

PRELIMINARY AGENDA

Tuesday, December 4, 2001

Release 4.0



West Harlem Environmental Action presents a national conference and community dialogue on:

Human Genetics, Environment, and Communities of Color: Ethical and Social Implications

Monday, February 4th, 2002

8:30AM – 5:30PM

**Columbia University
Lerner Hall (115th & Broadway)
New York City, NY**



Co-sponsors: the National Institutes of Environmental Health Sciences (NIEHS), the NIEHS Center for Environmental Health at the Mailman School of Public Health (Columbia University), and the Harlem Health Promotion Center.

The “decoding” of the human genome – the collective genetic make-up of human beings –, announced in June 2000, has been heralded as one of the major scientific breakthroughs in recent history, with the potential to usher in a new era of human health protection. However, many concerns have arisen about the potential for exploitation and misuse of this technological breakthrough. As the research and development of human genetics unfolds with increasing speed, do adequate structures exist for communities to address the ethical and social implications created by these new technologies? How will genetics research impact on communities of color, and how can we best inform and prepare ourselves to handle both the challenges and opportunities posed by this new knowledge?

This national conference will bring community advocates, policy makers, and scientists from across the country together to educate one another and to answer these questions. Conference participants can expect to learn some of the science upon which genetics research is based, and

participate in discussions around critical ethical, legal, and social implications of human genetics for communities and people of color and for environmental justice.

HOTEL INFORMATION: A block of rooms has been reserved at the **Empire Hotel** (<http://www.empirehotel.com>) at 44 West 63rd Street, between Broadway and Columbus Avenue in Manhattan. Please call **(888) 822-3555** and reference the "Genetics Conference" group rate. Reservations must be made by January 5th to receive the conference rate.

GENETICS 101 SESSION: On Sunday evening February 3rd, 2002, a Genetics 101 session will take place at the Empire Hotel from 6:00PM to 8:00PM. This session is free and open to the public, although RSVP's are requested. To RSVP, please contact the conference hotline at **(212) 961-1000, ext. 333** and leave a message, or address an e-mail message to **Conference@weact.org** with "Genetics 101 RSVP" in the subject line confirming your ability to attend.

PRELIMINARY PROGRAM

Last Updated: Tuesday, December 4th 2001

<http://www.weact.org/conference/>

8:30AM:	Continental Breakfast
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9:00AM:	Welcome: Regina Santella, Ph.D., Director, NIEHS Center for Environmental Health, and Peggy Shepard, Executive Director, West Harlem Environmental Action (WE ACT)
9:15AM:	Introductory remarks: Kenneth Olden, Ph.D., Director, NIEHS <i>“The Role of Gene-Environment Interaction in Health Disparities.”</i>
9:45AM:	Keynote: Troy Duster, Ph.D., Professor of Sociology, New York University <i>“Human Molecular Genetics and the Subject of Race: Contrasting the Rhetoric with the Practices in Law and Medicine”</i>

10:30AM:	Break
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10:45AM:	Plenary Session:
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Opportunities and Challenges of Genetics Research for Communities of Color and for the Environment

This panel will present an overview of both the opportunities and some specific ethical and social challenges posed by human genetics research for communities of color, including the role of genetics in disease causation, genetic reductionism, the meaning and implications of “race-based” genetics research, and concerns surrounding potential discrimination in the workplace.

ROOM:	Arledge Auditorium
MODERATOR:	TBA
SPEAKERS:	Paul Miller, Commissioner, Equal Employment Opportunity Commission Debra Harry, M.A., Indigenous People Council on Biocolonialism Charmaine Royal, Ph.D., National Human Genome Center at Howard University

12:00PM:	Luncheon
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1:00PM:	Breakout Sessions Part A (<i>Four Concurrent Sessions</i>)
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A1) What It’s All About: Human Genetics 101 and Gene-Environment Interactions

This session will provide a basic overview of genetic science, focusing on the interaction between genes and the environment in the causation and treatment of disease, on the Environmental Genome Project and on toxicogenomics.

ROOM:	Satow Room (Fifth Floor)
MODERATOR:	Regina Santella, Ph.D., Director, NIEHS Center for Environmental Health in Northern Manhattan
SPEAKERS:	Jose Morales, Ph.D. Public Interest Biotechnology

	<p>Monique Mansoura, Ph.D., National Human Genome Research Institute</p> <p>Jose Velasquez, Ph.D., National Institute of Environmental Health Sciences</p>
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A2) Genetic Testing on the Job? Genetics in the Workplace

Screening for genetic “predisposition” to occupational health hazards is already underway in some workplaces. This session will focus on the ethical and legal implications of genetic screening and monitoring in the workplace. The potential pitfalls of categorizing workers into categories of “high-risk” vs. “low-risk” will be discussed, and a case study of the recent legal action against Burlington Northern Santa Fe Railroad will be presented.

