WEBVTT

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AUDIO: Recording in progress.

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Hmm.

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SANDRA SOO-JIN LEE: Well, happy new year,

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Well, Happy New Year! Everyone. I am Sandra Sujin Lee, and I'm delighted to welcome you to our January Lc. Friday.

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everyone. I am Sandra Soo-Jin Lee, and I'm

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Forum, entitled Wrestling with Social and Behavioral Genomics.

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delighted to welcome you to our January ELSI

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Friday Forum, entitled Wrestling with Social

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and Behavioral Genomics. The Forum is hosted by the Center for ELSI Resources and Analysis and held on the 2nd Friday of every month for one hour starting at 12noon Eastern time. We also have a Zoom room reserved for more informal discussion immediately after the panel for 30 minutes.

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This forum is hosted by the center for Lc resources and analysis, and held on the second Friday of every month for 1 h, starting at 12 noon Eastern time.

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We also have a zoom room reserve for more formal discussion immediately, after the panel for 30 min, and we'll be dropping a link in the chat to direct you to that.

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And we'll be dropping a link in the chat

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to direct you to that Zoom room.

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For those of you who might be new to the

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Center for ELSI Resources and Analysis, or

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CERA, we provide resources to support research

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on the ethical, legal, and social implications

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of genetics and genomics, and aim to connect

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Zoom room for those of you who might be new to the center for Lc resources and analysis, or Sarah, we provide resource to support research on the ethical, legal, and social implications of genetics and genomics and AIM to connect scholars, scientists policymakers journalists members of the

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scholars, scientists, policy-makers,

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journalists, members of the public, and others

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to engage ELSI issues. The CERA is funded by

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the National Human Genomic Research Institute,

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Public, and others to engage Lc. Issues. The Sera is funded by the national Human Genome Research Institute at Nih.

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NIH, and is managed by teams at Stanford and

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Columbia Universities in partnership with the

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And is managed by teams at Stanford and Columbia Universities in partnership with the Hasting Center and Harvard University.

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Hastings Center and Harvard University.

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I encourage you to visit CERA's online

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I encourage you to visit Sarah's online platform.

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platform, ELSIhub.org, for the recording and

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transcript of this forum and related

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references that we will be providing throughout

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Lc. Hub. Org for the recording and transcript of this form, and related references that we will, providing throughout the session.

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the session.

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Please use the link in the chat to access

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Please use the link in the chat to access the new Lc.

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the new ELSIhub Collection entitled Genomics of

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Education in Education: ELSI Concerns about

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Hub Collection, entitled Genomics of Education in Education, Lc.

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Genomic Prediction in Educational Settings,

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Concerns about genomic prediction and educational settings, curated by Lucas Matthews, and Natalie White.

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curated by Lucas Matthews and Natalie White.

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This reading list explores the practical

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utility of polygenic scores in educational

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This reading list explores the practical utility of polygenic scores and educational settings.

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settings, the perspectives of parents and

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teachers on genomics in the classroom, and

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The perspectives of parents and teachers on genomics. In the classroom and potential harms.

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potential harms.

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I also invite you to go to the website to join the Lc.

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I also invite you to go to the website to

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join the ELSI Directory, um, the scholarly

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directory, sign -- and sign up for newsletters

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and other events like this one at ELSIhub.org.

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Directory, the Scholarly Directory site, and sign up for newsletters and other events like this one at Lchub Org.

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You can get daily updates and news on our

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You can get daily updates and use on our twitter.

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Twitter.

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Ah, so just some quick housekeeping

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information. If you wish to use closed

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captioning, please turn on the CC, uh, button

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So just some quick housekeeping information. If you wish to use closed captioning, please turn on the CC.

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at the bottom of your screen. Please note that

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panelists' presentations today will be very

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brief in order to conserve a significant

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Button at the bottom of your screen. Please note that panelists presentations today will be very brief in order to conserve a significant portion of our time and discussion.

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portion of our time in discussion. Please use

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your Q&A button, which you will find at the

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bottom of your screen, to write in questions

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for the panelists at any point during the

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session. You can register your enthusiasm for

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a question and elevate it up the list by using

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Please use your Q. And a button, which you will find at the bottom of your screen to write in questions for the panelists at any point during the session you can register your enthusiasm for a question, and elevated up the list by using the upvote button in the q a

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the upvote button in the Q&A box. And the chat

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Box and the chat box, of course, is available for further engagement.

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box, of course, is available for further

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engagement. We will post links to resources

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We will post links to resources, referenced in today's discussion there as well.

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referenced in today's discussion there as well.

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If at any time you have questions, please

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If@anytimeyouhavequestionspleaseemailinfoatlchub.org.

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e-mail info@ELSIhub.org.

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So now it's my distinct pleasure to

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So now it's my distinct pleasure to introduce our moderators for the form today.

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introduce our moderators for the forum today.

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Michele Meyer is an associate professor at

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Geisinger and chair of the Department of

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Bioethics and Decision Sciences at Geisinger,

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where in addition to engaging in normative

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scholarship, she investigates judgments and

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Michelle Meyer is an associate professor at Geysinger and Chair of the Department of Bioethics and Decisions Sciences at Geyser, where, in addition to engaging in normative scholarships, she invests judgments and decision-making related to health science and technology, Eric parents is a

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decision-making related to health, science, and

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technology. Erik Parens is a senior research

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Senior Research scholar at the Hastings Center.

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scholar at the Hastings Center. Eric has

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published many distinguished volumes on

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questions of emerging technologies and is a

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Eric has published many distinguished volumes on conceptual and normative questions of emerging technologies, and is a leading expert in bioethics on sociogenomics.

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leading expert in bioethics on sociogenomics.

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I could say more about Michele and Eric's

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I could say more about Michelle and Eric's backgrounds, and how lucky we are to have them today moderating this important topic.

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backgrounds and how lucky we are to have them

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today moderating this important topic. I

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encourage you to look up their bios through the

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links in the chat. But for the sake of time,

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I encourage you to look up their bios through the links in the chat, but for the sake of time I'm going to now hand it over to Eric

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I'm going to now hand it over to Erik.

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Thank you so much, Sandra. It's a pleasure to be here with you and everybody else today.

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ERIK PARENS: Thank you so much, Sandra.

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It's a pleasure to be here with you and

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everybody else today. First slide, please.

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So, sometimes my work at the Hastings

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Center is about... wrestling with a complicated

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First slide, please. So sometimes my work at the Hastings Center is about wrestling with a complicated and hard problem.

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and hard problem. So, for example, in the

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1990s, I co-led a project on prenatal testing

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and disability rights. And our purpose was to

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think, at once, about... the disability

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community's critique of selective abortion?

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So, for example, in the 1,900 and Ninetys I co- led a project on prenatal testing and disagree rights, and our purpose was to think at once about the disability Communities Critique of selective abortion and at the same time about pregnant people's

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AND, at the same time, about pregnant people's

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abortion rights. By contrast, in 2022, some of

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my colleagues and I just finished a project

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that did NOT entail wrestling with what we took

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Abortion, rights by contrast, in 2,022, some of my colleagues and I just finished a project that did not entail wrestling with what we took to be a complicated and hard problem.

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to be a complicated and hard problem. Rather,

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our project called The Art of Flourishing,

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colon: Conversations on Disability, was for the

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Rather our project called The Art of Flourishing Colon Conversations on Disability, was for the sake of broadcasting, a clear and distinct idea.

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sake of broadcasting a clear and distinct

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idea -- the idea that contrary to the

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imaginings of many people who currently live

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without a disability, people WITH disabilities

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The idea that, contrary to the imaginings of many people who currently live without any disability, people with disabilities can and do flourish

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can and do flourish.

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So, contrary to the impression that some

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of you MIGHT have gotten from SOME advertising

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of today's event? The project we're here to

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talk about today is NOT broadcasting any clear

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So contract to the impression that some of you might have gotten from some advertising of today's event the project we're here to talk about today is not broadcasting any clear and distinct idea.

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and distinct idea. Rather, the project we're

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Rather the project we're here to talk about today is all about wrestling

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here to talk about today is all ABOUT...

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Indeed, it's title is wrestling with social and behavioral genomics.

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wrestling. Indeed, its title IS: Wrestling

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with Social and Behavioral Genomics: Risks,

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Potential Benefits, and Ethical Responsibility.

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And, I offer our sincerest thanks to the

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Risks, potential benefits and ethical responsibility, and I offer our sincere thanks to the funders listed on the slide next slide.

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funders listed on the slide. Next slide,

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Please.

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please.

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So Sandra Lee, Daphne, Marchenko, and Paul Applebound joined Michelle.

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Meyer and me to form a steering committee for the project.

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So, Sandra Lee, Daphne Martschencko, and

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Michele Meyer joined me on the project. We

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We were joined by 14 other highly diverse scientists and scholars to form our 19 Member working group.

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were joined by other highly distinguished

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scholars to form our 19-member working group.

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I hope you can read the wonderful list of names distinguished.

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I hope you can read the wonderful list of name.

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Distinguished are they ALL. If all goes

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according to plan, this coming Tuesday, our

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working group will submit the final version of

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our project report to the Hastings Center

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Report, and that project report will appear in

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Are they all? If all goes according to plan this coming Tuesday, our working group will submit the final version of our project report to the Hasting Center report, and that project report will appear in a special issue of the march.

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a special issue of the March/April HCR. (ding)

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April. Hcr. That special issue of the Hcr.

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That special issue of the HCR will also include

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an essay about our experience creating a

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Will also include an essay about our experience creating a community sounding board for the project.

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community sounding board for the project.

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So, with the term social and behavioral

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genomics, SBG, we are referring to the efforts

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of social and behavioral scientists to

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collaborate with geneticists or to adapt the

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methods OF genetics research to investigate how

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genomics differences are associated with

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So with the term social and behavioral genetic spg, we are referring to the efforts of social behavioral scientists to collaborate with geneticists or to adapt the methods of genetics research to investigate how genomic differences are associated with differences, in social and behavioral phenotypes

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different social and behavioral phenotypes.

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The huge range of phenotypes investigated by

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SBG researchers has included schizophrenia,

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smoking and eating behavior, sense of

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wellbeing, introversion, risk-taking

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preferences, income, intelligence, and, indeed,

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The huge range of phenotypes investigated by Sbg researchers has included schizophrenia, smoking and eating behavior, sense of well-being, introversion, risk-taking preferences income intelligence and indeed, educational attainment the term we've already heard today

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educational attainment, a term you've already

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heard today.

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So, as everyone in this virtual room knows

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very well, research claiming to shed light on

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phenotypes as complex as intelligence and

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educational attainment has a VERY long history,

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which stretches back at least as far as the

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So, as everyone in this virtual room knows very well, research claiming to shed light on phenotypes as complex as intelligence and educational attainment, has a very long history which stretches back at the least as far as the Father of the term Eugenics Francis Galton

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father of the term "eugenics," Francis Galton.

