

membership and volunteer leaders about the Human Genome Project as it relates to mental retardation. A large number of identified causes of mental retardation are genetic, and many family members of The Arc deal with issues related to a genetic condition on a daily basis. We believe it is critical for our members and leaders to be educated about the scientific and ethical, legal and social aspects of the HGP, so that the association can evaluate and discuss the issues and develop positions based on adequate knowledge.

The major objectives of the proposed three-year project are to develop and disseminate educational materials for members/leaders of The Arc to inform them about the Human Genome Project and mental retardation and to conduct training on the scientific and ethical, legal and social aspects of the Human Genome Project and mental retardation using The Arc's existing training vehicles.

The Arc will develop and disseminate educational materials oriented toward families and conduct training at its national and state conventions, local chapter meetings and at board of director's meetings. The American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP) will assist with the project by providing needed expertise. The AAUAP membership includes university faculty who are experts on the genetic causes of mental retardation and on related ethical, legal and social issues. An advisory panel of university scientists and leaders of The Arc will guide the project.

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Pathways to Genetic Screening: Molecular Genetics Meets the High- Risk Family

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The proliferation of genetic screening and testing is requiring increasing numbers of Americans to integrate genetic knowledge and interventions into their family life and personal experience. This study examines the social processes that occur as families at risk for two of the most common autosomal recessive diseases, sickle cell disease (SC) and cystic fibrosis (CF), encounter genetic testing. Since each of these diseases is found primarily in a different ethnic/racial group (CF in European Americans and SC in African Americans), this research will clarify the role of culture in integrating genetic testing into family life and reproductive planning. A third type of genetic disorder, the

thalassemias, has recently been added to our sample in order to extend our comparative frame to include other ethnic and racial groups. In California, the thalassemias primarily affect Southeast Asian immigrants, although another risk group is from the Mediterranean region. Thalassemias, like cystic fibrosis and sickle cell disease, have a similar pattern of inheritance and raise similarly serious bio-medical challenges and issues of information management.

Data are drawn from interviews with members of families in which a gene for CF, SC or thalassemia has been identified. Data collection consists primarily of focused interviews with approximately 400 individuals from families in which at least one member has been identified as having a genetic disorder (or trait). In the most recent phase of the research, we are conducting focus groups selected to achieve stratified homogeneity around key social dimensions such as gender and relationship to disease. This is clarifying the social processes that facilitate and inhibit genetic testing.

We are currently assessing the concerns expressed by respondents about the potential uses of genetic information. We find strong patterns of concern, often based on personal experience, that genetic information may be used in ways that family members perceive as dangerous and/or discriminatory. First among these concerns is fear of losing access to health care. Additional concerns include fear of genetic discrimination in employment and other types of insurance, particularly life insurance. Similar patterns of concern exist among members of each ethnic group, and are frequently the focus of attention among family members, but take somewhat different form within each cultural group. These concerns constitute a growing obstacle to widespread use of genetic testing.

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Intellectual Property Issues in Genomics

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Intellectual property issues have been uncommonly salient in the recent history of advances in genomics. Beginning with the filing of patent applications by NIH on the first batch of expressed sequence tags (ESTs) from the laboratory of Dr. Craig Venter, each new development has been met with speculation about its strategic significance from an intellectual property perspective. Are ESTs of unknown function patentable, or is further work necessary before they satisfy patent law standards? Will patents on such fragments promote commercial investment in product development, or will they interfere with scientific communi-