

Conference Overview

This is the tenth anniversary conference in an annual series that addresses current ethical and legal issues related to genetics. The focus of this year's conference is direct to consumer marketing of genetic services and genetic tests, using as a model Myriad's campaign to inform the public and encourage them to consult their doctor about genetic testing for breast and ovarian susceptibility. Over the next few years policy decisions will almost certainly be made in this area, making the topic both timely and of high impact. Conference attendees will explore the scientific and ethical concerns about the risk of misinformation or misuse of direct-marketed genetic tests, concerns compounded by the pressures of the marketplace and consumer choice. The conference will culminate in a mock exercise that convenes attendees as a regulatory committee representing the disparate opinions of stakeholders' from industry, health care systems and consumers. The charge of the committee is to make recommendations for legislative proposals and policy options concerning the optimum conduct of future direct to consumer marketing campaigns. All attendees will have the opportunity to participate actively in all phases of the conference.

This broadly-based conference targets health care professionals and physicians, researchers, businesses, ethicists, attorneys, ethics committee members, institutional review board members, and individuals interested in the impact of genetic medicine on personal and institutional action.

Course Registration

DIRECT TO CONSUMER MARKETING OF GENETIC SERVICES AND GENETIC TESTS
July 22 - 24, 2005

Register on-line at: www.uchsc.edu/cme and click on the "Register Now" button. Payment by Visa or Mastercard is required to register on-line. When you register on-line, you will receive immediate confirmation of your conference registration. (This site uses industry-standard Secure Sockets Layer (SSL) encryption technology to protect your credit card information.)

Last Name _____ First _____ MI _____
(print name as you'd like it to appear on your CME certificate or certificate of attendance)

Degree: M.D. D.O. Ph.D. J.D. Other _____

Specialty _____

Address _____

Zip _____ City _____ State _____

Office Phone No. _____ Fax No. _____

E-Mail _____

(We will not provide your email address to anyone outside the Office of CME.)

Registration:	On or Before 6/3/05	After 6/3/05	Student Fee*
	\$275	\$325	\$150
Total Due: \$	_____		

Enclosed is my check made payable to: University of Colorado School of Medicine

Visa MasterCard

Credit Card Number _____ Exp. Date _____

Cardholder Signature _____

(Only registrations with credit card payments are accepted by fax, phone and on-line registration. We will accept registrations through Friday, July 15; thereafter, you may register onsite.)

 If you have a disability and may require accommodation in order to fully participate in this activity, please be sure to notify Mary Lou Wallace of your special needs.

Mail to: Genetics & Ethics, UCHSC • 4200 E. 9th Avenue, B137
Denver, CO 80262 • Or Fax to: 303-315-0820

General Information

THE GIVEN INSTITUTE

The program will be held at The Given Institute, a very comfortable and pleasant site for a meeting. The building, specially constructed for this purpose in 1973, is surrounded by beautifully landscaped grounds, which are used for informal discussion and social events. The Institute is located at 100 E Francis St., at the corner of Garmisch & E. Francis Streets, 3 blocks north of Highway 82. Visit: www.giveninstitute.org The telephone number during conference meeting times only is 970-544-6000; to leave a voice message: 970-925-1057.

ASPEN, COLORADO

Aspen is located 200 miles west of Denver at an elevation of 7,900 feet, in the midst of the White River National Forest, near some of the most spectacular scenery in Colorado. Aspen may be reached from Denver by automobile via Routes 285, 24, and 82 which is a breathtaking ride over Independence Pass (approximately 3.5 hours), or via Glenwood Springs on Interstate 70 and Route 82 (approximately 4 hours). Colorado weather features warm days, cool evenings and occasional late afternoon showers. Bring clothing suitable for temperature ranges between 55-85 degrees. Casual wear is appropriate and encouraged. Sunglasses and sunblock are advised. Please be sure to bring an umbrella or raingear for occasional afternoon rain showers.

ASPEN ACTIVITIES

For information on Aspen activities visit: www.aspenchamber.org or www.snowmassvillage.com

TRANSPORTATION

We are pleased to work with CJ Rigsby of Aspen Ski Tours, who has a track record of getting people to and from Aspen at great savings. Parent Company, Ski.Com has its own contracted discount (bulk) airfares with all major airlines. To assist you with your air travel or any transportation needs, please contact CJ at 800-332-7736, ext. 212, or by email at cj@ski.com.

ACCOMMODATIONS

Please reference the Genetics & Ethics Conference, University of Colorado when calling for reservations.

Hotel Aspen: 2 blocks from The Given Institute. Contemporary classic offers a variety of room types, some with jacuzzis, balconies, solariums, outdoor pool and hot tub. Breakfast included. Rates from \$159. Room block released June 23. 800-527-7369

Molly Gibson Lodge: 2 blocks from The Given Institute. A variety of room types, some with jacuzzis, fireplaces, kitchens, courtesy shuttle to and from the airport, complimentary continental breakfast, and wireless internet service. One-speed bicycles available for use. Rates starting at \$157 if you book directly. 800-356-6559 To take the virtual tour of the property, visit www.mollygibson.com but to receive the group rate, please call the Lodge directly.

For additional lodging information, telephone Aspen Central Reservations at 970-925-9000, www.aspen4u.com or www.snowmassvillage.com

There are many events occurring in Aspen during this time, so your early decision regarding lodging and airline reservations is strongly advised.

ACCREDITATION

CLE Credit: This course has been accredited by the Colorado Board of Continuing Legal and Judicial Education for a maximum of 11 units of credit (11 general units, 7 of which are ethics units).

CEU: An application for CEU credits has been submitted to the American Board of Genetic Counseling.

