

University Initiatives Fund Program in Public Health Genetics
in the Context of Law, Ethics, and Policy:
Report of Review Committee
March 28-29, 2001

As originally proposed, the University Initiatives Fund Program in Public Health Genetics in the Context of Law, Ethics and Policy had three aims:

1. Develop a multi-level education program, with innovative core content and diverse students, presented by a multidisciplinary, multi-school cluster of existing and new faculty,
2. Organize research on the population significance of genetic variation and new genetic tests, and generate a legal, ethical, cultural, and policy framework for decisions on what genetic services to provide, to whom, by whom, at whose cost, and with what legal protections and cultural sensitivities,
3. Inform environmental regulatory decisions about variation in risks among people through research on genetic biomarkers, education of current and future academics and practitioners, and policy dialogues with stakeholders about chemical, infectious, and radiation hazards.

During the four-year period since its inception, the program has been extraordinarily successful in meeting these aims. As outlined below, the success in achieving the first goal has exceeded all expectations. With respect to the second goal, the UIF-funded pilot projects have provided an opportunity for research development, and this has led to the leveraging of outside funding for projects that bridge basic science with issues of public health concern. One example is the inclusion of an ELSI core in the renewal of the NIH-funded Center for Ecogenetics and Environmental Health. With respect to the third goal, the impact of the PHG Program on health care policy statewide is difficult to judge so early on. However, the PHG Program is already emerging as a player in the national discourse on genetic testing. Such visibility and demonstrated strong links to the State Department of Health suggest that that promise too will be fulfilled.

Academic Programs. The educational program began with an M.P.H. degree program and a certificate in public health genetics, currently in their second year. This is the first M.P.H. program in this area in the nation. An M.S. program in genetic epidemiology has already been approved by the graduate school council, and a self-study for a proposal for a Ph.D. program in public health genetics has been completed. The development of these three different academic programs, which are the first of their kind, is extremely impressive, especially in so short a time.

These academic programs provide a very effective bridge between basic sciences and their broader applications to community health. The faculty is extremely diverse. Its members come from a wide range of departments and schools within the university, including the SPHCM, the School of Law, the School of Pharmacy, the School of Nursing, the School of Medicine, and the College of Arts and Science (Anthropology Department). Members are also included from the Fred Hutchinson Cancer Research Center and, importantly, the Department of Health of Washington State. A series of courses has been developed specifically for the M.P.H. program. Students also receive broad training in public health, through the series of courses included in the breadth requirements for all M.P.H. students at the SPHCM. Within the ELSI concentration, there is substantial strength in the areas of law, ethics and economics. However, the policy

development/implementation component appears less developed and might profit from a closer collaboration with the Evans School and Department of Political Science.

The current students have diverse backgrounds including law, molecular biology, and anthropology; most had previous training in biological sciences and are interested in developing careers in public policy and ethical issues in human genetics. They seem bright, articulate, and excited about their academic programs and practicum experiences. The program appears to be attracting highly qualified students. Many were offered positions in other programs, but decided to come here because of the unique characteristics of this program. The market for the program is evidently great; 20 applications to the M.P.H. were received in 2001, and this can be expected to grow rapidly.

Faculty Interactions. One of the most important goals of the UIF was to promote multi-college, multidisciplinary interaction among faculty members. Judging from interviews, this goal has been achieved.

Faculty members are clearly extremely excited about their participation in the program. Program participants appear to work well together, forming a cohesive group despite their diverse areas of expertise. The multidisciplinary nature of the program is exemplified not only by the inclusion of faculty from different departments, but also by the inclusion of extraordinary individuals who have training in multiple relevant areas. For example, one faculty member has both an M.D. and J.D. degree, another has a J.D. and M.P.H., and a third has an M.D. and a Ph.D. in economics. These combinations are highly unusual and provide an important asset to the program.

The faculty has achieved a remarkable level of integration and interdisciplinary communication, founded on a sense of mutual respect and belief that “no one person can do it all.” This strong sense of community and collaboration is reinforced through several mechanisms. One of the most important factors is the tireless leadership of Dr. Melissa Austin. All program participants meet on a biweekly (formerly weekly) basis, to discuss issues related to the program, such as admissions, curriculum, pilot projects, and new academic program development. A conscious decision was made not to create subcommittees, and this has worked very well to ensure maximum involvement of the full faculty in the program. All of the faculty participants appear to feel that their views are heard and respected by the group. More than one faculty member observed that because of the many different perspectives expressed, these meetings provide an opportunity for the faculty to practice what they expect the students to learn to do.

The courses are all taught by teams of faculty, who bring different areas of expertise to the topics. Integration among the different courses is achieved through the use of the same examples, or disease applications, in the different courses. The pilot projects supported by the program provide an opportunity for faculty members with different research backgrounds to work together. Faculty members serve together on student committees, and this activity will be expected to increase when the Ph.D. program gets underway. Also, program participants meet with the students on a quarterly basis to evaluate student progress.