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On the other hand, when, for example, the

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National Institute on Aging funds genomic

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research to explore the relationship between

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Alzheimer's disease and educational attainment,

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it does so in the belief that such research

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CAN, ultimately, help to shed light on that

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disease.

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On the other hand, when, for example, the National Institute, on Aging Funds, Genomic research to explore the relationship between alphabet's disease and education attainment, it does so in the belief that such research can ultimately help to shed light on that disease so the thesis of today's

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So the thesis of today's webinar, and the

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thesis that we take more than 35,000 words to

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webinar and the thesis that we take more than 35,000 words to defend in our forthcoming report.

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defend in our forthcoming report...! Our

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thesis is that social and behavioral genomics

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research warrants wrestling WITH. That is: We

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organizers of today's webinar do NOT think it

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is sufficient, for ELSI scholars or anybody

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else, to simply dismiss this line of research

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Our thesis is that social and behavioral genomics, research warrants, wrestling with, that is, we organizers of today's webinar do not think it is sufficient for Lc scholars or anybody else to simply dismiss this line of research as pseudoscience or as

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as pseudoscience or as old poison in new

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bottles, NOR do we think it is sufficient for

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SBG researchers, or anybody else, to ignore our

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historical and social context OR to make

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extravagant claims about the potential benefits

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old poison in new bottles. Nor do we think it is sufficient for Sbg researchers or anybody else to ignore our historical and social context or to make extravagant claims about the potential benefits of such research like personalized education is in the office

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of such research -- like "personalized

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education is in the offing."

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Our first speaker today. Benjamin Neil is coming.

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Our first speaker today, Benjamin Neale,

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is codirector of the program at medical and

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population genetics at the Broad Institute and

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Director of the Program and Medical employment genetics at the Broad Institute and as director of Genetics at the Stanley Center for Psychiatric research.

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is Director of Genetics at the Stanley Center

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Our second featured speaker, Evelyn Hammond is the Barbara Gutman Rosenkranz, Professor of the History of Science and Professor of Act in an African-american Studies at Harvard University, and is former Dean of Harvard College.

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for Psychiatric Research. Our second speaker, Professor Evelynn Hammonds is the Barbara Gutmann Rosenkrantz Professor of the History of Science, Professor of African and African American Studies in the Faculty of Arts and Sciences and Professor of Social and Behavioral Sciences at the Harvard T.H. Chan School of Public Health at Harvard University. .

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the wonderful thing about having had the past

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three years to wrestle with the hard issues

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raised by SBG research is that the members of

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our working group have had enough time to

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actually practice talking WITH, as opposed to

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The wonderful thing about having had the past 3 years to wrestle with the hard and complicated issues raised by Sbg research that the members of our working group have had enough time to actually practice talking with as opposed to talking past each other.

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talking PAST, each other. Although the

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disciplinary differences between Evelynn and

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Ben, for example, are rather large, as we will

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see, the substantive differences between them

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may be smaller than you might imagine -- and

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Although the disciplinary differences between Evelyn and Ben, for example, are rather large, as you will see, the substantive differences between them may be smaller than you might imagine, and smaller than they, and Michelle and I might have imagined when we started.

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smaller than they and Michele and I might have

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imagined when we started our project more than

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Our project more than 3 years ago.

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three years ago.

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So with that, I will turn it over to you,

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So with that I will turn it over to you, Ben.

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Ben.

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Thank you, Eric, and thank you to the Lc.

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BENJAMIN NEALE: Thank you, Erik. And

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thank you to the ELSI forum for hosting this

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event. I thought, you know, just to get us

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started and to sort of frame the conversation,

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and mindful of the... a few things. One, that

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this is an audience primarily focused on

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ethical, legal, social issues associated with

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Form for hosting this event, I I thought, you know, just to get us started into sort of frame the conversation, and mindful of the a few things one, that this is an audience primarily focused on ethical legal social issues associated with research, and also mindful of the fact that genomics is a

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research. And also mindful of the fact that

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genomics as a discipline is... rapidly

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discipline is rapidly evolving and continuing to rapidly evolve and change.

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evolving? And continuing to rapidly evolve,

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and change, and is very dynamic? I thought it

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was worthwhile to focus at least the opening

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remarks on where the science is, a sort of

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brief overview of some of the things that are

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happening in the research space, and some of

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And is very dynamic. I thought it was worthwhile to focus at least the opening remarks on where the science is a sort of brief overview of some of the things that are happening in the research space, and some of the potential benefits.

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the potential benefits, but also challenges,

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when confronting research in extremely complex

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But also challenges when confronting research in extremely complex and socially kind of related traits.

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and socially... um, kind of related traits.

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So without further ado, I'll just start

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with a few conflicts of interest, for

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So without further ado, I'll just start with a few conflicts of interest for disclosures.

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disclosures. Most of this work is a

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consequence of the genetics, ah... of

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schizophrenia work that I pursue quite doggedly

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in most of my time. And I'll talk about

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Most of this work is a consequence of the genetics of schizophrenia work that I pursue quite doggedly, and in most of my time and I'll talk about schizophrenia today.

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schizophrenia today, but obviously social and

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behavioral genetics and genomics is, is much

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broader than just questions around mental

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But obviously social and behavioral generations and genomics is, is much broader than just questions around mental illness and things like schizophrenia.

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illness and things like schizophrenia.

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So whenever talking about... these issues,

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and talking to a general audience, and thinking

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about questions around understanding traits,

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So whenever talking about these issues and talking to a general audience and thinking about questions around understanding traits, understanding creates more more generally.

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understanding traits more generally, I often

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start with this paper from 19895 from Jet Brose

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that was communicated in the Journal of

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Epidemiology, which is where I caught site of

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sight of

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it. And there are a number of ideas in this

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I often start with this paper from 1985 from Jeff rose that George David Smith, from communicated in the International Journal of Epidemiology, which is where I caught sight of it, and there are a number of ideas in this paper that are extremely important but I think this this figure figure

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paper that I think are extremely important.

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But I think this figure, Figure 2, is actually

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2 is, is actually quite a powerful figure in its own. So what what we have in figure 2.

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quite a powerful figure in its own right. So

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So so Jeffrey is a epidemiologist, so not not working on genetics per se.

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what we have -- so, he's an epidemiologist, not

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working on genetics per se, but genetics does

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But genetics does crop up at least a little bit in the discussion around this paper.

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crop up a little bit in the discussion around

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this paper. There's a sample that they've

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collected of individuals from London that are

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civil servants. And here you see on the x-axis

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the systolic blood pressure. You know, kind of

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So there's a sample that they've collected of individuals from London that are civil servants and here you see on the X-axis the systolic blood pressure, you know, kind of guidelines are 1 20 is what you're aiming for for the systolic blood pressure to

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guidelines are 120 is what you're aiming for,

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for the systolic blood pressure, to get a

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diagnosis of like hypertension or elevated

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Get, a diagnosis of like hypertension, or elevated blood pressure that 120 line is about the kind of crossover point.

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blood pressure; that 120 line is about the kind

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of crossover point. And you see there's a

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distribution of individuals that are London

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civil servants, and then a distribution of

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individuals that are Kenyan nomads. And that's

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And you see the there's a distribution of blood pressures for individuals that are London civil servants, and then a distribution of blood pressures for individuals that are Kenyan nomads, and that's all that's kind of presented here.

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all that's kind of presented here. And... you

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know. There are likely a number of dimensions!

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Among which individuals that are Kenyan nomads

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are quite different from individuals who are

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London civil servants. And that induces -- or

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at least, shows us, at least from the sampling

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And you know there are likely a number of dimensions among which individuals that are Kenyan nomads are quite different from individuals who are London civil servants, and that induces, or at least shows, us at least from the sampling point of view that there are huge mean differences in these

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point of view, that there are huge mean

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differences in these distributions. But at the

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same time, the distributions themselves

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overlap. And there is no ability for us to

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tell you which of all of the things that are

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different, between the group of individuals

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that are Kenyan nomads and the group of

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individuals that are London civil servants,

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distributions, but at the same time the distributions themselves overlap, and there is no ability for us to tell you which of all of the things that are different between the group of individuals that are Kenyan nomads and the group of individuals that are London still servants that are giving rise to this difference

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that are giving rise to this difference in

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systolic blood pressure. This is... assuredly

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in systolic blood pressure. This is, I assuredly environmentally mediated in one way or another could be. Diet.

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environmental mediated, in one way or another.

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Could be diet; could be stress; could be

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alcohol; could be any number of exposures or

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Could be. Stress could be alcohol could be any number of exposures or other phenomenon it could.

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other phenomenon. It could be genetics, at

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some level! We just don't know. And I think

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the reason that I like this slide so much is

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that it shows that a lot of the traits that we

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The genetics at some level. We just don't know, and I think the reason that I like this slide so much is that it shows that a lot of the traits that we study even traits in medicine that aren't.

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study, even traits in medicine that aren't...

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you know, these kind of social and behavioral

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You know this kind of social and behavioral traits that we're gonna spend most of today talking about.

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traits that we're gonna spend most of today

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talking about, it is very hard to figure out

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where these kinds of mean differences come

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from, and it is very challenging to make strong

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claims about those things. And that we...

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should NOT, in a sense, make a simple

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It is very hard to figure out where these kinds of mean differences come from, and it is very challenging to make strong claims about those things, and that we should not in a sense, make a simple explanation from, what is an apparent data phenomenon.

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explanation from what is an apparent data

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phenomenon; we should strive to understand what

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the sources of those differences are, and

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understand what is going on in the trait.

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And from my OWN point of view, I believe

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that genetics and genomic research can -- help?

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It will not answer ALL of the questions, but it

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We should strive to understand what the sources of those differences are, and understand what is going on in in the trade, and from my own point of view, I believe that genetics and genomic research can help it will not answer all of the questions, but it, can help understand and identify not only some of

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can help understand and identify not only some

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of the underlying biological aspects that may

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shape these distributions within each of those

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environments, but it may ALSO, potentially,

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provide us some ability to -- at least...

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sharpen our understanding about what

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environmental exposures could be a potential

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source! Of this apparent mean difference in

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traits.

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The underlying biological aspects that may shape these distributions within each of those environments, but it may also potentially provide us some of ability to at least sharpen our understanding about what environmental exposures could be a potential source of this apparent mean difference in in traits so just just always important

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So, just -- just always important to

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remember that every complex trait geneticist...

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To remember that every complex, straight geneticist understands that the environment matters, the environment is dynamic.

