HUMAN GENOME TEACHER NETWORKING PROJECT

Final Report

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I. OBJECTIVE

This project was designed to increase teachers' knowledge of the Human Genome Project (HGP) with a focus on the ethical, legal and social implications of genetic technology. The project provided educators with the newest information on human genetics including applications of genetic technology, updated teaching resources and lesson plans, peer teaching ideas to disseminate genetic information to students and other educators, and established liaisons with genetic professionals.

II. PROJECT DESIGN

The four-phase program during two school years included two consecutive summer workshops:

PHASE I: FIRST ONE-WEEK WORKSHOP: FIRST ONE-WEEK WORKSHOP

The first one-week workshop emphasized the ethical, legal and social implications of Human Genome Project technology through interaction with professionals familiar with HGP/ELSI issues including: geneticists, genetic counselors, clinicians, educators, researchers, ethicists, attorneys, and consumers (individuals with genetic conditions or those who utilize genetic services). Participants attended didactic lecture sessions, family panels, ethics panels, laboratory hands-on activities, computer labs, curricular and lesson plan demonstrations and role play sessions to obtain content and resources for classroom applications. Teachers were introduced to new curricular ideas and given resources for their classrooms.

PHASE II: CLASSROOM USE OF MATERIALS AND INFORMATION

During the school year, teachers used the DOE / BSCS curriculum *Mapping and Sequencing the Human Genome: Science, Ethics and Public Policy* as well as other curricular ideas from the workshop with their students. These new curricula foster an increased level of understanding and comfort in teaching about the Human Genome Projects' ethical, legal and social implications. Teachers developed and updated lesson plans, initiated mentor relationships, and introduced students to genetic information. Genetics Education Center staff maintain our World Wide Web site: *http://www.kumc.edu/gec* which provides a wealth of information and resources that are utilized by participants in their classrooms. (See Appendix D for a list of organizations that link to our home page.)

PHASE III: SECOND ONE-WEEK WORKSHOP

After using new curricular materials and information with their students, teachers returned

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the following summer for a second workshop. During the workshop, they shared experiences; exchanged successful teaching methods, lesson plans, curricula concepts, and integration methods; discussed curricular changes; and focused on ideas for peer teaching and dissemination. Workshop sessions updated teachers on cutting-edge HGP information to establish a solid foundation of knowledge. Additional family panels, ethics discussions, hands-on activities, as well as online Internet sessions, helped coalesce all of the project elements.

PHASE IV: PEER TEACHING

After the two summer workshops, each participant was required to complete three peer teaching sessions to disseminate information about human genetics and the Human Genome Project. They referred to a *Teacher List* for educators in their region who are interested in Human Genetics, or they invited teachers in their school, district, region or state to attend peer teaching sessions. They may also have made presentations at district, state, and national teacher meetings to circulate new information and resources about the Human Genome Project and ELSI issues. Project participants surveyed the effectiveness of their human genetics presentations and documented their presentation including the title, location and details of each session.

PHASE IV: COLLABORATION

Each participant was required to initiate links with three (3) genetic or ELSI professionals participating in our Mentor Network to acquire new sources of information about human genetics and ELSI topics. They also expanded classroom access of information through personal and online computer communications such as our World Wide Web site: *http://www.kumc.edu/gec*. Participants referred to the *Mentor Network* list of genetic and ELSI professionals from their region to initiate contacts with professionals and request resources that mentors are willing to provide. Participants documented how Mentors assisted them and returned this information to the Genetics Education Center.

PROGRESS

- A one week workshop was held for 17 teachers in June 1992, 68 teachers in June 1993, 89 teachers in June 1994, 57 teachers in June 1995, 58 teachers in July 1996 and 32 teachers in July 1997. (see Workshop Agendas in Appendix)
    - 177 teachers completed Phase I and began Phase II
    - 71 teachers completed Phase III
    - 42 participants completed Phase IV

- 142 mentors were available.

