National Human Genome Research Institute

Background Paper on Internal Educational Activities at the National Human Genome Research Institute

An inventory prepared for the NHGRI Education and Outreach Workshop

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By Larry Thompson
Communications and Public Liaison Branch

Introduction

Education is not the primary mission of the National Human Genome Research Institute (NHGRI). Yet, because of the uniqueness of the Human Genome Project (HGP), NHGRI has made special efforts to support a number of educational and outreach programs aimed at specific audiences. These range from crucial professional training programs that help ensure a supply of scientists trained in genomics, to general education material for K-12 and college level students, as well as audiences within the general population. The institute's leaders believe that both professionals and the public need to understand genetics and genomics if they are to make informed choices about the future uses of these technologies.

While the education workshop will spend little time on the professional educational programs, this paper will survey the institute's current efforts so workshop participants will have an overall sense of the institute's existing educational activities.

Institute Structure

Like all institutes at the National Institutes of Health (NIH), NHGRI is organized into divisions. Each division has different areas of responsibility and each has some educational effort included within its portfolio, including:

1. The **Office of the Director (OD)** plans and coordinates all activities for the institute and provides critical centralized services, such as budget, information technology, human resources and communications. The OD includes the Office of Policy, Planning and Communications that has one staff member specifically designated to overseeing educational programming. OD has funded specific educational efforts, such as curriculum development.

2. The **Division of Intramural Research (DIR)** coordinates research conducted in NHGRI labs on the NIH campus. It also runs a substantial number of educational efforts, particularly professional training and career-development programs. DIR also has an Office of Scientific Education (OSE) that supports many of the training programs and also runs some non-training educational programs, such as the Summer Short Course for college-level biology teachers.

3. The **Division of Extramural Research (DER)** oversees the institute's grant- and contract-making activities and supports training grants at academic institutions around the country. It also provides funding for educational activities, such as the upcoming Fred Friendly Seminar on genetics, to be aired on PBS. In addition, DER

contains the Ethical, Legal and Social Issues program, or ELSI. Historically, ELSI has spent about 20 percent of its budget on education and outreach projects, including curriculum development, workshops and seminars on genomics-related issues.

K-12 and College Education Efforts

NHGRI has created two successful teaching tools to support teachers in the classroom.

1. **Exploring Our Molecular Selves:** This award-winning education kit was created in the OD and released in February 2001 when the International Human Genome Consortium published its first analysis of the human genome. The kit contains several modules, including the documentary "Exploring Our Molecular Selves"; an animated "Milestones in Genetics Timeline"; "Genes, Variation and Human History"; "How to Sequence a Genome"; "Ethical, Legal and Social Implications"; and a "Glossary of Genetic Terms." NHGRI distributed 60,000 kits (including an interactive CD-ROM, video and booklet) to teachers around the country. The kit has been repurposed and is now available on the Internet at With the American Society for Human Genetics (ASHG), NHGRI established a mentoring program through which teachers using the kit can seek assistance from genetics and genomics professionals and have them come to their classroom.

2. **Human Genetic Variation Curriculum Supplement:** [science-education.nih.gov] NHGRI financed the development of a curriculum supplement by the NIH Office of Scientific Education. The kit provides five basic activities that focus on the basics of human genetics, its potential to improve human health and its application towards understanding human evolution. More than 25,000 copies of the curriculum supplement have been distributed to high school teachers; an additional 15,000 copies will be published. The NIH OSE also runs teacher training with the kit. On-line version [science-education.nih.gov].

3. **Summer Internship Program:** The National Institutes of Health (NIH) Summer Internship Program offers high school, college and graduate students an extraordinary opportunity to perform biomedical research in the NHGRI Division of Intramural Research (DIR). The program immerses students in a unique environment devoted exclusively to biomedical research and training of the highest standards. Additional information [training.nih.gov].

4. **NHGRI Summer Workshop in Genomics:** Each summer, DIR runs a four-day, lecture-driven workshop for faculty from colleges and universities with substantial minority enrollment. Participants interact directly with leading NIH investigators, clinicians and other professionals in small, seminar-sized groups. In addition, hands-on laboratory tours allow participants to experience state-of-the-art, laboratory procedures. Audio and slides from the lectures are available on the Web.

5. The **National Institutes of Health** [training.nih.gov] plays an essential role in training research scientists at education levels ranging from high school student to tenure-track professors and physicians. NHGRI's DIR, especially, has heavily invested in a series of specialized training programs within the NIH system for professionals as well as educational programs for individuals not developing a research career. In addition, NHGRI's Office of the Director has responded to concerns that health professionals no longer in school need continuing education in genetics and genomics.

6. **National Coalition for Health Professional Education in Genetics (NCHPEG):** [nchpeg.org] A non-profit coalition of more than 100 organizations, NCHPEG was established with NHGRI's help to promote health professional education and access to information about advances in human genetics to improve the health care

of the nation.

7. **Intramural Research Training Awards (IRTAs):** This DIR program helps develop future research scientists by supporting a period of research training in laboratories at NHGRI. Science students can come work at the institute in at pre- or post-doctoral levels under the IRTA program.

8. **Visiting Investigator Program (VIP):** The VIP program provides tenured or tenure-track researchers the opportunity to spend six to 12 months in DIR's laboratories to pursue significant research objectives. Visiting investigators generally come to work in labs pursuing research related to their own interests. The collaboration is established by mutual consent with NHGRI's senior investigators.