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understands that the environment matters, the

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environment is dynamic, it is changing, it is

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difficult to study. It does not mean that we

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should not study it? But it is not something

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that -- you know. But there's also like, in a

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sense, a century of observational epidemiology,

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150 years-plus of observational epidemiology,

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Is changing. It is difficult to study. It does not mean that we should not study it, but it is not something that you know, but there's also like, in a sense, a century of observational epidemiology, 150 years plus of observational epidemiology trying to establish some

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trying to establish some understanding about

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what environmental exposures matter.

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And, the other thing that I think is, you

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know, probably one of the key distinctions

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between the environment and inherited

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genetics... is that the inherited genetics are

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Understanding about what environmental exposures matter and the other thing that I think is, you know, probably one of the key distinctions between the environment and inherited genetics is that the inherited genetics are fixed at birth.

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fixed at birth. So it is a consistent exposure

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So it is a consistent exposure over life, and that that property is useful.

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over life. And that -- that property... is

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useful. But it is obviously not the only

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story. And we'll get into some examples of why

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I think that matters and how that operates in

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But it is obviously not the only story, and we'll get into some examples of why I think that matters, and how that operates in that way.

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that way.

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So over the course of the last 20 years or

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so, we have, on the genomic science side, moved

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from mapping and sequencing the human genome,

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creating a human genome reference, to efforts

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to systematically characterizing what common

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genetic variation exists in humans in general,

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So over the course of the last 20 years or so we've on the genomic science side moved from mapping and sequencing the human genome, creating a human genome reference to efforts to systematically characterizing what common genetic variation exists in humans in general to the development of

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to the development of technologies that either

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study all -- you know... enough common variants

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to get a pretty comprehensive picture of what

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Technologies that either study all you know enough common variants to get a pretty comprehensive picture of what common variation is operating within an individual.

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common variation is operating within an

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individual, what common variation an individual

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carries. And now with the emergence and rise

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of sequencing technologies, maybe a kind of

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systematic investigation of ALL genetic

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What common variation in individual carries. And now, with the emergence and rise of sequencing technologies, maybe a kind of systematic investment of all genetic variation.

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variation. So we are now in a position -- so,

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20 years ago, it cost us, as a society, a

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billion dollars plus to sequence a genome.

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Right now, we can sequence a genome for maybe

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So we are now in a position. So 20 years ago, it cost us as a society a 1 billion dollars plus to sequence the gene right now, we can sequence the genome from maybe somewhere in the neighborhood of $500 a $1,000 depends on volume.

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somewhere in the neighborhood of $500, 1,000.

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Depends on volume and a bunch of other things.

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But quite a number of orders of reduction in

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our ability to just collect the sequence of

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bases that everyone carries upfront.

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And, indeed, that kind of variation that

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you carry is a reflection of the variation that

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And a bunch of other things, but quite a few orders of magnitude and reduction in our ability to just collect the sequence of bases that everyone carries upfront, and indeed, that kind of variation that you carry is a reference of the variation that you're parents carried and that the

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your parents carried. And that variation they

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carry is a reflection of the variation their

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Variation they carry is a reflection of the variation their parents carried.

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parents carried. And indeed, we have this

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global human family tree! And this lovely

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And indeed, we have this global human family tree and this lovely paper from Brenna hen and colleagues, in Pn. A. S.

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paper from Brenda Henn and colleagues in PNAS

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in 2012, you know, talks about the migration

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patterns of humans as a species across the

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globe. And through that migration, and that

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series of different -- what we refer to as

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bottlenecks in population genetics, and other

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In 2,012, you know, talks about the migration patterns of humans as a species across the globe, and through that migration and that series of different what we've referred to as bottlenecks and population genetics and other forces that shape the genetic variation.

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forces that shape the genetic variation you

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carry, it's a reflection of the variation that

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your ancestors have carried. And that, that

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genetic variation... that is carried by

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You carry because it's a reflection of the variation that you are ancestors have carried, and that that genetic variation that is carried by different people is reflected in their human history.

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different people, is reflected in their human

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history, and there's a relationship between

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your own personal history and your variation

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that you carry. And that actually gives rise

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And there's a relation between your own personal history and your variation that you carry, and that actually gives rise to the ability to make some admittedly uncertain.

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to the ability to make some -- admittedly

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uncertain? But some, inferences about our

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story... as a species more generally.

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So, the idea that who your ancestors are

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But some inferences about our story as a species more generally so, the idea that who you are an ancestors are shapes.

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shapes what genetic variation you have is very

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important and very powerful, because who your

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ancestors are also correlates with a lot of

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other things. And that causes a lot of

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challenges in the interpretation of what

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genetic variation is doing.

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What genetic variation you have is very important and very powerful, because who your ancestors are, also correlates with a lot of other things, and that causes a lot of challenges in the interpretation of what genetic variation is doing with the emergence of gwasts those sniff chips that I

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With the emergence of GWAS, those chips

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that I was talking about, the colleagues in

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2008 took a component analysis focused on

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individuals for whom... you know. Their most

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Was talking about John November, and colleagues in 2,008 took principal component analysis focused on individuals for whom you know their most recent ancestors were from a specific part of Europe, and then plot.

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recent ancestors were from a specific part of

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Europe. And then plot the genetic patterns of

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variation against those... kinds of

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The genetic patterns of genetic variation against those kinds of individuals.

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individuals. And again! This reinforces this

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notion that there is some kind of relationship

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between who your ancestors are and what

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And again. This reinforces this notion that there is some kind of relationship between who' your ancestors are, and what variation you carry, and who your ancestors are.

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variation you carry. And who your ancestors

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are, they're not randomly scattered across the

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world necessarily; they may be concentrated in

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certain places. And so there's some kind of

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They're not randomly scattered across the world necessarily they may be concentrated in certain places and so there's some kind of correlation between where your ancestors were living.

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correlation between where your ancestors were

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living, what variation they carry because of

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What variation they carry because of where they are in the human family tree.

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where they are in the human family tree.

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Now, those aspects of genetic ancestry are

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Now those aspects of genetic ancestry are a source of very you know.

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a source of variation -- you know. They're a

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source of variability in what genetic variation

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They're a source of variability in what genetic variation you carry.

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you carry. And that is very important to

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control for in the context of studying complex

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traits like, say, schizophrenia. So here is a

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picture of genome-wide association analysis,

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systematic evaluation of pretty much every

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common genetic variant, tested one by one

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And that is very important to control. For in the context of studying complex traits like, say, schizophrenia, so here is a picture of genome-wide association analysis, systematic about evaluation, of pretty much every common genetic variant tested one by one across the genome to ask whether it is more common

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across the genome, to ask whether it is more

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common amongst individuals that have

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Amongst individuals that have schizophrenia versus not.

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schizophrenia versus... not. And, you know,

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these sample sizes are now getting to the kind

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of tens of thousands, maybe hundreds of

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thousands of individuals, or samples from

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individuals, along those lines. And the

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overriding story that we see for schizophrenia,

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And you know these sample sizes are now getting to the kind of tens of thousands, maybe hundreds of thousands of individuals or samples from individuals along those lines, and the overwriting story that we see for schizophrenia, and for many other traits and I'll talk about a few others

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and for many other traits -- and I'll talk

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about a few others in a moment -- is that the

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In in a moment is that the underlying genetic architecture is complex.

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underlying genetic architecture is complex.

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There are lots and lots of small genetic

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effects -- so, having a specific genetic

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variant means that you're on average slightly

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more likely to have schizophrenia or not. That

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There are lots and lots of small genetic effects. So having a specific genetic variant into the year, on average, slightly more likely to have schizophrenia or not, that is the test that we are doing.

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is the test that we are doing. And we see

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many, many, many regions across the genome.

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And that actually, I think, reinforces our

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notion of the biological complexity of the

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And we see many, many, many regions across the genome, and that actually I think, reinforces our notion of the biological complexity of the underlying traits that we're trying to understand.

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underlying traits that we're trying to

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understand and interpret.

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And interpret with the emergence of sequencing technologies.

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With the emergence of sequencing

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technologies, we can now go further down the

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We can now go further down the Allele frequency spectrum.

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allele frequency spectrum. So look at rarer

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and rarer genetic variation. Potentially even

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variation that is newly arising, that maybe

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So look at rarer and rare genetic variation, potentially even variation that is newly arising, that maybe neither of your parents have.

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neither of your parents have, but you yourself

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But you yourself carry a new genetic variant, because mutation happens, and that's one of the force, you know.

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carry a new genetic variant. 'Cause mutation

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happens, and that's one of the forces -- you

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know, that's one of the processes by which

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That's one of the processes by which genetic variation entries into the population.

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genetic variation enters into the population.

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We've got, you know, emerging genes, emerging

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associations, coming across... for complex

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outcomes like schizophrenia, and in some

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We've got, you know, emerging genes, emerging associations coming across for complex outcomes like schizophrenia, and in some instances some of these rare variants have very strong effect sizes.

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instances some of these rare variants have very

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strong effect sizes, maybe effect sizes of 10

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or 20 or even 50. So maybe a fifty-fifty shot

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that you develop schizophrenia, versus a 1%

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Maybe effect sizes of 10 or 20, or even 50, so maybe a 50, 50 shot that you develop schizophrenia versus a 1% chance of schizophrenia, more generally in in the population.

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chance of schizophrenia more generally in the

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population. These are clues to some aspect of

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the biology. They are not a comprehensive

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answer to everything that we are interested in

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These are clues to some aspect of the biology. They are not a comprehensive answer to everything that we are interested in understanding.

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understanding.

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Now, schizophrenia is where I spend a lot

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of my time, but there are a number of social

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and societally-shaped traits that are under

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study using similar approaches and

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technologies. Systematic collection of genetic

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variation and asking the question whether

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Now this schizophrenia is where I spend a lot of time, but there are a number of social and societally shaped traits that are under study using similar approaches and technologies systematic collection of genetic variation and asking the question whether certain genetic variants are more common amongst

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certain genetic variants are more common

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amongst individuals that either present with a

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given outcome or are slightly higher or lower

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Individuals, that either present, with a given outcome or slightly higher or lower, on some kind of quantitative trait like educational attainment, that you've heard about earlier.

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on some kind of trait, like educational

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attainment that you heard about earlier.

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There's also work on things like income, or

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efforts that I participated in looking at the

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question of same-sex sexual behavior! Which --

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I mean personally, as a gay man, matters to me?

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But also, I think, was amongst the most public

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There is also work on things like income or efforts that I participated in looking at the question of same sexual behavior which I mean personally, as a gay man matters to me, but also I think was amongst the most public interest pieces of work I have ever engaged in throughout my entire career.

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interest pieces of work I have EVER engaged in

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throughout my entire career.

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So, you know, these questions are

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So you know, these questions are difficult to grapple with, and they're they're difficult to get simple answers to.

