



COLUMBIA UNIVERSITY

*College of Physicians
and Surgeons*



*Ethics of Genetics
in Research:
Perils and Promises*

Friday & Saturday, May 19 & 20, 2006



Program Description & Objectives

Rapid developments in genetic and genomic research present increasingly complex ethical, legal, social, and policy issues that challenge physicians, researchers, IRBs, public health workers, and others involved in the research enterprise. Most are not fully informed about the perplexing issues nor are many aware of the latest regulations and guidances. To meet this need, the National Institutes of Health's National Human Genome Research Institute (NHGRI) has awarded the Columbia University Center for Bioethics a grant to educate the research community on this very timely and important topic.

The Ethics of Genetics in Research: Perils and Promises, a state-of-the-art national conference, responds to the need for enhancing the knowledge and application of ethical principles to genetic and genomic research. Over one and a half-days, presenters will address emergent genetics research and its ethical and policy implications, as well as the newest regulations and policies pertaining to our topic. Plenary sessions and interactive workshops will promote the opportunity for information exchange and discussion of how to advance basic, translational, and clinical genetics research ethically.

At the end of this one and a half-day conference, participants should be able to:

- Understand the ethical issues for informed consent in genetic research
- Describe procedures to protect privacy and maintain the confidentiality of genetic information
- List examples of stigma or discrimination in the research or work setting
- Be knowledgeable about current federal and state regulations for genetic research
- Be familiar with the ethical issues involved in using genetic databases, registries, and the use of personal genetic identifiers
- Identify varied ethical issues of genetic research with diverse ethnic and cultural groups, as well as vulnerable and special populations such as women, newborns, children, and adolescents
- Identify ethical issues in genetics of behavioral and mental health research
- Describe the controversy about race as a genetic reality or social construct

Course Director

Ruth L. Fischbach, Ph.D., M.P.E.

Guest Faculty

Kathy L. Hudson, Ph.D., *Associate Professor and Director, Genetics and Public Policy Center, Berman Bioethics Institute & Institute of Genetic Medicine, Johns Hopkins University, Washington, D.C.*

Thomas H. Murray, Ph.D., *President & CEO, The Hastings Center, Garrison, New York*

Kenneth Offit, M.D., M.P.H., *Chief, Clinical Genetics Service, Memorial Sloan-Kettering Cancer Center; Professor, Medicine and Public Health, Weill Medical College, Cornell University, New York, New York*

Columbia University Medical Center Faculty & New York-Presbyterian Hospital Staff

