

University of Victoria School of Law Colloquium, February 20, 2017

DRAFT Chapter: Please do not circulate or reproduce without permission

Please forgive the incompleteness of this paper. As you will see, the first part of it is written as the afterword to a conference on critical theory and the health sciences, and is forthcoming in the *Boston University Journal of Law and Medicine*. This particular version, however, is a longer, still evolving, and very-much-to-be-reworked draft attempt at a chapter for my forthcoming book, *The Talking Helix*.

Breeding, Or The New Black: On Fashioning Genetic Brand

by Patricia J. Williams

This conference has asked us to take a critical look at the concept of race and its diverse applications in health sciences, medical research, empirical and data analytics, as well as social sciences. For all the apparent breadth of that mandate, there are three themes that have united our concerns.

First is the question of privatization--or claiming, naming and ownership. Any monetization of life forms, body parts, or the chemistry of our DNA always raises ethical concerns. Particularly as filtered through the lens of race, our unprecedented technological revolution in concert with the explosive industrialization of life sciences begs for careful attention to matters of relativized value, branding as exclusion, profit as extractive, data-mining as invasive, commodification as objectifying.

Second is the issue of what Dorothy Roberts referred to as punitive governance¹ and what Alexandra Stern called out as a problem of triumphalist master narratives.² This discussion imbricates forensic handling and uses of genetic material; and also how socially constructed hierarchies become superimposed upon ostensibly neutral biological terrain. Hubristic assumptions about intelligence, disability, contamination and eugenics can have serious legal consequence if they underwrite rules about criminal propensity, educational opportunity, or civil segregation.

Third is the complex unwieldiness of "race" itself: so reductively productive, contagious yet inert, intersectional yet exclusionary, plastic yet intractable, narrowly construed yet capaciously inscribed, magically invoked yet technologically layered, so unnaturally natural, so hypervisible, hidden and haunting.

¹ [https://www.law.upenn.edu/cf/faculty/roberts1/workingpapers/59UCLALRev1474\(2012\).pdf](https://www.law.upenn.edu/cf/faculty/roberts1/workingpapers/59UCLALRev1474(2012).pdf)

² Stern, *Eugenic Nation*,

Privatization

The _____, 20__ issue of The New Yorker Magazine was advertised on the stands with the big teaser “Can We Edit Our Genes”? And of course the answer is *why yes we can*, as never before, with unprecedented efficiency; and the magazine's cover tantalized with the promise that “it may lead to a new generation of cancer drugs.”³ But...the question really isn't whether we can edit our genes--that's not the problem. The real question is whether I can edit my children's genetic variants and whether this one over here can edit the genes of whole populations over there, and whether anyone with a basic knowledge of biology can change the heritable traits of future generations”?⁴

The problem with the question on The New Yorker cover was that it was framed as an individual consumer choice: an amorphous market of “we's” who want to get rid of bald pates and flat feet. Humankind desires to rid itself of cancers. Worried about Alzheimer's? Breast cancer? Parkinson's? Simply edit it out of your body and/or that of your children's children. Want strong bones? Resistance to heart disease? Oh snap. The process is so simple and low-cost, that, according to geneticist George Church, it's “going to get to the point where it's like you are doing the equivalent of cosmetic surgery.”⁵ [1]

From this perspective, it's simply a matter of plugging those assumed preferences, those private choices, those jobs to be done, those missions to be accomplished, into the options proffered by the automat of science, wait for the product to pop out--put a bow on top; it's genomic Yuletide.

While much of the quest for so-called “precision medicine” is being framed as inevitably beneficial, it signals a shift in ethical guidelines that is breathtakingly broad. As philosopher Nikolas Rose has observed, the very project of medicine seem to have shifted from a metric of health versus disease to one of ever-expanding “perfectibility” of the species itself.

A related concern is that public health organizations like the NIH, the FDA and the FTC seem increasingly aligned with organizations whose ethics are driven by proprietary interests rather than public health. The structure of labs in today's world means that individual researchers stand to make billions, through assays and patents. This is not to blame scientists: that's their job, their passion, as well as their profit. They will of course adhere to a model that renders “science” their god, and the mysteries of its unraveling as the highest good. Knowledge will be pure and will yearn to be “free” as well as “freed.” Nothing will go wrong because their intentions are pure. Don't you want to cure all human disease! We are not Nazis! We'll be careful!

3

⁴ is this really a quote? if so, where does this begin and end?

5

But the trouble with profit motive as an ethical framework for human health and heredity is that it deploys a risk-benefit analysis. It directs our gaze to the brand new! miraculous! happy making! potential of product rather than patient. Corporations are responsible to their stakeholders not to public interest. And if there are risks, they will be downplayed, as the lessons of lead or tobacco or coal companies should have taught us. Negative or unintended consequences are more likely to be passed over. And even where there are “miracle cures,” the benefits of that research will not necessarily be available without price. Where there is no plan for distributed benefit, we will have what we have: a system where “perfected” or socially preferred traits will be available only to the highest bidder—to narrow classes of stakeholder, defined by wealth or other privileged access.

The narrowing of ethical concern from human health to products that “fix” or “perfect” means that other aspects of market value drive the pursuit. What’s going on now is also a rat race to “beat out” others in the charge to the patent office, a lunge to own all parts of the genome, to close down the public commons in the bio-territory of the genome. Hence, much of this has an urgency to its framing that exploits our anxiety about mortality itself. Hurry up or you’ll die of an ugly disease! And do it so that “we” win the race—for everything’s a race. A race against time. A race to file patents. A race to market. A race to better babies, better boobs. There is never enough glory or gain, there is always the moving goal post.

