Public Comments to the Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children

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1. ***Infant through Adolescent Rights to Genetic Information***

   Market forces and economic incentives dictate that in order to receive the economies of scale in the genetic testing arena, larger numbers of newborns and children must be tested for an ever increasing number of heritable disorders and genetic diseases. These tests, most likely will not be individual tests, but rather *across the board*, testing with the particular disorder or disease reported on to primary physicians and parents. This may leave a *balance* of genetic information on other disorders and diseases available for review at various times through a child's development and into adulthood.

   For instance, a teenage girl may want to know her genetic information with regard to BRCA whereas her mother may not want to know this information. Given the information has implications and ramifications for both mother and the daughter, a conflict may arise. Committee recommendations built on the market and economic incentives for today may have consequences for future individual rights for vulnerable populations of children and their rights toward assent and informed consent.

   Recommendation:

   Build in *sunsetting* provisions for Committee recommendations made in light of today's rights, ethical issues, knowledge, and technologies. Legislative and statutory *renewal* time allows for the inclusion of changes in the social milieu, e.g. cultural change, new demographics, changes in rights and responsibilities for children and young adults and their access to their own genetic information.

2. ***Review of Social Forces which Impact Assumptions about Genetics in Populations***

   Historically, the field of genetics has always acknowledged differences in populations. From an ethnic perspective, this has included different disease frequencies in various populations, e.g. sickle cell anemia in African-American populations, *beta*-thalassemia in Mediterranean and Middle Eastern populations, and cystic fibrosis in Celtic populations. However, social and cultural forces also influence populations and thus alter these disease frequencies, especially in the case of autosomal recessive disorders.

   For instance, in some highly segregated African-American communities, the consanguinity rates may have risen due to the combination of high levels of incarceration of young black males, the resulting skew of male-to-female ratios, the phenomena of multiple matings, and the lack of knowledge about family histories and thus genetic backgrounds. Similar consanguinity issues arise as U.S. demographics change with an increase of Middle Eastern populations where cousin-cousin marriages are the norm. These demographic changes and levels of hypersegregation have distinct geographic perspectives. Examples are the inner city neighborhoods and rural towns with >95 percent African-Americans and cities with an increase of Middle Easterners. There are certain cities that have experienced extremely high growth in the Arab populations within the heading *Middle Eastern*.

   In 2000, (576,000) Arabs (or 48 percent of the Arab population) lived in five states: California, Florida, Michigan, New Jersey, and New York. The Arab populations in Florida and Michigan experienced high growth rates as well as large numerical increases. The Arab population in

Florida grew by 57 percent, from 49,000 to 77,000 between 1990 and 2000. One of the counties with the highest Arab population is Wayne County, Michigan and over 30 percent of the population in Dearborn, Michigan is Arab. http://www.census.gov/prod/2003pubs/c2kbr-23.pdf .

Recommendation:

Identify the social and cultural forces that influence populations, and thus alter the frequency of heritable disorders and genetic diseases. Identify new geographic areas where the combination of immigration and cultural mores may influence genetic and reproductive outcomes.

3. ***Cultural Aspects of the Medical Home Model and Infant/Child Health***

In many cases, the *Medical Home Model* assumes a stable *one-place* geographic location for the newborn or child and the primary care physician. Immigration models and hidden cultural dynamics alter this assumption. For instance, in the case of immigration, many groups no longer come to the United States with the express plan to stay only in the United States. Many Mexican, Central American, and Caribbean populations are *dual nationals*, or migratory. Simply, they live in *both* the United States and their former countries with extensive visits back and forth. This necessitates an international component to the *Medical Home Model*, with links established between "medically-shared locales" [MSLs], rather than a unitary locale model.

For native U.S. populations, many ethnic groups have cultural habits that act in much the same way as *dual-nationalism* albeit domestic and interstate rather than international. These interstate treks have more of a gene-environment interaction component in disorders and diseases than those that are strictly heritable in the classic sense. For instance, African-Americans in the *North* and *Midwest* often send young children to visit extended family members in the "South" during the school vacation, summer periods. Given the high carcinogenic and toxic areas located in the South, usually near minority communities—children of color often are exposed to higher levels of lead contamination.

Yet, in many cases, pediatricians who serve communities of color and whose practice may be the medical home of the child in question do not take into consideration these cultural habits. With some African-American children, their *back home* visits to the South may represent 25 percent, (3 months) of a child's exposures to high lead contamination that takes place in an environment different from the location of the unitary medical home. These exposures often manifest as increases in blood lead levels during rapid childhood growth.

A similar situation exists for young woman exposed to high lead contaminations that repose in their bones. Bone lead mobilizes during times of increased bone turnover, such as during pregnancy and lactation. Again, blood lead levels show seasonal periodicity. Due to the environmental justice movement, a growing literature is developing on how these exposures and blood-lead mobilizations have an impact on conception, reproduction outcomes, fetal lead exposures and fetal neurobehavioral disorders.

Recommendation:

Develop *Medical Home* models that take into consideration *dual-nationalism* and migration patterns and forge relationships with the primary care physicians in those *medically-shared locales* that serve populations in which complex travel patterns are norm.

4. ***Inclusion of Indigenous and Traditional Knowledge and Social Capital in the Community-based Participatory Research Aspect of Heritable Disorders and Genetic Diseases in Newborns and Children***

Currently, the United States is undergoing rapid demographic shifts. Old World populations in this country share living space with new immigrants. Scandinavian and German populations in Minnesota and Wisconsin now share space with Somalians and Hmong. Polish populations in

Hamtramck, Michigan share space with Arabs and Muslims. These new populations come to the United States eager to visit Western primary care physicians, but they still maintain ties with their traditional and indigenous healers, shamans, and curanderos. Western physicians, however, forfeit valuable information on beliefs, world views, practices, and community allegiances by classifying this information as magico-religious rather than medical information.

Recommendation:

Incorporate immigrants as well as their ethnic healers, shamans, curanderos, and the like into the practices of primary care physicians as collaborators rather than marginalized competition.