- Lawrence Amsel, M.D., M.P.H.**, *Assistant Professor of Clinical Psychiatry; Director of Dissemination Research for Trauma Treatment and Studies; Associate for Medical Education at The Hastings Center*
- Ronald Bayer, Ph.D.**, *Professor of Public Health*
- Heather Butts, J.D.**, *Institutional Review Board (IRB), Regulatory Specialist*
- Mary Byrne, Ph.D., M.S., M.P.H., F.A.A.N.**, *Professor of Clinical Nursing*
- Wendy K. Chung, M.D., Ph.D.**, *Herbert Irving Assistant Professor of Pediatrics in Medicine; Director of Clinical Genetics*
- Amy Fairchild, Ph.D., M.P.H.**, *Assistant Professor; Assistant Director, Scholarly and Academic Affairs, Center for the History & Ethics of Public Health*
- Gerald D. Fischbach, M.D.**, *Executive Vice President for Health and Biomedical Sciences; Dean of the Faculty of Medicine; Hatch Professor; Professor of Pharmacology in the Center for Neurobiology and Behavior*
- Ruth L. Fischbach, Ph.D., M.P.E.**, *Professor of Bioethics; Director, Center for Bioethics*
- Robert Fullilove, Ed.D.**, *Professor of Clinical Sociomedical Sciences; Associate Dean for Community and Minority Affairs; Co-Director of the Community Research Group*
- George Gasparis**, *CUMC Institutional Review Board (IRB) Executive Director*
- Deborah S. Hasin, Ph.D.**, *Professor of Clinical Public Health*
- Robert Klitzman, M.D.**, *Associate Professor of Clinical Psychiatry*
- Marianne J. Legato, M.D.**, *Professor of Clinical Medicine; Founder and Director of the Partnership for Gender-Specific Medicine*
- Rudolph L. Leibel, M.D.**, *Professor of Pediatrics and Medicine; Head, Division of Molecular Genetics; Co-Director, Naomi Berrie Diabetes Center*
- Barron H. Lerner, M.D., Ph.D.**, *Angelica Berrie Gold Foundation Assistant Professor of Medicine & Public Health*
- Karen S. Marder, M.D., M.P.H.**, *Kerlin Professor of Neurology in the Gertrude H. Sergievsky Center and the Taub Institute*
- Ruth Ottman, Ph.D.**, *Professor of Epidemiology in Neurology and the Sergievsky Center*
- Victor B. Penchaszadeh, M.D., M.Sc.**, *Professor of Genetics and Public Health*
- Ruby Senie, Ph.D.**, *Professor of Epidemiology and Sociomedical Sciences*
- Scott A. Small, M.D.**, *Herbert Irving Assistant Professor of Neurology*
- Zena Stein, M.D.**, *Professor Emeritus in Public Health; Special Lecturer in Epidemiology*
- David H. Strauss, M.D.**, *Associate Clinical Professor of Psychiatry; Chairman, Institutional Review Board; Director, Office of Human Subjects Research*
- Dorothy Warburton, Ph.D.**, *Professor of Clinical Genetics & Development*
- Myrna Weissman, Ph.D.**, *Professor of Psychiatry and Epidemiology; Chief, Division of Clinical and Genetic Epidemiology*
- Nancy Wexler, Ph.D.**, *Higgins Professor of Neuropsychology; President, Hereditary Disease Foundation*



Friday, May 19, 2006

- 7:00 a.m. *Registration; Continental Breakfast*
- 8:00 a.m. Welcome & Introduction
Ruth L. Fischbach, Ph.D., M.P.E.
- 8:20 a.m. KEYNOTE ADDRESS:
Genetics Policy: Progress or Paralysis
Kathy L. Hudson, Ph.D.
- Panel I - Basic Issues: What You Need to Know**
Moderator: Ruth L. Fischbach, Ph.D., M.P.E.
- 8:50 a.m. Key Issues in Informed Consent in Genetic Research
David H. Strauss, M.D.
- 9:05 a.m. Genetic Privacy, Stigma, and Discrimination
Lawrence Amsel, M.D., M.P.H.
- 9:20 a.m. Issues in Family/Pedigree Studies
Ruth Ottman, Ph.D.
- 9:35 a.m. Panel Discussion
- 10:00 a.m. *Refreshment Break*
- Panel II**
Genetic Research: Considerations with Special Populations
Moderator: John Loike, Ph.D.
- 10:10 a.m. Genetic Research in Communities and Across Cultures
Victor B. Penchaszadeh, M.D., M.Sc.
- 10:25 a.m. Genetic Research Involving Newborns, Children, and Adolescents
Wendy K. Chung, M.D., Ph.D.
- 10:40 a.m. Genetic Research in Mental Illness
Myrna Weissman, Ph.D.
- 10:55 a.m. Panel Discussion
- 11:20 a.m. *Commuting Time*
- 11:35 a.m. **Morning Workshops**
1. Informed Consent in Genetic Research
Barron H. Lerner, M.D., Ph.D.,
David H. Strauss, M.D. &
Jennifer Williamson-Catania, M.S.
 2. Genetic Privacy, Stigma, and Discrimination
Lawrence Amsel, M.D., M.P.H. &
Robert Klitzman, M.D.
 3. Genetic Research Involving Newborns, Children, and Adolescents
Mary Byrne, Ph.D., M.S., M.P.H., F.A.A.N. &
Wendy K. Chung, M.D., Ph.D.
 4. Genetic Databases, Registries, and the Use of Genetic Identifiers
Ronald Bayer, Ph.D. &
Amy Fairchild, Ph.D., M.P.H.