Let me be clear: I am not anti- research (since it seems always necessary to say that). But the human body is a complex system, a biome within biomes. We are at the very beginning of our appreciation of its genetic as well as cellular, bacterial and viral complexity. We are still only beginning to understand the cascading effect that the stresses, starvations or traumas of one generation can transmit epigenetically to future generations.

From thalidomide to global warming, short-term risk-benefit analyses rather than long-term disinterested methodologies and controlled study have led us down paths of irretrievable harm. What we fail to imagine becomes “inconsequential,” swept under the rug as “side” effects, collateral damage, lessons learned rather than lives ruined. The post-World War II aversion to eugenics—that despite whatever variability from one human to another, no one life is worth more than another in the scheme of things—that caution has eroded. Never have we more needed thoughtful models of transparency, public discussion, and distributive justice.

The extreme privatization of medicine, pharmacology, and public health should give us pause in other regards as well. For example, the recently updated Common Rule, to be phased in by 2018, eliminates any requirement that federally funded researchers procure consent before being

able to exploit patients' tissue, blood, cells, or DNA.⁶ The rule also fails to address protocol for non-federally funded clinical trials. Efficiencies of cost-benefit emerge as the motivating rationale in the Common Rule's new configuration. The impact of cutting patients out of the loop is minimized quite glibly as merely dealing with "secondary analysis of data or biospecimens. Risks related to these types of research studies are largely informational, not physical; that is, harms could result primarily from the inappropriate disclosure of information and not from the research interventions themselves."⁷ But the degree to which the assets and wealth generated by the Human Genome Project may be swallowed up by profit-motivated structures ought to make us reflect upon lost opportunities: we will have missed an opportunity to correct the kinds of inequities that have long allowed certain bodies to be mined (like that of Henrietta Lacks), while others enjoy the expensive privilege of high-end medical consumerism (like those who can afford IVF or replacement parts in private organ exchanges). We seem to be making "health" a product to be purchased by the highest bidder, or turning it into a competition for an individually-chosen product rather than an artful delivery of human service. This eclipses the historical role of democratic government--and its complex negotiation of resource allocation and distributive justice.

Many, if not most, recent inventions, patents and venture capitalized, bio-prospected discoveries are unfolding within well-guarded, proprietary geographies. A framework of ultra-libertarianism generally concribes the work of research labs in government, commerce and universities alike. From James Watson to Ann Wojcicki to Peter Thiel, the distrust of public insight, accountability or regulation seems to have won the day. While the lack of collective oversight is justified variously as trade secret or return on investment or marketized wealth generation, at stake is a disregard for collective interest either in the form of universal insurance or in public health as a governmental interest....

Here's an example: Some time ago I attended a conference at which Anne Wojcicki, founder and CEO of the personal genomics company 23andMe, was a featured speaker. Even before she opened her mouth, the poster for the conference was powerfully suggestive of the values embedded in her talk. Her talk was entitled "Deleterious Me: Whole-Genome Sequencing, 23andMe, and the Crowd-Sourced Health Care Revolution." The poster depicted the double helix as a spiral staircase with little Lego-like people climbing upwards, ever upwards, toward a darkly glooming heaven.

⁶Federal Policy For The Protection of Human Subjects, <https://www.federalregister.gov/documents/2017/01/19/2017-01058/federal-policy-for-the-protection-of-human-subjects>
see also, "Scientists Needn't Get A Patient's Consent to Study Blood or DNA, NPR, January 18, 2017, <http://www.npr.org/sections/health-shots/2017/01/18/510442240/scientists-neednt-get-a-patients-consent-to-study-blood-or-dna>

⁷ Id, section 1A

These images too provide a very effective metaphor for our concerns about this entire subject, this industry, this bio-prospective enterprise. DNA is too often figured in the popular imagination as an inevitably uplifting stairway to heaven, an infallible path to higher truth doing the heavy lifting toward Utopia. This, in turn, leads to a credulous suspension of both ethics and caution.

Consider again the peculiar locution of Wojcicki's very title, "*Deleterious Me*." It posited the intimacy of "Me," the individual, as inherently self-destructive. It's an odd but very effective and increasingly ubiquitous recasting of mortality as autoimmunity. One's essence, the Me, is framed as noxious, diseased, and decaying. Health care and health, by contrast, are positioned on the other side of that colon, "*Whole-Genome Sequencing...and Crowd-Sourced Health Care Revolution*." They are located squarely in the geography of crowd as source. If the individual is framed as dangerous, lonely, and self-annihilating, its rescue lies in the comfort of crowds, safety in numbers, and collective shelter from the harmful Me. There is power in this conjoint set of idealized genetic references, a poignant longing for embodied self-perfection, yet fear and loathing of the assured self-betrayal.

There is something very nearly Shakespearian about the tension—tremulously human, mythically themed, with just a hint of hovering tragedy. Indeed the urgencies of our technological revolution beg for philosophizing our negotiation on some theatrical public stage, some Faustian oratorio where narrative and necromancy meet for a solemn duet. That's why I love performances in artwork. We need more of that as a unifying and creative expression for what is amorphous and needs to be shaped humanely.

In the twenty-first century, however, our greatest passion plays are placed in the realm of private contract rather than in public good or participative democracy. So it is that privately held companies like 23andMe can own, store, and re-sell to anyone the most elemental biological markers of individual identity while marketing themselves as direct-to-consumer purveyors of "personal self-knowledge."

The Center for Genetics and Society has written a statement entitled "Values for a New Biopolitics." Those values are social justice, human rights, the common good, a precautionary approach, and democratic governance. all of those values exist on the generous side of a moral spectrum. [flesh out] In law, we have a sort of moral hierarchy with narrow libertarian, contractarian values at one end of the spectrum, and broad considerations of how we behave towards one another as a society, values protected in our Constitution and embodied in human rights, on the other end.

