Whitehead Policy Symposium

The Human Genome Project: Science, Law, and Social Change in the 21st Century

Cambridge, Massachusetts
April 23-24, 1998

More than 800 people attended the Whitehead Institute's national policy symposium, "The Human Genome Project: Science, Law, and Social Change in the 21st Century," on April 23 and 24, 1998 in Cambridge, Massachusetts. The symposium, co-sponsored by the American Society of Law, Medicine & Ethics (ASLME), was one of the largest and most diverse science policy programs ever held in the United States.

The audience included attorneys; justices from state and federal courts; more than 100 consumers; physicians; nurses; genetic counselors; professors from schools of law, medicine, and public health; state legislators; students; clergy; high school teachers; business leaders; and scientists. Reporters covered the meeting for *The Boston Globe*, National Public Radio, *The Dallas Morning News*, *U.S. News and World Report*, *The Atlantic Monthly*, *Scientific American*, Black Talk Radio, and more than a dozen other news outlets.

In addition to media coverage, follow-up included a special conference CD-ROM containing edited plenary talks with slides, syllabus materials, and relevant web links; a commentary for *Nature Genetics* written by Drs. David C. Page and Philip R. Reilly; and a special issue of ASLME's *Journal of Law, Medicine, and Ethics* (scheduled for fall release). Whitehead and ASLME also have provided assistance to other organizations seeking to develop programs on genetics and public policy and they have initiated new programs of their own.

The Whitehead/ASLME symposium was supported in part by the Alfred P. Sloan Foundation; the Institute for Civil Society; the Office of Biological and Environmental Research of the U.S. Department of Energy; and the Ethical, Legal, and Social Implications Research Program of the National Human Genome Research Institute, National Institutes of Health.

Other supporting organizations included Biogen, Inc.; Bristol-Myers Squibb Company; Coopers & Lybrand L.L.P.; Epstein, Becker & Green; Genzyme Corporation; Hamilton, Brook, Smith & Reynolds, P.C.; Kendall Strategies, Inc.; LEK/Alcar; Massachusetts Bar Association; Massachusetts Biotechnology Council; Massachusetts Department of Public Health; McDermott, Will & Emery; Medical Science Systems, Inc.; Millennium Pharmaceuticals, Inc.; Museum of Science (Boston); Ropes & Gray; and Sametz Blackstone Associates, Inc.

The Whitehead Institute and ASLME are grateful for all support. This support enabled us to mount a major outreach campaign, resulting in registration levels that to our knowledge far exceeded that of any previous science policy symposium on human genetics.

February 17, 2000

Background

Advances in the biomedical sciences, especially in human genomics, will dramatically influence law, medicine, public health, and many other sectors of our society in the decades ahead. The public already senses the revolutionary nature of genomic knowledge. In the United States and Europe, we have seen widespread discussions about genetic discrimination in health insurance; privacy issues raised by the proliferation of DNA data banks; the challenge of interpreting new DNA diagnostic tests; changing definitions of what it means to be "healthy"; and the science and ethics of cloning animals and human beings.

Despite broad interest, however, there have been few attempts to bring together large numbers of professionals from different fields to share ideas and prepare for the challenges ahead. The Whitehead Institute and ASLME held such a conference on April 23 and 24, 1998, under the direction of Dr. David Page, a pioneer in human genome research and chairman of the Whitehead Task Force on Genetic Testing, Privacy, and Public Policy; Dr. Eric Lander, director of the Whitehead/MIT Center for Genome Research; Dr. Philip Reilly, a leading clinical geneticist and attorney; and Mr. Benjamin Moulton, Esq., executive director of ASLME and an experienced health care lawyer.

The primary goal of the Whitehead/ASLME Policy Symposium was to provide a bridge between the research community and professionals who were just beginning to grasp the potential impact of new genetic technologies on their fields. *The Human Genome Project: Science, Law, and Social Change in the 21st Century* initially was designed as a forum for 300-500 physicians, lawyers, consumers, ethicists, and scientists to explore the impact of new genetic technologies and prepare for the challenges ahead.

