the organization in caps with three intersecting circles of different colors: lime green, light blue and gray.

Alondra and Jenny, thank you both so much for being here with us today. I'm really looking forward to this conversation exploring the links between genomics and justice. You two have in common that you have been researching and writing for the past decade or so on the topic of race and genomics, and in fact, I learned in our conversation the other day that this includes writing your books alongside each other. It seems like an excellent place to start would be to hear from each of you about the links you see between your books and your work in general.

And maybe, Jenny, you could start us off.

Jenny Reardon

Thank you, Katie. And thanks for having me and Alondra on today. I've had the good fortune to have Alondra Nelson as a colleague for many years. I think back at Brown University, many, many years ago, brought together by colleagues like Evelyn Hammonds, Lundy Brown, and a huge community of folks that had come together around issues of race and genetics in the last millennium. I really want to acknowledge that group of scholars, too, that still I think are very much a part of the community in which Alondra and I work.

So, yeah, we also had the good fortune of managing, to find time to share our chapters, get on Skype, and go through the process of writing books together. Alondra is a bit speedier than me but I eventually got there. So we shared chapters back and forth.

I would say where Alondra and I come together, it's not just in our most recent book, but really our whole oeuvre. If you go back to *Body and Soul* with Alondra, her work and my work across all the four books, or five books, have really been interested in looking at, along with other scholars, the emergence of health, medicine, and science as new terrain for political work.

But particularly I think Alondra and I have been interested in the questions of racial justice and social justice, and the ambivalent new terrain that new forms of science and technology provide.

I think in *Body and Soul*, Alondra makes a really interesting point about the Black Panthers and how they really moved from, you know, in the post-Civil Rights era looking at, ok: that didn't really solve the whole problem. How do we move towards human rights, and claiming health and medicine as that new terrain? And actually, early on embracing new forms of genetic science. They were doing sickle cell testing way back in the early 1970s.

So I think we're interested in a similar move. The law hasn't quite solved the social justice issues. The civil rights movements didn't quite do it. That move towards high-tech science is potentially a new phase, and medicine is a new phase. And I think we're both interested in both the possibilities and the fraught aspects, of doing that. So the contradictions - the way that justice gets easily wrapped up in commercial interests - I think both of us have looked at that, the way that the initial enthusiasm for questions of justice and democracy can get displaced at the end of the day by just more genomic data or genetic data; the way in which you end up reifying the things you were trying to actually take down through the process of doing these things. These are some of the fraught contradictions I think we look at.

And I think, at least in my own work, I came to this through seeing the limits of an ethical, legal, and social implication approach of doing work and wanting to move towards justice as a frame, and I think Alondra has that in common.

And I think finally I'd say that we're not just interested in critique. I think both of us have been interested in understanding the possibilities for new forms of meaning-making here, for new forms of life. So that's what I would say.

Katie Hasson

Alondra? Alondra, could you check your mic? We can't hear you.

Alondra Nelson

[...] How's that?

Katie Hasson

Perfect.

Alondra Nelson

Good. Sorry about that. It's great to see you both. And thank you for getting us started, Jenny.

You know, I think it's been - I almost have a nostalgia about our book writing process, Jenny, because it was I think for both of us trying to write second-generation books about genetics and inequality, so I think both of our first books, [which] we might imagine as the first generation, come very much out of the experience of being trained and, indeed, nurtured by Lundy Braun, Evelyn Hammonds, and Troy Duster.

And one of the insights I think in writing *The Social Life of DNA* was so much [of what] we were writing about in the sort of emergent sociology of genetics was about what might come. So after the sort of Human Genome project, where you actually have projects and vehicles and clinical applications - you know, things that people are actually doing - it took a lot of our work from the kind of speculative, to really dealing with practical problems and people's practical engagements with these new kinds of tools and changes.

So I think at least for our own trajectories, I think you might think of our books as sort of the second-generation endeavors to, as Jenny said, move beyond critique. My work is interview-based and ethnographic. The critique wasn't really fitting all of it, what I was finding. And I needed a way to think about the experience of the people that I was encountering. This was true of those I interviewed who had been in the Black Panther Party, or affiliates of that organization working on projects around genetic testing and, true, of course, of the contemporary projects as well. And I felt that sometimes our sort of over-determination of the critique frame left us only with something like, "oh, they have false consciousness - if they only knew better, these people wouldn't be endeavoring to think that genetics could do something interesting in the world, rather than really trying to understand what folks thought they were doing".