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difficult to grapple with, and they're

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difficult to get simple answers to. And

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indeed, I would say that the overriding message

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from the genetics is that, yeah, that

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complexity that you think is there? It's

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certainly there from a biological genetic point

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of view. That there are lots and lots of

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And indeed, I would say that the overriding message from the genetics is that, yeah, that complexity that you think is there it's certainly there, from a biological, genetic point of view that there are lots and lots of effects going on and it is a very very very complicated landscape.

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effects going on, and it is a very, very, very

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complicated landscape that we're trying to help

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That we're trying to help facilitate interpretation of

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facilitate interpretation of.

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Two main downstream purposes of genetics

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2 main downstream purposes of genetics that I think people talk about regularly.

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that I think people talk about regularly. One

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is that kind of personalized education that, or

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One, that kind of personalized education that we're precision education, that Eric was mentioning in the kind of polygenic risk or way.

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precision education, that Erik was mentioning

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in the kind of polygenic risk score way, and

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I'll talk about how polygenic risk scores are

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made. But the other is trying to understand

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And I'll talk about how polygenic risk scores are made, but the other is trying to understand biology, trying to understand how these phenomena come to be.

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biology! Trying to understand how these

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phenomena come to be. And, you know. A

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genetic association, being associated to a

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specific genetic variant, does not specify what

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the mechanism by which that genetic association

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is operating. And a very good, concrete

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example of that is looking at the GWAS of lung

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And you know, a genetic association being associated to a specific genetic variant does not specify what the mechanism by which that genetic association is operating, and a very good concrete example of that is looking at the G Wash of lung cancer so here we've got the same sort of

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cancer. So here we've got the same sort of

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systematic test, common variants across the

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Systematic test. Common variance across the genome. This region, on 15 q.

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25. If you go and look at a G.

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genome. This region of 15q25? If you go and

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look at a GWAS of how heavy smoking behavior is

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Woss, of how heavy smoking behavior is in an individual, how many cigarettes per day they consume.

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in an individual, how many cigarettes per day

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they consume? That same region of the genome

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strongly associated to lung cancer is strongly

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associated to cigarettes per day, phenotype.

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That's same region of the genome that is associated to lung cancer is strongly associated to cigarettes per day as a female type, and that, you know now, kind of suggests a clear mechanism of action whereby you have a genetic variant that changes your body's metabolism.

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And that suggests a mechanism of action! You

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have a genetic variant that changes your body's

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metabolism of nicotine. The way you metabolize

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nicotine changes the degree to which you are

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likely or not to get addicted to nicotine. And

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if you are more addicted to nicotine and smoke

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Of nicotine, the way you metabolize nicotine changes the degree to which you are likely or not to get addicted to nicotine, and if you are more addicted to nicotine, and you smoke, more that is more exposure of something that is clearly a oncogenic

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Phenomenon. It is a process by which lung cancer is occurring.

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more, that is clearly more exposure to an

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oncogenic phenomenon, a process by which cancer

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And so here we have an environmental exposure driving a genetic association on lung cancer that is being mediated through a behavior that the individual is engaging in.

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is occurring. So here we have it mediated

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through a behavior that the individual is

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Okay, that is what I mean by mechanism can be complicated.

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engaging in. Okay? That is what I mean by

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mechanism can be complicated. And in reality,

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this is among the simplest examples! In so far

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as we have a clear idea of what may actually be

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going on. I don't think we're there for many

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And in reality this is amongst the simplest examples, insofar as we have a reasonably clear idea of what may actually be going on, I don't think we're there for many of the other complex traits that we are looking at, and indeed there are low sigh in the kind of lung

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of the other complex traits we're looking at --

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cancer landscape, that are potentially mediated through other exposures that we don't really appreciate or understand or interpret.

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and indeed, there are things potentially

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mediated by other exposures that we don't

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understand or interpret at this point in time,

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either.

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At this point in time, either. So here's our little hypothesis, causal kind of path of what the genetic effect is doing, how that then translates.

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So here's our hypothesized kind of path of

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what the genetic effect is doing, how that

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translates. And obviously, if there was no

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smoking -- if the efforts to ban cigarettes

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altogether were effective -- that would

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potentially take this association off the table

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And obviously, if there was no smoking, so if the efforts to ban, you know, cigarettes altogether were effective, then that would potentially take this association off the table if that's the only mechanism by which this genetic variant is operating just to close on what a

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if that's the only mechanism by this genetic

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variant is operating.

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Just to close on what a polygenic risk

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Polygenic risk score is so taking the common genetic variant association, study, so G.

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score IS. So taking the common genomic

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Wass on the left-hand side, comparing case control.

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association study, GWAS, on the left-hand side.

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Comparing case control. You can then take

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those estimated effect sizes for each of the

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association tests, sum them up, use the math in

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a couple of different ways, and then try and

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get some notion of a distribution! Some risk

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You can then take those estimated effect, sizes for each of the Genetic Association tests, sum them up, do some math in a couple of different ways, and then try and get some notion of a distribution, some risk, prediction.

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prediction. These things are always

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probabilistic, at this point in time. And I

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think that is one of the most important things

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These things are always probabilistic at this point in time and I think that is one of the most important things to underscore that most geneticists view this stuff as being primarily probabilistic.

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to underscore: that most geneticists view this

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stuff as being primarily probabilistic. It is

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not -- genes are not fate.

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It is not fake. Genes are not fate, so Prs isn't being applied in a variety of places, right?

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So! PRS is being applied in a variety of

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So one's on, you know, kind of research, trying to understand and interpret genetics.

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places! Right? One is research, trying to

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understand genetics. There's potential for

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There's potential for clinical trials in terms of stratifying individuals in terms of whether or not they're going to develop a disease.

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clinical trials, in terms of stratifying

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individuals in terms of whether or not they're

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going to develop a disease, and that might

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And that might change your opportunity for success or failure. In a clinical trial point of view.

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change your opportunity for success or failure

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Maybe they'll get into routine clinical use.

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from a clinical trial point of view. Maybe

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they'll get into a routine clinical use?

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People are trying to do that? But there are

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People are trying to do that, but there are also efforts out there right now to try and pursue embryo selection.

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also efforts out there right now to try and

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pursue embryo selection, using this kind of

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information. Which I certainly object to

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Using this kind of information, which I certainly object to personally, and indeed, many on this call have written papers about why, that is not a good idea.

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personally, and indeed many on this call have

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From an ethics point of view, least of which is, we do not understand how this Prs is operating.

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written about why that is NOT a good idea from

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So it's all being mediated through environmental exposures.

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an ethics point of view, least of which is we

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don't know how it's operating! What are wow

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Then, like, what are you selecting on, or if it's all doing something about a referral, of how the trade is shaped.

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selecting on? Or, if it's about how the trait

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is shaped, what are you selecting on? It's

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What do you selecting on? It's it's very I mean, there are a lot more risks than benefits in that space at this point.

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very -- a lot more risks than benefits in that

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space.

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So just to conclude and wrap up: Genetics

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So just to conclude and wrap up genetics is a source of variation for most traits.

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is a source of variation for most traits.

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Again, it is not fate, but it does create

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differences amongst people. Being able to

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understand those differences offers the

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opportunity to learn things about... what

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biology matters! What environments matter!

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Again, it is not fate, but it does create differences amongst people being able to understand those differences, offers the opportunity to learn things about what biology matters, what environments matter how we might take that complexity down a notch and try and understand little specific aspects of this, to get a more

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How we might take that complexity down a notch

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Comprehensive view of the complex traits that we're trying to understand.

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and study more specific aspects of this to try

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and get a more complex view and understand.

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The something that a genetic variant does? Is

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The something that a genetic variant does is something. But what that's something is we just do not understand.

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something! But what that something is, we just

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DO not understand, in almost all cases across

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almost all genetic variations that have been

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identified at this point in time. And just to

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In almost all cases, across almost all genetic associations that have been identified at this point, and just to like conclude, there's a lot that we don't know.

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conclude: There's a lot that we don't know?

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And... I would say that, like, the opportunity

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to try and learn something NEW... about how

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certain exposures really are potentially more

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And I would say that, like the opportunity to try and learn something new about how certain exposures really are potentially more causal or not.

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causal or not, genetics does give a stun line

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on that question? But it is only part of the

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Genetics does give us some line on that question, but it is only part of the answer.

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answer! It is actually best when it is

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contextualized with other lines of evidence

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that support the overriding kind of emergent

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It is actually best when it is contextualized with other lines of evidence that support the overall, overriding kind of emergent result that is coming from science.

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result that is coming from science. So this is

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That this is the scientific process that you're seeing play out.

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the scientific process that you're seeing play

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out. And I would love to have more answers

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And I would love to have more answers about how everything works.

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about how everything works? But... part of our

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job is to try and help figure out how those

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answers might be realized.

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But part of our job is to try and help figure out how those answers might be realized.

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With that, I'll thank you and turn it over

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Would that all? Thank you, and turn the floor over to Evelyn

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to Evelynn!

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EVEYLNN HAMMONDS: Thanks, Ben. I really

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appreciate, as always, the attention to detail

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that you give us about the genomics work that I

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think is really, really important.

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Thanks, Ben, I really appreciate, as always, the the the attention to detail that you give us about the genomics work that I think is is really really important.

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So, let me begin -- and hopefully we can

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leave enough time for questions. I just want

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So let me begin. And and hopefully we can leave enough time for for questions. I just want to emphasize a couple of points.

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to emphasize a couple of points. The group

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that worked on this report, with Michele and...

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and Sandra and, um, Erik and others, we're an

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interdisciplinary group of social scientists,

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including historians, psychologists,

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sociologists, legal scholars, bioethicists,

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The group that worked on this report with Michelle and and Sandra and Aarick and others, we're an interdisciplinary group of social scientists, including the historians, psychologists, sociologists, legal scholars, bioethicists, behavioral economists, and genetic and genomics

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behavioral economists, and genetic and genomic

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Scientists, and I would have mentioned that interdisciplinary background.

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scientists. And I want to mention that

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interdisciplinary background -- that

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interdisciplinary background... because much of

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my work together focused on how the differences

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IN our disciplinary backgrounds and

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perspectives shaped our views on what

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constituted the benefits and harms of social

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Of that interdisciplinary background, because much of our work together, in my view, focused on how the differences in our disciplinary backgrounds and perspectives shaped our views on what constituted the benefits and harms of social and behavioral genomics research and I think that's

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and behavioral genomics research. And I think

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that's important, because I think we had to

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learn how, as Erik mentioned briefly, how to

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talk across those differences and see what

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those angles and different perspectives

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actually brought to the table.

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Important. Because I think we had to learn how, as Eric mentioned briefly how to talk across those differences and see what those angles and different perspectives actually brought to the table.

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And I think it's fair to say that both the

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risk and the benefits we identified were many,

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And I think it's fair to say that both the risk and the benefits we identified were many, and there was no simple breakdown between what constituted wisdom.

