

FY 1999 HISTORICALLY BLACK COLLEGES AND UNIVERSITIES (HBCU) REPORT

National Human Genome Research Institute

Part A: SUMMARY

1. Goals and Objectives. The overall mission of the National Human Genome Research Institute (NHGRI) is to understand the structure and function of the human genome and the role it plays in human health and disease. To that end, the NHGRI supports the Human Genome Project, which is developing research tools that will accelerate scientists' understanding of the molecular basis of disease and ultimately lead to improved diagnostic, prevention and treatment strategies. Research efforts at NHGRI include the identification of genetic factors that contribute to diseases that disproportionately impact African Americans and into understanding the ethical, legal, and social implications of genetic research involving diverse populations. The NHGRI also focuses efforts on training minority scientists and students by: (1) providing opportunities for established scientists to conduct research in genomic and genetic disease research; (2) making training opportunities available at all career levels; and (3) increasing awareness about genomic and genetic research through NHGRI presentations at workshops, courses and symposia and by supporting minority faculty and students to attend relevant workshops, courses, and symposia.

2. Exemplary programs that could be replicated in other agencies. The National Human Genome Research Institute is involved in an innovative research collaboration with investigators at Howard University to identify genetic factors that contribute to diseases the disproportionately affect African Americans. The collaboration between the National Human Genome Research Institute's Division of Intramural Research and Howard University has proved to be a very effective means of enhancing the research capabilities of Howard University. This collaboration works for several reason: (1) Dr. Georgia Dunston, a Howard University Professor, spent a sabbatical year in the intramural program studying a research problem that was of mutual interest to her and her host, Dr. Francis Collins, Director of NHGRI. Because of the success of this collaboration and the potential for future collaborations, it was decided that a more formal collaboration should be developed when Professor Dunston returned to her home institution; (2) both collaborators recognize that the diseases being studied represent a major health problem and that the results could have implications for how other complex diseases are studied; (3) both collaborators are committed, competent and involved; (4) both research sites are within easy commuting distance thus, facilitating communications; and (5) NHGRI maintains dedicated staff time for this activity.

3. Total Awards to HBCUs during FY 1999.

The FY 1999 NHGRI budget for HBCUs through grants and training activities was \$5,792,000 (including reimbursables). This includes \$1,792, 000 of NHGRI funds and \$3,496,000 provided by ORMH for the cooperative research effort between ORMH, NHGRI, and Howard University.

4. Differences in Award Levels between FY 1998 and 1999.

The FY 1998 NHGRI budget for HBCUs through grants, training activities and IPAs was \$4,007,000 (including reimbursables). This figure included ORMH funds of \$2,584,000 utilized for the cooperative research efforts between the ORMH, NHGRI and Howard University. The NHGRI component of the FY 1998 amount to HBCUs was \$1,423,000. Thus the FY 1999 NHGRI budget for HBCUs reflects an increase of \$369,000 over FY 1998.

Part B: AWARDS AND NARRATIVE INFORMATION

(1) Research and Development:

ORMH - NHGRI - Howard University Collaboration: Center for Research on the Genetics of Diseases that Disproportionately Affect African-Americans

HBCU = Howard University

FY 1999 = \$1,589,000 (NHGRI) + \$3,495,000 (ORMH)

During the past several years the Office of Research on Minority Health (ORMH) has supported an innovative research collaboration between investigators from Howard University and scientists in the intramural research program of the NHGRI. The collaboration involves support for projects involving African-Americans affected with diabetes. In FY 1997 the NHGRI added hereditary prostate cancer within this core of collaborative projects. In addition, Howard University and the NHGRI are serving jointly as research-training sites for African-Americans involved in these projects.

The goal of these studies is to establish a Center at Howard University for collaborative research on genomic analyses of diseases that disproportionately affect African Americans. Initial efforts to define the scientific focus and objectives of the center have been addressed through peer-reviewed contracts with Howard University as Coordinating Center for the African American Diabetes Mellitus (AADM) Study and Coordinating Center for the African American Hereditary Prostate Cancer (AAHPC) Study.

Africa America Diabetes Mellitus Study (AADM): Because of the high frequency of environmental risk factors for type 2 diabetes in the African-American population, it is more productive to study genetic risk factors in West Africans, since they are thought by many anthropologists to be the founding population of modern African-Americans and have fewer dietary and nutritional confounding variables. To establish recruitment sites for the study, five sites were selected through a peer review process from a total of 24 applications, three of them in Nigeria and two of them in Ghana. Because of logistical challenges involved in doing a study of this type in West Africa, the study was planned in stages to allow assessment of the sites' ability to recruit appropriate patients and collect blood, urine, and other clinical data, and successfully send the samples and data to the Coordinating Center at Howard University. The one-year pilot project fully met its goal of recruiting 15 affected sib pairs/site. Based on this experience, a full-scale study was

implemented in September 1998 with an anticipated total of 400 affected sib pairs and 200 spouse controls from West Africa by the end of the study period.