What I think is so wonderful about Jenny's book in this sort of second-generation, you know, move is that she takes us to think about not just the U.S. context; to think more broadly about other places in the world as these technologies are moving forward, and being elaborated - and popular realms, medical realms, and to think about sort of how that's similar to what's happening in the U.S. and how there are different things afoot as well.

Katie Hasson

And it seems like, moving into the second-generation questions about making genomics, the questions about social justice and racial justice may have expanded over time. Both of you

have written eloquently about how DNA can be used to do certain kinds of justice work. So I'm curious to hear from you about how you have developed this frame of justice in terms of talking about genomics.

Jenny Reardon

I guess I'll answer that by saying - well, when I started working on this second-generation project, it precisely was, as Alondra said, people on the ground facing dilemmas. I was pretty insistent that what I was doing was not writing a book to begin with.

I had started out, actually, as genomics person. I wanted to work with Mary King because I read an article in which she talked about the importance of the work for social justice causes. So I very much had a practical bent in that sense - I wanted to make a difference.

So every case that I chose in this book, I chose because there was something about it that was inspiring to me. And the big wave that was happening after the end of the Genome project, and in the wake of the diversity project, which I had written about originally, was how do we do better, and not do science that is accused of being racist and bio-colonialist. And there was a huge embrace democratizing genomics. That was the big thing happening at the turn of the millennium. "Let's include people": inclusionary practices, new representational practices that really are there to try to give people a voice.

What I realized in studying it is that those liberal democratic moves really had limits. And what we were really coming up against were more fundamental questions about how we live together collectively in this moment where high-tech versions of science and technology are the new medium through which people are living their lives, whether or not that's online.

I mean, what we're doing right here is a form of that. New forms of collectivity, conversation through the digital world, and genomics is a part of that. We were reaching the limits of liberal modes of working. And this turns to justice with a recognition that people were making fundamental questions and saying the system is fundamentally not working for us.

And often people will claim justice when they feel that the system is not working for them. I think the genomics has been a space in which people have been making those claims. So the turn to justice is partly, for me, intellectually, a kind of urging of us to move to those much more fundamental questions about what are the first principles around which we should come together and live. Is it inclusion? Is it property? Is it the public? What should we be thinking about?

Of course, equity and access are huge issues, in an age of inequality - these new forms of medicines that are coming out from genomics are really - they're reaching crises we've never seen with drugs, close to \$1 million a year for some of these new immunotherapy drugs. So there's obvious injustice in issues like that. But then there are I think even the much more fundamental questions about how we live together collectively.

Alondra Nelson

Nicely put. And I think those are the fundamental questions for this moment, genetics aside or not.

For my part, because I also work on social movements, I think I'm always interested in people's claims about justice and equality and inclusion in their communities. But I didn't start out writing a book about justice. I actually thought I was writing a book of critique, a book about about racial identity, a book about a new emergent form, a commercial form, direct-to-consumer genetics, and what that new form sort of did and meant in people's lives.

I thought very much, and I've said this many times now, that the project I was working on was not going to be unlike these sort of genetic genealogy television shows, where I was going to be telling stories of people's "before and after's" with their identity, you know? These days the clichés are the Ancestry.com ads about how people think they were - think and thought they were that. I went in very much thinking, as I do now, if we understand it all as social analysts, the way that community works, the way that identity works, that those kinds of accounts were not totally reliable about what these tests were doing in the world. But still I was interested.

So that's what I thought I was doing. It was very much a kind of targeted interview project. And then it became a more deeply, richly ethnographic project in which I came to try to reckon with what people doing with the tests. And I found myself - not myself - looking for ways in which genetics was being interlaced with justice, but having to make an account of how the people that I was spending time with came to see these things intertwined in their lives.

So one of the more meaningful moments, it happened quite a lot - and I don't use the word justice so much. I use it a little bit in my work - I use the concept of reconciliation projects, and I use the concept to think about how we've turned to DNA more generally in the last 15 years, not only with direct-to-consumer genetics, but with forms of humanitarian DNA, with other forms of uses of genetic analysis to answer questions about the past, to resolve social issues and political issues. And I'm always careful to use the word - to suggest that these are endeavors, right? Not that justice is a necessary outcome, and that what people might be doing might, indeed, be the opposite of justice. But I'm interested in the endeavor on the parts of actors who think that they are doing something to advance justice as understood for them in their world.