- Over 150 collaborations between participants and mentors have occurred since the project began. (see Collaborations in Appendix H)

• Approximately 300 peer teaching sessions have occurred since the project began. (see Dissemination and Networking in Appendix I)

• 177 educators have participated in the project with an impact on approximately 12,600 peer teachers. (An additional 7 educators attended the workshops at their own expense.)

• These Approximately 12,777 teachers impact more than 1,852,665 students during the project.

• Project cost: $.53 per student

• Workshop participants completed different phases of the project this year:

Group 1	Phase II **3**	Phase IV	
	Phase III **3**	**3** partial	**9** complete
Group 2	Phase II **7**	Phase IV	
	Phase III **17**	**15** partial	**27** complete
Group 3	Phase II **3**	Phase IV	
	Phase III **15**	**9** partial	**2** complete
Group 4	Phase II **5**	Phase IV	
	Phase III **21**	**7** partial	**4** complete
Group 5	Phase II **2**	Phase IV	
	Phase III **15**	**8** partial	**0** complete

III. WORKSHOP DESCRIPTIONIII. 1996 WORKSHOP DESCRIPTION

SPEAKERS

Professionals with first-hand expertise in helping families deal with the complex decisions of new genetic technology presented didactic, interactive sessions. The speakers included genetic counselors and clinical geneticists. Other speakers were lawyers and ethicists familiar with HGP / ELSI and public policy issues, researchers using DNA technology, curriculum developers, consumers, and teachers experienced in presenting HGP / ELSI topics in their classrooms. (see Presenters List in Appendix B)

The Chief, Genetics Education Program Coordinator from the National Institute of Health demonstrated activities including an electrophoresis laboratory, chromosome laboratory, DNA sequencing activity, and PCR technology laboratory. Case studies, role play, demonstrations, and discussions reinforced the application of technology and its integral role in ELSI. Lead teachers also presented hands-on classroom activities and exercises to promote inquiry and discussions about the applications of genetic technology and the acquisition of laboratory equipment.

Speakers conducted a variety of sessions and topics:

- careers in human genetics
- classroom integration of HGP topics
- curricular development sessions
- collaborating with genetic professionals
- DNA sequencing concepts
- DNA transfer & data analysis
- harnessing DNA
- educational resources
- educational standards
- ELSI issues of the HGP
- advances in cancer and genetic research
- frequently asked questions
- gene therapy
- genetic research
- information access on World Wide Web
- misconceptions about inheritance
- peer teaching human genetics
- DNA-based identity testing
- public policy issues
- simulated genetic counseling sessions
- current status of the HGP
- impact of HGP on Clinical Genetics
- genetics and public health

FAMILY PANELS

Family panels gave educators a humanistic context about genetic conditions unavailable from any other source. The families' personal stories supplement textbook descriptions and expand knowledge of the human perspectives of genetic technology. Textbooks often present worse-case scenarios when describing genetic conditions. These textbook descriptions, frequently the only information available to teachers, are more appropriate to educate medical students or other health care professionals about diagnosis. They are less appropriate for the public in their understanding of genetic conditions.

Family panels promote a different perspective. They are a valuable way to understand the impact of genetic technology on the decisions made by individuals and family members. Teachers have reported that family panels are a very valuable aspect of the workshop; that they can no longer teach human genetic conditions in the same textbook-based way; that they now think of, and teach about individuals with genetic conditions as members of families, communities, and society, not just "a disease" described in a book.

The interactive panel format uniquely affected the attitudes of teachers about the social, ethical and legal implications of having a genetic condition. Families presented information on the influence genetic conditions have on their lives, and discussed misconceptions about their condition. (See Comments in Appendix C)

Panels of family members presented information on the impact of genetic conditions. The following conditions were represented:

- ataxia
- Charcot-Marie-Tooth disease
- cleft lip and/or palate
- Cornelia de Lange syndrome
- cri-du-chat syndrome
- cystic fibrosis
- Down syndrome
- Duchenne muscular dystrophy
- dystonia
- Ehlers-Danlos syndrome
- hemophilia
- Huntington disease
- ichthyosis
- Klinefelter syndrome
- Lowe syndrome
- Marfan syndrome
- neurofibromatosis
- Noonan syndrome
- ocular albinism
- organic acidemia
- osteogenesis imperfecta
- polycystic kidney disease
- proteus syndrome
- retinitis pigmentosa
- Rubinstein-Taybi syndrome
- short stature
- sickle cell anemia
- spina bifida
- Turner syndrome
- VATER Association
- von Hippel-Lindau syndrome
- von Willebrand disease

RESOURCES

Educational Materials

Educators were able to review current resources on human genetics, ethical, legal and social topics of human genetics, genetic technology, and the Human Genome Project. All workshop participants received a total of approximately 120 different resources and materials to update their curricula.

A resource room was set-up for participants to access current genetics information on-line; and to view videotapes on genetic conditions, genetic technology, careers in genetics, laboratory techniques, and the Human Genome Project. New curricula, textbooks, reference materials, and hands-on kits were available for teachers to review to attain new teaching ideas. (See Educational Resource List in Appendix E)

Genetic Internet ResourcesResources
Workshop participants attended hands-on computer labs where they completed several internet exercises that enabled them to locate and research various genetic conditions and issues. A reference librarian/education specialist also provided valuable information concerning accessing the www and the various search engines available. Participants were able to attend a group exchange at the end of the day and share the internet tools they had acquired with each other.

Lesson Plan ExchangeExchange
An important component of the workshop was an exchange of teaching ideas and resources. Teachers presented their classroom ideas to each other during the workshop and discussed ways of modifying lesson plans to incorporate the broad scope of Human Genome Project implications into their classroom discussions.

(See Teacher Presentations, Lesson Plans and Teaching ideas in Appendix F)

IV. MENTOR NETWORKIV. MENTOR NETWORK

The mentor network helps teachers remain current on new developments and changes in genetics. Once teachers begin integrating and expanding their human genetics curricular content, frequently they and their students have specific questions regarding clinical aspects of genetic conditions including legal, social, and ethical topics. Throughout the project, participants were linked with Mentors: professionals who assist them with the development and implementation of curricular materials to provide ongoing support, information, and resources.

A large database has been established of professionals willing to assist teachers with curricular content. These professionals, with expertise in genetics or in ELSI topics, have been recruited through notices in professional genetics journals (*American Society of Human Genetics Journal*, *Perspectives in Genetic Counseling*, and *Human Genome News*), through professional meetings (American Society of Human Genetics national meetings, National Society of Genetic Counselors national meetings, and HUGO), and through personal contacts at ELSI or DOE Project Directors Meetings.

The mentors, some of whom have access to funds for teacher education programs through state or regional sources, were given the names of teachers in their CORN (Council of Regional Networks) Region. And, each teacher received a list of Genetic Resource Professionals in their region. Each mentor agrees to 2-3 half days per year of collaboration with science educators by helping teachers develop and implement genetic lesson plans, providing laboratory tours, agreeing to speak at state teacher meetings, allowing students to observe during genetics clinics, giving classroom presentations, and preparing slides for teacher presentations.

Currently 142 mentors have volunteered to help teachers. These professionals include:

- 11 Clinical Geneticists
- 24 Educators
- 1 Ethicist
- 67 Genetic Counselors
- 1 Genetics Nurse Specialist
- 4 Genetic Coordinators
- 1 Consultant
- 10 Laboratory Geneticists
- 1 Science Lecturer
- 15 Medical Geneticists
- 1 Metabolic Dietician
- 2 Science Writers
- 3 Research Scientists
- 1 Administrator

(See Mentors List in Appendix G)

Participants have initiated over 150 collaborations with genetics and ELSI professionals since the project began. These collaborations include:

- acquiring current genetics resources
- arranging laboratory tours for students and teachers
- assisting with summer workshops for teachers
- discussing genetic research with students
- loaning slides for genetic presentations
- making contacts with speakers for classroom presentations and inservice workshops
- organizing and moderating family panels
- presenting genetic information to students
- participating in planning committees for peer teaching workshops
- providing answers to students' genetics questions
- providing case examples of genetic counseling sessions for students
- providing students with career information
- providing information on a new computer networking system for biotechnology

(See Collaborations List in Appendix H)

V. DISSEMINATIONV. DISSEMINATION

The project was designed to prepare teachers to serve as Genetic Resource Specialists throughout their state and CORN region by providing information and demonstrating new resource materials to their colleagues. During the workshops, participants acquired methods to update curriculum in their classroom and acquire new information throughout their professional lives.