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and there was NO simple breakdown between what

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constituted risks and benefits of the basic

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research. And I think the risks were, ah,

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identified... that we identified were dependent

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on a number of factors. And this is MY reading

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We're going benefits of the basic research. And I think the risk were identified that we identified were dependent on a number of factors in and this is my reading of it.

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of it. Including how researchers and

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And including how Researchers and Journalists, presented the newest genomic research.

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journalists presented the newest genomic

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research. I think we are getting really quick

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I think we're getting a really really quick examples of how that that can happen.

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examples of how that can happen. General

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public, the general public's understanding of

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how genetic results impact, or in some cases,

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General public, the general public's understanding of how genetic results impact, or in some cases determine human behavior and specific illnesses.

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DETERMINE human behavior and specific

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illnesses. And lastly, how claims about

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And, lastly, how claims about the results of basic research could be used to address important social problems?

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research can be used to address important

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social problems.

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Indeed, I think one way to identify these

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risks, as we DO in the report, is to ask the

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Indeed, I think one way to identify these risk as we do in the report is to ask the question, How much of this research?

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question: How much of this research...

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actually tell us about the role of genetics in

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any individual's phenotype -- such as

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educational attainment, for example -- and what

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can the results tell us about educational

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Actually tell us about the role of genetics in any individual screen of type, such as an educational attainment, for example, and what can the results tell us about educational attainment between and among various human groups?

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attainment between and among various human

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groups, and how are such groups defined?

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If we DO take into account the role of the

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And how are such groups defined? We do take into account the role of the environment, as many studies try to do.

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environment, as many studies try to do, what

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would such results MEAN for social policy? Or

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What was such results mean for social policy, or should these results drive social policy?

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SHOULD these results drive social policy,

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WHETHER the impact of genetics is large or

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Whether the impact of genetics is large or small, and it then also depends on what how we define impact.

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small! And it also depends on what, how we

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define impact!

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And I think this question is particularly

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relevant now, given that today many GWAS,

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genome-wide association studies, STILL are

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widely carried out on fairly homogeneous

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populations. And research does not acknowledge

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And I think this question is particularly relevant now, given that today Mini Gwas Genomewide Association studies still are overwhelmingly carried out on fairly homogeneous populations and research is not acknowledged, that the results cannot be meaningfully applied across all

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that the results cannot be meaningfully applied

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across all human groups.

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Human groups. And this points to one of the things that we've been a fair amount of time talking about.

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And this points to one of the things I

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always spend a fair amount of time talking

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about: The concept of genetic populations,

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which is a scientific term, is easily conflated

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The concept of genetic, populations, which is a scientific term, is easily conflated with social, scientific, and lay concepts of a population.

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with social, scientific, and lay concepts of a

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population. Therefore, the conflation of

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genetic terms, genomic terms, with

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social-scientific and lay terms is also a risk

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that social behavioral genetics research

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Therefore the compllation of genetic terms, Genomic terms with social, Scientific, and lay terms is also a risk that social behavioral genetics research reveals that we are.

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reveals. That we are, we can often talk past

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one another because we're using similar terms

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but in very, very different ways that have

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We can often talk past one another because we're using similar terms, but in very, very different ways, to have very, very different meanings.

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very, very different meanings.

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Another question that I think points to

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Another question that, I think points to possible risk is whether or not the results of value of genomics.

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possible risk is whether or not the resultant

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Research might be overstated as as Ben mentioned, or even for some critics.

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value of genomics research might be overstated,

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as Ben mentioned, or even for some critics...

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Okay. Mike might consider that this research is actually useless.

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might consider that this research is actually

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useless. And the debates on this point are

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And the debates on this point are contentious and ungoing, and in many, many venues.

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contentious and ongoing, and in many, many

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venues right now, with respect to the

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predictive power of current genomic research

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results.

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I would argue that the risks that drew a

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good deal of discussion among our group focused

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upon the following things: The potential for

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stigmatization of various individuals and

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Right now with respect to the predictive power of current genomic research results, I would argue that the risk that drew a good deal of discussion among our group focused on the following things, the potential for stigmatization of various individuals in groups, the reification of race and ethnicity as biological

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groups. The reification of race and ethnicity

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as biological concepts and the potential for

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racializing genetic risk. Unethical

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applications of social behavioral research

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results. Inaccurate assertions that genetic

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results make social and environmental policy

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Concepts and the potential for racializing genetic risk, unethical applications of social behold, behavioral research results, inaccurate assertions that genetic results make social energy environmental policy issues useless.

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issues useless. And lastly, assertions that

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resources should be diverted, at THIS point in

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time, away from environmental and social

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factors in developing policy solutions to

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socially significant problems.

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And lastly, associates, that resources should be diverted at this point in time, away from environmental and social factors, in developing policy solutions to socially significant problems so I won't be remiss at this point.

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So, I would be remiss at this point if I

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didn't interject here that among the risks that

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I just listed, that I believe that the

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potential of SBG research to racialize genomic

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risk is among the most significant issues that

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If I didn't interchange here that among the risk that I just listed that I believe that the potential of Svg research to racialize genomic risk is among the most significant issues that this research reveals.

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this research reveals. And as one of the

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historians in our group, I believe that there

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was a need FOR our group to have a deeper

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understanding, and reflection on, the history

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And as one of the historians in our group, I believe that there was a need for our group to have a deeper understanding and reflection on the history of genetics research in the Us.

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of genetic research in the U.S. Why? Because

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the historical narratives driving research

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approaches today, AND the social science

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Why? Because the historical narratives, driving research approaches today and the social science response to those rep approaches and results.

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RESPONSE to those approaches and results,

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currently tend to rely on historical narratives

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that did NOT adequately reflect the

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long-standing, though changing, debates among

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and between geneticists and social scientists

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and bioethicists over the use of concepts of

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Currently Tim to rely on this historical narratives that did not adequately reflect the longstanding though changing debates among between geneticists and social scientists and biopathicists over the use of concepts of race and ancestry and ethnicity as biological

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race and ancestry and ethnicity as biological

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concepts. And for many historians, we DO see

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in the current moment what we feel like is

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really old wine in new bottles, rather than a

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deep engagement with the problematic uses of

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Concepts, and for many historians we do see in the current moment what we feel like is really all wine and new bottles rather than a deep engagement with the problematic uses of race and contemporary contemporary genomic research.

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race in contemporary genomic research. There

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is an appalling lack of knowledge! Among

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scientists and social scientists, and certainly

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There is an appalling lack of knowledge among scientists and social scientists, and certainly among lay publics of the definition of race.

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among lay publics, of the definition of race,

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the history of the social and scientific uses

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of racial categories, that is severely limiting

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our understanding of human genetic variation.

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The history of the social and scientific uses of racial categories that is severely limiting our understanding of human genetic variation and our ability to develop.

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And our ability to develop antiracist practices

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throughout our society! We can't decide on

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Anti racist practices throughout our society. We can't decide on definitions.

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definitions, we can't decide on the meaning of

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We can't decide on the meaning of various categories.

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various categories, we can't decide on the

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relationship to the biology -- biological

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We can't decide on the relationship to the biological reality of human variation.

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reality OF human variation. And therefore, as

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these things come together and collide... we

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find ourselves in a really soup of confusion

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that I think is deeply affecting our ability to

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understand some of the research that Ben just

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so carefully laid out for us. Because we bring

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to it that lack of consensus about what we mean

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And therefore, as these things come together and collide, we find ourselves in a in a really soup of confusion that I think is deeply affecting our ability to understand some of the research that then just so carefully laid out for us, because we bring to it that lack of consensus about what we mean by the ways in which we

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by the ways in which we group our society,

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specifically in the United States, into groups

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Group, our societies specifically in the United States into groups that are called races.

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that are called "races." And what that means,

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in terms of contemporary biological and genetic

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research. As well as socialist -- social and

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And what that means in terms of contemporary, biological and genetic research as well as Socialist social and and bioethical research.

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bioethical research!

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So, another aspect, I would say, of the

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historical work was to examine the history of

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So another aspect. I would say, of the historical work was to examine the history of Eugenics in the context of the Us.

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eugenics, in the context of the U.S., in the

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POST-world War II period -- a history that many

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scientists, and some social scientists, were

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largely unfamiliar with. Specifically, the

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continuation of debates about the genetic

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components of intelligence and racial

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differences in those debates about the meaning

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In the Post World War, 2. Period history that many scientists and some social scientists were largely unfamiliar with specifically the continuation of debates about the genetic components of intelligence and racial differences in those debates about the meaning and value of measuring IQ whatever IQ is and so

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and value of measuring IQ, whatever IQ is? And -- so those debates have continued since

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Those to base have continued since the post work. Awesome world War 2.

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I'm too. But we also tried to to walk a line.

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the post-World War II period. But we also

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tried to walk a line, I think, in our

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discussions to note that there ARE eugenics

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aspects in current research... but we also

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wanted to appreciate the linkages between a

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focus on genetic differences in something like

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intelligence and social behaviors, with efforts

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to ALSO really think about the ways in which

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I think, in our discussions to note that there are Eugenics aspects in current research, but we also wanted to appreciate the linkages between a focus on genetic differences in something like intelligence and social behaviors with efforts to also really think about the ways in which I society is structured in various ways

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our society is structured in various ways that

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implicate, ah, race, class, and ableist

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elements of the status quo. Which -- which, in

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That implicate race, a class and ablest elements of our of the status quo which which, in fact, risk the risk.

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fact, risk -- the risk here is the furthering

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and continuing the persistent stigmatization of

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already marginalized groups in the United

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Here is the furthering and continuing and present stigmatization of already marginalized groups in the United States.

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States. We tried to be, get into those nuances

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We tried to be, get into those nuances and trying to understand what was actually happening.

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and tried to understand what was actually

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happening.

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And then, lastly, social risks abound when

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using genetics to understand human behavior.

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Particularly when trying to use that knowledge

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to solve social problems, as our report

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And then, lastly, social risk of bound when using genetics to understand human behavior, particularly when trying to use that knowledge to solve social problems as a, as our report indicates, and as all of us involved.

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indicates, and as all of us involve know. I

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think for genomic researchers, it is

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particularly fraught, as they develop new and

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ever more sophisticated tools to study genetic

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Note, I think, for genomic researchers. It is particularly fraught as they develop new and ever more sufficient tools to study genetic variation in individuals and in groups.

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variation in individuals and in groups. This

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work almost inevitably forces them to

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recognize, and seek to try to avoid! Some

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This work, almost inevitably forces them to recognize and seek to try to avoid some social pitfalls, that their work exposes.

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social pitfalls that they're exposed to. On

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the other hand, I think our project showed,

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too, the necessity for social scientists and

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bioethicists to be more deeply engaged in

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understanding the technical details of genomics

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research and the complex ways in which the

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social and the scientific collide...! In

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On the other hand, I think our projects show to the necessity the social scientists and bioethicists to be more deeply engaged in understanding the technical details of genomics, research, and the complex ways in which the social and the scientific collide in everyday research practice this must be done for

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everyday research practice. This must be done

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for ALL of us, in the service of the social

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profile -- social pitfalls that can lead to

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serious ethical issues for all of us.