So you know, one of the more meaningful moments for me in doing my research was - I was invited to join a couple of dozens of people at a ceremony, a West African Sierra Leonean ceremony called Asara, which is practiced in intervals, usually one year after someone's passing, seven years after someone's passing, in sort of intervals in time (and Asara's spelled A-S-A-R-A), to rest the souls of the people who have been lost. And so in this encounter, in this endeavor, in this attempt to reconcile the past and the present, there were people - a group of people there who called themselves DNA Sierra Leoneans, who had used genetic ancestry testing to be able to lay claim to a Sierra Leonean identity, and many of them knowing well the sort of limitations of the technology, knowing well - I mean, this was - this would have been in about 2008. So people who weren't sort of necessarily true believers in the technology, but were true believers in what they thought the technology could bring them in their lives.

So I was able to observe a very meaningful ceremony that I think in the frame of genetic injustice was a kind of self-fulfilling and small community-fulfilling kind of justice about

reckoning for individuals and for the small community with the history of the transatlantic slave trade. The ceremony took place on the banks of the Ashley River where there had been slave auctions just outside of Charleston, South Carolina, and included the actor Isaiah Washington who identified as a DNA Sierra Leonean, as well as other folks who laid claim to Sierra Leone through the slave trade.

So that was a very poignant moment, and it was a moment that I thought that critique, and critique indeed of the technology, critique of what people thought they could do, was not the only thing that I had to - that I felt obligated to say about that moment.

Katie Hasson

I think this brings up an interesting tension because we tend to hear about inequality and justice work around genetic technology as being about inclusion, as both of you mentioned to some extent. How can we include many people in these projects, or how can we get as many people as possible, [to] have access to their genomic data? But what both of you do so beautifully is bring up the problem and the possibilities of interpretation - what do we do with that data? How do we make meaning from it?

I know Jenny, in your book, you talk about that that wasn't actually built into the project of sequencing the human genome, "what do we make of it?". And Alondra, your book showed the active ways that people have interpreted and made meaning from the data. So I wonder if you could talk a little bit about that tension between inclusion and interpretation for meaning.

Jenny Reardon

Yeah. No, the ironic part of the human genome project is there were very few humans involved, and the whole point was to get the humans out of the way so that the machines could do it because they were better, faster, more accurate. The problem is, you actually need human beings to do interpretation. Machines don't interpret data and create meaningful things for humans alone.

And I think that's right. Alondra, my work - my work and Alondra's work are both really around that really critical issue of interpretation. We have all the genomic data, but what does it mean? And that question means we have to be listening to and talking to the people on the ground who are trying to make sense of it.

If you do that, then the kind of response to that, the genome project response to that, was, "ok, we'll include people, we know that that's a problem, we want to include people". But they didn't really know quite how to do that.

If you are 24/7, you know, the whole limelight was on making the faster, better machines. The whole limelight was not on how do we create the social, political, intellectual infrastructures to bring people together to do the hard work of understanding what any of this means so it leads to better lives, which is what we all want. We want better lives for people. But for that to happen there has to be - you know, one of the big points of our field, scientific technology studies, is to say you can't have the scientific technology over here and then just add social inclusion later. Yet there was still very much that hope with the genome project.

The inclusionary process has to be imbricated. I'll tell one great story, the story that begins my book. Again, it was an accidental project - a lot of this book was a bit of an accident. I had gone to Tuskegee, Alabama, to talk to people who were trying to include the voices of diverse peoples in the policy conversations about genomics; not in doing the science and technology. And when I got there, I discovered that there was an effort to create a genome center at Tuskegee. And these two efforts were not aligned. They started out separately. And there was a real effort to try to bring them together.

But the story there, in Tuskegee, was one of how you don't start with that integration from the beginning. And when you don't start with the concerns of the people on the ground, it's very hard to add it later. So that is a fundamental problem that the infrastructure of genomics has, is that it fundamentally did not include interpretation, which is a human activity, into it from the very beginning.

Alondra Nelson

I would add that the interpretation piece for certain, but also the infrastructure, as Jenny mentioned, and the kind of institutional or social places where genetics takes place.