Contract jurisprudence is styled as the realm of personal choice needing little regulation or oversight because self-interest will save the day. It is a jurisprudence that also imagines that the objects of contract exchange are things that are inanimate, fungible without feeling, industrial

without value other than what the parties to the contract choose to embody in the price for that thing.

But at the other end, constitutional jurisprudence looks at the duties of care we owe each other and to the common geography we share – with the culture that constitutes us, the constitutive values that cohere us as a society. Violations of constitutional rights are injuries to identity as a legal person, as a free subject whose citizenship is beyond price and sale, whose autonomy is inalienable rather than alienable. The remedy to these violations requires regulating or restoring political order, civic enfranchisement, and civil rights including revoking or amending laws.

In response to a question after her talk, Anne Wojcicki said that there is no difference between a customer, consumer, purchaser, and citizen. But there is. If we try to fight any of our battles on behalf of consumers, customers, and purchasers, we are instantly limited by a contract frame. We will already have acceded to a market model with the least moral stake in any kind of state regulation because consumers are contractors and contractors act alone. They are rugged individualists, they choose their fate with little discernible detriment or interaction with others.

So here's a caution about framing in all this: Legal and political actions styled as tort crimes, human rights, or constitutional law will tend to have a greater societal and therefore structural impact than those focused on contract. In order to recognize the human interest, the personhood of people, we need to root claims in language that invokes the values of citizenship and the values listed in that memo. I offer this as something to bear in mind as we go forward with either legal claims or political action at a moment when, in the United States as elsewhere, our ethical and social foundations are challenged daily and shifting rapidly.

Meanwhile, if any aspect of our collective health remains as a matter for address in the public sphere, it would seem to be in the context of population control rather than democratic exchange. As of March, 2017, the Centers for Disease Control (CDC) will have expanded emergency powers to quarantine people anywhere in the United States, without consulting local authorities⁸---just at a political moment when we are witnessing the reemergence of notions of ethnic contagion, vocabularies of religious virality, and panic about proximity and infestation. All this is occurring against the backdrop of the very real--empirical--possibility of actual pandemic, whether Zika or antibiotic-resistant tuberculosis. The incoherent policies resulting from such cognitive dissonance are exemplified by New York City's decision, in September of 2016, to spray anti-Zika and anti-West

⁸ "Control of Communicable Diseases, <https://www.federalregister.gov/documents/2017/01/19/2017-00615/control-of-communicable-diseases>
see also, "CDC Seeks Controversial New Quarantine Powers to Stop Outbreaks," NPR, February 2, 2017
<http://www.npr.org/sections/health-shots/2017/02/02/512678115/cdc-seeks-controversial-new-quarantine-powers-to-stop-outbreaks>

Nile insecticide by zipcode, and only in certain parts of the five boroughs—for example only in Manhattan’s Spanish-speaking neighborhoods above 137th street.⁹ The logic was that those were places where there might be people who had traveled to the Caribbean or South America or other areas where there were active mosquito infestations. But it was a logic based on an imaginary Maginot line, an obedient world ordered along such rigid contours of residential segregation that no one could imagine those mosquitos taking the train--or hopping a rat-- downtown. This is more than an investment in ignorance about science. It's one of the ideological consequences of privatized, contractarian thinking.

As I write, we are still in the early moments of the political upheaval that has followed the presidential election of 2016. While much remains unpredictable, the overall direction points toward a great deal of budget-slashing at institutions like like the FDA, CDC or the NIH. President Trump’s his choice of Dr. Tom Price, a free-market champion, to head the Department f Health and Human Services would seem to indicate less oversight across the board.¹⁰ Hence, one might predict that the so-called public-private exchanges of the Precision Medicine Initiative will become pretty much j just private. Whatever uncertainties haunting the Trump administration, there seems no lack of deference to unfettered corporate interest. With a majority-Republican congress apparently poised to eliminate nearly a century's worth of regulatory structures, large pharmaceutical companies, genomics conglomerates and a slew of venture capitalists stand ready to gain from the expiration of the notion of a common wealth.

If knowledgeable government investment in health science may be on the wane, popular mythologies of biologic determinism are not. Law professor Jonathan Kahn and biostatistician Jay Kaufman worry that we are thinking too narrowly when uninterrogated attributions in the name of "the numbers" or "the genes" become disproportionately authoritative--and where the finality of that authority is derived from imagistic factors, or blind faith in easy maxims like "math is power." One may worry too that it is not only that an amorphously decontextualized concept of "science" is becoming exclusive in its power, but that behind the curtain of exclusivity, individual researchers get to stake privatized claims and literally plant little colonial flags that re-impose social baggage on biological terrain that says nothing of the sort. Here I am thinking of ancestry tracking companies that use racial descriptors--and percentages thereof!--in the delivery of their results. Or population geneticists who speak of the "purity" of indigenous origin. The social and historical incoherence of whom we call--and who identifies as--"Hispanic" or "native American" or "Caucasian" is being rapidly reified by this process. It is the eugenicist's dream come true at last: we are making race biological.

