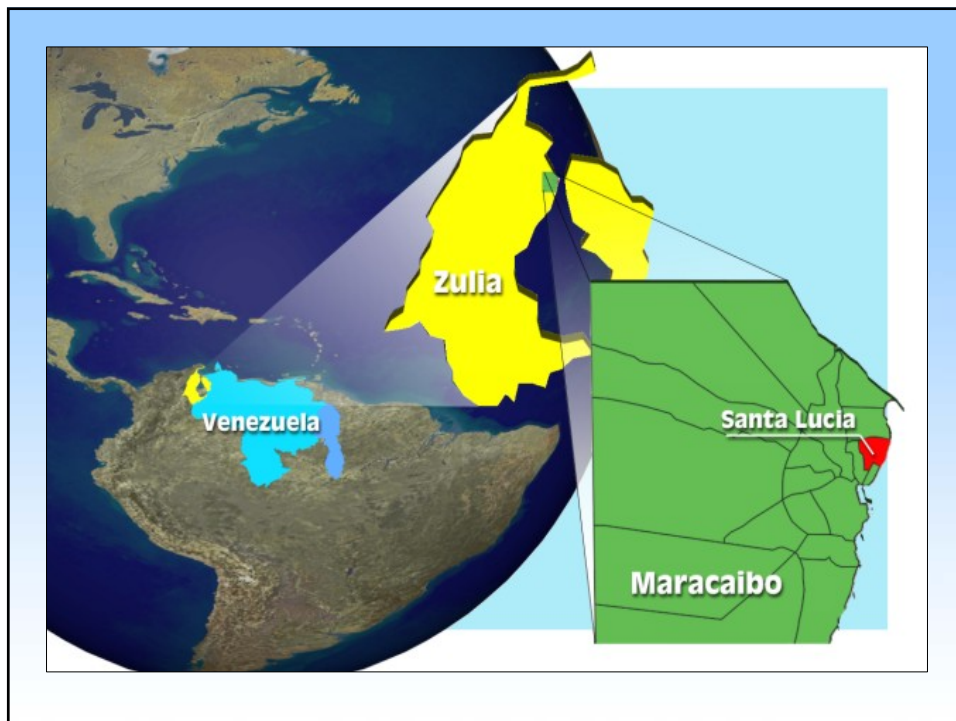


# **Ethics of Genetics in Research: Perils and Promises**

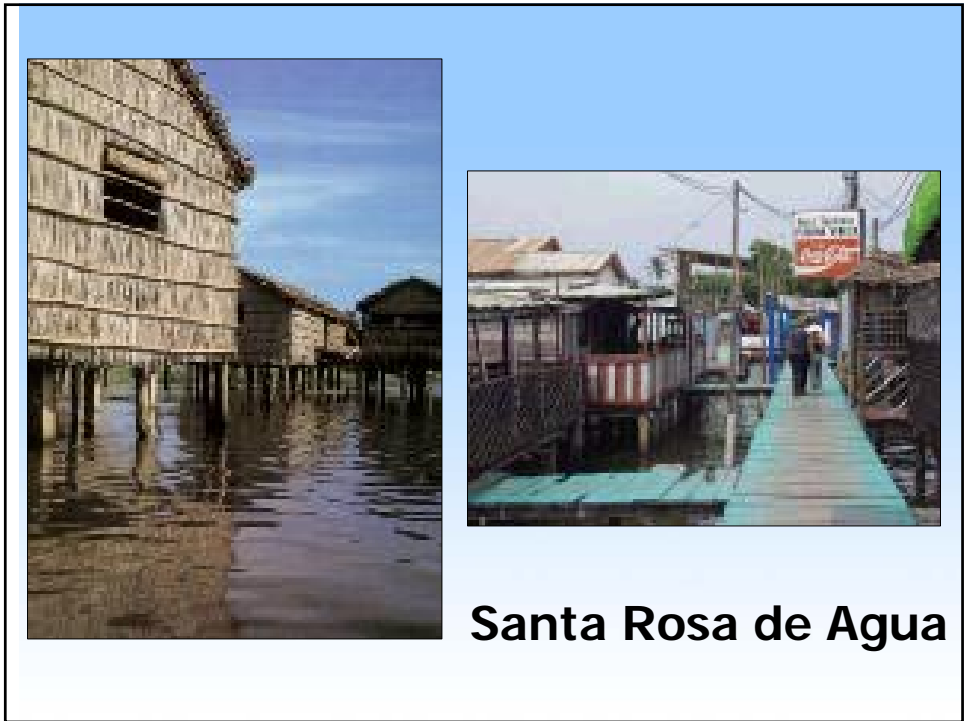
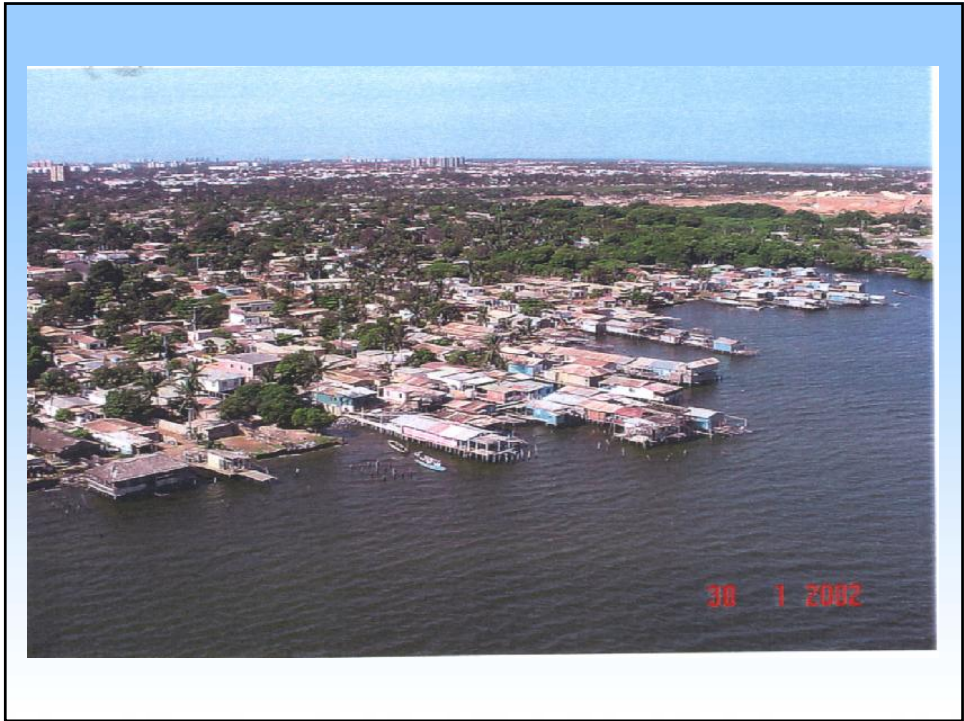
## **Genetic Research in Communities and Across Cultures**

