Enhancement of K-12 Human Genetics Education:

Creating a Cooperative Plan

American Society of Human Genetics
Education Summit
September 9-10, 2004
Bethesda, Maryland

The American Society of Human Genetics (ASHG), founded in 1948, is the primary professional membership organization for human geneticists in the Americas. The nearly 8,000 members include researchers, academicians, clinicians, laboratory practice professionals, genetic counselors, nurses and others involved in or with special interest in human genetics.

The principal objectives of ASHG include **(l)** providing venues to bring investigators opportunities to share their research findings in the many areas of endeavors in human genetics; **(2)** informing health professionals, legislators, health policy makers, and the general public about all aspects of human genetics; and **(3)** facilitating interactions between geneticists and other communities including policy makers, industry, educators, and patient and public advocacy groups.

Invited Participants

Cora Beth Abel
Massachusetts Biotechnology Council

Beth Balkin, MS, CGC
GlaxoSmithKline

L. Tony Beck, PhD
National Institutes of Health/DCRR, NCRR

Vence L. Bonham, JD
National Human Genome Research Institute

Mark Bosveld
National Science Teachers' Association

Joann Boughman, PhD
American Society of Human Genetics

Jennifer Bowans
U.S. Department of Energy Genome Program

Tyson Brown
National Science Teachers' Association

Rodger W. Bybee, PhD
Biological Sciences Curriculum Study

Sarah Chalvo
Broad Institute of MIT and Harvard

David B. Campbell, PhD
National Science Foundation/ESIE/HER

Kristi R. DeCourcy, PhD
Fralin Biotechnology Center/Virginia Tech

Sioban Dolan, MD, MPH
March of Dimes

Daniel Drell, PhD
U.S. Department of Energy

Kathy Frame
Biotechnology Institute

Bruce A. Fuchs, PhD
National Institutes of Health/Office of Science Education

Jon R. Geiger, PhD
The Jackson Laboratory

Paula Gregory, PhD (ASHG)
Louisiana State University HSC

Susanne B. Haga, PhD (ASHG)
The Center for the Advancement of Genomics

Lori Hamby, MS, CGC
Johns Hopkins Bloomberg School of Public Health

Kimberley S. Lightle, PhD
The Ohio State University

Dennis WC. Liu, PhD
Howard Hughes Medical Institute

Melinda Lowy
The American Physiological
Society/NABT

Carol F. Massey
Genentech, Inc.

Joseph D. McInerney, MA, MS
NCHPEG

David Micklos
Dolan DNA Learning Center/Cold
Spring Harbor Laboratory

Robert L. Nussbaum, MD (ASHG)
NHGRI/NIH

Loraine A. Oman-Ganes, MD (ASHG)

Eric Packenham
National Science Teachers'
Association

Megan J. Robinson, PhD
Pfizer Global Research &
Development

Louisa A. Stark, PhD
University of Utah

Dr. Lee L. Zia
National Science Foundation

INTRODUCTION

The American Society of Human Genetics (ASHG) convened a meeting of 32 representatives from a variety of public, private, and professional organizations that have a demonstrated interest and expertise and/or a proven track record of materials development for K-12 classroom education in human genetics. The invitational meeting was held on the FASEB campus over a two-day period. The primary motivation for this event was recognition of the need to develop a cooperative plan to enhance human genetics education in classrooms, disseminate information and generate excitement in our youth for possible pursuit of careers in human genetics and related fields. Given that ASHG has a valuable resource in its "Mentor Network" of 1,200 genetics professionals willing to bring genetics to the classroom, among the list of meeting participants were several representatives from the National Science Teachers Association and the National Association of Biology Teachers. It was imperative that representatives from the teaching community attend as their perspective was crucial in determining efficient ways and means of (1) identifying issues; (2) assessing needs; and (3) disseminating web-based knowledge already developed.

PERSPECTIVES

TEACHERS

The 21st century has brought about an exponential growth of science knowledge and science-related technologies and an increasing demand for graduates who can effectively contribute and use these advances in understanding. When viewed along with an apparent decrease in the number of qualified science

teachers that will be available to teach a growing population of students, the pressures on science programs and science education becomes apparent.