So part of what I think makes the work second generation, if we want to carry forward with that generational metaphor, the genealogical metaphor, is that not only do we have different applications for genetic technologies, they're happening in all sorts of different places simultaneously. So a lot of our earlier conversations were about what would happen in clinical settings or medical settings, and we have now a proliferation of genetics from everything from, you know, beauty to healthcare to the criminal justice system to clinical health to clinical research.

So the sort of rolling out, the diffusion of genetic technologies that is forcing people who had never had to think about genetics before, to do so I think is part of the reason that makes this interpretation piece so urgent and important in this moment. Because we've really got to figure out what's going on. But it's also the case that these different social sites have different - bring different sorts of shapes. You know, thinking about the kind of sociological question of structure and agency. There are different structural things in the world that give shape to what genetics can mean.

Part of what became interesting for me and part of what I mean by the "social lives of DNA" is how all of these forms of genetic analysis circulate at the same time in people's lives. So many of the folks that I talk to would do genetic ancestry testing because they had questions about the past, particularly because I worked with African Americans, questions that had some bearing for them on the history of slavery, and for some, provided a retort to an increasingly sort of colorblind society that said the past didn't matter.

The things that genetic ancestry testing offers is a way to talk about the past, and a way to talk about the past that's very personal, that can't be questioned by other people because it's your rendering of the past. And, indeed, it comes from tissue that comes from your very body.

But this is happening at the same time as growing forensic databases in the criminal justice

system, a rollout of mass incarceration so significant that we are, and rightly so but also sadly so, happy about something like the Innocence Project, that has now freed, through DNA analysis, something like 300 people. And that is an incredible social movement, incredible advocacy organization that in some ways only becomes necessary under a regime of mass incarceration. Right? And under a regime in which we think genetics tells us something about the world.

But there's no volition, there's no picking and choosing like there is with genetic ancestry testing. There's no negotiation with the criminal justice system, particularly for communities of color. And similarly, decisions are made, being made, in clinical and medical genetics about identity, and about the stakes of what certain genetic profiles mean for people with experience, mean for their access to certain protocols, and potentially to certain drugs.

So all of these three things are happening at once, and I think to the extent that there's a second and hopefully a third generation of research in the States, it's really having to grapple with all of those things at once. All of that interpretation that's getting input from all of these different social sites simultaneously.

Katie Hasson

Yeah. Great.

Let's try to get one more quick question in before a pause in about five minutes.

I wanted to hear a little bit about the reception that your work has had. Both of you do a lot of work in various public, with various publics, presenting, and clearly you have goals that go beyond critique, as you said, so I'm curious about what kind of reception your work receives.

Jenny Reardon

That's a really good question. The kind of work that I think we both do, it's very important to think about those questions of reception. A lot of the reception of my book happened before it came out, because I shared a lot of it with the people who were my main informants, because I certainly didn't want to have a conversation posted without that - these are very, very touchy issues. People feel passionately about these issues. I often like to say that no one goes into genomics to start the next generation of racism. Many of these people that I work with are trying to make the world be a better place. And it can be very hard to have their work link back to not just a Kumbaya, bringing everyone together moment. How do you do the important work of allowing people - telling stories that bring people in conversation with other perspectives that are not there, that might be critical?

And that's always been the art of storytelling for me in this genre, is how to do that; how to push things to a point where you keep as many people in the room together without breaking the polity.

I will say in terms of post the book coming out, it's been interesting. I was in Europe last month where some of my colleagues thought that the chapter on personal genetics wasn't critical enough, and here back in the states I have people telling me that it's too critical. I think I must be doing something right this time. It's definitely generating - I definitely have put an argument

out there that is gaining attention.

[With] the *Nature* review, unfortunately, it felt like - I was accused of saying that I was arguing for the corporate corruption of science which is precisely what I was *not* doing, but these are things that happen. When a book is out in the world, you don't control how people make sense of it anymore. But it's certainly generating conversations.

Alondra Nelson

Yeah. For me - so my book has been out two years this month, actually. You know, I specifically, deliberately, wrote a book with a trade press, a mainstream press, because I felt that this was a topic that I wanted to be able to reach a wider audience.

Also - and Jenny experienced this as well - working on...my first book [was] on a historical topic, so I [didn't] actually publish anything really from that project until the book [came] out. But this book, you know, as quick as I can do the research, I'm being asked to speak about it and talk about it because it's this new emergent technology that many people are wanting to hear about.