The Summer Institute provides another means for faculty to work together, and also allows for wider visibility of the program. This serves the important function of providing postgraduate education in genetics in public health. The first Summer Institute was fully subscribed and very successful.

Public Health and Community Impact. The PHG program has close links with the Washington State Department of Health. Debra Doyle, State Coordinator for Genetic Services and PHG faculty member, is charged with arranging practicum experiences for MPH students. Among areas mentioned were genetic screening programs for newborns, pre-pregnancy counseling and ethical and legal issues concerning genetic testing in the workplace. A program to explore genetic vulnerability to chronic disease is under consideration and may provide for further interactions between genetics, behavioral nutrition and the prevention of chronic disease. The PHG program appears to have an impact at state level, judging from the creation of two new positions at the Department of Health

In addition, PHG faculty is increasingly used as a resource by several Washington State agencies. Organizing Summer Institutes and co-sponsoring conferences is an effective way to promote the public outreach and service components of the PHG Program. The January 2001 conference in Tacoma was co-sponsored by the Board of Health, the Department of Health, the Department of Social and Health Services, the Office of the Insurance Commissioner, and the Supreme Court. These efforts document the fulfillment of the second main goal of the initial UIF.

Administrative Issues. The program is administratively housed within the Department of Epidemiology of the School of Public Health and Community Medicine (SPHCM). Recently, the Office of the Provost approved the formation of an Institute for Public Health Genetics as an administrative entity to house the growing Public Health Genetics program. The creation of the Institute reflects the prominence of the program in the University, promotes student identity, and provides a possible mechanism for leveraging outside funding. Promotion of public health genetics is clearly an important part of the strategic aims and goals for the SPHCM. Schools of public health nationwide currently recognize the importance of genetics in public health, but only two have programs in place (neither with degree programs specifically in the area). The pioneering Institute for Public Health Genetics at the University of Washington is an outstanding model for other schools of public health. The program also has great value for pharmacy, nursing, and law. It is an important part of the strategic plans for each of those schools as noted by the deans.

The PHG program weaves together in a unique way a number of strands that were already in place. It enriches graduate training at the University of Washington and may have a lasting impact on the conduct of interdisciplinary research. The contacts between Health Sciences and the Upper Campus are particularly welcome and attest to the success of the program. The welcome collaborations between the School of Medicine and particularly the Department of Medical History and Ethics and the SPHCM will most likely develop further as the scope of the program widens. This could have an impact on the practice of medical genetics. Although the faculty of the Institute of Public Health Genetics includes representatives from a wide range of departments within the University, the program would benefit from more involvement from the Division of Human Genetics of the Department of Medicine. It would be helpful to develop mechanisms for increased communication and collaboration with them.

This program can be expected to grow rapidly, as the recognition of the importance of the area grows, and its visibility increases. UIF funding provides key support without which it would have been impossible to develop this extraordinary resource. However, new growth will bring new financial pressures. For example, funds are needed for student support, expansion of pilot projects, and faculty support for teaching and curriculum development in this rapidly changing

field. It will be important to develop mechanisms to increase the funding base of the program. This is a difficult problem. The interdisciplinary nature of the program implies that grants submitted by its faculty go through their departmental affiliations, and hence the usual mechanisms for return of indirect costs are not available. Other mechanisms are needed to generate funding, whether through private donations, University budget allocations, or alternatives to the usual indirect cost procedures. This problem will be especially important for the development of the Ph.D. program, where student research assistantships would be a tremendous asset for recruitment of outstanding students.

The students in the PHG program have no common area where they can congregate, and expressed the feeling that they are "homeless." Interaction among students as well as faculty is one of the most important goals of the UIF, and this goal is very difficult to achieve if the students have nowhere to go. This is especially problematic in an interdisciplinary program such as this, in which the faculty is decentralized, with offices all over the University. Mechanisms should be sought to find space for a student lounge or office.

The interdisciplinary nature of the program presents some complexities with respect to faculty promotion, tenure, and merit increases. Clear guidelines should be developed to ensure that faculty who devote effort to the program receive commensurate recognition within their respective departments.

Summary. Dr. Melissa Austin has developed a unique, outstanding program in an area that is vital to the future of public health. Rapid developments in genetics in recent years have created an acute need for integration of knowledge in basic science, ethics, law, and public policy. This program is the first to provide multidisciplinary education in this area. Its graduates may be expected to contribute to a rapidly growing workforce in genetics policy and service delivery in government, health care, industry, and academia. Moreover, both the faculty and students involved in the program are virtually unanimous in their praise and enthusiastic about what they are learning and how it has helped them to develop professionally.

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