ROOM:	Cinema (Entrances on 2 nd and 3 rd Floors)
MODERATOR:	George Friedman-Jimenez, M.D., Bellevue Occupational Clinic
SPEAKERS:	<p>Paul Steven Miller, Ph.D., Commissioner, Equal Employment Opportunity Commission</p> <p>Eula Bingham, Ph.D., University of Cincinnati</p> <p>Paul Schulte, Ph.D., National Institute of Occupational Safety & Health</p>

A3) What Will This Test Tell Me? Genetic Testing, Genetic Counseling and Risk Communication

As the practice of medicine increases its ability to conduct genetic tests to determine individual or family risk for certain genetically influenced diseases, support structures are needed to ensure that this testing takes place in an ethically sound manner. These ethical implications and the unique needs of communities of color for genetic counseling will be discussed in this session, including a discussion on the need to increase representation of people of color in the field of genetic counseling.

ROOM:	569 / 570
MODERATOR:	Caroline Lieber, Sarah Lawrence College
SPEAKERS:	<p>Vivian Ota Wang, Ph.D., Arizona State University</p> <p>Kwame Anyane-Yeboah, M.D. Director of Clinical Genetics, Columbia University</p> <p>Ilana Mittman, M.A., Johns Hopkins School of Public Health</p>

A4) How Informed Can Consent Be? Participation of Communities and People of Color in Genetics Research

(First of two similar sessions, this session emphasizes the process of research. Followed by Session B2 at 3:00PM)

Various human genetics research projects are increasingly focusing on socially identifiable groups like communities of color or certain ethnic groups. The process of conducting research in communities of color raises a host of issues and challenges rooted in a historical context of lack of trust between communities of color and biomedical research. This session will explore questions like: What does “informed consent” mean for communities of color? How can both group rights and individual rights be respected during a genetics research project? What safeguards can be implemented to ensure that communities that are the “subjects” of research adequately benefit from this research?

ROOM:	555
MODERATOR:	Cecil Corbin-Mark, Program Director, West Harlem Environmental Action (WE ACT)
SPEAKERS:	Kim Nickerson, Ph.D., Director, Minority Fellows Program, American Psychological Association Richard Sharp, Ph.D., NIEHS Patricia A. Marshall, Ph.D., Case Western Reserve University

3:00PM: Breakout Sessions Part B (*Four Concurrent Sessions*)

B1) Is it Genes or is it the Environment? Community Environmental Health and Genetics.

This session will focus on the how community environmental health will be impacted by genetics research, including a discussion on the potential that genetic information has to redefine “susceptibility” to environmental exposures. Asthma will be presented as a case study of the complex interactions between genetics and environmental exposures in an illness that disproportionately affects people of color.

ROOM:	Satow (Fifth Floor)
MODERATOR:	Jose Morales, Ph.D. Public Interest Biotechnology
SPEAKERS:	John Pappas, M.D., New York University School of

	Agency
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B2) How Informed Can Consent Be? Participation of Communities and People of Color in Genetics Research

*(Second of two similar sessions, this session focuses on the potential use of genetic information to define group and individual identity. **Preceded by Session A4 at 1:00PM**)*

Various human genetics research projects are increasingly focusing on socially identifiable groups like communities of color or certain ethnic groups. The process of conducting research in communities of color raises a host of issues and challenges rooted in a historical context of lack of trust between communities of color and biomedical research. This session will explore questions like: What are the implications of the use of genetic information to define groups? Who gets to decide whether and how genetic information is used to define groups?

ROOM:	555
MODERATOR:	Sandra Soo-Jin Lee, Ph.D., Stanford University
SPEAKERS:	Charmaine Royal, Ph.D., National Human Genome Center at Howard University Vence Bonham, J.D., Michigan State University Debra Harry, M.A., Indigenous Peoples Council on Biocolonialism

B3) What Do People Really Think of This? Community Perceptions of Genetics Research

The first step to creating the policy infrastructure necessary to adequately address the ethical and social concerns around genetics research expressed by people of color and other communities is to create a space in which community residents can fully express those concerns. The results of focus groups conducted around the country will be presented, and community participants will be given the space to speak for themselves.

ROOM:	569 / 570
MODERATOR:	Vernice Miller-Travis, Ford Foundation
SPEAKERS:	Tene Hamilton, M.A., Tuskegee University Morris Foster, Ph.D., University of Oklahoma Yvonne Lewis, Faith Access to Community Economic Development

B4) Who is Regulating Genetics? Legislative, Policy, and Judicial Responses to Genetics Research

The current state of policy initiatives for regulating various aspects of genetics research will be presented in this session, focusing on the prevention of discrimination in insurance and medical care, the protection of individual privacy, and intellectual property rights, cloning, and inheritable genetic modifications.

ROOM:	Cinema (Entrances on 2 nd and 3 rd Floors)
MODERATOR:	TBA
SPEAKERS:	Paul Billings, Ph.D., Board of Directors, Council for Responsible Genetics Marcy Darnovsky, Exploratory Initiative on the New Human Genetic Technologies Jonathan King, Ph.D., Massachusetts Institute of Technology; Board of Directors, Council for Responsible Genetics

4:45PM: Plenary Session:

The Future of Human Genetics Research, Communities of Color, and Environmental Justice

ROOM:	Cinema (Entrances on 2 nd and 3 rd Floors)
MODERATOR:	TBA
SPEAKERS:	Deeohn Ferris, Global Environmental Resources Inc. Kathleen Rand Reed, geographic Genetic Systems.

5:30PM: Adjourn

This conference is supported in part by the **California Endowment**, **The StarFire Fund of the Philanthropic Collaborative**, and **The Warsh/Mott Legacy**.