In fact, the conference brought together more than 840 people, including federal judges (expenses paid by the Federal Judicial Center in Washington, D.C.), justices of the Massachusetts Superior Court; entire classes from the genetic counseling programs at Brandeis University and Sarah Lawrence University; commissioners and other officers from state public health departments across the country; biotechnology and pharmaceutical executives; postdoctoral fellows and medical residents; and almost 200 students. The diversity of experiences is evident from some of the evaluations:

- *This was marvelous! Thank you for inviting us."* [Massachusetts Superior Court Judges]
- *I want to thank Whitehead for the scholarship that allowed me to attend this conference. I teach Allied Health students at a community college that lacks a budget sufficient to send me to a conference like this. I have gotten a lot of new information and ideas that will be very useful in the genetics portion of my freshman biology classes, as well as my 2^nd^ year courses.*
- *Please do this again! As a lawyer, I need more scientific education on the HGP* [Human Genome Project] *and a broader discussion of policy issues, outside of clinical care, e.g., DNA data banks.*

- *I hoped to learn more about the state of the art in genetic testing. However, I found the discussion by the lawyers, psychologists and other non-medical people far more interesting and I am happy that this conference was interdisciplinary.*
- *It's encouraging that you got such a large response. Perhaps society is paying attention after all.*

Organization

The Whitehead Policy Symposium was developed by a planning committee consisting of Drs. Page, Lander, and Reilly, Mr. Moulton, and the following members of the *Whitehead Task Force on Genetic Testing, Privacy, and Public Policy*: Eve Nichols, Coordinator of the Whitehead Task Force; Elliott Hillback, Senior Vice President of Genzyme Corporation; Robin Blatt, Director of the Genetics Program in the Massachusetts Department of Public Health; Jacqui Weinstock, assistant to Representative Jay Kaufman in the Massachusetts legislature; Greg Moore, Esq., and Dacia Clayton, Esq., of the law firm Ropes & Gray; Judith Beard, a cancer survivor and consumer advocate; Dr. Fran Lewitter, Whitehead's Associate Director for Biocomputing; Corrine Strickland, a genetic counseling student; and Gus Cervini and Katie Ansbro, event planners for the Whitehead and ASLME, respectively.

Through regular monthly meetings, this committee oversaw all aspects of the conference, from planning and design to fundraising, publicity, preparation of materials, and evaluation. The first task was to create a coherent program that would appeal to the full spectrum of professionals and interest groups in the target audience. Two factors proved critical in meeting this goal: the diversity of the planning committee and their past experiences planning and attending large national meetings. For example, it quickly became apparent that lawyers and scientists on the committee had very specific expectations with regard to recruitment and program design; reconciling these different expectations at the outset allowed the committee to structure the final program in a way that would best meet the needs of all participants.

After much discussion, the group decided to offer four plenary sessions integrated with three sets of concurrent forums. This format required eight plenary speakers and twenty-eight workshop moderators and speakers. Among the speakers were nationally prominent lawyers, scientists, physicians, ethicists, insurance executives, scientists from the pharmaceutical and biotechnology industries, clergy, and consumer advocates. The final program appears in Table 1.

Outreach

The next major task was to organize the outreach strategy. Each member of the planning committee contributed to this effort by identifying target audiences and sites for save-the-date postcards, fliers, brochures, and posters, as well as web sites and appropriate journals for advertising. In addition, the committee sought advice from education and outreach coordinators in other organizations at the state, regional, and national levels.

Table 1
The Human Genome Project: Science, Law, and Social Change in the 21st Century

April 23, 1998

Welcome and Introduction
Dr. Gerald R. Fink, Whitehead Institute for Biomedical Research
Dr. David C. Page, Whitehead Task Force on Genetic Testing, Privacy, and Public Policy
Mr. Benjamin W. Moulton, Executive Director, ASLME

Plenary Session 1: The Information Revolution in Genetics
Dr. Eric S. Lander, Whitehead/MIT Center for Genome Research
Dr. Uta Francke, HHMI, Stanford University Medical Center