Gladys E. Maestre, M.D., Ph.D.

Columbia University    University of Zulia  
New York USA        Maracaibo Venezuela







**Santa Rosa de Agua**

**Santa Lucia**



Santa Rosa



Santa Lucia



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# Maracaibo Aging Study

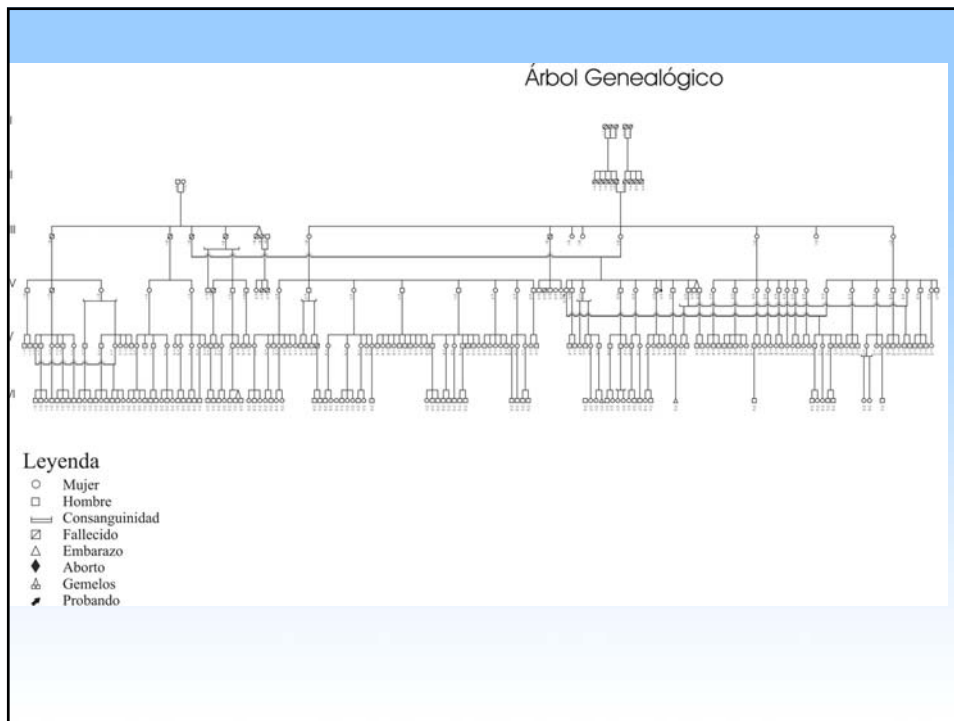
- Survey-based registry
  - Door to Door
  - People over 55 years of age
- Informed consent
  - Community Consent
  - Family Consent –head of the family
  - Individual Consent

## 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



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## 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 fo the neighborhood and the press will come



**Community Meeting on Genome Research  
in Santa Rosa de Agua**

## 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** 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



- ✓ **Capacity Building**
- ✓ **Public Engagement**
- ✓ **Sustainable Health Services**

Genetics of Common Heritable Disorders in Venezuela Research Training Program

COLUMBIA UNIVERSITY      UNIVERSIDAD DEL ZULIA

## 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

John E. Fogarty International Center

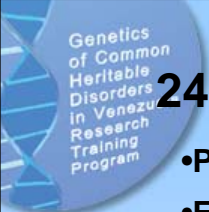
NATIONAL INSTITUTE OF HEALTH

FUNDADESARROLLO



## 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**

Genetics of Common Heritable Disorders in Venezuela Research Training Program

## How to Initiate and Sustain Collaborations for Research and Training?

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



### PUBLIC ENGAGEMENT





Thank You...

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