So I had published peer review articles, book chapters, and an edited collection along the way, and I really wanted, having done that other work, to be able to try to - I felt like it offered the opportunity to also try to talk to a broader community about this. And I also thought I wanted to have a book that the genealogists, you know, the conventional and genetic genealogists that I spent so much time with could read and could feel that even if they didn't agree with the interpretation that it had some alignment with what they lived, and what I was describing.

So the reception has been - you know, I think that - it's been widely reviewed, I've been very happy with that, in both the popular press and in academic conversations. I think academics want it to be more academic, and the popular readers, I think, think some places are still too academic - I've gotten a few reactions from people that are just like, "I don't know what you're saying in these paragraphs", although I tried really hard to write really clearly.

I think as Jenny said, I guess you've got to be satisfied with being betwixt and between. But I do hope that I have brought into the public conversation - a lot of my work has been in this book, and the works that preceded it, have really been about the imprecisions, the negotiation, the sort of disorientation that comes with this testing, as opposed to the sort of surety that we're often - that's often reflected.

I've been happy to see over the last two years, hopefully in part because of the book, that the sort of public discourse about genetic ancestry testing is changing a little bit. You're more likely to see, I think, news accounts that are reflecting the sort of space of liminality and negotiation that these tests open up, instead of the kind of forward march into our certain identity. So I'd like to imagine that this book had some role in that, but who knows.

Katie Hasson

Great. So many interesting things to keep talking about, but right now we're going to pause for just a few minutes before bringing in questions and comments from everyone else.

For now I'd like to turn it over to CGS' Executive Director, Marcy Darnovsky.

Marcy Darnovsky

Katie, thank you, and Jenny and Alondra, thank you so much for your wonderful comments and your important work.

This is Marcy. I'm going to leave my camera off so you can see the slides that we want to share. As Katie mentioned before, we're audio transcribing for those on the phone, and those with vision impairments. A reminder: we invite you to participate in this Talking Biopolitics event via Twitter.

This slide shows the Twitter logo and next to it the word "Live-Tweeting" along with the hashtag we're using, which is "TalkingBiopolitics," all spelled out [in] one word.

Below that are the names and photos of our speakers, Alondra Nelson and Jenny Reardon, who you've just been listening to, along with pictures of their book covers: Alondra's *The Social Life of DNA: Race, Reparations and Reconciliation After the Genome*, and Jenny's book, *The Postgenomic Condition: Ethics, Justice and Knowledge After the Genome*.

I'll also take this moment to remind you that you can send questions using either that Q&A box on your screen, or the chat box on your screen. And in just a moment Jenny and Alondra will get to as many of them as they can.

The next slide is titled: "Recently on *Talking Biopolitics*", and displays the speakers in our previous *Talking Biopolitics* event. On the left is a photo of Shobita Parthasarathy; and on the right, a photo of Tania Simoncelli, and between them, in the background, is the cover of Shobita's book, *Patent Politics*, which was the focus of their conversation. The cover image is a closely-cropped photo of a cow with a yellow tag in its ear that says "Patent 0815." You can find a recording of this conversation, and actually a treasure-trove now of other Talking Biopolitics conversations, on the CGS website and on our YouTube Channel.

The next slide is headed "Coming up in March: Two Bay Area Film Screenings & Discussions", and I'm pleased to tell you about these events that are not online: we are going to be screening of the 1997 film *Gattaca*, followed by two different panels of speakers. The slide gives the dates and venues: "Tuesday, March 6th, at David Brower Center in Berkeley, and Thursday, March 8, at the San Francisco Main Public Library". The slide also shows, on the left, a publicity image of the film *Gattaca*. Below the title of the film is a picture with the faces of the three lead characters: Uma Thurman on the left, with her face divided by a double helix from the faces of Jude Law and Ethan Hawke.

The bottom of the slide says "Stay tuned for more details", and we will be sending out information about these events very soon.

The next slide says "Forthcoming in March", and this is an opportunity where I get to tell you that CGS has a book coming out, an anthology. This slide shows the book's cover: it has a

bright yellow background, and against it is the title: *Beyond Bioethics: Toward a New Biopolitics*; and also the names of the editors, Osagie K. Obasogie and me, Marcy Darnovsky. And, this is cut off, but the cover also shows the words "Foreword by Troy Duster, Afterword by Patricia J. Williams", and the image is a stylized double helix with about a dozen icons along its strands that represent some of the themes the book addresses. We are very fortunate to have a wonderful collection of contributors to this anthology, including Jenny Reardon.