Concurrent Forums 1

1. *Keeping Abreast of Genetic Tests: New Challenges in the Patient-Doctor Relationship*
    - Moderator: Dr. Susan Pauker, Harvard Pilgrim Health Care Foundation
    - Dr. Robert M. Greenstein, University of Connecticut Health Sciences Center
    - Janice Platner, Esq., JRI Health
2. *Medical Records, Privacy, and Informed Consent in the Post-genome World*
    - Moderator: Dr. Maimon M. Cohen, GBMC Healthcare, Inc.
    - Mr. George Annas, Health Law Department, Boston University
    - Nancy R. Rice, Esq., Ropes & Gray
3. *The Impact of Genetics on Drug Development: New Corporate Interest in Patient Records*
    - Moderator: Dr. Glenn Miller, Genzyme Corp.
    - Dr. Penny Manasco, Glaxo Wellcome Inc.
    - Dr. Larry Gostin, Georgetown University Law Center
4. *Training IRBs to Evaluate Genetic Study Protocols*
    - Moderator: Dr. Charles Simmons, Children's Hospital
    - Dr. Barbara Handelin, Handelin Associates
    - The Rev. Dr. Colin Gracey, Northeastern University

Plenary Session 2: Privacy and Genetic Discrimination: Effects on Individuals and Society
Mark A. Rothstein, Health Law and Policy Institute, University of Houston Law Center
Dr. Nancy Wexler, Columbia University College of Physicians and Surgeons

Concurrent Forums 2:

1. *Creation and Use of DNA Data Banks*
    - Moderator: Judge Stephen Neel, Massachusetts Superior Court
    - Dr. Paul Ferrara, Division of Forensic Science, Commonwealth of Virginia
    - Barry C. Scheck, Esq., Benjamin N. Cardozo School of Law
2. *Genetic Discrimination in Employment*
    - Moderator: Dr. Philip Reilly, Shriver Center for Mental Retardation
    - Barry A. Guryan, Esq., Epstein, Becker & Green
    - Commissioner Paul Miller, Esq., Equal Employment Opportunity Commission
3. *Insurance: How Will Genetic Tests Affect Insurability and the Long-term Structure of the Insurance Industry*
    - Moderator: Representative Jay Kaufman
    - Dr. J. Alexander Lowden, Crown Life Insurance Co.
    - Dr. Jonathan Beckwith, Harvard Medical School

Table 1 (continued)

April 24, 1998

Plenary Session 3: Altering Genes in Individuals and Populations

Dr. James M. Wilson, Director, Institute for Human Gene Therapy, University of Pennsylvania

Dr. LeRoy Walters, Director, Kennedy Institute of Ethics,
Georgetown University

Concurrent Forums 3:

1. *What Are the Limits of Gene Therapy?*
    Moderator: Dr. Robert A. Weinberg, Whitehead Institute
    Dr. Glenn Dranoff, Dana Farber Cancer Institute
    Professor John Robertson, University of Texas School of Law
2. *Can We Change the Gene Pool? Should We?*
    Moderator: Dr. David Page, Whitehead Institute
    Dr. Christine M. Eng, The Mt. Sinai School of Medicine
    Dr. Edward J. Larson, University of Georgia Law School
    Dr. Sheldon Krimsky, Tufts University
3. *State-Mandated Genetic Screening: Past, Present, and Future*
    Moderator: Representative Harriette Chandler
    Dr. Harvey Levy, Children's Hospital, Boston
    Victoria Odesina, St. Francis Hospital

Plenary Session 4: Society Responds to the Genomics Revolution

Dr. Philip R. Reilly, Shriver Center for Mental Retardation
Commissioner Howard Koh, Massachusetts Department of Public Health

At the state and regional levels, contacts included the Massachusetts Medical Society; the Museum of Science in Boston (who proved extremely helpful in developing an outreach strategy for minority communities in Massachusetts); the Harvard School of Public Health; the Kennedy School of Government at Harvard; the Massachusetts Biotechnology Council; Associated Grantmakers of Massachusetts (for advice in contacting program officers who might be interested in attending the conference); science producers at WGBH; the Ecumenical Roundtable on Science, Technology, and Faith; the Life Insurance Association of Massachusetts; the Massachusetts Division of Insurance; the New England Regional Genetics Group; and the Massachusetts Bar Association.

