



DEPARTMENT OF HEALTH AND HUMAN SERVICES

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Welcome to the Twin Registry Feasibility Study ELSI (Ethical, Legal, and Social Issues) Workshop and thank you in advance for committing your time and experience to this project. As you know, twin research offers great potential for estimating the relative contributions of genetic and environmental factors to disease or behaviors. With structural equation modeling, multivariate analyses and other statistical tools, twins can be used to measure the extent to which allelic variants influence phenotypic traits. Then by comparing the shared and non-shared environments of twins, we can learn more about how gene-environment interactions influence complex disease. Therefore, the National Institute of Environmental Health Sciences is conducting this study to determine the feasibility of establishing a National US Twin Registry and disease specific twin registries for type 1 diabetes, multiple sclerosis, and systemic lupus erythematosus.

Over the last few years, however, twin participation rates in registries have decreased due to several factors, foremost being the public's increased awareness about privacy issues and informed consent. Individuals increasingly perceive recruitment attempts as invasions of privacy, and are concerned that personal information will be passed on to insurance companies, employers, and others, and lead to discrimination. These increased concerns have made it more difficult for twin organizations to ascertain, trace, and recruit potential registrants. Also relevant to establishing a representative national twin registry, is the current under-representation by subpopulations such as children and minorities in already existing twin registries. We will explore this issue in depth, as well as possible methods to increase participation by these subgroups. Your input into these issues will be valuable to us in deciding whether to pursue national twin registries or other alternatives in the future.

Sincerely,

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