Friday, May 19, 2006 (Continued)

Morning Workshops (Continued)

5. Genetic Testing and Population Identity:
Ethnic Groups & Other Special Populations
**Karen S. Marder, M.D., M.P.H. &
Ruby Senie, Ph.D.**

6. Is Race a Genetic Reality or a Social Construct?
Robert Fullilove, Ed.D.

1:00 p.m. LUNCH AND SPECIAL PRESENTATION:
Ethical and Legal Challenges in
Researching Cancer Genetics
Kenneth Offit, M.D., M.P.H.

**Panel III - Hot Spots in Ethics of Genetic
Research: Genetics of Obesity, Genetic Testing in
the Workplace, and Genetic Research on Alcohol
and Drug Use**
Moderator: Joyce Plaza, M.S., M.Be.

2:15 p.m. Genetics of Obesity
Rudolph L. Leibel, M.D.

2:35 p.m. Genetic Testing in the Workplace
Thomas H. Murray, Ph.D.

2:55 p.m. Genetic Research on Alcohol and Drug Use:
From Abstinence to Dependence
Deborah S. Hasin, Ph.D.

3:15 p.m. Panel Discussion

3:40 p.m. *Refreshment Break & Commuting Time*

3:55 p.m. **Afternoon Workshops**

1. Role of the IRB in Protecting Participants,
Families, and Communities
George Gasparis

2. First, Do No Harm: Are There Boundaries of
Genetic Research Beyond Which We Should
Not Go?
**Thomas H. Murray, Ph.D. &
Ruth Ottman, Ph.D.**

3. Neurogenetic Challenges: Prevention of Harm and
Protection of the Vulnerable
Nancy Wexler, Ph.D.

4. Genetic Research in Communities and
Across Cultures
**Victor B. Penchaszadeh, M.D., M.Sc. &
Gladys Maestre, M.D., Ph.D.**

5. What Should IRBs Consider When Reviewing a
Protocol in Which Race will be Identified?
**Heather Butts, J.D., M.P.H., M.S.
Ruth L. Fischbach, Ph.D., M.P.E.**

6. Genetic Enhancement
**Robert Klitzman, M.D. &
Jennifer Williamson-Catania, M.S.**

5:15 p.m. *Adjourn*

Saturday, May 20, 2006

- 8:15 a.m. *Registration; Continental Breakfast*
- 9:00 a.m. KEYNOTE ADDRESS:
Conducting Genetic Research Abroad
Zena Stein, M.D.
- Panel IV-**
Issues in Genetics and Genomics of
Women's Health
Moderator: Ruth L. Fischbach, Ph.D., M.P.E.
- 9:30 a.m. Genetics and Pregnancy Loss
Dorothy Warburton, Ph.D.
- 9:50 a.m. Gender Specific Differences in Heart Function and
Bone Metabolism
Marianne J. Legato, M.D.
- 10:10 a.m. Panel Discussion
- 10:40 a.m. *Refreshment Break*
- Panel V-**
Issues in the Genetics of Behavioral and
Mental Health Research
Moderator: Robert Klitzman, M.D.
- 10:55 a.m. Genetics of Dementia
Scott A. Small, M.D.
- 11:15 a.m. Genetics of Autism as a Window into the Future
Gerald D. Fischbach, M.D.
- 11:35 a.m. Panel Discussion and Closing Remarks
- 12:00 p.m. *Adjourn*

Additional Information

Contact: Center for Continuing Medical Education
Columbia University College of Physicians & Surgeons
630 West 168th Street, Unit 39
New York, NY 10032
Telephone: (212) 305-3334
Fax: (212) 781-6047
e-mail: cme@columbia.edu
<http://columbiacme.org>

Acknowledgements

The co-sponsorship with Public Responsibility in Medicine and Research (PRIM&R) is gratefully acknowledged.

This conference is supported by a conference grant to the Columbia University Center for Bioethics from the National Institutes of Health (NIH) National Human Genome Research Institute (NHGRI), Grant Number 1R13HG003943-01.

Meeting Location

Hammer Health Sciences Building
Columbia University Medical Center
701 West 168th Street at Fort Washington Avenue
Room 401
New York, New York 10032

Discounted parking is available at the Columbia University Medical Center parking lot, located on the southwest corner of Fort Washington Avenue and West 165th Street.