Contacts at the regional and national levels included the Office of Biological and Environmental Research of the U.S. Department of Energy; the Office of Communications at the National Human Genome Research Institute; the Federal Judicial Center; The Genetic Alliance; the Biosciences Division of the Special Libraries Association; the Federation of Children with Special Needs; Biotechnology Industry Organization; PhARMA; the Council of State Governments; the State Center for Judicial Education; and many others. Table 2 provides a partial overview of outreach activities.

Table 2. Outreach and Advertising (Partial List)

Distribution of Fliers and Posters
- Annual Meeting of the American Society of Human Genetics
- Annual Meeting of the New England Regional Genetics Group
- Monthly Meeting of the Whitehead Seminar Series for High School Teachers
- All students at Harvard Medical School
- Boston area teaching hospitals

Save-the-date Postcards and/or Meeting Brochures
- American Society of Law, Medicine & Ethics
- National Society of Genetic Counselors
- American Society of Human Genetics
- The Genome Action Coalition
- Federal Judicial Center
- Biotechnology Industry Organization (BIO)
- Science and Technology Society
- New England Regional Genetics Group
- Massachusetts Medical Society
- Massachusetts Bar Association
- Whitehead Media List
- Council for Responsible Genetics
- Massachusetts Community Health Centers
- Ecumenical Roundtable on Science, Technology, and Faith
- PhARMA (national and international)

Advertising
- *Journal of the American Society of Human Genetics*
- *Journal of the American Medical Association*
- *Family Advocate*
- *Judges' Journal*

Calendar Announcements
- *BiologyWeek*
- *Genetics*
- *Journal of the American Society of Human Genetics*
- *Science and Engineering Ethics*
- *Vital Signs*
- *The Gene Letter*
- *The Genetics Resource*
- *Bioline* (Massachusetts Biotechnology Council)
- *State Government News*
- *Newsletter of the Alliance for Genetic Support Groups*
- *Massachusetts Association of Biology Teachers Newsletter*
- *Boston Museum of Science Magazine*
- *Massachusetts General Hospital Newsletter*

E-mail Servers
- Association of Independent Research Institutes
- Kennedy School of Government, Medical Professionals Program
- Directors of Graduate Programs in Genetic Counseling
- Harvard University School of Public Health

Links to WWW Pages (in addition to Whitehead and ASLME)
- American Society of Human Genetics
- National Society of Genetic Counselors
- International Society of Nurses in Genetics
- Genetics Society of America
- Council of Medical Genetics Organizations
- National Cancer Institute Directory of Genetic Counseling Experts
- Association of Professors of Human or Medical Genetics
- Council of Regional Networks
- Department of Energy Human Genome Site

In addition, Whitehead Director Gerald R. Fink and Dr. Phillip Sharp, Nobel Laureate and Head of the Department of Biology at MIT, co-signed a letter to 103 chairs of biology departments at universities in the eastern United States emphasizing "the critical need for young scientists to understand the impact of their work on society," and encouraging the department chairs to publicize the conference to their graduate students and postdoctoral fellows.

Conference Format

Site Preparations. The symposium plan included reservation of MIT's Kresge Auditorium (total capacity 1,200) for all plenary sessions. This made it possible to accommodate the rapid increase in enrollment that occurred in the weeks just prior to the conference.

In addition, the organizers conducted a survey of the first 400 registrants to determine which forums they would be most likely to attend. Based on this survey, the concurrent forum in each session with the greatest predicted attendance was located in Kresge, and the other two or three forums were assigned to rooms in the adjacent MIT Student Center. A few of the sessions were standing-room-only, but no one was turned away for lack of space.

All sessions were audiotaped and the plenary sessions and forums in Kresge Auditorium were videotaped. The audiotapes and subsequent transcripts of the plenary talks provided the foundation for the conference CD-ROM. Forum speakers used the audiotapes as a basis for their papers for the *Journal of Law, Medicine & Ethics*. The audiotapes also proved vital to reporters who arrived late or missed key sessions for other reasons. Two productions companies have inquired about using the videotapes as the basis for educational programs; the Whitehead Task Force will explore this issue further in the fall.

