

3RD ANNUAL INTERNATIONAL

Bioethics F O R U M

APRIL 22-23, 2004 • BIOPHARMACEUTICAL TECHNOLOGY CENTER • MADISON, WI

WHO KNOWS?
WHO SHOULD
KNOW?

Welcome to the World
of Genetic Testing!

Overview

Focusing on genetic testing, as relevant to human health issues, keynote presentations and break-out sessions are designed to facilitate participants' understanding of:

- How are genes identified and analyzed? How are genes associated with human health conditions? What do these genes really tell us?
- Ethical issues related to genetic testing
- The diversity of viewpoints regarding these issues and the complexities involved in understanding both the scientific and social dimensions of genetic testing.

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Center for Biology Education, UW-Madison
Department of Medical History and Bioethics, UW-Madison
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Schedule of Events

Thursday, April 22, 2004

- 8:00am Registration and Continental Breakfast
8:30am Welcome - *William Linton*
Moderator: *Todd McVey*
8:45am Genetic Testing: The Issues from a Global Perspective - *Henry T. Greely*
9:45am Privacy and Genetics - *Robyn S. Shapiro*
10:45am Break
11:00am Concurrent sessions:
a. The Right Not to Know - *Ryan Spellecy*
b. Stem Cells and Genes: What's the Connection? - *Nancy Block*
c. Diagnosis and Treatment of Genetic Diseases - *Dr. David Wargowski*
Lunch
12:15pm Targeting Drugs by "Race": What's at Stake in Human Genetic Variation Research? - *Barbara A. Koenig*
2:15pm Reflections from Diverse Faith Perspectives - *Father Razz Waff, Imam Ronald Beyah, John Dunne and Rabbi Andrea Steinberger*
3:45pm Reception

Friday, April 23, 2004

- 8:00am Continental breakfast
8:30am Ethics and the Use of Pre-implantation Genetic Diagnosis: From Avoiding Disease to Creating Donors - *Jeffrey P. Kahn*
9:30am The U.S. Supreme Court and the Future of Morals Legislation - *R. Alta Charo*
10:30am Break
10:45am Concurrent sessions:
a. Genetic Counselors: Our Purpose and How We Work - *Catherine A. Reiser*
b. Finding a Gene: Current Technologies - *Sandra Splinter M. BonDurant, Rick Salatino, and Eric B. Vincent*
c. Genetic Enhancement: Where Do We Draw the Line Between Treatment and Enhancement? - *Thomas May*
12:00pm Lunch: Chat Circles [pre-registration required]
a. *Imam Ronald Beyah and John Dunne*
b. *Henry T. Greely*
c. *Jeffrey P. Kahn*
d. *Barbara A. Koenig*
e. *Thomas May*
f. *Catherine A. Reiser*
g. *Dr. David Wargowski*
1:30pm Closing Panel: What Does the Future Hold? - *Henry T. Greely, Jeffrey P. Kahn and Barbara A. Koenig*
2:30pm Closing Reception

NOTE: For those interested in participating in a laboratory activity, an additional opportunity is offered: "PCR for Genetic Testing," scheduled for 3:00–4:15pm on Friday. There is no extra charge, but registration is limited to 72 participants and pre-registration is required.

Keynote Speakers

Imam Ronald Beyah is a Chaplain at Dodge Correctional Institution, Waupun, WI.

R. Alta Charo, J.D. is the Elizabeth S. Wilson - Bascom Professor of Law and Bioethics at the University of Wisconsin Law and Medical Schools and the Associate Dean for Research and Faculty Development at the University of Wisconsin Law School.

John Dunne, Ph.D. is an Assistant Professor in the Department of Languages and Cultures of Asia at UW-Madison.

Henry T. Greely, J.D. is the C. Wendell and Edith M. Carlsmith Professor of Law and serves as Codirector of the Stanford Program on Genetics, Ethics, and Society at Stanford University.

Jeffrey P. Kahn, Ph.D., MPH is the Director of the Center for Bioethics and Maas Family Chair in Bioethics at the University of Minnesota. He is also a Professor in the Department of Medicine, School of Medicine; Division of Health Services Research and Policy, School of Public Health; and Department of Philosophy at UM.

Barbara A. Koenig, Ph.D. is an Associate Professor in the School of Medicine at Stanford University.

William Linton is the Chairman & CEO of Promega Corporation, an international biotechnology firm headquartered in Madison, WI.

Todd McVey is the Community Relations Director for HospiceCare Inc., Madison, WI.

Robyn S. Shapiro, J.D. is the Director of the Center for the Study of Bioethics and the Ursula Von der Ruhr Professor of Bioethics at the Medical College of Wisconsin. She is also the Director of the Health Care Practice Group for Michael Best & Friedrich, LLP, Milwaukee, WI.

Rabbi Andrea C. Steinberger serves the Hillel Foundation, The University of Wisconsin, Madison, WI.

Father Razz Waff, D.Min., B.C.C. is the Director of Pastoral Care and Ethics for Vista Health, Waukegan, IL.

Concurrent Sessions: Descriptions

Thursday, April 22, 2004

a. The Right Not to Know

Ryan Spellecy, Ph.D. is an Assistant Professor of Bioethics, Center for the Study of Bioethics, at the Medical College of Wisconsin.