This next slide is titled "About Us". It reads: "The Center for Genetics & Society is a nonprofit social justice organization that works to ensure an equitable future where human genetic and reproductive technologies benefit the common good". It also lists the values in which we ground our work toward a new biopolitics: social justice, human rights, ecological integrity, the common good, and democratic governance.

The final slide, entitled "Learn More About CGS", says "Follow CGS on Social Media". Below that are four hyperlinked words and their accompanying icons: first on the left for Twitter and Facebook, then an icon with an open envelope and a double helix over it and the words "Subscribe to CGS' Newsletter" – this is our free monthly newsletter.

And lastly, an icon that says "Support Our Work" with a dollar sign below it, and that's inviting you to help us continue what we're doing. At the bottom of the slide is the URL of CGS' website: www.geneticsandsociety.org.

Ok. That's it. Thank you very much for your attention to these announcements. And now we'll go back to Alondra and Jenny and Katie, and bring in your questions and comments into the conversation. So, all three of you, make sure your mics are unmuted and you're sharing your webcams.

Katie Hasson

Okay, let's just make sure we are all three back...wonderful.

Thanks so much everyone for excellent questions we've received. I'm not sure we'll get to all of them, but we'll try. I wanted to start with one about how much you consider the ways in which, Jenny and Alondra, you differ on issues of justice versus reconciliation. Alondra, you mentioned the 300 freed by the Innocence Project, but [the fact] that this comes in the context [of] mass incarceration sort of makes it a reconciliation project. So, "What are the limits of biopower in realizing social equality?" is one of the questions, and I also wanted to relate it back to what Jenny mentioned much earlier about the limits of liberal extensions in the way that we've approached making science do justice work.

Jenny Reardon

That's a great question. I'd love to have a much longer conversation with Alondra about how our conceptions in this field come together and maybe depart. The connections are much more obvious to me but I'm sure we would find differences if we were looking at different cases, so different things will come out in different places.

I do think that one of the important things that we hold in common is that what justice means is

going to be highly contested. It's not a simple project. Genomics is playing out in really different contexts and means really different things to different people. This relates to a question we're going to get to I think a little bit later, but I think one of the hard things for the scientists and the engineers, and maybe one of the differences between Alondra and I, is that I work probably more so with the scientists and engineers on a day-to-day kind of way, and Alondra was situated more with the genealogists.

But with the scientists and engineers I work with, there's a real desire to fix things, you know, to instrumentalize, have an instrumental approach to the justice problem. So this is where, you know, just wanting to instrumentalize what inclusion meant became part of the problem. So when they got to Tuskegee, Alabama, and they were trying to include people who didn't have healthcare, who didn't have a hospital in that community, it was hard for them to understand that people wouldn't want to be included because how were they going to access any of this if they didn't have basic healthcare to begin with?

I raised that - I think that's one of the most fundamental - if I were going to define the justice issues, one of the most fundamental justice issues is how can we be pushing forward these technologies when so many people don't have access to basic healthcare?

One of the things that scientists and engineers said to me, and the people who worked at NIH, who really cared about this - there were people at NIH who tried very hard to provide healthcare to the communities they were working with, individuals who did this, and they actually came through on one of those promises in one instance. But those are individuals working very hard, and working upstream against an institution that supports health *research*, not *healthcare*.

There was a recent article in *The New York Times* by Robert Pear at the beginning of the year, [about] how one thing that all our congressional folks, Republicans and Democrats, can come together behind is, "Yay, research! Yay, genomics research! Yay, stem cell research!", but no healthcare. So hooray for research, but no healthcare. This is something we need to address. And there are practical policy solutions to this. This is not just a "we can't possibly figure this out" [kind of situation]. We sequenced the human genome. We can figure out how to get healthcare to people. I think there has to be a will and a way to do that.

Sorry, I went off a little bit on a rant there, but this is a little bit about how I've been thinking about it, and some of the policy solutions I talk a little bit about at the end of the book. Should we, for example, have a tax on genomics research, and 5% goes towards healthcare? What are some of the things we can imagine in this space?