Box lunches were provided for all conference participants at tables arranged by MIT Conference Services in two field houses adjacent to Kresge Auditorium. The networking that occurred during these lunches was most gratifying. Consumer representatives and insurance company executives mingled with lawyers and scientists to discuss the issues of the day. Lunch on April 23 also featured a play titled, "The Human Genome Project," provided free-of-charge by the Boston Museum of Science Theater Group. The play dealt with a young couple coping with questions about prenatal screening for a life-threatening genetic disease.

Materials. Upon arrival, every conference participant received an 800-page syllabus containing a broad range of materials:

- Symposium program
- Maps, restaurant guide, and information on continuing education credits for physicians, nurses, and lawyers
- Biographical sketches on speakers and program organizers
- Speaker outlines and recommended reading

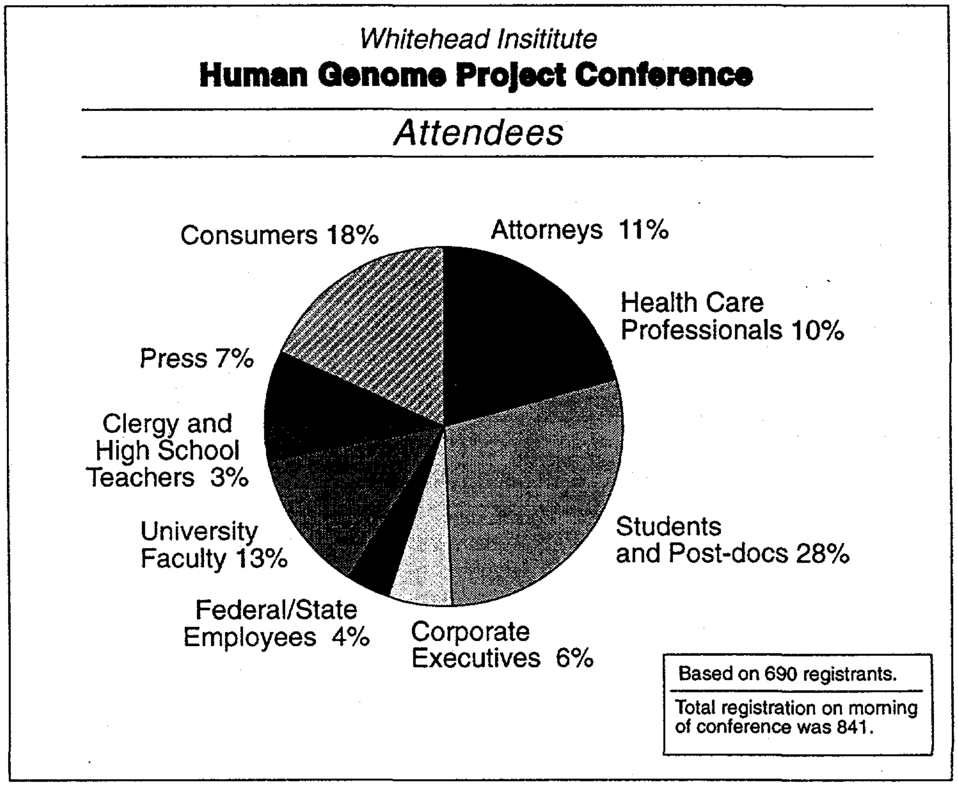
- Journal articles and other information organized in the following categories: Basic Genome Science, Application to Medicine, Ethics, Health Care Policy, and Law.
- Relevant web sites obtained from the *DOE Human Genome Program Report.*

The conference organizers obtained copyright permission for all journal articles and book excerpts included in the syllabus. The permission request letters specified that the materials would be used for both the syllabus and the conference CD-ROM. The conference organizers complied with special conditions and included acknowledgments as requested.

ASLME editors will publish the special conference issue of the *Journal of Law, Medicine & Ethics* in the late fall of 1998. Both plenary and forum speakers submitted papers for this issue.

The conference CD-ROM, produced by Dr. Fran Lewitter at the Whitehead Institute, has been distributed to all conference participants, as well as medical schools across the country. Whitehead is now working on distributing the CD-ROMs to state legislatures, and ASLME is distributing them to law schools.