Approximately 300 peer teaching sessions have been conducted to more than 12,600 teachers and members of the general public. Dissemination was done at regional or national conventions, state meetings, district workshops, and teacher in-services.

Dissemination is the driving force of the *Genetics Education for Middle and Secondary Science Teachers* project. Teachers' networking with peers and colleagues broadens the impact of summer workshops and enables other educators to be exposed to the

immense amount of information available. This helps ensure that educators begin teaching about the complex concepts and decisions intrinsic to the Human Genome Project in a cohesive and sensitive manner. (See Dissemination and Networking in Appendix I)

VI. EVALUATIONVI. EVALUATION

The project is being evaluated in terms of its content, concepts and organization, its ability to increase teachers' knowledge about HGP / ELSI topics, how the workshop enables teachers to transfer that knowledge to their students, and how students increase their knowledge of human genetics and ELSI issues.

WORKSHOP EVALUATION

Participants were asked to list new concepts and ideas they learned as well as their comments about the session for each speaker, lab tour, panel or laboratory activity each day of the workshop week. These comments and pre- and post-survey information enable the workshop coordinator to assess the efficiency and impact of the workshop and enabled the planning committee to assess content to plan future workshops.

TEACHER EVALUATION

During the workshop in July 1996, a pre-survey and post-survey were administered to the 26 new participants attending Phase I of the project, and a post-survey was administered to the 32 participants returning for Phase III of the project. This survey enabled evaluation of the effectiveness of the workshop to teach new concepts and increase comfort levels in teaching human genetics.

STUDENT EVALUATION

In January 1996, a post-survey was sent to the 57 participants of the 1995 workshop to complete the assessment of change in student knowledge. Participants administered the post-survey to the same class tested in September 1995. A post-survey was also sent to be administered to a sensitivity group: a different class not tested in September 1995.

The same post-survey was also sent to 12 control group teachers who had received the pre-survey in September 1994. Teachers administered the post-survey to one class of approximately 30 biology students as well as to a sensitivity class not previously surveyed.

In May and June 1996, a second student post-survey was administered to students of the 1995 workshop participants and to the control group to assess the effect of the second workshop on the teaching style and content of workshop participants.

Results will follow analysis of that data.

VII. ADVERTISING

In an effort to further expand the scope of this project, several advertising mediums were utilized encouraging educators to attend one of the workshops at their own expense. The following advertisements were distributed:

- 500 flyers were distributed at the NABT Convention, October 14-20, 1996 and 300 flyers at the October 1997 NABT Convention during sessions on genetics and biotechnology.
- An advertisement was placed in the Chronicle of Higher Education for the July 1996 workshop and the July 1997 workshop was listed in the Chronicle of Higher Education's calendar of events.
- Several e-mail notifications were sent to metropolitan Kansas City area secondary biology instructors and college biology instructors.
- Brochures were developed and distributed at the biotech?????? convention in 1997.
- A mailing was sent in February 1997 to approximately 175 college biology instructors who had attended a 1996 genome conference in Dallas, TX.
- The University of Kansas offered graduate credit for attendance of the July 1997 and July 1998 workshops. These workshops were listed in the Summer Timetable of Classes. (The 1998 workshop was cancelled due to insufficient enrollment.)
- The Genetics Education Center's World Wide Web site: *http://www.kumc.edu/gec* listed the 1995-1997 summer workshops and included an online registration form.

APPENDICESAPPENDICES