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And I'll stop there so we can take some

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All of us in the service of the social profile, social pitfalls that can lead to serious ethical issues for all of us, and and I'll stop there so we can take some questions

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questions.

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MICHELLE MEYER: Ben and Evelynn, thank

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you so much for two really wonderful, rich

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Ben and Evelyn. Thank you so much for 2 really wonderful rich presentations.

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presentations. I have so many questions to

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ask, but I... I will limit myself, so that we

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I have so many questions to ask, but I I will lose it myself, so that we can take some of the questions that are coming in.

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can take some of the questions that are coming

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in.

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Let me start with Evelynn, and then I'll

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Let me let me start with Evelyn, and that I'll follow up with the question for both of you.

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follow up with a question for both of you.

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Well, this question might be for both of you,

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Well, this this question might be for both of you too. But let me start with that one.

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too, but let me start with Evelynn. So, as you

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know, there have been many calls -- not just

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currently, but historically, over decades, and

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probably longer -- to reform both the way that

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genetics researchers "group" humans for

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inclusion and exclusion in their studies, and

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also how they describe those groups. And in

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So, as you know, there have been many calls, not just currently, but historically, over decades, and probably longer to reform both the way that genetics, researchers, group humans for inclusion and exclusion in their studies, and also how they describe those groups and in particular the embedded is behind this these

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particular, the impetus behind this, these

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calls for reform is to avoid reifying this

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mistaken notion of race and ethnicity as

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biological as opposed to social categories.

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So, as an historian, Evelynn, how does history

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suggest, your take on history, how does it

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Calls for reform is to avoid reifying this mistaken notion of race and ethnicity as biological as opposed to social categories, so as an historian, Evelyn, how does history suggest your takeo on history how does it suggest that these reforms are likely to fare and then, we pack?

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suggest that these reforms are likely to bear?

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Hmm.

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And let me back in a part two. If your answer

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In a part 2. If your answer is that the outlook is maybe somewhat grim.

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is that the outlook is maybe somewhat grim...

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do you have any advice for genetics

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Do you have any advice for genetics, researchers.

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researchers?

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EVEYLNN HAMMONDS: Yeah. Well, I actually

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Yeah, well, I actually don't think the outlook right now is grim.

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DON'T think the outlook right now is grim. I

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think -- first, I think it's really important

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that people spend a -- MUCH more time on the

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history, and understanding the earlier debates,

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and how meaningful those earlier debates,

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certainly in the post-World War II period,

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collapsed! Where lots of international groups

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I I think at first I think it's really important that people spend a lot of a much more time on the history and understanding the earlier debates, and how many of those earlier debates certainly in the post World World World War 2 period the last where lots of international groups and national groups of scientists got together.

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and national groups of scientists got together

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and tried to figure out what is, how to, how to

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fix this problem of how we think about racial

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And tried to figure out what is, how to how to fix this problem of how we think about racial categories, in especially in the Us.

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categories, and especially in the U.S. context.

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And they couldn't figure it out. Okay. But we

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should, we need to go deeper into WHY they

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Could, and they couldn't figure it out. Okay. But we we need to go deeper into why they couldn't figure it out.

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couldn't figure it out. But NOW, I think that

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we are in a moment that I think is hopeful,

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because we need to take advantage of this

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moment of the commitment of many more

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But now I think that we are in a moment, that we that I think is hopeful because we need to take advantage of this moment of a commitment of many more institutions in the Us.

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institutions in the U.S. society, especially

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Society, and especially within science, the national sciences. Foundation, nih.

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within science -- the National Science

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Foundation, NIH, various professional

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organizations who say: Can we just sit down

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now and try to figure out what it is we're

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Various, professional organizations who say, can we just sit down now and try to figure out what it is we're doing, and why it is not working.

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doing and why it is NOT working? And what the

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future SHOULD look like. Right. What IS a way

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we can do this research, understand human

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differences, genetic variation, IN ways that

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actually are positive for the growth of the

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And what the future should look like. Right. Way. What is a way we can do this research understand human differences, genetic variation in ways that actually are positive for the growth of the science as well as positive for understanding?

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science as WELL as positive for understanding

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who we are in our own society? And of course

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the scientists and researchers and all of us

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Who we are in our own society, and of course the scientists and researchers and all of us are part of that society.

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are part of that society!

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So, I think we are at a GOOD moment? I

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can't predict the outcome of the moment, of

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So I think we had a good moment. I can't predict the outcome of a month of this moment as a good historian I would be.

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this moment. As a good historian, I would

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be -- I'm never gonna say we can predict the

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future. But the past suggests that it's going

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to be -- it is complex, and it's not going to

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I am never gonna say we can predict the future, but the passage that is going to be it is complex and it's not going to be as easily solved as many people think.

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be as easily solved as many people think it is.

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It doesn't -- it's not going to be solved by

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It is. It doesn't. It's not going to be solved by simply putting a label call anti-racist on something.

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simply putting a label called "antiracist" on

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something. It is going to involve deep

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engagement about why these notions of innate,

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immutable differences between human groups

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defined in particular ways continues to animate

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It is going to involve deep engagement about why these notions of innate, immutable differences between human groups, defined in particular ways, continues to animate and drive.

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and drive how we think about the work that we

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do, and what we're trying to understand! Both

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How we think about the work that we do and what we've trying to understand, both in the science and in this social science

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in the science, and in the social science!

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MICHELLE MEYER: Thanks. Ben, I'd like to

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Thanks. Ben. I I'd like to hear if you have any thoughts to follow up on that.

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hear if you have any thoughts to follow up on

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But let me put the next question, which is to both of you.

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that, but let me put the next question -- which

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is to both of you, but I'll ask you to start.

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But but I'll ask you to start as Eric and and Evelyn and Bez.

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As Erik and Evelynn, as we all have said, this

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project was sort of deliberately created to

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We've all had said this project was sort of delayed, created to bring together people with very different perspectives.

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bring together people with very different

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perspectives, disciplinary perspectives, all

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kinds of perspectives. And so I'd like to ask

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both of you to reflect on whether your own view

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of social and behavioral genetic research

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changed, over the course of the three years,

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and if so how. But then, please, if you have

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Disciplinary perspectives, all kinds of perspectives. And so I'd like to ask both of you to reflect on whether your own view of social and behavioral genetic research changed over the course of the 3 years, and if so, how but then, please, if you have questions about the population descriptors, and inclusion

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questions about the population descriptors, and

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inclusion, exclusion, please... go for it.

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BENJAMIN NEALE: So. I mean, just a brief

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Exclusion, please.

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note on the population descriptors and some of

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So so, yeah, I mean, just a brief note on the population descriptors and some of the conceptualizations.

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the conceptualizations. I... I mean, if you

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just look at the genetics, if we go far back

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I I mean, if you just look at the genetics, if we go far back enough in our family tree, we're all African cause.

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enough in our family tree, we're all African.

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I mean, that's where all of our species is.

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And... I think there's a lot of... I, I think

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that's a very important, and powerful,

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I I mean, like, that's where all of our species is, and I think there's a lot of, and I think that's a very important and powerful statement.

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statement. And, and one I've heard a number of

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other geneticists make over the years. And,

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And and one I've heard a number of other geneticists make over the years and and I think that that that also underscores.

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and I think that that, that also underscores --

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and, you know, just... (chuckles) Reinforces

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the point that is coming from... a lot of the

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social sciences, about how race is a social

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construct! Because, like, how you pick a time

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and a place, when thinking about a continuous

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process of human genetic diversity and

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And you know, just re reinforces the point that is coming from a lot of the social sciences about how race is a social construct, because, like how you pick a time and a place when thinking about a continuous process of human genetic diversity and variation being shared across our species and across

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variation being shared across our species and

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across our world...! You know, it just... it

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forces you to reconsider, and reflect on, what

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Our our world. You know it just. It forces you to reconsider and reflect on what you are doing.

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you are doing and what you are operationalizing

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and what you are calling things, and how easy

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it is to just fall back into the racialized

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And what you are operationalizing, and what you are calling things, and how easy it is to just fall back into the racialized world that you are a culturated into.

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world that you are acculturated into. And I

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would say that's, like, both a comment about

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And I would say, that's like both. A comment about the previous question.

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the previous question, but ALSO one of the

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things that I've taken away most clearly and

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strongly from the dialogue in the

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interdisciplinary landscape is that... you

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know. The TRUE story of our species is one

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where we are way more similar than different.

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But also one of the things that I have taken away most clearly and strongly from the dialogue in the Interdisciplinary landscape is that you know the true story of our species is one where we are way more similar than different, and that is the case at almost any anything that you want to look

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And that is the case at almost any, ANYthing

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that you want to look at, in terms of an

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outcome or trait or whatever, in terms of

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underlying biology. That like underlying

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biology is shared, and that shared humanity

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aspect is something that we SHOULD talk about

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more in the communication of our results!

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at in terms of a kind of outcome or trader, whatever, in terms of the underlying biology that, like underlying biology, is shared in that shared humanity, aspect, is something that we should talk about more in the communication of our results, because we like as geneticists we just focus on

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'Cause we -- like, as geneticists, we just

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focus on the tiny little bit of difference,

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'cause we're trying to get leverage on

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understanding and interpreting what maybe

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genetic variance is doing; we're trying to

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understand the history of our species as it has

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migrated across the world and set up shop in a

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the tiny little bit of difference because we're trying to get leverage on understanding and interpreting what maybe a genetic variant is doing or trying to understand the history of our species as it has migrated across the world and set up shop in a whole bunch of different pockets and corners of this

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whole bunch of different pockets and corners of

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this planet. Right, like. All of those things

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are... We focus on those differences because

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that's where there's opportunity to engage and

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learn in science. And I think that sometimes

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leads us to a place where we don't trumpet and

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triumph the shared... you know. That which

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planet, right? Like all of those things, are we we focus on those differences because that's where there's opportunity to engage in, learn in science. And I think that sometimes leads us to a place where we don't trumpet and triumph the shared, you know the that which shares and

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shares and unites us...! And, you know. THOSE

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unites us, and you know those messages. I think we could and should, and I now do, spend more time communicating.

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messages, I think we could and should, and I

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now DO spend more time communicating. I guess

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this answer in itself is a great example of

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I guess this answering it itself is a great example of exactly what I mean, but I've taken that away from the dialogue.

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exactly what I mean.