Audience Composition. One of the primary goals of the organizers of the Whitehead Policy Symposium was to bring together people from a broad range of professions and interest groups to discuss the impact of the Human Genome Project on society. As stated earlier, the event far exceeded everyone's expectations. The figure below shows the breakdown of the first 690 registrants by category.



Scholarships. As a result of the generosity of our donors, more than 200 conference scholarships were available for undergraduate and graduate students (in law, medicine, public health, and genetic counseling), high school teachers, legislators and their staffs, and consumers. These scholarships enriched the program and brought students from as far away as California and London.

Evaluations

Each syllabus contained an evaluation form to assist the conference organizers in developing future programs and to meet the requirements of accrediting organizations for continuing education credits in law, medicine, and nursing. Of the 840 participants, 163 completed the evaluation form. Appendix A summarizes their responses. The following are of particular interest:

- 70 percent of respondents gave the conference a general rating of "excellent"
- when asked about the major strengths of the conference, 75 percent selected "its multidisciplinary approach"
- 96 percent said they would advise colleagues to attend a similar program
- 81 percent said that the conference was geared to their level of expertise (which is gratifying given the great diversity of the audience)

In addition, the organizing committee received e-mail and written comments from a variety of attendees and speakers:

From the CEO of a medical technology company:

> *The Symposium was, without question, the best organized and most informative meeting I have ever attended; really, a great credit to the Whitehead Institute and to all who contributed their efforts.*

From the president of the Museum of Science in Boston:

> *Last week Thursday and Friday were a very special time. I enjoyed greatly the plenary sessions and the various group sessions I attended. I came away feeling invigorated and challenged intellectually . . .*

From Commissioner Paul Steven Miller of the Equal Employment Opportunity Commission

> *It was one of the most interesting and enjoyable conferences I have attended in a long time.*

From J. Alexander Lowden, M.D., Ph.D., F.R.C.P.C., F.C.C.M.G., a forum speaker and a leader on genetic issues and the insurance industry:

> *What a great meeting! You must be extremely pleased with the attendance and the audience participation. I think everyone felt the conference did much to advance our understanding of the problems new technology can bring in many different fields.*

Goals for the Future

The Whitehead Institute and ASLME are both pursuing new projects in genetics, law, and public policy. The organizers learned a great deal from the symposium and look forward to applying that knowledge to future programs. For example,

- Future programs on this scale might begin with an optional workshop on the day preceding the conference to familiarize non-scientists with the terms and ideas that will be used in the upcoming sessions. (Despite exceptionally good introductory talks, many attendees expressed a desire for more preparation.)
- Sessions with the greatest potential appeal could be repeated; many attendees regretted not being able to attend concurrent sessions.
- Given its large size, the syllabus might have been more accessible with a different organizational plan. The search function on the conference CD-ROM has alleviated this concern.
- Several forum panelists served dual roles: they were expected to speak as both consumers and law or health care professionals. While these speakers did an excellent job, the situation may have created some confusion for the audience. The organizers would include a broader range of consumer representatives in the future.
- Introductory talks by forum speakers could have been shorter to allow more time for interaction between speakers and participants—moderators did a remarkable job, especially given the large size of some forum sessions

<u>Judges.</u> Following the policy symposium, several justices of the Massachusetts Superior Court approached the Whitehead Institute and volunteered to participate in the development of science-based education programs for judges. Whitehead scientists and the judges are working together to develop such a program with input from the Federal Judicial Center in Washington, D.C.

<u>BIO.</u> The Biotechnology Industry Organization has asked the organizers of *The Human Genome Project: Science, Law, and Social Change in the 21st Century* to

participate in the development of an ethics and public policy program for BIO 2000, expected to be the largest gathering of biotechnology executives ever held.

Whitehead Policy Symposium II. The Whitehead Task Force on Genetic Testing, Privacy, and Public Policy has begun plans for another major policy symposium in the year 2000, probably in late April or May. Many participants in the recent program expressed interest in pursuing the topics covered in more detail. They also offered many suggestions for additional topics, including behavioral genetics; the role of public education in combating genetic illiteracy; the "duty to warn," especially in state-funded programs; the future of genetic counseling; and international bioethics.