In addition, the Federal legislation of 2001, "No Child Left Behind", requires states, districts, and teachers to develop science education standards and to prepare assessments for all students in at least one grade level band of 3-5, 6-8, and 9-12 by the academic year of 2007-8. This legislation puts further demands on teachers and on an already overloaded system. Clearly there is a need to assist the teaching community by providing, in general, science standards and guidelines, but from the genetics perspective specifically, the genetics community must be available and willing to assist the K-12 educational community in developing proper standards for attaining genetic literacy.

Communication links between teachers, schools, and the community are essential to facilitate development and to limit the isolation of teachers. A program called "Building a Presence" sponsored by the National Science Teachers Association has already demonstrated that an effective communications network of State Coordinators, Key Leaders and Points of Contact can facilitate communication, education and assistance for teachers.

FEDERAL AGENCIES

Several federal agencies participated in the summit, briefly discussing their own successes and challenges in science education. The National Science Foundation (NSF) representative, Dr. Lee Zia, and his colleague Ms. Kim Lightle presented the NSF Digital Library Project (NSDL), a collection resource and portal to other resources, and its companion the Eisenhower Center. They also discussed important models and methods of partnering. The next deadline for NSDL applications is April 2005.

Mr. Vence Bonham presented information on new products and educational resources from the National Human Genome Research Institute, and reiterated the importance of continued collaboration with ASHG on DNA Day and the Family History Initiative. He also discussed the potential opportunities to reach out to underserved populations, possibly through schools in those communities. Dr. Bruce Fuchs from the NIH Office of Science Education emphasized the need for education reform in life sciences, but also made clear that we must provide rationale for why the general public needs to be more scientifically literate, with a focus on both health-related and workforce skills issues being of paramount importance.

PRIVATE SECTOR

Dr. Rodger Bybee, Executive Director of the Biological Sciences Curriculum Study (BSCS), challenged the group on several issues and put forward several questions to consider so that proposals and action plans are developed.

> "In a supply and demand context, the genetics community is on the supply side, with expertise, willingness, human and materials resources to provide to teachers and students. We are lacking, however, a strong consensus on the principles and content that comprises "genetic literacy". At the same time, we are challenged by the ongoing development of state science standards and assessments. Our community must envision a plan that can accomplish the tasks at scale (comprehensive and national)."

It is apparent that the group needs to think about and determine what "type of action" should be pursued and what categories of "change" can be realistically accomplished to assist in both the development of teachers and students. For instance, in addition to providing materials and resources to enhance student learning, should professional development for teachers be a goal for the group and/or enhancement of the NSTA Building a Presence program by integrating the mentors within the school districts or states. Can the group effect "change" by modifying policy development for state standards and assessments in genetics? Can it effect "change" by modifying goals within the educational systems. Shall goals include overall science literacy, not just enhancing the workforce of science professionals? How can the Mentor Network be more effective? Can they serve as advocates, sources of information or full partners within the school districts/states?

It is essential that partnerships be established, with organizations developing long-term relationships. It is gratifying that ASHG has stepped forward to facilitate these activities.

GENETICS COMMUNITY RESOURCES

There are at least 40 websites generated from the various groups that represented at the meeting (See Appendix 1). Huge amounts of information are available, some providing virtual science centers, animation, community education programs as well as summer student internship programs. For example, GlaxoSmithKline's website is targeted to 8 to 12 year olds providing basic genetic information, interactive games illustrating key genetics concepts and animated sections. Other sites provide curriculum development for genetics

and teacher professional development. Other institutes with educational web-sites represented at the summit include the Genetics Science Learning Center at the University of Utah, the Dolan DNA Learning Center affiliated with Cold Spring Harbor Labs, the National Human Genome Research Institute, the Fralin Biotechnology Institute, the Massachusetts Biotechnology Council, the Howard Hughes Medical Institute and the National Coalition of Health Professional Education in Genetics (NCHPEG). NCHPEG could be an initial starting place as they have already developed core principles and an examination of the National Education Standards.