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But I've taken THAT away from the

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dialogue. I've taken away -- and once you

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start to understand, or start your journey to

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understand, what it means to live in a

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I've taken away that, and and once you start to understand, or as you are continuing your journey to understand what it means to live in a racialized world, and how that shapes your professional activities, even when you're trying to be a scientist and even when you're trying to be

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racialized world, and how that shapes your

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professional activities, even when you're

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trying to be a scientist or trying to be

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unbiased or taking a clinical perspective or

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any of those things... you know. Just trying

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to think about that, trying to incorporate that

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into the way that you approach the problem, and

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trying to, in a sense, remove that from

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unbiased and you know, or taking a clinical perspective, or any of those sorts of things, you know, just just trying to think about that, trying to incorporate that into the way that you approach the problem and trying to in a sense, remove that from contaminating the work that you are trying to

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contaminating the work that you are trying to

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accomplish? THAT has come through super

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clearly as a lesson for me, and I think many of

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the other genetic scientists and genomic

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scientists working in this workgroup, as our

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social responsibility AND professional

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responsibility. Because the degree to which we

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are contaminated by this racialized world in

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accomplish that has come through super clearly as a lesson for me, and I think many of the other genetic scientists and genomic scientists working in this work group as our social responsibility and professional responsibility, because the degree to which we are contaminated by this vers racialized world in terms of trying to understand what

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terms of trying to understand what is actually

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going on! What the truth of the matter is!

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Which is something that I, as a scientist, care

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is actually going on. What the truth of the matter is, which is something that I, as a scientist, care about very, very deeply.

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about VERY, very deeply. It just -- it makes

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It. Just it makes our jobs harder and and like this, work is in service of doing that.

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our jobs harder! And like this work is in

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service of doing that.

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And so I've taken that away, and I very

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much thank the group and the experience for

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enriching my own self and my own science in, in

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those domains.

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And so I've taken that away. And I I very much think the the group and the experience for enriching my own self and my own science in in those domains

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MICHELLE MEYER: Thank you. Evelynn?

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EVEYLNN HAMMONDS: Well, I think one of

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Thank you. Absolutely.

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the biggest things that I've taken away from

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this group is that: It's a lot harder! To

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come to terms -- to cross these bridges between

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the social scientists, social sciences and the

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Well, I think one of the biggest things that I've taken away from this group is that it's a lot harder to come to terms to cross these bridges between the social scientists social sciences and the sciences of genetics and genomics.

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sciences of, of genetics and genomics than I

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thought it was. And I -- and it took a while

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Then I thought it was, and and I and and it took a while for me to try to figure out.

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for me to try to figure out, well, why IS it so

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Well, why is it so hard? What is so comfortable about this?

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hard? What is so complex about this? And I

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realize that part of what was happening is what

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I mentioned about this need for a particular

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kind of translation that I didn't realize...!

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I'm thinking I understand the word population,

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And I realized that part of what was happening is what I mentioned about this need for a particular kind of translation that I didn't realize I'm thinking I understand the word population, and I use it in a particular way.

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and I use it in a particular way, and I

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understand when I'm looking at the work of

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And I understood when I'm looking at the at the work of genomics, I'm saying.

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But what do you? That's that doesn't make sense.

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genomickists, I'm saying, but what does -- what

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doesn't make sense, then! And then, of course,

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through these long conversations we had, and

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Then, and then, of course, through these long conversations we had, and also other conversations I've been able to have we've been it.

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also other conversations I've been able to had

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with Ben, I finally realized we are not talking

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Finally, we're not talking about the same thing. We are fundamentally not talking about the same thing.

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about the same thing! We are fundamentally not

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Why are these points of translation needed? And that was just.

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talking about the same thing! Why are these

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points of translation needed? And that was

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just ONE point, population itself. But other

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things -- ancestry! All of these other things

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were coming into play. And I realized almost

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that we needed a kind of, a, a translator to

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Oh, that was just 1 point, but population itself. But other things ancestry, all of these other things were coming to play, and I realized almost that we needed a kind of a, a, a, a a a translator, to help us move across these these sites.

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help us move across these sites! And once we

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moved across, and once I felt I moved across,

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And once we moved across and was actually I moved across. Then I had a much deeper understanding and appreciation.

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then I had a much deeper understanding and

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appreciation OF the fact that -- you know,

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which I came in thinking I understood -- that I

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DO believe genetics has a role to play in human

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Of the fact that you know which I came in at thinking I understood that I do believe genetics has a a role to play in human behaviors.

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behaviors! I actually believe that! I didn't

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think it was determinative! But I did believe,

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I actually believe that I didn't think it was determinative, but I did believe I did think of it played a role.

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I did think it played a role! How do I

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How do I understand? How did I understand that? Well, I didn't understand it.

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understand, how did I understand that role? I

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DIDN'T understand! But now? (chuckling)

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After three years, and intense conversations

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through many, many examples, I really began to

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appreciate... what it means to try to get to

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the answer of that question! What KIND of role

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does genetics play in complex phenotypes and

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But now, after 3 years, and and it's his conversation through many, many examples, I really began to appreciate what it means to try to get to the answer to that question, what kind of role does genetics play in complex phenotypes and human behaviors and human illnesses and I think there's a really

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human behaviors and human illnesses?

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And I think that's a really important

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question? I think those are questions that we

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share? But we just didn't know how to talk

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about it, I think. And, and when we say three

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Important question. I think those are questions that we share, but we just didn't know how to talk about it, I think, and and and and what we say 3 years and some of those, some of those workshop meetings were really long and difficult.

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years! And some of those workshop meetings

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were REALLY long and difficult! And that's

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And that's what so I'm not saying something about it's a facile change that we have to make.

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what -- so I'm not saying something about it's

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a facile change that we have to make. This is

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a deep! REALLY deep engagement, at an

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intellectual level. And I would say that, you

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know... that's the kind of work! This whole

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This is a deep, really deep engagement at an intellectual level, and and I would say that that you know, that's the kind of work it's this, this whole edifice of how we think about genetic variation.

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edifice of how we think about genetic

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variation, human variation, has been built over

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Human variation has been built over 100 and hundreds of years.

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hundreds and hundreds of years! We're not

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gonna fix it even in three! But at LEAST, we

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jumped into the deep end and began to struggle

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We're not going to fix it even in 3, but at least we jumped in deep in and began to struggle through, and I think we came out.

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through. And I think we came out -- and I

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think wrestling is absolutely the right

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metaphor for what we were up to. And now, I

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I think wrestling is absolutely the right metaphor for what we were up to, and and and now I appreciate the rest. Link

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appreciate... the wrestling.

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MICHELLE MEYER: Thanks so much. Welcome

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back, Erik. Let's open it up to some of the

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questions that have been coming in. Erik, do

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Thanks so much. Welcome back, Eric. Let's open it up to some of the questions that have been coming. Eric, do you have one in mind

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you have one in mind?

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ERIK PARENS: Well, you wanna start with

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Well, you wanna start with the hardest a hard one

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I'm gonna start with it.

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the hardest -- a hard one? Wanna start --

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MICHELLE MEYER: I'm not on the panel, so

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I'm on the panel, so sure

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sure! (chuckles)

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ERIK PARENS: Ah, all right! So can you

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share which cases the group thought would yield

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Alright, so can you share which cases the group thought would yield the highest benefit.

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the highest benefit? If as something to be

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controlled for in social science questions, how

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does this square with Ben's point that we don't

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If as something to be controlled. For in social science questions, how does the square with Ben's point that we don't understand what mediators the Prs is capturing?

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understand what mediators this is capturing.

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BENJAMIN NEALE: So, I can talk a little

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So I I I can talk a little bit about where that might work and where it might not work from the sort of math stats point of view.

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bit about where that might work and where that

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So let's say you have some continuous outcome.

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might not work, that point of view. So let's

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say you had some continuous outcome. If you

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control for a source of variability in that

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continuous outcome that is unrelated to the

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thing that you are studying? It makes it

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If you control for a source of variability in that continuous outcome, that is unrelated to the thing that you are studying, it makes it easier to identify the relationship with the thing that you are studying.

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easier to... identify the relationship with the

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thing that you are studying. So, shrinking the

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variability of your outcome with... variability

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completely unrelated to what you're looking at,

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is where the kind of perceived value add may be -- from a statistical power analysis point

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of view. I think the, the risk Anna's raising

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So shrinking, the variability of your outcome with the variability completely unrelated to what you're looking at is where the kind of perceived value add, maybe from a statistical power analysis, point of view, I think that the risk Anna is raising about if we're conditioning on things that we

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about... if we're conditioning on things that

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we don't understand how they're operating, what

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does that DO to everything? I mean, like,

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that's, that's a pretty legitimate -- that's a

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Don't understand how they're operating. What does that do to everything I mean, like, that's that's a pretty legitimate that that's a very legitimate risk.

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very legitimate... risk! And I think that...

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relates, in part, to -- you know. The

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And I think that relates in part to you know, the polygenic risk.

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polygenic risk ideas are... you know. They are

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maybe getting us to a place of making informed

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predictions or guesses? But they are not

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getting us to a place where we understand the

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mechanisms by which the underlying genetic

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Ideas are, you know, they are maybe getting us to a place of making informed predictions or guesses, but they are not getting us to a place where we understand the mechanisms by which the underlying genetic effects are being manifest, and that is why I think it is essential that we knew we

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effects are being manifest. And that is why I

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think it is... essential! That we do not leave

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it alone as just simply the polygenic risk.

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With at least SOME attempt at understanding

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what the genetic variation is doing. Because

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if you can't understand what the genetic

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variation is doing, you -- like, one other

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Do not leave it alone at just simply the polygenic risk, with the at least some attempt at understanding what the genetic variation is doing, because if you can't understand what genetic variation is doing, you like one other possible thing that you can get into in terms of like personalized education, or whatever if

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possible thing that you can get into, in terms

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of like personalized education, or whatever, if

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you're gonna go throw this thread, is that our

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You're gonna go follow this thread. Is that our Prs, as it is currently constituted, is a reflection of what our education system currently values.

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PRSR, as it is currently constituted, is a

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reflection of what our education system

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currently values. And if we want to change

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what our education system values -- in any way!

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And if we want to change what our education system values in any way more social control, less social control, more math, less math whatever.

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More social control, less social control, more

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Any of the dimensions under which that skilled transform is meant to be happening.

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math, less math -- whatever! Any of the

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dimensions under which that skill transfer is

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meant to be happening societally. Then just

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Societally, then just using the Prs as it is current.

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using the PRS as it is currently constituted is

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Currently, cost is potentially even working against that AIM in and of itself.

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potentially even working against that aim, in

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and of itself!

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So I think there is, there is ANOTHER

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risk, above and beyond some of the risks that

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Evelynn articulated, and chief amongst those in

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my mind is just reinforcing our current

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And so I think I think there's there is another risk above and beyond some of the risks that Evelyn articulated, and chief amongst those in my mind is just reinforcing our current structures insofar as we now have a prs that has a set of weights that

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structures. In so far as we NOW have a current

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PRS that is reflecting a certain set of

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is reflecting a certain set of priorities from the educational system, and maybe we want to shift those priorities, and we won't have the agency to do so.

