



PLENARY 9:
**Global Networks for the Prevention of Birth
Defects and Preterm Birth**

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CAPABILITY is

a three year (2007-2009) model project

developed jointly by

units 3 (Community Genetics and Public Health) and 6 (Education) of the Network of Excellence: Genetic Testing in Europe Network for test development, harmonization, validation and standardization of services (EuroGentest)

and

leading experts from: Argentina, Egypt and South Africa, the latter being currently engaged in major development projects to integrate genetic services in primary care and prevention in their countries

<http://www.capabilitynet.eu>



**Capacity Building for the
Transfer of Genetic Knowledge
into Practice and Prevention**

CAPABILITY Networking Goals

- To promote an internationally shared set of basic quality standards for genetic testing and the provision of appropriate genetic services in primary care and public health
- To lay the foundation for a sustained collaboration, that will continue and be open for international partners
- To start collaboration by joint projects



CAPABILITY's overall objectives are to contribute to:

- **the efforts to establish and sustain a worldwide harmonisation process for quality standards for the integration of genetic test/genomic knowledge applications into practice and prevention and**
- **to serve as a model project for successful, sustainable collaboration between EU research centres and centres from non-EU countries, especially emerging economies (middle income countries).**

Greater Sekhukhune Outreach Programme: an evidence based approach for developing medical genetic services in South Africa

Project Leader: Arnold L. Christianson



Community Education in Health Aspects of Genetics

Project Leader: Randa Kamal Abdel-Raouf

Capacity Building Project (Community Education in Health Aspects of Genetics)

Goal:

- ❖ To develop and implement a module for community education on the prevention and care of genetic disorders.

Phases of the Project:

I. Preparatory Phase:

1) Selection of:

- a) setting
- b) target population

❖ Criteria for selection of the setting:

- Rural area
- Closed Community
- Inaccessible tertiary care
- High prevalence of genetic disorders

❖ Criterion for selection of target population:

- Persons who have an influence on the community:

a) Community Leaders:

- Mayor of the village
- Emam, Priest
- Members of popular assembly

b) Traditional birth attendants (Daya)

c) Influential persons in the family:

- Mothers, mothers in law, grandmothers

2) Situation analysis: Study of the sociodemographic characteristics of the selected community

- * Education
- * Family size and family planning
- * M/F ratio
- * occupation
- * Culture (beliefs, behaviors, attitude)
- * resources
- * Consanguinity

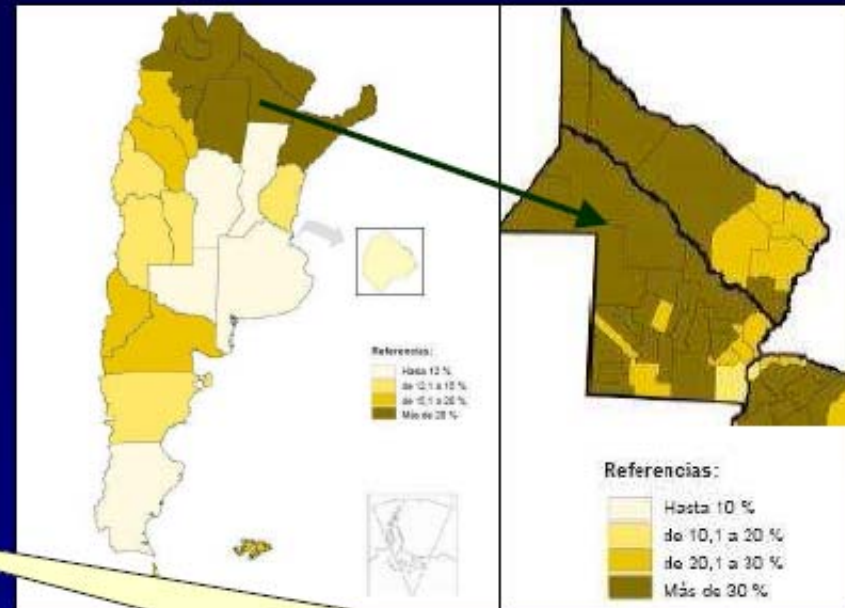
Chaco “Las Breñas”

Project Leader: Cristina Barreiro

The province of Chaco was chosen for a demonstration project

Local Characteristics:

- **Office for Distance Communication** connecting local health care centers and the Garrahan Hospital in Buenos Aires.
- **Public Health Project:** designed to improve quality of medical assistance.
- **Current Project: On-line Clinical Records (HCUA)**
- **Well-functioning Referral System** (ambulances, cars)



Our aim is to develop a program of genetic diagnosis and counseling in the province of Chaco through capacity building

When social conditions are hard, the burden of genetic disease is increased

Why networking....

- **Share resources and experiences (“not invent the wheel again”)**
- **Transfer knowledge and good practices**
- **Link shareholders**
- **Intensify dialogue and strengthen shared issues**



Capacity Building for the
Transfer of Genetic Knowledge
into Practice and Prevention

Why networking....

- **Achieve synergies and coherence among international groups**
- **Develop joint projects**
- **Promote capacity building in low and middle income countries**