⁹ "Mosquito Spraying Events," <http://www1.nyc.gov/site/doh/health/health-topics/west-nile-virus-spray.page>

¹⁰ "Trump's Health Secretary Pick Leaves Nation's Doctors Divided," https://www.nytimes.com/2016/12/26/us/tom-price-hhs-donald-trump-cabinet.html?_r=0

Rendering race genetic is not just a problem of carelessly reductive taxonomy; it is also an unexamined ritual of naming as owning--and owning frequently implies the hubris of assuming we know exactly how something works. And it is far too easy to think we know what race "does." Simply put, I wish we could label alleles and continental origins and haplotype grouping with the same kinds of non-specific designations we deploy when we are looking at the heavens. In ancient times, sailors would name what they saw after the stories they knew; the heavens with galloping horses and bears and hunters and heartbroken maidens and household objects like water dippers. In the same way, too many in labs are charting the human genome with the same romantic cluelessness. Since the invention of super-telescopes, however, we have had to approach the heavens with more awe. We know how much we do not know. We pause. We become inarticulate in the face of the sheer magnitude of celestial objects. That inarticulate humility marks a recognition that we have departed from the realm of the familiar. I think it would serve us well if we should bring that same sense of the unfamiliar to the infinitely combinatorial wonders of genetic cartography. By way of example, the International Astronomical Union has developed conventions of nomenclature, a systematized authority for assigning mostly numerical designation, mapped and catalogues by coordinates in the sky.

If only we had the same sense of unknowable scale, reverence for an unfolding ecology about which we are babes in the woods, pilgrims in the wilderness. We seem to be following the learned script of our near ancestors. We colonize and plant flags and plot geographies and build fences in the name of patents. We claim authorship of DNA texts, we pretend to own alleles as disconnected infobits whose chemical formations are the same as words, sentences, and speech. But that is a blindness precisely to the complexity as well as the simplicity of chemistry. Our spoken language, including that of race, is magical in its ability to teach us through the use of metaphor. But it is also reductive. It works only so far as we are dealing with qualities or quantities that can be analogized because known. But when we are mapping the still-unknown, when we are trying to describe that which had not been hitherto been seen, we would do well to hesitate before tagging new phenomena with the closest familiar handle. Race is a property assertion, a fantasy, an imaginative constitution. Just as family names signify associations, allegiances, marriages, borders to be asserted---but not necessarily biology--so too, religions, ethnicities, nationalities are metaphors with baggage, history, extra expectations.

In short, I wish we would number our discoveries, numbers being a nominally less familiar figuration, rather than give etymologically significant names to the patterns, the data sets, and the designs emerging from this marvelous technology. We are gazing at the universe. Let us not burden it with the divisions and boxes and geographies of not just the past but past wars.

Punitive Governance

Dorothy Roberts has raised "punitive governance" as a problem in a number of forensic contexts, particularly the law's ability to privilege, encode and enforce social inequalities ascribed to biological difference: her presentation featured an article describing the effect of MAOA in young men that flattened the topic to one of "aggression" being "in the genes" of gang members. Along with a highly evocative illustration of a row of young Hispanic men handcuffed in front of a line of police dressed in military gear, one is left with the affective or subliminal implication that they are immutably prone to violence, and thus felony disenfranchisement is perfectly reasonable. We know how such careless tropes work: we know how welfare mothers' wombs, figured as dangerous factories of social parasites and inferior product, have been subjected to forced sterilization; and antimiscegenation laws have been rationalized as perfectly justifiable.

I think punitive governance is a helpful term because it implies a certain kind of ritualized exclusion from civic space. It evokes the Roman law concept of *civilter mortuus*, or civil death. Ritual exclusions, in turn, require liturgy and repetition. That's why Alexandra Stern's exploration of "triumphalist master narratives" seems particularly interesting to consider alongside, or as a feature of, those rituals of civil death.

Consider: It is practically a mantra to recite that we live in a nation with the highest number of prisoners on the planet. With 2.2 million (not counting juveniles or immigrant detentions), we have twice the number of prisoners as China, the next closest--and nearly six times the rate, given an overall population of 322 million as compared to China's 1.4 billion. We normalize that extraordinary state as the necessary product of controlling crime. But with numbers like these, perhaps the abstract category of "crime" is not really the point. We Americans seem to have gone a step further in actually naturalizing carcerality as rational sacrifice, the unpleasant but necessary cull of ritualized gill-net fishing for certain shapes and types of bodies, all to ensure that they remain outside the aesthetic realm of civic existence.

Furthermore, racial embodiment and mental health are two of the most indicative metrics of who will end up behind bars in our society. There are lots of social factors why that may be so--Dorothy Roberts' and ____'s presentations reminded us of a long history that dates back to slavery's contortions, to Galton, Cartwright, and Davenport--but however familiar that history, we are nevertheless facing newly calibrated biologized states of exception. We don't need biology to invent difference or to ghettoize, but with technologies like CRISPR(cas)9, which enables quick and easy recombination and editing of genes--including the human germ line¹¹--we certainly are at a threshold

¹¹ <https://en.wikipedia.org/wiki/CRISPR>

where the risk is higher than ever before of merging the social and biological by "breeding" different sets of humanity and divvying them up into denationalized or denaturalized states of statelessness.

Critical race theory is one lens through which to examine lived experiences with new and old states of exception. How are some people deemed less worthy of the protections of due process, pushed into conditions of eternal emergency, and made the objects of control rather than shared communion? How has race become an actual signifier of displacement from the law? Indeed, anyone who is beyond the pale becomes *per se* "raced" in American ideology, in the same way that African Americans historically have been. Until 9/11, for example, Muslim immigrants from the Middle East and South Asia were largely considered "model minorities" in the United States. In an astonishing short period of time that status has changed--beginning with the USA Patriot Act and culminating in Donald Trump's executive order attempting to ban refugees from seven mostly-Muslim countries. Muslims everywhere have been criminalized with a very broad brush, bestialized and demonized with pluralizing stereotypes that are used to justify detention, quarantine and dehumanization.