9. **Physician Scientist Development Program (PSDP) in Genomic and Genetic Medicine:** The program is designed for board eligible/certified physicians who seek additional training to develop an independent research program that integrates the field of genomics with clinical investigation in genetic medicine. It is the goal of the program to train investigators who will be competitive for independent faculty positions at the NHGRI, other NIH institutes, or other top medical research institutions.

10. **Medical Genetics Residency and Fellowship Training Programs:** NHGRI offers a three-year residency program in medical genetics that trains physicians to diagnose, manage and counsel patients with genetic disorders. Participants gain broad experience in clinical and molecular genetics, metabolic diseases and cytogenetics.

11. **Combined Pediatrics and Medical Genetics Residency Program:** NHGRI and the Children's National Medical Center in Washington, D.C., offers medical school graduates a combined, five-year residency program in pediatrics and medical genetics. This special program trains physicians in pediatric medicine as well as in the diagnosis, management and counseling of patients with genetic disorders. Participants gain broad experience in pediatrics, clinical and molecular genetics, metabolic diseases and cytogenetics.

12. **Genetic Counseling Graduate Program:** NHGRI and the Johns Hopkins University (JHU) offer an opportunity to earn a Master's degree (ScM) in genetic counseling from the Department of Health Policy and Management at the JHU Bloomberg School of Public Health. The program is unique in its emphasis on psychological aspects of genetic counseling as well as research methodology and public policy issues.

Internet

Throughout the school year, NHGRI receives many requests each month from middle, high school and college students working on assignments related to the Human Genome Project. Currently, the public liaison staff refer students to specific pages on the institute's current Web site: Educational Resources and Careers and Training.

NHGRI's Web site is a credible source of high-quality information about genetics and genomics that is always available to teachers and students. The Educational Resources section includes a portfolio of basic information that students will be able to use to assist with these assignments. It includes some of the following:

1. **Talking Glossary:** Developed by the DIR Office of Science Education, the Talking Glossary provides a multimedia look at the basic genetics definitions. The glossary includes text definitions, audio file supplements and illustrations. A Spanish version of the Talking Glossary will be released in the near future.

2. **Fact Sheets:** NHGRI recently updated a series of fact sheets about basic genetic and genomic principals and issues. They provide reliable information from which students and reporters can work.

3. **Illustrations:** NHGRI's Web team is developing a Visual Media Database that will allow users to search for relevant, high quality, high-resolution images that can be downloaded and used in publications. These will include images from the glossary and other relevant images of genomic research.

4. **Online Genetics Education Resources:** NHGRI's Web team has assembled an extensive list of educational Web sites that will help students and teachers find relevant information on genetics and genomics.

5. **GROW: Genetics Resources on the Web:** [nchpeg.org] NHGRI has been working with other organizations to develop a search function that organizes high-quality genetics sources on the Internet. Still a work in progress, the current iteration is on the NCHPEG Web site.

Education Budget

NHGRI supports educational efforts through a variety of funding mechanisms, including grant making by the Ethical, Legal and Social Implications (ELSI) program in the Division of Extramural Research (DIR). The amount of money committed to education varies somewhat each year. In fiscal year (FY) 2001, the NHGRI budget office reported a total of $3,096,000 expended on public health education, a specific budgetary category that includes all education programming. Of that, $2,099,000 was distributed as grants by the ELSI program in FY2001.

In the current fiscal year, 2002, NHGRI has budgeted a total of $4,700,000 for public health education, including $3,285,000 to be distributed as grants by the ELSI program. The budget request for fiscal year 2003 in this category is $5,124,000, with $3,613,000 going to ELSI.

Ethical, Legal and Social Implications (ELSI) Projects

NHGRI's Ethical, Legal and Social Implications program is unique among federal institutions. Since the beginning of the Human Genome Project, James D. Watson, Ph.D., the project's first director, determined that it would not be enough for the federal government to only fund and lead the technological side of the Human Genome Project. Watson decided that 5 percent of the project's budget should be spent on research seeking to understand the ethical, legal and social implications of genetic and genomic research. That percentage has held constant, even after the genome center became an institute.

NHGRI has spent a total of $86,571,585 on the ELSI program between 1990 and 2001. Of this total, $18,185,415 was spent on education, or about 20 percent. The rest of the ELSI budget was spent on: privacy/fair use (24 percent); clinical integration (46 percent); and research issues (10 percent). Investigators and academics primarily initiated the funded projects.

Recently, staff from the NHGRI Office of the Director conducted a review of the ELSI education portfolio "to provide an overview of the portfolio in terms of status, purpose, audience and whether or not objectives have been achieved." The OD team evaluated 48 ELSI education grants, of which 12 (25 percent) were still open and the rest were closed. Of the 48, 33 grants were given to make a product (including curriculums, videos and manuscripts); 21 grants went for conferences or seminars; and five grants went for other purposes, such as education programs for certain populations. Some grants had more than one purpose and more than one audience.

The target audiences for the various products were identifiable for most of the projects. They include:

#TARGET AUDIENCE	NUMBER OF GRANTS	PERCENT OF GRANTS*
1Professional	32	67
2Graduate students	8	17
3Undergraduate students	6	12
4K-12	7	15
5General public	19	40
6Legislators	1	2

* (*Some grants have more than one target audience, so the percentages exceed 100 percent.*)

In evaluating effectiveness of the grants, the reviewers were able to determine that 24 grants, half of those issued, achieved their objectives. One grant did not achieve its objective. The remainder could not be categorized.

ELSI program staff has raised the question about whether ELSI should continue to award grants for education and public outreach efforts.