

# Charge to the Expert Panel

This Expert Panel has been assembled to review and respond to an NIEHS-commissioned study to determine the feasibility of establishing a national twin registry and three disease specific registries.

The primary responsibilities of the Panel are to 1) discuss the feasibility of establishing a national twin registry, and three disease-specific registries in the United States, with alternative options; and 2) decide which options to pursue after an in-depth discussion of the preliminary report provided by Alpha Gamma Technologies.

The Expert Panel will receive and review periodic reports from the contracting specialist, Alpha-Gamma Technologies, Inc. The results of these reports will be discussed in three meetings over an 18 month period. A timeline for delivery of the preliminary and final reports to the expert panel for their review and response is attached.

Specifically, the Expert Panel will:

- ❖ Respond to and refine estimates of the potential size and composition of a national twin registry, based on the demographic characteristics of twins in the US.
- ❖ Respond to and refine estimates of the potential size and composition of disease-based twin registries for Type 1 Diabetes Mellitus, Multiple Sclerosis, and Systemic Lupus Erythematosus. Also, delineate diagnostic criteria for each condition and special surveillance programs that might be needed.
- ❖ Explore and recommend alternative strategies for identifying and recruiting twin pairs, considering the enrollment methods used, response rates achieved, and lessons learned with existing twin registries. This discussion will also touch upon special efforts that may be required to enroll women and subpopulations with historically low research participation rates (minorities, non-English speakers, residents of rural areas, members of low SES groups.
- ❖ Explore the ethical, legal, and social issues that may be encountered in establishing and operating national and disease-specific twin registries and assess how these factors could influence participation rates among various population subcategories with particular emphasis on special disclosure and confidentiality legislation, including the Health Insurance Portability and Accountability Act and the Privacy Acts.)
- ❖ Based on the demographic data provided and the strategies identified for identifying and recruiting twin pairs, determine the feasibility of establishing a national twin registry, and explore alternative approaches – such as the feasibility of merging existing regional registries to create a comprehensive, national twin registry. Assess the feasibility of creating one or more smaller registries comprised of representative populations of twins.
- ❖ Based on the demographic data provided and the strategies identified for identifying and recruiting twin pairs with one of the three specific diseases selected, determine the feasibility of establishing three disease-specific twin registries, and explore alternative options for creating U.S. resources of twins with these conditions.
- ❖ After making a recommendation regarding the feasibility of establishing a national twin registry, respond to and refine an outline of methods for establishing, operating, and maintaining this and three disease-specific twin registries. Review an analysis of associated current and projected registry costs.