Alondra Nelson

I love it when you go off, Jenny. That's fantastic. That was great and right on.

For me, I think my conclusion, I think, is less positive. But I am interested in, as I said, the endeavoring towards justice. I end the book picking up from the 1970s, this Alvin Weinberg idea, or this word trans-scientific. And his suggestion, in 1972, that there are questions that science can't answer, or can't be posed to science, and they're called trans-science or

trans-scientific. So, he's writing at a moment where he's really trying to draw a line between science and politics, and obviously I'm using the word in a different way, because I assume these things are imbricated - I think a useful reminder there is that issues of justice are not technical issues. They are issues about ethics and morals.

So I'm interested in the endeavors of the reconciliation projects but at one point, somebody who I was working with on the book said, you know, "you're selling the no". Each case is not, like, a wildly successful end to how technology moves forward to adjust outcome. In some cases there's failure, you know, [like] in the reparations case, and in some cases it's much more inconclusive, even though it might be meaningful for people, individual and in communities.

So I guess - you know, Jenny has sort of said it all, but I guess I would just add, as an adjunct to this particular line of questioning or conversation, that we need to really be serious about - that genetics is not the domain in which justice occurs. And this is true as well of the Innocence Project. So genetics is being used there to right wrongs, but the sort of bigger impetus that we need are on issues that far exceed science and far exceed genetics.

Katie Hasson

I think this ties well to another question that's come in about whether it's possible to square the potential positive developments of these technologies and their potential to do good with the past history of eugenics, and the ableism that has been built into our past exploration of genomics. And I think that this question takes on a particular importance as we're moving towards the ability to not just collect and disseminate and interpret genomic data, but to start being able to alter people's genomes, alter the genomes of future generations with new gene editing tools.

So I wonder if you can address that - How do we square the legacies that are built into these technologies, and the potential they may have to do good?

Jenny Reardon

Well, I want to start by going back to something my colleague, Donna Haraway, and one of the great inspirers for me in this field, has often said, which is we need to inherit our past. In this domain, genomics attempts - one of the moves it made was to say "we're different from genetics, we're genomics. Eugenics is part of 'new genetics', and genomics is different". I think all of our work, Alondra and my work, all speak to the fact that the past is always pressing on the present. There are many pasts that we must learn to live with. We live in a country that's not very good at that. We're always forward-looking, progress. These are our goals, moving into the future. But one doesn't move into the future very well if one doesn't learn how to live with their past.

I think that's one of the real - I end the book in Berlin partly because I think that is a space in which I found there's much more space for living with the past, as painful as it has been. And I think it would behoove us to learn how to do that better, both in our country, but also in high-tech science and technology, which is very American. Its values are very liberal throughout the world, wherever you are. It values futuristic thinking.

So, I don't know, I'm not answering the "how to do that" [part] yet, but it's important to do that. And the book is partly an effort to tell stories that allow people to do that. So getting those different stories out there, as difficult as they might be to write and to hear, is part of it.

Alondra Nelson

I don't know that I have anything to add. [Laughter]

Katie Hasson

Well do you think that different questions of justice do emerge when we're talking about the power to alter Genomes, and not just the study of them?

Alondra Nelson

Sure, yeah. In part because the contextual piece that I mentioned earlier, sort of, you know, the altering of genomes is happening in laboratories with people of significant power, and the power to control not just the technological kind of manipulation, but also sort of how that's spins out and what it means in the world. And, of course, the sort of input increasingly will be elites who have the ability to sort of drive the agenda of who and what should or should not be edited variously.

I think there's also a bigger phenomenon, which is just the increasing...sort of glut of genetic data everywhere. That partly comes out of genetic ancestry testing, but the sort of more general, I think, move in which genetics is something out there, that lives outside of us, that can be variously read, reread and manipulated. So we might want to think about the gene editing piece in that sort of bigger terrain, which is also, you know, about some genetic direct-to-consumer testing companies making - using the genetic data for other purposes, people not really being able to have control over where that technology goes.

So the editing we could understand - it could be on a designer baby spectrum, but I think it also needs to be thought about on a spectrum of sort of just the glut and availability of DNA everywhere that's open to all the kinds of manipulation and transformation that people choose and opt into on the one hand, and on the other hand don't even know as being sort of used for research and manipulation.

Katie Hasson

Jenny, did you want to add anything?