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priorities from the educational system. And we

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want to shift those priorities and we want to

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So I agree with your concern, and it is a risk.

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have the agency to do so.

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So, I agree with your concern, and it is a

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But you may also, but not controlling for it may confound your analysis.

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risk, but we may also -- but, NOT controlling

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for it may confound your analysis, may confound

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May confound your association may confounded your interpretation.

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your social issue, may confound your social

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issue. A great example of that comes from work

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on ADHD and smoking, and maternal smoking in

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particular. And, you know, there were great

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efforts to prevent maternal smoking. And, and

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A great example of that comes from work on Adhd, and smoking and maternal smoking in particular, and you know there were great efforts to prevent maternal smoking, and and what Brian Denofrio and I need a fabric did was look at parents the mothers where they smoked for one

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what Ryan Dinofrio did was look at the mothers,

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where they smoked for one pregnancy and didn't

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smoke for another, because of the association

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between maternal smoking and ADHD, and saw

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Pregnancy, and didn't smoke for another pregnancy because of the association between smoke, maternal smoking, and Adhd, and saw exactly the same rates in the kids with Adhd.

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exactly the same rates in the kids with ADHD,

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whether the mom was smoking during their

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Whether the mom was smoking during their pregnancy or not.

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pregnancy or NOT smoking during their

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pregnancy. And so that's the sort of, like,

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environmental ascertainment that if you don't

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take the -- at least underlying either familial

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or genetic components that are driving the ADHD

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into account, you can arrive at an intervention

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Smoking during their pregnancy, and so that's the sort of like environmental ascertainment that if you don't take the at least underlying either familiar or genetic components that are driving the Adhd into account you can arrive at an intervention that you push a lot of

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that you push a lot of effort behind that has

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no impact on the outcome that you're trying to

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effort behind that has no impact on the outcome that you're trying to pursue.

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pursue.

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So, risks on both sides! But we gotta, we

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So risks on both sides. But we gotta we gotta learn more, I guess, is the position might

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gotta learn more, I guess is the position I'd

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take.

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ERIK PARENS: So. Evelynn, here's an --

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So, Evelyn, here, here's an here's one from Stephanie. Man!

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here's one from Stephanie Mann. How can health

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educators use your analysis -- and by "your

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How can health professions, educators, use your analysis, and by your analysis, I think, Stephanie, man is referring to the the working groups.

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analysis," I think Stephanie Mann is referring

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to the working group's analysis? How can --

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how can health educators use your analysis and

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thought process to address the diversity issues

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that we're grappling with to be more inclusive

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and to reduce educational inequity and health

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Analysis. How can how can we help educators use your analysis and thought process to address the diversity issues that we're grappling with, to be more inclusive and to reduce educational inequity and healthcare disparities

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care disparities?

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EVEYLNN HAMMONDS: Well, as a educator

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myself? Um... I, I am currently -- you know.

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As we ALL are. Working through... the best way

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to sort of... get ourselves in a better place

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to understanding the issues in front of us that

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could lead us, as a society, toward greater

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Well as a as a educator. Myself. I I I am currently, you know, as we all are working through the best way to sort of get ourselves in a better place to understanding the issues in front of us that could lead us as a society for greater equity equity and inclusion, okay, so if I'm I'm

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equity and inclusion. Okay? So, if I'm

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Starting as an educator. I'm just. I start with the curriculum.

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starting, as an educator -- I start with the

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curriculum, itself. We all have to reeducate

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It's we all have to re-educate ourselves in some kind of way through.

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ourselves, in some kind of way. Through three

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years of a serious working group like this? Or

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3 years of a series working group like this or through, you know, just intensive reading.

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through, you know, just intensive reading.

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But... the absence of the history, and how we

00:56:15.000 --> 00:56:18.000

But the absence of the history, and and how we got here.

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GOT here...! Is, to me, so critical! We tend

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to tell a story that... that sort of these

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framing and animating narratives? That

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It's to me so critical. We tend to tell a story that that that that sort of these framing and animating narratives that actually don't get us going in any way, and linked to 2 examples.

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actually don't get us going anywhere! Let me

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give two examples.

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First example is, you know, throughout

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COVID, people -- journalists were writing all

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these stories about the reason that

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African-Americans were mistrustful of, uh, of

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needing to do certain things with respect to

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COVID had to do with the history of

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African-Americans in U.S. medicine. And they

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First example is, you know, throughout Covid people, journalists were writing all these stories about the reason that African Americans were mistrustful of need to do certain things with respect to Covid had to do with the history of African Americans in us, medicine, and they only gave 3 examples one James Marian Sims.

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only gave three examples. One, of James Marion

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Sims and his gynecological surgery in the

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And his Guy Nicola Surgery in the middle of the nineteenth century, with without honestyes. Right?

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middle of the 19th century without anesthesia,

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right, on these Black women. Two, the United

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Only these black women to the the United States Public Health Service study of untreated syphilis in African American men.

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States Public Health Service study of untreated

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syphilis in African-American men. Three is the

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story of Henrietta Lacks and her tumors and her

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cells that are used to create a cell line that

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3. 3 is the story of Henrietta Lax as, and her tumors, and the and her cells that were used to create a cell line that became one of the most productive cell lines in in biomimicry.

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became one of the most productive cell lines in

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biomedicine. Those three! You know. Totally

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important cases, but they DO not represent the

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sum of the, of generations of persistent

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practices within medical theory that -- I'm

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sorry, supported by medical theory, that attend -- that continued to say: Black bodies

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Those 3, you know. Totally important cases, but they do not represent the sum of the generations of persistent practices within medical theory that I'm sorry, supported by medical theory, that attended that continued to say black bodies and wipeide is a fundamentally different bodies.

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and white bodies are fundamentally different

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bodies. That our biology is different! And

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it's innate and immutable! That was locked in

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in the 19th century. NEVER gets dislodged. To

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the point where today, we still have people

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talking about Black people don't experience

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That our biology is different, and it's innate and immutable that locked in in the nineteenth century never gets this lodge to the point where today we still have people talking about black people don't experience paying the same way.

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pain the same way white people do, and

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therefore they should not be medicated in the

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White people do, and therefore they should not be medicated in the same way, or given any kind of support.

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same way, or given any kind of support in the

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same way. That kind of -- THAT kind of fact?

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In the same way that kind of that that kind of fact is still normal and accept.

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Is still... normal? And accepted? Means that

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we have to undo a whole lot of things to get

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people to become practitioners in health care

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It means that we have to undo a whole lot of things to get people become practitioners in health care industries, to understand what is going on.

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industries to understand what is going wrong!

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So, that just requires a lot of work and

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So that just requires a lot of work and attention to that.

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attention to that. And so, I think the medical

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And so I think the medical curriculum which I'm involved in at Hms.

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curriculum, which I'm involved in at HMS, we're

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starting from just basically even getting

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We're starting from just basically even getting students to understand what is right.

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students to understand what is race! We have

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some of the smartest students in the country,

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We have some of the smartest students in the country in Harvard Medical School classes.

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in Harvard Medical School classes. We did a

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We did a little focus group to try to understand what they understood about race.

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little focus group to try to understand what

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they understood about race. They didn't

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understand a thing. They could not make

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They didn't understand a thing they couldn't not make coherent sinuses a about what race is, how is defined?

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coherent sentences about what race is. How

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it's defined, who defines it, why -- how it

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affects us.

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So we have to go back to some kind of real

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first principles and recognize that we have NOT

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done a good job of explaining how we've got,

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how we've come to this point where our

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Who defies it, why, how it affects us! So we have to go back to some kind of real first principles and recognize that we have not done a good job of explaining how we've got how we've come to this point where our understanding of a group and differences individual differences genetic

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understanding of group and... differences,

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individual differences, genetic differences --

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we've gotta do what we haven't been doing:

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Differences. We we've got to do what we haven't been doing. Teach

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teach.

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MICHELLE MEYER: Thank -- thank you, SO

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much. Again, for a rich conversation. And

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Thank you so much again for a rich conversation, and I, unfortunately, we have so many great questions.

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unfortunately -- we have so many great

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questions, but unfortunately I think it's time

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to hand it back over to Sandra.

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SANDRA SOO-JIN LEE: Yeah. No, I think

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Unfortunately, I think it's time to turn back over to Sandra

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this is a terrific start to a very important

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Yeah, no, I I think this is a terrific start to a very important conversation.

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conversation. I'd really like to thank our

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panelists today for their presentations and

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discussion, and for all of you for your

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I'd really like to thank our panelists today for their presentations and discussion, and for all of you, for your thoughtful questions.

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thoughtful questions. As Michele mentioned, we

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weren't able to get to most of them; however!

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For those who can, please join us for a

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post-event discussion for about 30 minutes.

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The link should be in the chat. And we hope to

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see you on February 10th for our next ELSI

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As Michelle mentioned, we weren't able to get to most of them, however, for those who can please join us for a post event discussion for about 30 min the link should be in the chat and we hope to see you on February tenth for our next Lc Friday Forum it is

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Friday Forum. It is entitled Indigenizing

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Genomics and Advancing Indigenous Data

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Indigenizing

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Genomics and Advancing Indigenous Data

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Sovereignty. We will have panelists Philip

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Wilcox and Krystal Tsosie, and the session will

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Entitled Indigenizing Geneticics, and Advancing Indigenous Data Sovereignty, we will have panelists, Philip Wilcox and Crystal, so see and the session will be moderated by Joe Josie Johnston the registration link

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be moderated by Josie Johnston. The

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registration link is in the chat, so please

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visit ELSIhub and subscribe to the newsletter

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Is in the chat. So please visit Lc. Hub, and subscribe to the Newsletter for details on these events and others.

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for details on these events and others.

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Importantly, you will receive a post-event

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Importantly, you will receive a post. Events survey, and I really am.

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survey, and I really encourage you to fill this

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out. Our organizing committee takes your

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Encourage you to fill this out. Our Organizing Committee takes your comments and suggestions seriously.

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comments and suggestions seriously. It informs

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on, us on how to improve the forum and also

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It invs on us, on how to improve the Forum, and also bring new topics and speakers to the series.

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bring new topics and speakers to the series.

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So please do fill it out.

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Again, I wish you all a wonderful weekend,

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So please do fill it out again. I wish you all a a wonderful weekend, and thanks so much for attending this session.

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Take care!

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Thank you. Sandra.

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and thanks so much for attending this session.

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Take care.

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Thanks.

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Thanks. Everyone.

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ERIK PARENS: Thank you, Sandra. And the

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And the link is

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link is...?

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SANDRA SOO-JIN LEE: The link is -- should

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be in the chat?

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Yes, so just don't