Prepared by Eve K. Nichols
Coordinator, Whitehead Task Force
on Genetic Testing, Privacy, and Public
Policy

Appendix A

CLE/CME Form Results

(total of 163 forms submitted)

1. Occupation

Attorney	24	Bioethicist	15
Physician	34	Teacher	14
MD/JD	5	Allied Health Professional	8
Nurse	9	Student	26
RN/JD	1	Postdoctoral Fellow/Resident	2
Ethics Committee Member	9	Corporate Executive	12
Hospital Administrator	2	Clergy	1
Risk Manager	1	Federal/State Government	5
Insurer	1	University Faculty	17
Social Services	3	Other	30

2. Type of Facility

Law Firm	6	Medical School	24
Group Practice	4	Law School	2
Private Practice	17	HMO / PPO	7
Hospital	18	Government	18
University	46	Other	25

3. Are you a member of ASLME?

Yes	27	No	140

4. How did you learn about the conference?

Brochure	85	Colleague	32
Newsletter	4	Website	10
Poster	8	Other	23
Ads	9		

"Other" = e-mail; save-the-date card; NIH Calendar of Events; announcement in U.S. Patent Quarterly; Whitehead Teachers Program.

5. What are the major strengths of the program?

Multidisciplinary Approach	122	Location	56
Timeliness of Subject	102	Schedule	25
Written Materials	51	Other	1
Faculty	85		

6. In general, the conference was:

Excellent	116	Fair	4
Good	45	Poor	0

7. Was the program geared to your level of expertise?

Yes	132	No	19

8. What were your objectives in attending this conference?

- (58) Generally, to learn.
- (2) Learn about cloning issues.
- (5) CMEs / CLEs.
- (7) Learn about confidentiality/privacy issues.
- (3) Learn about discrimination issues.
- (2) Learn about DNA technology.
- (5) Learn about ELSI issues.
- (12) Learn about ethical issues.
- (7) Learn about gene therapy.
- (6) Learn about advances in genetic research/testing.
- (7) Learn about legal issues/implications.
- (3) Learn about IRBs.
- (7) Networking with colleagues.
- (8) Learn about social issues.
- (31) Update on all current issues.

9. Do you feel these objectives were met?

Yes	144	No	15

10. Would you advise colleagues to attend a similar program?

Yes	156	No	5

11. Would you change any aspect of your professional practice as a result of this conference?

Yes	67	No	73

12. Did you find the conference materials to be informative and useful?

Yes	150	No	5

14. Amount of practical information gained

Great deal	60	Fair	13
Sufficient	82	Little	4

15. Audience discussion periods were:

Sufficient	85	Unproductive	8
More Needed	67		

16. Concurrent sessions were:

Sufficient	115	Unproductive	4
More Needed	24		

17. What topics did you find most interesting / useful to your professional activities?

- (6) All.
- Clinical trials.
- (3) Cloning.
- Constitutional v. Individual issues.
- Corporate interest in genetics.
- (17) DNA issues / DNA data banks.
- (5) Doctor-patient relationship.
- (2) Educational issues.
- (6) Employment discrimination.
- (10) Ethical issues for individuals, professionals and/or society.
- Eugenics.
- (2) Forensics.
- (21) Gene therapy.
- Gene therapies -- success and failures.
- (5) Genetic discrimination issues.
- Genetic disease treatment.
- (10) Genetic testing.
- (2) Genetics history/future.
- (10) Genetics and genetic research.
- Discussion of genetics, genetics research – reliance for pharmaceutical industry.
- Human rights issues.
- (6) Informed consent.
- (4) Insurance discrimination.
- (10) Insurance.
- (6) IRBs.
- (16) Legal issues.
- (2) Legal analysis of genetics issues.
- (3) Medical and medical-legal issues.
- (11) Medical records.
- (5) Newborn screening.
- (26) Privacy / confidentiality issues.
- (5) Public health issues.
- Public policy formation – Role of Government.
- (4) Science and technology in genetics.
- (5) Social issues / societal aspects.
- (2) Uta Francke's presentation.
- Howard Koh's presentation.
- (3) Eric Lander's presentation.
- Mark Rothstein's presentation
- (2) Nancy Wexler's presentation: how much we should know.
- (3) J. Wilson's presentation.
- L. Walters's presentation.
- I enjoyed the Forum with G. Annas and N. Rice. It was a great union because of the two different views brought up.
- Discussion on plenary sessions were most useful.
- Plenary topics on Day One.
- Factual presentations.

