

Feasibility of Establishing a National Twin Registry and Three Disease Specific Registries as Resources for Investigations of Genetic Susceptibility and Environmental Influences in Complex Diseases

ELSI Workshop – November 13 and 14, 2005

AGENDA

November 13, 2005

**Location: Wyndham Garden Hotel – Main Dining Room
4620 South Miami Boulevard, Durham, NC 27703**

7:00-9:00 pm **Working Dinner**
Opening remarks (Chulada / Lombardo)
Workshop member introductions: background, expertise, and specific interests

November 14, 2005

**Location: NIEHS Main Campus, Building 101, Rodbell A
111 T.W. Alexander Drive, Research Triangle Park, NC USA 27709**

08:15-08:30	Continental Breakfast
08:30-08:45	Opening Remarks / Introductions (Chulada / Lombardo)
08:45-09:30 08:45-08:55 08:55-09:05	Recruitment Familial recruitment issues (Botkin) Recruitment issues from the subject perspective (Hobart)
09:30-10:00 09:30-09:40	Retention MidAtlantic Twin Registry experience (Corey)
10:00-10:15	BREAK
10:15-11:00 10:00-10:10	Ethnic diversity VET Registry and Black Elderly Twin Registry Experience (Goldberg)
11:00-11:30 11:00-11:10 11:10-11:20	Community Involvement Alzheimers and African American Study experience (Byrd) Carolina Breast Cancer Study experience (Millikan)
11:30-12:00 11:30-11:40	Ethical Oversight Committee composition, reporting structure, research review (Lombardo)
12:00-01:00	LUNCH
01:00-01:10	Twin Registry Survey results (Vannappagari)
01:10-01:40 01:10-01:20	Informed Consent What are the procedures and issues? (Lombardo)
01:40-02:10 01:40-01:50	Privacy / Confidentiality What is the difference? What are the issues? (Lombardo)
02: 10-02:25	BREAK
02:25-02:55 02:45-02:55	Data sharing (participants and 3rd Parties) and Data Security Data sharing and consent issues (Cho)
02:55-03:25 03:15-03:45	Stored Data and Biological Samples Genetic Alliance Biobank experience (Hobart)
03:25-03:45	Discussion of Additional Issues (Lombardo)
03:45-04:00	Closing Remarks (Lombardo)