Genetic knowledge, unlike other medical knowledge, inherently has ramifications for others; we inherit and pass on our genes. Ethically, are we obligated to learn as much as we can about our own genetic makeup? Do we have obligations to assist others in obtaining such information? Or, can we choose not to know? This session will use cases, as well as discuss issues of autonomy and informed consent, to address this question.

b. Stem Cells and Genes: What's the Connection?

[to be determined]

c. The Hows, Whys, and Why Nots of Genetic Diagnosis and Treatment

Dr. David S. Wargowski is a physician with UW Health, specializing in Pediatric Genetics & Metabolism at the University of Wisconsin Children's Hospital.

The prospect of applying genetic testing to a broader range of more common medical conditions is 'raising the stakes' and has brought this process more squarely into the public dialogue. This session will include review of the various approaches medical geneticists use currently to diagnose and treat genetic disorders, with attention to the limitations, benefits and risks associated with these processes.

Special Announcements for Teachers...

Funded in part by Madison Area Technical College (MATC) and the Wisconsin Department of Public Instruction, there are fifteen \$120.00 stipends available for teachers attending this year's forum. Approved in the past, an application for CEU credits has been submitted. For more information, please contact Karin Borgh (karin.borgh@promega.com).

... and for Attorneys and Chaplains:

CLE and CCE credits have also been applied for — please visit www.btc.org for updates.

Friday, April 23, 2004

a. Genetic Counselors: Our Purpose and How We Work

Catherine A. Reiser, MS, CGC is the Director of the Genetic Counseling Training Program at UW-Madison.

Genetic Counselors receive specialized training to assist families with decision making around genetic testing. The genetic counselor functions as an educator, advocate and support person. Case scenarios and discussion will be used to illustrate problems and approaches.

b. Finding a Gene: Current Technologies

Sandra Splinter M. BonDurant, Ph.D. is an Assistant Researcher at the University of Wisconsin Biotechnology Center, UW-Madison. Rick Salatino, M.S. is a Technical Training Manager and Eric B. Vincent, Ph.D. is a Technical Services Scientist, both employed by Promega Corporation, Madison, WI.

Are you curious about the methods scientists use to identify genes and determine their functions? Two techniques currently favored by many in the life science community will be discussed: SNP detection (Single Nucleotide Polymorphism - used to determine the genotype of an individual at one specific locus) and microarray analysis (used to screen for many genes in a single test).

c. Genetic Enhancement: Where Do We Draw the Line Between Treatment and Enhancement?

Thomas May, Ph.D. is an Associate Professor of Bioethics and Director of the Graduate Program in Bioethics, Center for the Study of Bioethics, at the Medical College of Wisconsin.

This session will explore the difficulties faced in drawing a line between genetic enhancement and treatment. Specific issues addressed include the purposes that such a distinction might serve, and possible problems of justice raised by attempts to draw this distinction.

“PCR for Genetic Testing” Lab Activity (3:00–4:15pm)

Barbara Bielec, M.S., Kristen Jenkins, Ph.D. and Amy Prevost, M.S. are Education Specialists for BTCI.

Participants will perform polymerase chain reaction (PCR), a powerful technique that has revolutionized the life sciences. Through discussion and hands-on lab work, they will increase their understanding of the scientific concepts key to PCR, as well as how it is utilized in genetic testing. Scientists and non-scientists welcome; pre-registration required.

In conjunction with the *Third Annual International Bioethics Forum*, the Center for Biology Education and the University of Wisconsin Biotechnology Center are co-hosting a panel discussion on the UW-Madison campus. Focused on the forum's theme, "Who Knows? Who Should Know? Welcome to the World of Genetic Testing!," R. Alta Charo will serve as the moderator and be joined by keynote speakers Henry T. Greely and Barbara A. Koenig. This event is open to the public and free of charge.

Thursday, April 22, 2004 7:00–8:30pm
Genetics/Biotechnology Center Auditorium
425 Henry Mall, UW-Madison

For event details, please visit: www.btc.org

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Bioethics FORUM

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Registration Form

On-line registration option also available: www.btc.org

Name: _____

Address: _____

City: _____ State: _____

Zip Code: _____ Country: _____

Phone: _____ Fax: _____

E-mail: _____

Profession: _____

Registration Fee: \$65.00

Please make check out to: **Bioethics Forum/BTCI**

Visa Mastercard

Card Number: _____

Expiration Date: _____

Please indicate your **1st** and **2nd** choices for the **Concurrent Sessions**:

Thursday	Friday
_____ a. Right Not to Know	_____ a. Genetic Counselors
_____ b. Stem Cells and Genes	_____ b. Finding a Gene
_____ c. Genetic Diseases	_____ c. Genetic Enhancement

Friday Noon Chat Circle Registration:

Chat circles are limited to 15 people. Please indicate your top two choices. Chat circles will be filled on a first come, first served basis.

_____ a. Imam Ronald Beyah and John Dunne	_____ b. Henry T. Greely
_____ e. Thomas May	_____ f. Catherine A. Reiser
_____ c. Jeffrey P. Kahn	_____ g. Dr. David Wargowski
_____ d. Barbara A. Koenig	

Friday, 3:00–4:15pm “PCR for Genetic Testing”

Lab Activity

Yes No

Send completed form to:

BTCI

**5445 East Cheryl Parkway
Madison, WI 53711**

For more information please visit: www.btc.org or call: **608-273-9737**.

Registration and discussion session assignments will be confirmed by postcard prior to the forum.