- Short play during lunch.
- The obvious need for genetic counselors became clear.
- More specific to genetic information.
- Relation to industry and private sector.
- HGP as changing our conception of ourselves.

18. Please list additional topics you would like to have discussed at future programs

- Anthropological insight into other countries/cultures to genetic research.
- (8) Behavioral genetics.
- (4) Bioethical issues.
- Biotech. pharmaceutical prospects.
- Case studies.
- (4) Cloning. Many issues were raised at this conference, but actual, practical things that we can do about those issues were not addressed.
- Confidentiality issues in research.
- Consent issues.
- (2) Have consumer representatives/organizations/patient perspectives present.
- Death and dying issues.
- (3) Disease-specific genetic info., e.g., breast and colon cancer, cystic fibrosis, etc.
- DNA banking for research purposes.
- Duty to warn, especially for state mandated programs.
- (5) More ethical discussion.
- Family Registries (such as cancer families).
- Forensics.
- Genes and behavior/mortality; support and resistance for genetic transfer.
- (6) Genetic decision-making/counseling.
- Genetic disorders.
- Genetic illiteracy and role of public education; schools; media.
- Genetic patenting.
- Genetic research funding: public v. private.
- (4) Genetic screening issues.
- (3) Genetic testing development and implementation.
- Gene therapy.
- Global bioethics and how is the rest of the world dealing with the topics of this meeting and other topics of concern.
- Health care rationing issues at the beginning and end of life.
- (2) HMO and health care priorities.
- (2) Role of industry in HGP.
- (2) Insurance.
- Introduction involving brief and generic discussion of field.
- Intellectual property.
- (2) IRBs.
- IVFs
- Legal issues in medicine.
- (2) Legal aspects of genetic therapy/research.
- (3) Legislative and regulatory issues.
- Manipulation of germ cell lines.

- (3) Medical applications of the Human Genome Project. More about the practice of medicine and if it might be changed by genetics.
- Organ transplantation.
- Pain control.
- (2) Philosophical implications.
- Does prenatal genetic screening with the intention of terminating the pregnancy if a "defect" is present in a dangerous way come to replace research geared toward finding a cure?
- Public images of genetics; public understanding of genetics (including news, media presentations).
- Public opinion surveys, if any.
- (3) Public policy issues, including options, solutions, suggestions to address the numerous problems.
- (3) Religious aspects of genetics.
- (11) Science/technology and the consequences.
- Socioeconomic issues in the biotech industry
- Problems when society will need to know genes.
- Practical issues directed to teaching medical ethics to medical students and faculty.
- These issues revisited in 5 – 10 years.
- The use of literature and narrative as a public tool to understand genetics.
- The near absence of minority group members in the field and what that might portend; Why aren't they/we involved? Opportunities for post docs or fellowships to study biomedical technology and genetic engineering, particularly minority group members. (I'm African American). I think there were about 6 out of 840!

19.-20. Asked respondents about membership in other professional societies and attendance at other meetings.

21.-22. Evaluations of individual speakers and forum sessions.

23. Did the conference achieve its stated objectives?

To promote an understanding of how the Human Genome Project will affect clinical care?

Yes	97	Partially	60
No	3		

To identify the new challenges in patient-physician relationship posed by genetic information

Yes	105	Partially	44
No	4		

To discuss the medicolegal issues of privacy, discrimination, and medical record-keeping posed by application of the Human Genome Project

Yes	126	Partially	32
No	2		

To discuss how genetic testing will affect insurability, the creation of DNA data banks, and training issues for IRBs to evaluate genetic study protocols

Yes	118	Partially	40
No	2		

24. Was the program content relevant to the objective?

Yes	156	No	2

25. Were the physical facilities appropriate for this event?

Yes	144	No	14