Jenny Reardon: Oh, no. I think that what Alondra is saying about the many, many contexts, it's important to keep our eyes on all of that. There's a lot of stuff going on out there that's not making its way into the print, the way the stuff is being used. Ayo Wahlberg is actually going to be coming out with a new book on work in China, which I think is going to be very illuminating, in the spring. There's a lot going on right now, and there's definitely going to need to be a third generation, a fourth generation of work in this area.

Katie Hasson

One response to these issues has been a call for greater public participation, they need more engagement from the public. Scientists need to engage in the public in way that often get

interpreted as “scientists need to explain to people what they should think about it”. But I wonder if, drawing on your work, you have ideas about what new forms of meaningful public participation or engagement are possible - further generation work.

Jenny Reardon

Yeah, I mean this is really a crucial issue. When people critique me for the 23 and Me chapter, for being too sympathetic, one of the things I was trying to point out there is that the companies face the same problems and interpretation as anybody else. They're in there trying to solve the problems just like everyone else, but they also have become very important players in this space.

One thing that genomics did was it made this area of science into an area of science you could not participate in unless you had a lot of money, which meant that you *had* to have venture or capital in this space. It moved beyond the capacities of public government to fund - I mean *way* beyond the capacity of public government to fund. We've always had private funding in research, but this is a new order of private funding.

I currently sit in the hub of a lot of that, in Silicon Valley. Biomedicine meeting informatics, which is genomics' domain, is the new thing here, in terms of the bio-economy. So we're talking about billions of dollars at stake here, which is something we haven't talked about a lot today. There's the criminal justice system, and then there's the inequality. And I would have to say there's probably - when I think about justice in this moment from where I sit, those are what I would say my top two issues would be.

And on that inequality front, it is the growth of companies like Sales Force that is playing a major role in genomics these days – UCSF is partnering with Sales Force, I end my book there. How you work with customers is now the way that you work with consumers - or with patients, [so we are witnessing] the alignment of these fields. Which is not to say we're seeing corporate corruption of science - I don't think that's true. We're not seeing corporate corruption of science, although I sure do get nostalgic about CUDOS: communalism, universalism, disinterestedness, and organized skepticism, which we'll hail another political war to thinker Robert Merton. That's what got me interested in science, with that. As I begin the book, those moral norms of science are eroding quickly.

And that means that - and I'll end here quickly - that at the beginning of writing this book there were all of these democratic efforts to get people to participate, [but] at the end of it, you've got branding exercises that are happening. You've got billboards, branding exercises. People aren't even really trying to get people in a room anymore to talk to each other. I haven't told you how to solve that, but I'm giving you the picture of where I think we're at.

Alondra Nelson

I know we're short for time. For good and for not, direct-to-consumer genetics is kind of one of the ways of public engagement; in part because it gets - I saw this again and again in my work. You see it even in the troubling, wonderful, powerful work of Joan Donovan and Erin Karnovsky about the white nationalist use of papers that started coming out in August. It is a moment in which people start to think critically or seriously about genetics and their lives. And

it becomes, you know, this kind of threshold for people who haven't thought about genetics to think about it. So our options are to ask people, you know, to contact people at a community center and say: "we're going to give you a DNA 101 sort of presentation in the abstract, about the kind of abstract things" or we're going to say, you know, "I've had this experience with direct-to-consumer genetics and let's talk about it". Or, in the case of many of the folks that I talked to, there's been a real engagement with people engaged in their own kind of science literacy, in thinking about science and learning about it and the like.

So it's a very vexed space for all sorts of reasons: for technical reasons, for political reasons - but it's a space, a kind of entree for a lot of laypeople into thinking about genetics that at least allows you to talk to them about an issue that is less abstract and that they can care about. I mean, I don't know how we reach the public with conversations about genome-wide association studies or about exome analysis. I'm really not sure how to do that. Yeah, so I would just offer that as something to think about. I wouldn't offer it as a recommendation, but something that we have to wrestle with.

Katie Hasson

Great. Well, we've come to the end of the hour, so unfortunately, we need to wrap up, but I just want to say thank you so much, Alondra and Jenny, for this fascinating conversation, that could clearly go on for much, much longer. And thanks to all of you who sent in your questions and comments I'm sorry that we weren't able to get to all of them.

We would love to hear from you and ask that you please fill out the short survey that will follow this webinar. Thank you so much for joining us.