FEES

Fees include Friday evening reception, refreshments, Saturday lunch, syllabus materials and a non-refundable administrative charge of \$50. All fees are due in advance; registrations will not be accepted without payment. Only registrations with credit card payments will be accepted by fax, phone and on-line registration. We will accept registrations through Friday, July 15; thereafter, you may register on-site.

On or before June 3, '05	Postmarked after June 3, '05	Student Fee*
\$275	\$325	\$150

Cancellation: Through Thursday, July 7, a full refund, less the \$50 administrative fee, will be made for cancellations. No refunds will be granted after July 7 or for non-attendance. The conference committee reserves the right to cancel this conference in the event of an unforeseen circumstance, or if the minimum acceptable registration is not attained. In the event of a cancellation the Office of CME is obligated to refund the registration fee only.

*Proof of student status must be presented at check-in registration.



For Additional Information:

Call Mary Lou Wallace: 303-315-5096 or Marilyn Coors: 303-315-0203, University of Colorado at Denver and Health Sciences. Visit our website for links to Aspen/Snowmass websites and register on-line: www.uchsc.edu/cme

Schedule



Friday, July 22, 2005

PM

- 12:00 Registration
 1:30 **Welcome and Opening Remarks:**
Richard Spritz, M.D., F.A.C.M.G.
Mark Yarborough, Ph.D.
 1:15 **The Science and Applications of Genetic Testing**
Edward McCabe, M.D., Ph.D.
 2:30 **Human Genome: Commerce and Genetic Testing**
Brad Popovich, MSc., Ph.D., F.A.C.M.G.
 3:45 Break
 4:15 **Ethics of Commercializing Genetic Testing and DTC Advertising**
Benjamin Wilfond, M.D.
 5:15 Reception

Saturday, July 23, 2005

AM

- 9:00 **Government Regulation of Genetic Testing**
Carol Greene, M.D.
 9:30 **Ethics and Marketing: Review of the Profession's Code of Ethics**
Jeff P. Julin, APR
 10:00 **Marketing BRCA Testing or Alarming the Worried Well in Atlanta and Denver**
Andy Faucett, M.S., C.G.C.
 10:30 Break
 11:00 **Panel Dialogue: Personal Choice: Consumer, Professional and Industry View**
Patrick Terry, Benjamin Wilfond, M.D., Edward McCabe, Ph.D.
 12:00 Lunch
 1:00 **Mock Exercise: Direct-to-Consumer Genetic Testing: Stakeholder Positions and Regulatory Decision-making. Formulation of Stakeholders Positions**
 2:00 **Begin Mock Exercise (TBA)**
 3:00 Adjourn

Sunday, July 24, 2005

AM

- 9:00 **Finalize Stakeholders' Positions**
 9:45 Break
 10:00 **Presentation of Stakeholders' Positions at Regulatory Meeting and Decisions**
 11:30 Adjourn

Learning Objectives

After attending this conference, participants should be able to:

- ▲ Realize the impact of public and private interests and resources on genetic test development and on access to information about genetic testing.
- ▲ Describe the roles of "commercial" forces on the marketing of genetic testing to health care providers and to the public.
- ▲ Develop an appreciation of the tensions that arise when public responsibility for safety in genetic testing appears to conflict with free personal/individual choice in testing options.
- ▲ Evaluate the potential benefits and risks of various approaches for educating health care providers and the public about genetic tests.

Genes, Race and Ethnicity July 22-24, 2005


Guest Faculty

Andy Faucett, M.S., C.G.C.
 Director, Genomics and Public Health Program, and Emory University School of Medicine
 ORISE Fellow
 Centers for Disease Control & Prevention
 Carol Greene, M.D.
 Director, Clinical Genetics and Metabolism, and Medical Director, Masters in Genetic Counseling Training Program
 University of Maryland School of Medicine
 Jeff P. Julin, APR
 President
 MGA Communications, Inc.
 Edward McCabe, M.D., Ph.D.
 Director, Human & Molecular Development Training Program
 UCLA School of Medicine
 Brad Popovich, MSc., Ph.D., F.A.C.M.G.
 Vice President for Operations
 Xenon Pharmaceuticals, Inc.
 Benjamin Wilfond, M.D.
 Adjunct Associate Professor
 Department of Health Management and Policy
 Johns Hopkins Bloomberg School of Public Health
 Patrick Terry
 President, PXE International, Inc.
 Director of Consumer Advocacy, Genomic Health, Inc.
 Secretary and Member, Board of Directors, Personalized Medicine Coalition

Faculty

University of Colorado at Denver and Health Sciences Center Faculty

Marilyn Coors, Ph.D.
 Assistant Professor
 Center for Bioethics and Humanities
 Paul Spicer, Ph.D.
 Associate Professor of Psychiatry
 American Indian & Alaska Native Programs
 Richard A. Spritz, M.D., F.A.C.M.G.
 Professor and Director
 Human Medical Genetics Program
 Mark Yarborough, Ph.D.
 Associate Professor and Director
 Center for Bioethics and Humanities

 **University of Colorado at Denver and Health Sciences Center**
 Center for Bioethics & Humanities
 4200 East Ninth Avenue, B137
 Denver, Colorado 80262



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10th Annual Genetics & Ethics in the 21st Century

July 22-24, 2005
 The Given Institute of the University of Colorado
 Aspen, Colorado



PRESENTED BY:
 University of Colorado at Denver and Health Sciences Center
 The Human Medical Genetics Program
 Center for Bioethics and Humanities
 Office of the Chancellor

EDUCATIONAL SUPPORT:
 Affymetrix, Inc.
 Alpha-1 Foundation

Direct to Consumer Marketing of Genetic Services and Genetic Tests

This program is part of the Colorado State wide Extended Campus. State funds were not used to develop or administer this program.