Critical race theory is an analytic tool with which to study the ethical, legal and cultural implications of our technologically evolving world. To novel degree, the mining and assortment of our biological data--whether by CODIS, Facebook, or 23andMe--will make all of us ever more disembodied and displaced from the law. Our information is a disembodied asset. We have entered an era when we are subject to and subjugated by "economies of vitality," as philosophers like Michel Foucault and Nikolas Rose have called it: biotech, biovalue, biocapital, bioeconomies of accumulation and trade across contexts, species, geography. And the proprietors of this new information are packaging our pieces, our parts, our proclivities and our potentialities in ways that are pretty heedless of the lessons of history.

Genomic and phenomic profiles are now being aggregated with what we eat, how we dress, what we read, watch, where we work, play, whom we love, double-cross or betray--all conceivable sorts of data are aligned into new systems of social credit, aggregated into bio-profiles and predictive models of not just who needs what, but who is "worth it."

That question of worth: that's key. All this data could tell us how to improve our health, how to connect with family, and how to feed the poor, rescue the helpless and educate according to specific needs. But instead both national and global policies are too often framed in terms of who or what is worth "it." That question of worth is relentlessly situated with the structure of contract rather than constitution; by investment ethics rather than common good; by extractive colonial regard reemerging as libertarianism, and reasserted as the security of protecting "one's" interests rather than public interest. This unnecessarily narrow hierarchy of competitively individualized

worth distracts us from urgent ecological concerns. It blinds us to broader earth ethics that might address our shared planetary inheritance of ecological degradation, population displacement, global diaspora and wars over water, clean air and arable land.

Instead, our best--and worst--efforts at human uplift seem disproportionately concentrated upon germ line manipulation, eugenics as "cosmetic choice," and general technological heedlessness to unintended consequence in the rush to commodify life forms. We are on the cusp of being able to create race, to subdivide our species, and to manufacture race--if not as understood in present cultural terms, then something very much like it. I predict that "new! better!" racialized traits will have brand names. (Does it not seem ever more conceivable that the Ivanka Trump line of jeans may soon be switched out for the homophonic resonance of "genes"?) I'm being only half facetious: As Alexandra Minna Stern observes, the alt-right has been eyeing this potential for quite a long time. With the power of the presidency and the NSA behind them, identitarian nationalists are likely to become only more prominent players in defining and deregulating ethical limits. Platforms like Breitbart are already known for their brilliant deploys of communication and data collection and collation. Non-fact becomes fact. Why wouldn't we think that we will see the same sort of ethical quandary applied to genomic research?

More seriously, there is a logic even in the generation of non-fact, alt-fact or counter-fact. Jay Kaufman has observed that certain statistical models sometimes appear to be so entirely hypothetical that they disconnect from documented, real-world conditions on the ground.¹² Yet on closer examination, some of those modeled assessments turn out to be well-fashioned in at least one aspect: the results prove what their funders wanted the world to look like. By design, they follow the money, in other words. But they also perpetuate a kind of profit in disembodiment.

Triumphalist master narratives thrive upon that kind of disembodiment and the romance of disengagement from mortal temporal constraints. They manipulate time, speak to the affective, transport with images of freedom, liberation, immortality. They merge a sense of siege with deliverance from danger; they exceed the body and are carried forward in time and over time. Racial identity becomes a game of thrones. Genetic escape becomes the ladder upwards and out, a purificatory myth. And myth becomes more powerful than the empirical--for it is theological, faith-based, and resistant to rationality.

In the papers for this conference, Terence Keel and [Moya? Ruha? Chandra? can't read my own notes!] have spoken about race as a verb. Race is active, in other words, an activity through which biopower is manipulated to revive the past or protect the future. The power of race as verb is that it motivates with hauntings about what could happen, not what is. That's why facts don't matter. It's

¹² Kaufman's piece on epidemiology and negative controls

why books like Charles Murray's *Bell Curve* or Nicholas Wade's *A Troublesome Inheritance* are persuasive to some--they couldn't and didn't say that race is biological. They said *it could be*. James Watson did the same thing when he said he was pretty sure we will find African inferiority--not that there is any science or data to that effect. In the film *Race: The Power of Illusion*, to which Amani Nuru-Jete referred in her presentation, our colleague Evelyn Higginbotham is featured speaking about the eternal search for the Holy Grail of biological race: the supposed extra black leg muscle, the enormous penis, the distinctive brain pan--the elusively unique black "thing" that ought and must be found to explain "the difference" between "them" and "us."

So race not just a verb or a tense. It is also a mood--the subjunctive mood, the could, should, would--the mood of faith and *schadenfreude*, of fear and disease and affective disorder. In our culture, the regulation of race is also about the legislation of fear, the capture of the unspoken, the mimed not merely the implicit.

Intersectional Complexity

Race is challenging always. As social construct, it is layered, tangled, confused, contradictory, playing words and images against one another. It rationalizes the irrational. The linguistic genealogy of racism often manages to defeat both the humanity and the science of public health because it rides in on what Alexandra Stern called a coded lexicon, appealing to the unconscious with signifiers of aggrieved redemption. Let me return to Dorothy Roberts' commentary on the picture that showed of a row of tattoo'd, bare-chested young Hispanic men kneeling in front of a row of police in full robo-cop gear--and used to illustrate an article entitled "Gang-banging may be genetic." The caption, conveying a flat, non-empirical association between danger and genes--is upsetting and wrong all by itself. But it is the pairing of those words with an intimidating image that adds in the emphatic bottom line of preemptive quarantine by militarized police force.