DISCUSSION

Following the presentations of participants, a rich and lively discussion ensued. To capture the breadth of content while maintaining brevity, the conversations will be summarized into types of comments. In particular, ASHG sought advice on how the society could best enhance genetics literacy from "pre-K to gray" from the educational groups represented at the summit.

Issues to consider:

- Lots of useful educational materials, especially web-based, are being developed and made available
- Educational materials and activities should be connected to appropriate science standards (both national and state)
- Real urgency related to the coming assessment processes
- Non-patronizing attitudes are essential in approaching teachers

Characteristics vital to successful activities:

- Interdisciplinary approach
- Need to cover all ages (pre-K to gray)
- Special focus should be placed on middle school

Questions:

- How can ASHG and/or the larger groups establish a single vision or goal?
- How best can we display and disseminate resources?
- What will "success" look like and how will it be measured?

The discussion concluded with a summary of the major goals categorized by time-frames briefly summarized here:

IMMEDIATE GOALS

- Sign up ASHG Members as experts on the NSDL website to respond to questions from "ASK NSDL"

- Work with NIH to get genetics jobs on the career site called LIFEWORKS

- Make announcements about our progress at ASHG annual meeting in Toronto (Board meeting, Information and Education Committee, Business Meeting, and in the Presidential Address)

SHORT TERM GOALS

- Write report from the Summit
- Make report into a Position Paper to be disseminated
- Organize Mentor Workshop for Salt Lake Meeting in 2005
- Provide op-ed pieces to members willing to publish
- Add all URL's and materials to ASHG website
- 2005 DNA Day – enhance and improve outreach activities

EVOLVING ACTIVITIES WITH LONGER TIME LINES

- Mentor Network: Enlarge and enhance by improving dissemination of existing educational materials and development of new materials as needed; providing training workshop(s) at ASHG meeting, in modules, and kits.

- Develop a project with BSCS to submit to NIH Office of Education on "What Geneticists Can Do with K-12" that would include a working group to provide the real content around the outline provided in Table 1 resulting from group discussion.

TABLE I. WHAT GENETICISTS CAN DO FOR K-12?

Activity	Level of Commitment		
	Advocacy	**Resource**	**Partnership**
Engage public	Write op-ed talk to PTO/PTA	Speakers' bureau science museum	Chamber of Commerce
Classroom activities	Teach a class or lab or judge science fair	Prepare materials for teachers	Develop a team – scientist/master teacher
Materials development	Review text/chapter	Write chapter	Work on Web site
Professional development for teachers	Attend seminars	Develop materials	Develop courses
District activities	Speak to Board	Attend Board meetings; serve on committee(s)	Serve on Board
State science activities	Speak	Work on state standards or assessment	Work with State Science Coordinator

- Establish a Working Group to define "genetic literacy". This could build from the NCHPEG principles (or be redacted from them, but would require the determination of approximately five "golden nuggets." Eventually, these might become a part of a consensus document developed by all sectors of the genetics community.

- Create an activity guide for users (i.e., the schools) based upon available resources

- Develop materials on the points of contact with the National Science Standards and the activities of the genetics community

- Design and submit a regional pilot project that would more specifically define needs of various age groups, promote ways of utilizing available resources and materials, and develop and test specific activities.

APPENDIX 1.

Web-Sites of Summit Participants

FEDERAL GOVERNMENT SITES

U.S. Department of Energy Genome Programs
http://DOEgenomes.org/
Gateway to Human Genome Project, genome science, and genetics resources.

Human Genome Project (HGP) Resources for Educators and Students
www.ornl.gov/hgmis/education/education.shtml

Medicine and the New Genetics
www.ornl.gov/hgmis/medicine/medicine.shtml
Genetic disorder, gene testing, gene therapy, pharmacogenomics, and genetic counseling fact sheets and resources.

Ethical, Legal and Social Issues
www.ornl.gov/hgmis/elsi/elsi.shtml
Information about societal concerns arising from availability of genetic information: privacy and legislation, patenting, behavioral genetics, genetics in the courtroom, cloning, genetically modified foods and organisms, and minorities and genomics.