The study has not only started to yield high quality data, but has assisted in the recruitment of several top-flight scientists to the Center at Howard University.

African-American Hereditary Prostate Cancer Study Network (AAHPC): The Howard Center is also coordinating a linkage study of hereditary prostate cancer, the African-American Hereditary Prostate Cancer Study Network (AAHPC). The initial aim is to enroll 100 families with prostate cancer in which at least four men, diagnosed at or before 65 years of age, are affected in each family and there are four other (unaffected) relatives available for study. African-American prostate cancer families of this description are almost completely missing from other pedigree collections, despite the higher incidence and higher lethality of prostate cancer in black men. Through a competitive review, the AAHPC study network has funded seven centers (Detroit, Chicago, New York, Atlanta, Houston, Columbia, and Washington, DC). For most of these, the Principal Investigator is an African-American urologist. Community acceptance and participation has been good. Blood samples and clinical data are sent from recruitment sites around the country to the Center for DNA extraction. Over 40 families have already been identified and samples collected. DNA from these families will be studied to see if linkage can be found to a known hereditary prostate cancer location on chromosome 1 as well as whether other linkages exist.

Additional Studies: Pilot projects at the Center are now being planned to analyze existing data sets on the genetics of asthma and breast cancer.

The ORMH-NHGRI collaboration with the Howard Center also is facilitating the analysis of ethical, legal and social issues affecting African-American participation in genetic research: African-Americans have not participated in genetic research at the same level as other ethnic groups. Investigators at the Center are gathering and analyzing data pertinent to examining issues related to participation: access to information, informed consent, community attitudes toward genetic research, and methods to optimize informed decision making regarding participation in genetic research and use of the knowledge gained through this research.

Floyd Malveaux

HBCU = Howard University

FY 1999 = \$105,000

This supplement to Dr. Malveaux's grant supports Dr. Rick Kittles with a three year award to investigate genetic sequence variations in African-American and European-American men with prostate cancer as part of a larger collaboration with NHGRI and Howard University.

William Lester

HBCU = Tuskegee University

FY 1999 = \$77,000

Collaboration between Tuskegee University and University of Washington. This is a pilot project to allow Dr. Ed Smith from Tuskegee University to learn the latest genomic technologies in sequencing and data analysis. He will evaluate the DNA sequence variation in the low density lipoprotein receptor gene in African Americans. The study will provide evidence for the level and pattern of DNA sequence differences in this gene among African Americans. Dr. Smith will spend three summers at the University of Washington working with Drs. Maynard Olson and Deborah Nickerson. During this time, he will also transfer this technology to his laboratory in Tuskegee.

(3) Training:

The 1999 Genomics Short Course for Faculty at Minority Institutions

FY 1999 = \$21,000

The 1999 Genomics Short Course for Faculty at Minority Institutions had a total of 38 applicants from 23 national minority universities and colleges. From this pool of applicants, 29 faculty members were accepted and attended this year's Short Course. Among the 29 participants, 18 females and 11 males attended from 23 separate minority institutions, which included 17 African-American institutions. Regarding advertisement for the course, 143 advertisements were faxed to various Historically Black Colleges & Universities, Hispanic-American Universities, as well as Tribal Colleges. In addition, electronic (e-mail) messages were sent to last year's short course participants to spread the word. An advertisement was also placed in *The Chronicle for Higher Education*.

(11) Other activities (the following narratives describe NHGRI research or training activities which involve African-Americans at non-HBCU sites)

Research:

"Engaging Minority Communities in Genetics Policy Making"

(Principal Investigator, Toby Citrin, University of Michigan)

This renewal project, conducted by a consortium of three universities (University of Michigan, Michigan State University and Tuskegee University) will develop a process for engaging minority populations of diverse socioeconomic levels in the process of rational democratic deliberation on moral and political issues relating to genome research and its resulting technology, and will develop recommendations for laws, professional standards and institutional policies regarding the use and application of genome research and technology. Fifteen African American and Latino community-based organizations will identify participants for focus groups and for a series of five dialogue sessions held in the "home" communities. Focus groups will identify a menu of issues of concern, and dialogue sessions will discuss the issues and develop recommendations. Regional community policy meetings attended by all group participants will convert dialogue