In an overwhelmingly digitized world, the haunting effect of images speaking under, through, past, and often more powerfully than words is a phenomenon that we must learn to decipher. The powerful work of subliminal suggestion through the interplay of the seen and the spoken must be part of our work as critical theorists., another aspect of intersectionality as a critical lens. In the increasingly complex interfaces of identity and biotechnology, we will have to grapple not only with the way one might be socially constructed as black and female and Buddhist and poly-lingual and unemployed but also: how one might exist as an assemblage of genetic specimen and mammalian creature within a poisoned ecosystem, as well as digitized creation whose image circulates in that new extruder of social imagination, the brutally abstracting dream machine that is cyberspace or Instagram or Facebook or Breitbart.

This is not a new phenomenon--D.W. Griffith's *Birth of a Nation* was a technologically-enhanced, powerfully-propagandistic mash-up of racist narrative married to racist visuals. But the issue has particular urgency given the unregulated/free market-driven possibilities for human germ-line experimentation--for *heritable* alterations proffered by cheap, simple technologies like CRISPR/cas9, the infinitely varied power of whose cascading, intergenerational, unintended consequence has not begun to be taken seriously at any level by local, national or international public policy or law.

This failure is made even more invisible because couched--and hidden--among generally uninterrogated narratives of romantic self-improvement, as "positive" rather than negative eugenics. This is a cause for worry in the framing of a broad spectrum of new technologies, not just DNA. For example, the website of Ancestry.com or 23andMe greets one with narratives about how genetic information has transformed lives. Discovery of "who I really am." Communities of people who have the same ability to smell asparagus in urine, so they get married because they are just tickled that they have so much in common. The ads on these sites sell sameness, or quanta of Kumbaya, or universal brotherhood and we are the world-ism.

And they also sell difference: I never felt like I belonged, now I know why—*I'm not who I thought I was*. Adoptees who find their biological relations proclaim that they feel found, rescued, complete. People with lactose intolerance know to avoid milk now, and they owe it all to the miracles of a spit sample. They pursue the promised pathways to Health. Happiness. Royal roots. Indeed, the company I think of as Notorious BGI—the Beijing Genomics Institute--advertises itself in precisely those terms. If you haven't seen Bregtke van der Haak's documentary film, "DNA Dreams," about BGI (available on YouTube or Vimeo), I highly recommend it. It's about the material resources being expended, globally, upon utopian visions of "curing" just about every social misery through genetic manipulation. Disease, hunger, stupidity, will be edited out of the genome according to the soaring ambition of some techno-ideologues; whilst harmony, musicality and soaring intellectualism will become the new norm, all just by transplanting our mitochondria, editing our nuclei, enhancing our chemistry. The visuals of the film alone speak volumes: set mainly against the dystopic, concrete jungle that is Beijing, China, the landscape in and out of the lab is grey with bureaucratic heaviness and the ash of atmospheric pollution, testament to the anthropocene era's other crises of ecological short-sightedness, of hubris, and of overweening human error.

Of course if you believe that complex traits like intelligence or sociality or political disposition are entirely reducible to immutable genetic functions of memory and executive function, it'll be hard for me to dissuade you here. And surely our global media culture continues to play a frantic game of whack-a-mole, pressing what they hope will be the magic "genetic button" for x, y, or z trait and flip that switch to perfect health, self-control and immortality. Welcome to Oz.

But if you worry that epigenetics factors like education or diet or or stress or starvation or race or stress in the womb or other environmental factors—like kindness or cruelty—have at least equal claim upon our life prospects, then we must also take a look at societal and environmental factors begging for our collective attention, as citizens not consumers, as constitutional subjects not merely free agents, as guardians of humanity not merely hamsters in lab coats in a rat race for the next genetic gold mine.

The National Institutes of Health's "precision medicine" initiative promises "to leverage genomics, informatics, and health information technology to accelerate biomedical discoveries." Again, the panel overseeing the project includes not only academic researchers but representatives of insurance companies, corporations like Intel and Google, the Defense Department, and a healthy array of venture investment. The stated goal is the creation of a "national research cohort of about 1 million people, whose biological data, as well as environmental, lifestyle and behavioral information" is to be shared with researchers. Most of that cohort has come from anyone who's ever sent in a spit sample to direct-to-consumer kits or ancestry-tracking kits to companies like 23andMe, particularly those who've participated in the chat-room conversations hosted by such companies in order to mine your lifestyle choices. If so, you agreed to having your data used for research and development, whether you remember providing specific consent or not. Not that anyone reads the intricate online terms of service for much of anything anymore, but building data sets for experimentation and pharmaceutical development has always been the real wealth generator for such companies.

So taking spit samples is revealed as a backdoor marketplace, not a warm fuzzy community of chatting haplotype chums. Cure will come in the form of Big Data and associations across global population fields. Cure will come if only and only if the FDA approves of predictive associations between certain markers and disease risk.

But again, my concern is that that enormous industry is not generally what purchasers of such kits understand when they buy those kits; and the degree to which they consent to become human research subjects is pretty invisible to most people. The degree to which the data they actually *pay* to hand over has value—that it is an asset for which they are being vastly undercompensated, is generally not understood. 23andMe has amassed its million samples or so—from people the majority of whom have, again, participated out of altruism and curiosity and desire for some kind of romantic connection to sharing and learning to be healthy, and the satisfaction of knowing one's destiny. I'm not the first to compare what's going on to what happened with the immortal cells of Henrietta Lacks. Or the colonization of Manhattan in exchange for some relatively worthless beads and baubles.