Hotel Accommodations

A block of rooms has been reserved at On the Ave Hotel, at the special rate of \$225 per night, plus state & local taxes. These special room rates are available to the course attendees from May 18-20, 2006. Other rates and conditions may apply. Additional information can be obtained by calling On the Ave Hotel directly.

Reservations must be made directly with On the Ave Hotel. To receive this room rate, remember to mention that you are a registrant of the Columbia University Ethics in Genetics course.

Rooms will be held until April 18, 2006 or until the room block has been exhausted, whichever comes first. Reservations received after the cut-off date are subject to availability and prevailing rates.

On The Ave Hotel
2178 Broadway at 77th street
New York, NY 10024

(800) 497-6028
(212) 362-1100
Cut-Off: April 18, 2006

Accreditation/Designation of Credit

The College of Physicians and Surgeons of Columbia University is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

The College of Physicians and Surgeons designates this educational activity for a maximum of 10.5 *AMA PRA Category 1 Credit(s)*TM. Physicians should only claim credit commensurate with the extent of their participation in the activity.

The American College of Nurse Practitioners (ACNP) and the American Academy of Physician Assistants (AAPA) accept AMA/PRA category 1 credit from organizations accredited by the ACCME.

The American Nurses Credentialing Center (ANCC) accepts AMA/PRA category 1 credit toward recertification requirements.

Disclosure

Before the program, all faculty will disclose the existence of any financial interest and/or other relationship(s) (e.g., employee, consultant, speaker's bureau, grant recipient, research support, stock ownership, or any other special relationship) they might have with a) the manufacturer(s) of any commercial product(s) to be discussed during their presentation and/or b) any commercial contributor to this activity. When unlabeled uses are discussed, these will also be indicated.

Tuition

Professionals: \$100; Students: \$35; Residents and Fellows: \$35 (with a letter from program director certifying status). The fee includes the academic presentations, daily continental breakfast, lunch, refreshments, and the course syllabus. Confirmation of registration and directions to the Medical Center will be sent upon receipt of the registration form. Refund of registration fee, less a \$25 administrative charge, will be made if written notice of cancellation is received by **May 9, 2006**. No refunds can be made thereafter.

Registration

Space is Limited.

Early Registration is Encouraged.

By Mail:

Complete the registration form and mail with full payment to:

**Columbia University
College of Physicians & Surgeons
Center for Continuing Medical Education
630 West 168th Street, Unit 39
New York, NY 10032**

By Fax:

Registrants may fax the registration form with credit card information to:

(212) 781-6047

On-Line:

<http://columbiacme.org>

**Telephone registrations and/or
telephone cancellations are not accepted.**

Americans with Disabilities Act

The Columbia University College of Physicians and Surgeons fully complies with the legal requirements of the ADA and the rules and regulations thereof. Any participant with special needs should submit a written request to our office at least one month prior to the course date.

Registration Form

COLUMBIA UNIVERSITY

Genetics

(Please print or type)

Last Name Degree

First Name Middle Initial

Address

City State Zip

Daytime Phone Daytime Fax

e-mail

Institution

Specialty/Area of Interest

PARKING I will I will not require parking

WORKSHOP SESSIONS

Morning Workshop 11:35 a.m.
1st Choice _____ 2nd Choice _____

Afternoon Workshop 3:55 p.m.
1st Choice _____ 2nd Choice _____

- \$100 Professionals Psychiatry PM 99
May 19 & 20, 2006
10881/10.5
- \$35 Students
- \$35 Residents & Fellows (with a letter from program director)

Enclosed is a check or money order made payable to
Columbia University.
Checks must be in U.S. Dollars drawn on a U.S. bank.
Money orders must be in U.S. Dollars.

Please charge to: MasterCard Visa

Exp. Date _____

Card Number _____

Cardholder's Name _____

Cardholder's Signature _____

How did you learn of this course? Mailed Brochure Word of Mouth

e-mail _____

Poster/Flyer; specify _____

Website; specify _____

Other; specify _____



Columbia University
College of Physicians & Surgeons
630 West 168th Street, Unit 39
New York, New York 10032

*Ethics of Genetics
in Research:
Perils and Promises*

May 19 & 20, 2006