Ethics of Genetics in Research: Perils and Promises

Genetic Research in Communities and Across Cultures

Gladys E. Maestre, M.D., Ph.D.
Columbia University University of Zulia
New York USA Maracaibo Venezuela
Risk Factors for Dementia in an Urban Population of Venezuela

Gladys E. Maestre, M.D., Ph.D.
University of Zulia
Maracaibo, Venezuela
Risk Factors for Dementia in an Urban Population of Venezuela

Gladys E. Maestre, M.D., Ph.D.
University of Zulia
Maracaibo Venezuela
Santa Rosa de Agua

Santa Rosa de Agua
Risk Factors for Dementia in an Urban Population of Venezuela

Gladys E. Maestre, M.D., Ph.D.
University of Zulia
Maracaibo Venezuela

Santa Lucia

Santa Rosa

Santa Lucia
Maracaibo Aging Study

- Survey-based registry
  - Door to Door
    People over 55 years of age
- Informed consent
  - Community Consent
  - Family Consent – head of the family
  - Individual Consent

Objectives

- To define the aging profile of the local population and its determinants
- To assess the prevalence, incidence and risk factors for dementia
- To examine the association between cardiovascular and cognitive function
Assessment Protocols

- Survey
- Social worker at the home
- Neuropsychological tests
- Neuropsychiatric assessments
- Cardiovascular tests
- MRI
- Clinical Chemistry
- DNA
Why would you want to participate?

• Maybe I can make some money
• Maybe they will help me solve a health problem
• Maybe they can help us to get a job, a house, anything that we need
• Maybe they will find the cure for a disease that runs in my family
• Maybe is good for the neighborhood and the press will come
What can/should we give to the community in return for their participation?

Money?
Used clothes?
Toys for the kids?
A party?

Are we talking about charity or is it our responsibility to give back something to the community?

What can/should we give to the community in return for their participation?

They should benefit of the knowledge and expertise developed thanks to the study in a meaningful and sustainable way

• Specialized services available
• Should learn along the way
• Prevention of diseases
Goal of the Program

To strengthen the capacity of Venezuelan scientists based at the University of Zulia to study the genetics of common heritable disorders relevant to Latin America and the Caribbean.
Main Strategies

• Training of a critical mass of scientists and engineers in the design and conduct of modern genetic/genomic research
• Facilitating the development of a research and training infrastructure at the University of Zulia
• Establishing collaborative networks between Columbia/Chicago Universities and University of Zulia researchers

24 Preparatory Courses in 3 years

• Public Policy and Scientific Research
• English Writing
• Introduction to Biostatistics
• Statistical Genetics
• Genome Variation and Human Common Diseases
• Laboratory Skills
• Neurobiology
  • Basic Aspects of Brain Diseases
  • Neurodegeneration
  • Brain-Environment Interactions
• Genetic, Genomic and Public Health
Preparatory Courses

Dr. Jose Ortiz and Students of the Laboratory Skills Course
How to Initiate and Sustain Collaborations for Research and Training?

- Videoconferencing
- Exchange of Students
- Developing collaborative agreements
  - Visitis from scientists to Maracaibo
- Writing grants and applying for funding

PUBLIC ENGAGEMENT
Thank You...

gem6@olumbia.edu

www.neurociencias.org.ve