Then there's patent law, which not only puts a price on hoarding rather than sharing scientific knowledge, it constrains our ethical consideration. With patenting, you compete to own knowledge so that some processes of genetic manipulation and alteration are effectively rendered indistinguishable from owning the genes themselves; and when we think of that chemistry, those building blocks as "our genes" because they're our discoveries, then "we" can freely change because we own them. They become conceptually no different from ball bearings, their manipulation is isolated not only from the biomes in which they exist but the moral, social and public health ramifications that are written out of our vocabulary.

In a way, this also writes out the messy realm of human governance—of law, ethics, social norms. It gives a peculiarly independent life to protein chains and enzymes. They become righted—sort of like personhood amendments do to blastogenesis. They yearn to be liberated. They are waiting to be harnessed. They have agency and will and destinies of their own. They're tapping their putatively perfect little feet in great impatience. Anyone who would stand in the way of that promise, that pregnancy of progress, that utopian explosion, is probably anti-science, anti-rationalist—a denialist. In fact, "Denialism" is the title of a book written by Michael Specter in 2008? [Make clear: Specter, the author of the *New Yorker* article.] Specter was a fan of the marketization and the FDA's erstwhile approval of Bidal, a cardiac drug falsely advertised as having race-specific properties, and eventually taken off the market. He believes along with pundits like Dr. Sally Satel, of the Manhattan Institute, that race is a "good-enough" proxy for genetic dispositions. And if you don't agree, you're a politically correct science-denialist.....

One finds that carelessness, that tolerance for flawed proxies, that Polyanna-ish acceptance of risks of error throughout the literature about CRISPR, including in The New Yorker piece: The prospect of designer babies is "unlikely" Specter says. "Nobody is going to employ CRISPR technology to design a baby, let alone transform the genetic profile of humanity anytime soon..." He seems to agree with George Church's highly controversial conviction that what is done can be undone with no problem; this contention often passes without critique, even though it is a form of non-consensual human experimentation with future generations that violates every ethical protocol ever created: from the Hippocratic oath (a broad injunction to intrude narrowly and do no harm); to individual duties of care as between doctor/researcher and subject); to institutions (as in IRB overviews of proper protocol to guard against bias, exploitation, conflict of interest, pain or abuse); to the transnational (as in the Helsinki Accord or the Geneva Conventions).

The language of "fixing" and the dream of "correction" is pressed relentlessly throughout The New Yorker piece—I lost count of the number of times those words were used. Yet nowhere in the article could I find even one use of the word "eugenics" nor any reference to not just the vexed history, but its present reality, in either the US or in the global context. It is astonishing that an

article about so-called improvement of so-called flaws by editing the human germ line did not once at least give a little nod to the narratives of hubris.

Philosopher Kristin Ross has written that “the keeping of two stories apart” is “another name for forgetting one of the stories or for relegating it to a different time frame.”¹³ Anthropologist Ann Stoler goes further: “...forgetting and amnesia are misleading terms...Aphasia is perhaps a more apt term,” in that such cultural disconnect affects the ability to comprehend, and to put words and ideas together in meaningful ways.¹⁴

Anyone who thinks an ugly form of eugenics is not a clear and present danger today—I mean before we get to the question of heritability, anyone who things otherwise needs to look at the advertising literature of sperm banks, and the general trade in popular yearnings for tall, blond, Aryan prototypes.

I teach a class in Human Identity, Justice and The Scientific Revolution. When we study the significance of DNA, I begin by asking my students to draw what it means to them. It is such a free-floating signifier, such a fluid cipher, such a field of dreams: I like to just start by getting it all out there. And no matter what the background of my students—and they are very interdisciplinary—whether they have PhD’s biology or not—Few draw a double helix, or a molecular compound. Nearly all draw very fanciful pictures filled with romantic aspiration. A Harvard Beanie, a perfect seed, a golden key; or my favorite, a glowing book in a little glass box, located just behind the thorax.

There is a mythic cultural imaginary we project onto this technology. There is an economic imaginary, a geographical imaginary, and most dangerously, a racial and ethnic imaginary, that has no necessary relation to actual histories of migration. And it defies training or background. Let me give you an example of what I mean: recently I attended a conference on forensic pharmacology: One doctor gave a meticulous and eloquent presentation about what is missing in terms of good research knowledge before there can be appropriately titrated medical uses of marijuana. Yet when asked about the rumors of another drug that supposedly works more effectively among “Hispanic” populations--again, what on earth does that mean?--she said, oh yeah, she’d heard that and went on to discuss, with absolutely none of the exactitude, the precision that she’d brought to the earlier topic. She clearly knew what makes for a good clinical trial and the precision required. But many of the labels, the words, the vocabulary we use in our raced social world go under our best cognitive radar. We don’t hear it, we don’t interrogate, it we are taught to naturalize it, we are taught to look past it and through it because it is uncomfortable and taboo and incoherent. But it is precisely that

13

14

incoherence that we risk writing back onto the genome if we use those words to demarcate and pathologize actual allelic formations.

The concept of autonomy is central to American—and most Western-- juridical and political constructs of democracy. As largely-invisible data aggregators amass evidence of our every purchase, movement and heart beat, our identity as unique individuals will become subsumed to the much greater emphasis placed on our relation to some spectrum of actuarial expectation. Increasingly we will be advertised to, deflected from, assessed for criminality, disease probability or financial risk, assigned emotional valence, assorted, tagged, boxed, confined. A few years ago, there was a kerfuffle in Mexico over the use of neuroscience to monitor the response of constituents to presidential candidates' rhetoric and gestural language, complete with American political advisors to help—which should tell us something about how much American elections are being informed by biometric evaluation of sweat, heart-rate, blood pressure, pupil dilation, and brain waves. Pair this with genetic information and it's not your father's eugenic fantasy anymore.