Gene Gateway: Exploring Genes and Genetic Disorders
www.ornl.gov/hgmis/posters/chromosome/
Introductory guide to using bioinformatics resources to investigate genetic disorders, genomes, genes, and proteins. Form for requesting a free copy of the Human Genome Landmarks poster.

National Human Genome Research Institute
www.nhgri.nih.gov
http://www.genome.gov/Education
Provides educational materials about genetics and genomics for students, teachers and the general public.

National Center for Biotechnology Information
www.ncbi.nlm.nih.gov
Established in 1988 as a national resource for molecular biology information, NCBI creates public databases, conducts research in computational biology,

develops software tools for analyzing genome data, and disseminates biomedical information - all for the better understanding of molecular processes affecting human health and disease.

INDUSTRY

GlaxoSmithKline
www.genetics.gsk.com/kids/index_kids.htm
The GSK genetics website has a ***Kids Genetics*** site targeted to 8 to 12 year olds. The site includes basic genetic information, interactive games to play illustrating key genetics concepts, and animated sections. Its goal is to make genetic science an interesting learning experience for this age group.

Pfizer
www.pfizer.com
Education initiatives, traveling science exhibits, global education and local philanthropy, school partnerships, outreach

TEACHERS

National Science Teachers Association (NSTA)
http://webwatchers.nsta.org
A Science Guide is a classroom resource for science teachers interested in integrating the Internet into their teaching. Each science guide consists of web-accessible resources (URLs) that have been aligned to the National Science Education Standards and vetted across eight educational rubrics, such as Inquiry, Interactivity, Communication/Collaboraton, How Scientists Work, etc. These Web resources have been assembled in a thematic drill-down structure with associated lesson plans, reflective vignettes, samples of student work and audio files that demonstrate how the Guide's Internet Resources may be utilized in a classroom.

National Association of Biology Teachers
www.nabt.org

Biological Sciences Curriculum Study (BSCS)
www.bscs.org
It is a nonprofit corporation that develops and implementation of innovative science education curriculum for students in kindergarten through college. It has developed integrated science programs for elementary and middle schools, and biology programs for high school and college students. In addition, BSCS provides professional development for the improvement of science education and conducts research and evaluation that demonstrates the effectiveness of science programs.

PRIVATE INSTITUTIONS/FOUNDATIONS/NOT-FOR-PROFITS

The Fralin Biotechnology Center
www.biotech.vt.edu/outreach
Education and Outreach: Curriculum and materials; teacher-scientist partnerships; conferences; internships and fellowships

Massachusetts Biotechnology Education Foundation
www.massbioed.org
PROJECT BIOTEACH: gets students excited about science and the discovery process. BIOTEACH provides students with hands-on lab experiences that inspire scientific curiosity, understand and for some a career in the life sciences

The Howard Hughes Medical Institutes
www.biointeractive.org
BioInteractive is aimed primarily at a high school audience but components are used broadly across the K-12 spectrum and even into the college level. The focus is on illuminating the cutting edge of biomedical research through animations, in-depth virtual labs, webcast lectures, and click and learn interactive features. Free educational DVDs and CD-ROMs can also be ordered from the website.

Eisenhower National Clearinghouse (ENC)
A K-12 Math and Science Teacher Center
http://www.enc.org
ENC was established in 1992 to collect teaching materials for K-12 math and science educators and to identify and disseminate information about federally funded programs. Products and services have evolved to include a primary web site, *ENC Focus*, a free weekly web feature, a periodic print publication, as well as other publications and services.

