V. Partnering with Genetic Researchers

There are many ways in which community organizations can partner with genetic researchers to both facilitate more effective studies in racial and ethnic groups and ensure that the community they represent is adequately protected from the risks present in such studies. Much depends on the specific expertise of an organization as well as the type and size of the genetic study in question. In general, however, an organization will be more effective if it has members who are fluent in both the science used by researchers and the cultural values of the community. Where an organization envisions extensive collaboration with genetic researchers it may be worthwhile to provide members with basic training in genetics. In some cases, training may be available through the institution funding the research or through the researchers themselves.

Readings

Genetic Alliance [http://www.geneticalliance.org/] contains a considerable amount of resource material on community/research partnerships, some of which deals specifically with racial or ethnic communities.

National Human Genome Center at Howard University, Community Partnership Program [http://www.genomecenter.howard.edu/units/genethics/cpp_default.htm] provides information and resources on community engagement around genetics.

NIH, National Human Genome Research Institute, Collaborative Research for Minority and Special Populations [http://www.genome.gov/10001281] presents materials relating to community/researcher partnerships for genetic research.

NIH, National Human Genome Research Institute, Community Outreach and Public Education for Minority and Special Populations [http://www.genome.gov/10001279] discusses available educational materials for communities with respect to genetic research.

Power (2001) reports on the search for disease genes in isolated communities in Gioi, Italy and Talana, Sardinia, focusing on the relationship between researchers and community residents.

Further Readings