On top of this, the ancestry community or other genetic haplotype chat rooms or social media networks have not really lived up to the promise of replacing traditional intra-personas communities. Sociologist Alondra Nelson, in her book *The Social Life of DNA*, has documented the degree to which some forms of essentialized genetic identity are emerging instead as forces that fragment human engagement as much as they cohere. Along with global media monopolies, genetic information is too often used to herd erstwhile polities into imaginary "teams" and embattled formations of hype, tabloidization, disinformation and fear.

All these forces conspire to create a world and a citizenry of fewer and fewer upwardly mobile "speaking subjects." Instead we become locked into a shell-like status fixed by carelessly-composed data sets, as well as un-interrogated correlations made by invisible bureaucrats. Without oversight or due process, it will be harder and harder to challenge, never mind find out why, we came to be labeled "a this" rather than "a that." A flight risk or a cancer risk? A quick learner or a big spender?...Like it or not, willingly or not, these are the identity groupings by which we will be judged and from which we will struggle vainly to escape.

However reductive, these markers of our identity are valuable as intellectual property; they become monetized nuggets in the "knowledge economy"—little lego pieces of data used to construct the avatars and facsimiles that stand in for us in a world repositioned as efficiently heuristic rather than participatorily democratic. Genes, cells, fingerprints, blood or isolated phenotypes become "immortal" ciphers, or fixed character properties. Governments, pharmaceutical companies, and, yes, Google, attribute to particularized pieces of ourselves a separate life that engulfs or becomes more important than our complex embodied selves.

Law professor Jessie Allen, who authors the blog “Blackstone Weekly,”¹⁵ a contemporary take on 18th century English jurist William Blackstone, observes that what is happening now might be very similar, as a conceptual matter, to the beginnings of the corporation. In his “Commentaries on The Laws of England,” Blackstone described early entrepreneurs’ concern with the basic limits of their own humanity: People die. That’s bad for business. The invention of the corporation effectively created an immortal legal subject, untethered to human frailty. That immortality is, in effect, a way of extruding from particular bodies a use value that can be assigned to the ether of a legal fiction—a fiction that “speaks” through articles of incorporation, and whose profit may be divvied up among distant, abstract shareholders.

There is a similar process of dispossession in the mining of our habits, our bodies, our preferences and dispositions. It’s framed as “not about us,” at least as individuals—even though it may be used to powerfully confine us as individuals, can be used to mark us even as it can rarely be claimed by us.. It’s rather about one’s group, one’s place, one’s purportedly “anonymized” metrics.

The reconfiguration of the righted subject into what is effectively instantiation of the person *as corporation* has two implications for how privacy is perceived. First, the value of the individual is rewritten as alienable rather than inalienable, as cost-benefit, profit-motivated and value-added. (This explains, I suppose, the conversation I overheard among a group of high school students on the subway, busily working on a homework assignment in which they had been asked to “brand” themselves, to give that brand a catchy name, and to sell that brand in no more than five sentences, because with more than five sentences “you lose your audience.”)

Second, corporatized people don’t need healing; and indeed the rules of corporate law bend away from the idea of justice as individually remedial or personally restorative. A corporate being looks to the law not for civil rights but for the predictive, the risk-minimizing, the future-controlling immortality of guaranteed return. Through that lens, any legal system based on consent, or on individual cases and controversies begins to look cumbersome in comparison to the speedy efficiency of stochastic models.

I began by framing the issue as one of privacy, in particular genetic privacy; let me place that concern against the cultural backdrop of our general, if radically rosy, technophilic faith in the inevitable good of what genetic information will divulge. This is a remarkable moment, surely, with technology transforming human relations as profoundly as did the printing press. Technology is progressing so rapidly and sweepingly that it is almost impossible not to allow the imagination free reign, to push past what the science actually reveals. It is hard to resist romanticizing its possibility,

¹⁵ blackstoneweekly.wordpress.com

as enhancement beyond all known history. We are headed towards an era of superhumans, mechanical *Urbarmenschen*.! We cannot fail! Throw out the old! Bring on the bionics!

But I remain intrigued by that notion of neoliberalism as pushing humans into corporatized boxes and those boxes as ciphers for the ancient hubris of sought immortality--the immortality of a figurative body; the desired, even the consented-to crafting of a fictional, controllable or ideal mechanism that can be cobbled together from pieces and parts. But I do not believe in immortality. There is only the intimately creative integrity of an embodied self. If we fail to nurture that generative space, of which privacy is the guardian, we put distance between heart and head, and our flourishing becomes unmoored from any investment in the self that is not situated in a global market place of invisible, soul-crushing number crunchers. As Rabbi Abraham Joshua Heschel observed, the challenge is really “to know what we see rather than see what we know.”

Conclusion

In the United States, we think of ourselves as “inalienably righted.” Yet when race, gender, disability, criminality and class are exploited for the lowest common denominator, and played against one another with the speed and sophistication as they have been in our cyber-culture, the supposedly neutral citadels of science, and ultimately public health writ large, are surely not immune. Furthermore, there is a pronounced tension between contract’s sloshy alienations and the Constitutional right to have rights. A rather silo-ed, consumerist set of mind is pervasive in our culture. But such a mindset is an inadequate and ultimately hubristic stance when sitting on the brink of a technological revolution permitting ever-greater “efficiencies” of transformative body alteration, “designer babies,” and germ line (or heritable) modification. This points to our work going forward: we must begin to excavate the ethical, legal and social implications of our incautious yet far-reaching proprietary exploitations--of traits, of reproduction, of identity, and of citizenship. We must begin to have some thoughtful normative account of whether and to what degree incoherent pockets of private profitability and fears of biologized securitization will continue to map the collective face of our nation, or even the fate of our species.