The Genetic Science Learning Center, University of Utah
Genetics Resources on the Internet
http://gslc.genetics.utah.edu
Teacher resources; classroom activities; courses and workshops; hands-on activities for home and classroom

Your World Biotechnology and You
The Biotechnology Group
www.Biotechinstitute.org
The Group is committed to educational efforts that target teachers and students. The Institute offers hands-on workshops at regional science conference locations throughout the year as well as the National Biotechnology Teacher-Leader

Program. Web features career profiles and has power point presentations available for classroom presentations

National Science Foundation
www.nsf.gov
Featuring Digital Networks (digital library): A managed environment of multimedia materials in digital form, designed for the benefit of its user population, structured to facilitate access to its contents, and equipped with aids to navigate the global network

National Coalition of Health Professional Education in Genetics
www.nchpeg.org
Our primary focus is health professionals, but visitors to the site will find a range of educational resources related to human genetics and genetic medicine, including core competencies in genetics; core principles in genetics; a newsletter on the importance of the genetic family history in health care; educational modules on genetics in dentistry, genetics and major psychiatric illness, and genetics and common disease; and GROW – Genetics Resources On the Web – a search engine that searches only the genetics databases of selected websites, chosen for the accuracy and currency.

Dolan DNA Learning Center
http://www.dnalc.org
Get the latest information about genes and educational programs at the Dolan DNA Learning Center. This is also the portal to other resources and award-winning Internet content sites produced by the DNALC.

DNA from the Beginning
http://www.dnaftb.org
Discover the concepts and experiments that define the fields of genetics and molecular biology. This animated primer features the work of over 100 scientists and researchers.

Your Genes, Your Health
http://www.ygyh.org
Enter for clear explanations on the cause, inheritance, and treatment of 15 common genetic disorders. Watch video interviews with clinicians, researchers, healthcare providers, and patients who talk about the disorders.

Image Archive on the American Eugenics Movement
http://www.eugenicsarchive.org
Explore documents and photographs of the Eugenics movement from the early decades of the 20th century. Read annotated essays from social historians on subject relating to the Eugenics movement.

Genetic Origins
http://www.geneticorigins.org
Where did humans come from? Find out what DNA tells us and use your own DNA to explore human origins. Complete with laboratory protocols and information on how to send samples to the DNALC for sequencing.

Bioservers
http://www.bioservers.org
Analyze your DNA with the Dolan DNA Learning Center's bioinformatics tools. Compare your DNA with a database maintained by the DNALC.

DNA Interactive
http://www.dnai.org
Celebrate the 50th anniversary of the discovery of the DNA structure and the development of "DNA science." A large collection of videos and interactive 3-D animations provide an enriching experience.

MyDNAi
http://www.dnai.org/members
Register for teacher-oriented resources including downloadable teacher guides, activities, and lesson plans. Build your own web page and online lessons using the DNALC's *Lesson Builder*.

Inside Cancer
Coming Soon
Learn more about the pathways that lead to cancer and the molecular basis of new diagnostics and treatments.

Greenomes
Coming Soon
Bring students up-to-date on advances in plant genetics and genomics by integrating laboratory experiences with online bioinformatics resources.

March of Dimes Genetics Web site: *GENETICS & YOUR PRACTICE* ONLINE
http://marchofdimes.com/gyponline
The March of Dimes, with additional support from the Robert Wood Johnson Foundation, has created a freely accessible Web site that provides practical information and resources to assist the busy professional in integrating genetics into their patient care. This site is designed for health care professionals with a unique feature being the customization of its content for those working with a variety of following patient types (preconception/prenatal, infant/child, adolescent/adult). In addition, users can earn free CME Credits by completing

the interactive case study at the end of each module. CME credits have been jointly sponsored by the March of Dimes and Swedish Medical Center, Seattle. For further information about this site visit us at:
http://marchofdimes.com/gyponline

March of Dimes PeriStats Web site
http://marchofdimes.com/peristats
Get free, easy-to-access national, state (including D.C. and Puerto Rico) and county-specific perinatal health data, such as preterm birth, low birthweight, infant mortality, prenatal care, health insurance coverage, newborn screening, and more. Create custom graphs, tables and maps instantly by race, ethnicity and maternal age. Compare your state with the U.S. and Healthy People 2010 Objectives. Find current statistics, which can be easily cut and pated into needs assessments, grant proposals, educational materials, curricula and presentations.

March of Dimes General Web site
http://marchofdimes.com
Resources for consumers and professionals which comprehensively addresses perinatal topics such as preconception, pregnancy, prenatal & newborn care, newborn screening, preterm labor & birth, smoking cessation, etc. A convenient search engine feature directs users to relevant content that is up-to-date.